Aging with a Disability

For the Project: "Aging with a Disability: Research Phase"

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Table of Contents

Acknowledgements 5

Executive Summary 6
Purpose 6
Methodology 6
Findings 6
Conclusion 10
Recommendations 10

Introduction 13
Aging with a Disability 13
Defining Disability 14
Distinctions Between Seniors and People Aging with Disabilities 14

Methodology 15
A Community-Based Research Project 15
Project History 15
Phase 2 Starts 16
Facilitator Training 16
Focus Group Questions 16
Recruitment 17
Focus Groups 17
Focus Group Sessions 17
Participants 18
Limitations 18
Ethics 19

Findings and Analysis 21
Choice in Everything: Current and Future Needs 21
Social Positions of Disability 22
Structural and Institutional Concerns 27
Gender, Sexuality, and Race 30
Risk of Abuse 32
Gaps in Services 34
Transportation 38
Housing 40
Community and Culture 41
Assisted Dying 43

Recommendations 44
Policy and Regulatory Measures 44
Funding 44
Service Delivery 45
Education and Information 45

Conclusion **46**
References **47**
Appendices **49**
Glossary of Terms **68**

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Executive Summary

Purpose

This is the final report for the focus group phase of the *Aging with a Disability* project. We share the participants' experiences and stories throughout the report to make clear the need for substantive changes to policies and programs around disability and aging in Ontario. We describe the barriers people with disabilities face as they age and highlight recommendations for improved supports and services for aging with a disability.

Methodology

The project employs a community-based research methodology, which centres the participants and community organizations within the research. Disability experiences are the focus of the research project, and therefore we met with people with disabilities to gather their stories and experiences so that we could explore the process of aging for people with disabilities.

Data for the project was collected through surveys conducted in Phase 1 of the project and through focus groups completed in Phase 2. Three-hundred and thirty-two individuals with disabilities participated in the Consumer Survey. Thirty-five service providers completed a second survey specifically designed for the service sector. We also conducted 18 focus groups, which were attended by 128 participants.

Findings

The data we collected and the stories we heard share an underlying theme: the need for choice. People aging with disabilities want to choose how they will live in the later stages of their lives. Options for people with disabilities are meagre, and this report demonstrates the impact of these limited choices.

The findings from the project were divided into nine themes:

- Social Positions of Disability
- Structural and Institutional Concerns
- Gender, Sexuality, and Race
- Risk of Abuse
- Gaps in Services
- Transportation
- Housing
- Community and Culture
- Assisted Dying

Social Positions of Disability

Disability Attitudes

We found that two distinct social positions are central to understanding how participants experience aging. The first is attitudes: attitudes about disability that participants hold, including those they hold about themselves; attitudes that professionals hold about disability; and the general public's attitude towards disability. Our findings suggest that one's attitude about disability impacts their past and current involvement in social activism. Furthermore, it affects how they view themselves both now and as they age.

Social Class

The second social position that impacts people's experiences of aging is their social class, that is, their economic status. Participant's self-disclosed belonging to one of four income groups: middle-class income; living in poverty or on a fixed income; working poor; and/or people with episodic employment. An individual's economic position directly impacts their experiences of disability and aging, with those living in poverty or as working poor finding it very difficult to age with dignity as a person with a disability.

Structural and Institutional Concerns

Poverty

Poverty is intimately connected to the experience of disability. The focus groups revealed that participants' experience of poverty stems from systemic institutional issues, specifically with provincial support programs and the lack of affordable housing. Participants who live in poverty expressed deep concern about their future, especially about the cost of their supports (equipment, medicine, hours of service, etc.) as they aged. For some, poverty is considered either a lifelong sentence or something that will catch up with them in old age.

Gaps in Policy

In addition to their concerns about poverty, participants discussed other gaps in policy that are often directly related to aging. Their concerns included transitioning off of the Ontario Disability Support Program (ODSP); being able to continue directing their services; requiring additional care hours due to the increased complexity of their care needs; being able to "age in place"; and maintaining supported decision-making. Overall, participants were concerned that provincial programs are not adapting appropriately to the growing number of people aging with disabilities. Participants argue in favour of extending ODSP coverage past the age of 65 to maintain the program's benefits until the end of life. The current gaps in policy lower the quality of life for people aging with disabilities.

Gender, Sexuality, and Race

Women's Health

A number of women in the focus groups disclosed predominantly negative experiences of trying to access gender- specific healthcare services. Healthcare services and supports are not set up to accommodate the needs of women aging with disabilities. Participants pointed out that as the population continues to age and more women with disabilities require access to healthcare, it is going to be exceedingly more difficult to support women with disabilities within segregated, specialized medical units. Participants therefore argued for more accessible doctors' offices and healthcare services in areas all across the city.

Relationships and Sexuality

Regarding relationships and sexuality, three main topics were discussed: 1) those with partners fear that their partners' role will shift to that of a caregiver more so than that of a spouse; 2) people fear they will become more isolated as they age; and 3) those with children fear they will burden their children with their care. Overall, participants expressed a desire for developing and maintaining romantic and intimate relationships.

LGBTQ Communities

This research does not include the experiences of individuals with disabilities who are part of the Lesbian, Gay, Bisexual, Trans, Queer/Questioning (LGBTQ) community.

Racial Tensions

In describing their experiences with different care providers, participants recounted stories of racial discrimination. Participants share stories of being treated differently than others, and they assigned this difference to racism.

Risk of Abuse

Abuse is a topic that participants expressed concern about during several of our focus groups. Participants feared potential future experiences of abuse as older people with disabilities. Specifically, they are concerned with less attention to their care needs, that is, neglect of their care, if their cognitive abilities become impaired.

Gaps in Services

Focus group participants identified a number of gaps in services in various sectors including attendant services and supports; services for people with disabilities who are also care providers; access to proactive health professionals; and mental health services. Overall, we highlight these areas as having significant gaps in services for people aging with a disability.

Attendant services and supports

Regarding attendant services and supports, participants expressed a desire to maintain the current number of support options, such as Attendant Outreach programs, Supportive Housing programs, and Self-Managed Direct Funding. However, they also argued for increasing services overall, not simply to meet the current demands, but to ensure that services will be able to match the growing demand from people aging with disabilities.

Services for disabled care providers

Many of our participants, in addition to having disabilities themselves, are care providers to older family members or to spouses, partners, and/or children who also have disabilities. Increasing the hours of support for people with disabilities who are also care providers would help alleviate some of the burden on these families, especially as they age alongside those they are caring for.

Proactive healthcare

Access to proactive healthcare services was a substantial concern for participants. However, proactive healthcare services were generally inaccessible to participants because of a number of barriers, including financial limitations, structural or environmental barriers, and also attitudinal barriers from health professionals. Many participants considered addressing these barriers as a top priority.

Mental Health

Participants expressed deep concern about their future, which they point out, increases their anxiety and exacerbates any pre-existing mental health issues. The precarious nature of their future causes many participants to experience distress. The issue is two-sided — highlighting the need to access appropriate mental health services and simultaneously to address the social and economic positions of people with disabilities in society.

Transportation

Transportation was one of the major concerns identified in every focus group. The main themes are 1) access to public transportation; 2) navigating parallel accessible transit systems; and 3) parking/vehicle modifications. Transportation infrastructure needs to adjust to accommodate the increased number of people with disabilities and others accessing the service. The city and province must immediately address the issue of transportation services to better support people with disabilities to access safe, affordable, and efficient transportation.

Housing

There is a pressing shortage of accessible rental units and a shortage of rental housing that includes attendant services in Toronto. Of the accessible rental spaces available, many are located in underserved areas of the city and in poorly maintained buildings. Participants often complained that the location of their current home was determined based on the availability of accessible apartments with subsidy and service, rather than personal choice. A lack of diversity and choice in housing leads to a lower quality of life, long wait times, people aging in inappropriate settings, and finally, non-disabled people occupying accessible units in social housing.

Community and Culture

Participants expressed the importance of strong community connections. Many participants described aging as lonely and scary, and therefore argue that community support — ways to socialize and engage in public — are very important as they age. However, participants also highlight that there are many barriers to their participation in the community including transportation and structural or environmental barriers.

Assisted Dying

Within focus groups the topic of assisted dying evoked strong participant responses. Upon analysis, we determined that social class or economic status are markers that shape participants' opinions.

Conclusion

The work ahead is exciting as it points to the success of past initiatives, campaigns, and policies that have extended the lives of people with disabilities so that aging is now a primary concern. As the life expectancy of people with disabilities is increasing, so too is their expectation that society will include them in meaningful ways. It is the hope of the research team, and all those that support the project, that together we can aid in ensuring all people with disabilities live full lives.

Recommendations

Based on the findings from both the survey material and focus groups, we recommend addressing concerns about policy and regulatory measures, service delivery, funding, and education and information. Access Independent Living Services, in consultation with partner organizations and based on the findings of project, highlight 17 recommendations for policy-makers regarding aging and disability.

Policy and Regulatory Measures

- Enforce the *Accessibility for Ontarians with Disabilities Act (AODA)* and ensure compliance across all sectors in the province.
- Extend Ontario Disability Support Program (ODSP) coverage to the end of life.
- Ensure health and wellness offices (hospitals, medical offices, massage therapy offices, etc.) are accessible and have appropriate equipment with properly trained staff to support consumers to access healthcare services
- Develop and revise policies to take into consideration the experiences of people aging with disabilities who also belong to the LGBTQ community.
- Develop and revise policies to take into consideration the experiences of women aging with disabilities.

Funding

- Expand programs such as Attendant Outreach, Supportive Housing. and Self-Managed Direct Funding to meet the growing demand for support for people aging with disabilities.
- Establish a contingency fund to meet increased service demands to support consumers to age in place, including during critical health events.
- Increase the available funding for home renovations and other minor and major structural home changes so that people aging with disabilities can continue to live in their homes.
- Increase dedicated funding for abuse prevention training for direct service staff.
- Increase hours of support for people with disabilities who are also care providers.

Service Delivery

- Meet the growing demand for accessible and affordable housing with support services for people aging with disabilities. This includes maintaining current accessible and affordable housing services.
- Increase service hours for personal support workers so consumers can age in place.
- Develop and implement mandatory and comprehensive anti-oppression training for both service provider staff and consumers.

- Improve access to a variety of mental health services.

Education and Information

- Establish further opportunities for people aging with disabilities to learn about disability and the experiences of disability from diverse perspectives and through different mediums.

- Develop and distribute educational materials that detail the rights and responsibilities of people aging with disabilities in connection to attendant services and other support services in a wide range of accessible formats.

- Develop and distribute educational materials that detail information regarding the Registered Disability Savings Plans (RDSP), including training and information to major financial institutions.

Introduction

Aging with a Disability

This is the final report for the focus group phase of the *Aging with a Disability* project. This yearlong project, funded by the Ontario Trillium Foundation in 2014, consisted of 18 focus groups with 128 participants. We share the participants' experiences and stories to make clear the need for substantive change to policies and programs around disability and aging in Ontario. We describe the barriers people aging with disabilities face, as well highlight recommendations for improved supports and services in relation to aging with a disability.

People with disabilities are generally living longer and healthier lives. We can attribute this to advancements in medicine, improved living situations, care practices, and continued funding for disability supports, among other things (Bickenbach, 2011; Jongbloed, 2003; Krahn, 2011; Oliver, 1990; WHO, 2011). However, the current support systems are not equipped to handle the growing number of people aging with disabilities. One of the reasons for this shortfall is that there exists limited research about aging and disability from the consumer's perspective. For this reason, Access Independent Living Services, in partnership with a team of other organizations and with funding from the Ontario Trillium Foundation, embarked on a research project exploring the experiences of people with disabilities and the aging process.

We believe that people with disabilities should be able to age with dignity. This includes having access to the following:

- comprehensive social supports;
- access to information;
- allied health and wellness services;
- adequate physical support services;
- equipment required to receive services at home and in the community and to access health and medical services;
- educational programs on health;
- cultural events and programming; and
- housing in an appropriate, accessible, safe, and clean living environment.

The data we collected and the stories we heard share an underlying theme: choice. People aging with disabilities want to choose how they will live in the later stages of their lives. Choice is one of the central tenets of the Independent Living Movement. We will describe the many barriers people aging with disabilities face every day because of the many gaps within current systems.

The goals of this report are as follows:

1) to highlight and describe the barriers faced by people with disabilities as they age; and
2) to encourage policy-makers to address the concerns raised in this report in a timely and effective manner.

Defining Disability

We understand disability as a product of inaccessible spaces and increased barriers within society. We also understand that people with disabilities have a history and a culture and that increased accessibility does not equate to the elimination of disability. We acknowledge that the disability community is broad and complex and that no single report or organization represents all of the opinions within this community. Still, it is important for the readers of this report to understand how the researchers and coordinators compiling this report understand disability. We are critical of the social practices and mechanisms that continue to reject people with disabilities as contributing members of society. The report will seek to reveal how ableism — a set of beliefs and practices that supports ability over disability — is inherently problematic and leads to many of the issues people with disabilities face every day. It is our hope that by demonstrating how ableism works in everyday practices, we can start to break down and challenge ableist understandings of disability to aid in moving towards a more accessible, just society. Our project seeks to inform policies on disability and influence policy-makers as they decide on changes to disability supports.

Distinctions Between Seniors and People Aging with Disabilities

It is of central importance that we make a distinction between seniors and people aging with disabilities. A senior is typically described as a person over the age of 65 who may or may not have a disability and who may or may not identify as a person with a disability. Seniors are a growing population and their needs are often different from those of people with disabilities. People aging with disabilities differ from seniors. The process of aging for people with disabilities includes dealing with the changing nature of their disability as they age. A person with a disability in their twenties and thirties requires a different set of supports as they age, not simply because they are getting older, but because their disabilities may become more complex. In addition, the aging process may be accelerated for people with disabilities. Some people with disabilities have shorter life spans; therefore, they may start experiencing the effects of aging as early as the age of 30, but receive none of the supports guaranteed to seniors because they fail to meet the age requirements.

Methodology

A Community-Based Research Project

The *Aging with a Disability* project is a community-based research initiative, initiated and guided by community partners. The project follows the central qualities of a community-based research project, as outlined by the Centre for Community Based Research, which includes a community situated research topic developed by community members; shared financial and other resources with community groups; a commitment to collaborative work and a transparent process; community access to the final results; and a commitment to social change and social justice action (Centre for Community Based Research).

Project History

The project is divided into three large phases.

- Phase 1 – Surveys
- Phase 2 – Focus Groups and Research Report
- Phase 3 – Future Research and Implementation of Recommendations

The first phase of the project involved two large surveys, conducted in collaboration with our partner organizations located throughout the Greater Toronto Area {GTA).

- Consumer Survey: The goal was to gain insight into the issues and concerns that are immediate in consumers' minds regarding their quality of life as someone living with a lifelong disability and who is now entering "the aging process".

- Service Providers Survey: We asked service providers about the issues related to aging with a disability they see most commonly amongst their consumers.

The results for the Consumer Survey are in Appendix 1 - Consumer/Client Survey Results, and the results for the service provider survey are in Appendix 2 - Service Provider Survey Results.

We received a large number of responses to both surveys: 332 individuals with disabilities completed the Consumer Survey, and 35 service providers completed the Service Provider survey.

The results of the surveys indicated the need for further research. Therefore, the principal investigators of the project, Michael Mathieson, Cathy Samuelson, and Nancy Barry, applied for and obtained funding for this second phase of qualitative research from the Ontario Trillium Foundation.

Phase 2 Starts

Phase 2 of the project began with consultation meetings between the principal investigators and the project coordinator. We discussed the outlook for the project, developed the research questions, and organized the structure for the yearlong project. A meeting of the entire Working Group followed, (which included all the partner organizations of the project). From that point, the project coordinator visited with every partnering organization in their respective locations. The visits accomplished two tasks: 1) determining the partner organization's interest in the project and the significance of the project to their organization; and 2) scouting the space of each organization to determine if a focus group could take place at their location.

A List of Partner Organizations is in Appendix 3 - Partner Organization. Partner organizations were key figures in the development of the project and assisted through the data collective phase.

A List of Supporting Community Organizations is in Appendix 4 - Community Organization. We partnered with various community organizations that were interested in research topic and agreed to facilitate access for us to their clients/consumers.

Facilitator Training

We hired four facilitators to assist the project coordinator with the data collection in this phase of the project. Two of the four facilitators identified as having a disability. All the facilitators engaged in extensive training with the project coordinator. They were instructed to read literature about focus groups and on how to conduct focus groups with people with disabilities. Together, they took part in training for compliance with the *Ontario with Disabilities Act (AODA)*, as well as training in communication assistance and Augmentative and Alternative Communication (AAC) training. Each facilitator was trained to take on various roles (facilitation lead, note taker, recorder operator, etc.) so that we could cycle through and exchange duties given the circumstances of any given focus group. Also, facilitators met with the project coordinator throughout the project to plan for the following set of focus groups and to address any issues and concerns. The facilitators, in addition to attending the focus groups and assisting in facilitating, also engaged in a reflective practice with the project coordinator after each focus group. The team debriefed at the end of each session to reflect on what was said, to determine that session's main themes, and to address any concerns that arose for either the participants or the facilitators. Often challenges or concerns were addressed as a team, and solutions were implemented in the following focus group, if possible.

Focus Group Questions

The project coordinator, in consultation with the principal investigators, developed the focus group questions. The first set of questions we developed were adjusted following

the first focus group when we found we had too many questions, and that we did not provide participants with enough time to clearly answer all the questions.

The final list of questions is in Appendix 5 - Focus Group Questions

Recruitment

Our strategy used the listservs and other means of communication between partner organizations and their members to send out a call for participants (CFP). (An example of a CFP is in Appendix 6 - Sample Call for Participants). In the CFP, we provided participants with three options for registering for the focus group: online through Eventbrite; voicemail to a dedicated line; and through email, also to a dedicated account. In addition to these strategies, one organization opted to print and mail the CFP to its members.

Focus Groups

Preparation for the focus groups started in June 2014. In July, we began recruiting participants for the first set of focus groups slated to commence in August. The focus groups ran until February 2015. All the partner organizations held at least one focus group, with one organization holding five focus groups.

In total we organized 28 focus groups; however, 10 were cancelled due to low registration, weather issues, and issues with transportation. We conducted 18 focus groups attended by 128 participants. We held focus groups across Toronto, as well as additional focus groups in Brampton and Markham.

Focus Group Sessions

The focus groups were organized initially so that participants would be divided based on their type of disability. For some disability groups, meeting with individuals with similar disabilities was beneficial. For organizations that represent a diverse group of disabled individuals, for example the Centre for Independent Living in Toronto (CILT), individuals with varying disabilities attended the same focus group. We encouraged participants to choose a focus group that was most convenient and most suitable for their particular needs.

Two days before the event, the project coordinator sent out reminder emails or called participants to remind them of the details of the focus group to encourage their attendance. On the day of the focus groups, the project coordinator along with two, three, or four facilitators (depending on the number of participants in attendance) would arrive an hour before the start to setup the room and assist participants in settling in.

Setup included for the focus groups included: a laptop for note-taking; an audio record; two large flip charts; food and beverages; and, ensuring Attendants and American Sign

Language Interpreters, and dedicated AAC/Communication Facilitation were present, as required by participants.

In addition, each facilitator was responsible for reviewing the consent forms with participants and answering any questions. The project coordinator collected all consent forms, either before or at the end of the focus group. Participants were instructed that they could leave the focus group and the project entirely at any point.

We began each focus group with an introduction and welcome statement, attached in Appendix 7 - Introduction and Welcome.

Following the introduction, a facilitator began asking questions. Focus groups were scheduled for 3 hours, with 15 minutes in the beginning allocated for the introduction, and a half-hour break in the middle. At the end of each focus group, participants received an honorarium of $10 in the form of a Tim Horton's Gift Card.

Participants

Regarding disability, race, and gender, the participants who attended were very diverse. Their ages ranged from 21 to 80 years. We had participants from all social class backgrounds, including participants who were new to the country and to the city. Specific information about participants' finances and lifestyle were not formally collected. Information about social class and life style was, however, often disclosed in what participants spoke about and over what they expressed concern. Further, some of the focus groups were held in locations or communities with reputations of poverty or privilege.

Some participants also chose to have a close family member attend the focus groups. Other participants also asked that their attendants stay with them throughout the focus group. All participants' signed consent forms agreeing to uphold the privacy of those in the group.

Participants who attended the focus groups came from different disability communities. In addition to individuals with physical disabilities, individuals with sensory, intellectual, and development disabilities also attended the focus groups. A large number of non-speaking participants attended the focus groups. This diversity and the variety of experiences these groups bring are evident throughout the report.

Limitations

We discovered many issues regarding the participation rates of people with disabilities in the research project. Low registration did force us to cancel some of the focus groups. However, there were a variety of other reasons why participants could not attend focus groups (transportation and inclement weather being the top two barriers to attend). These issues are specific to this group, and we urge that such issues be addressed in future research. Specifically, we would urge funding agencies to provide information and supports

for accessibility, including funding for transportation other than public transit, such as taxis, and reimbursements for drivers. An increase in funding for accessibility and accommodations would mean a stronger number of participants engaging in research projects such as this one.

Also, clearly absent from the focus groups were indigenous peoples and individuals from the LGBTQ community. More effort must be made in the future to include individuals from these communities into conversations about aging and disability. Their needs may be unique and the current systems will have to discover new ways of accommodating individuals with multiple marginalized identities.

Furthermore, focus groups are inherently a group exercise and therefore, we could not guarantee confidentiality. We expect that sexuality would have come up more in one-on-one interviews. Finally, there were no questions developed that attempted to address aging, disability, and sexual orientation.

Ethics

The project followed ethical guidelines that were established by the research team. There were various ethical challenges to conducting research with partner organizations that also provide service for our participants. As such, it was made explicitly clear in the beginning that representatives from partner organizations, including members of the research team, would not be allowed to sit in during focus groups. Such measures were taken to ensure that participants could speak openly and critically about their experiences of aging with a disability, including their experiences with the affiliated organization.

Moreover, participants were allowed to bypass contacting the affiliated organization and directly communicate their interest in the project with the project coordinator. Only the project coordinator and facilitators have access to the personal information of the participants.

We developed consent forms for the project that are in **Appendix 8 - Consent Form**

We asked participants to read the consent forms (or facilitators read the consent forms to some participants as an accommodation), and to sign before leaving the focus groups. Participants signed in agreement to two items: 1) to participate in the study; and 2) to be audio recorded. We also gave participants the option of selecting their own pseudonyms — some of which will appear below. For participants that opted to use their real names, we clarified the potential consequences of making such a decision and advised them to reconsider.

Finally, for individuals with limited mobility and who could not sign the consent forms by themselves, the project coordinator and trained facilitators used a hand-over-hand method. This method allows for the participant to sign the document, while another

individual's hand holds it in place or guides it along the line. For individuals for whom hand-over-hand was not an option, we employed a witnessing process in which all consent was given verbally or through other means of communication, and signed by one facilitator and witnessed by either the project coordinator or another facilitator. The project coordinator and focus group facilitators found these methods both appropriate and in line with the project's ethical guidelines.

Findings and Analysis

Choice in Everything: Current and Future Needs

Choice is an underlying theme that runs through all the stories and experiences participants shared. Participants described how their choices are either being made for them, or how they are being prevented from making choices entirely through various structural and institutional barriers.

A primary example of this concern is evident in the reasons participants gave for attending the focus groups. They wanted to not only voice their concerns about their future needs, but also to express their increasing fears about their current situations. Participants took the focus groups as an opportunity to express their frustration with the current system, and at the same time, were interested in engaging with others to change the future. We surmise that, for many participants, it is difficult to talk about the future when so many are concerned with planning from day to day.

Our focus groups findings concur with the results from our surveys. The top five most important issues consumers listed in regards to current needs were identical to the top five most important issues they anticipated facing in the future: attendant care with accessible housing, communication assistance/AAC, financial support (access to income), access to health and dental services, and equipment needs. These findings demonstrate a growing need to change the system, not only for this new and growing population of people aging with disabilities, but also to address current shortfalls and demands.

Social Positions of Disability

Attitudes

A consistent theme among focus groups participants was the need to negotiate attitudes. This includes attitudes they have about themselves, their disability, and aging; attitudes professionals hold of them; and the general public's attitude towards disability. The following sections of the report will describe these perspectives.

Attitudes towards self, disability, and aging

Participants in the focus groups all came from different social positions, economic backgrounds, and disability experiences. These differences impact their understanding experiences of disability. The following three subsections describe some of the overall perceptions of disability that participants described: disability as individual loss or burden; disability as a political and social identity; and disability as an emerging problem.

Disability as individual loss or burden

Some participants understood disability as an entirely medical experience and a personal shortcoming. Individuals who expressed this view often spoke about being grateful for the available services, expressing that they feel "lucky" to receive services. In the same vein, individuals who feel that disability is an individual shortcoming — and self-describe as having access to money or other forms of support — often shared a story of overcoming. These individuals would often impress upon others in the focus group that it is the individual's responsibility to be a "better person". They felt that individual's should have taken on personal responsibility for saving for their future and care of their needs. We found that individuals who perceived of disability and supports in this way were less likely to have participated in disability politics or advocate for improved services.

Framing disability and supports as dependent on an individuals' capacity to move through the system puts the onus on the individual to change their behaviour, rather than on the system to make it more accessible and user-friendly. We are concerned that these experiences and understandings of disability are harmful and that more complex representations of disability will aid in changing harmful perceptions of disability (Walsh, 2009).

Disability as a political and social identity

Many other participants who attended the focus groups identified as a Disability Rights activist. Participants self-disclosed activist work they had done (and are doing), including ensuring better transportation, advocating for the recognition of disability as a protected status within the *Human Rights Code*, and lobbying all levels of government to improve existing programs and to implement more comprehensive disability services. These individuals spoke about a decline in general services. Activist participants fear that a decline in services will impact their ability to stay in their homes, and will thus force them

to move into an institutional setting. They felt these settings will treat disability as a medical issue and that their life experiences will be devalued. These participants expressed a sense of fear that nurses, doctors, and support staff would perceive of them as already broken, and therefore ignore their needs and treat them with less respect. In one focus group, an activist participant said jokingly that disability activists like her need an alternative place to live —a compound — where all those who understood disability as a political identity could grow old. These same individuals also expressed fear that the next stage in their life is going to be one of loneliness and poverty as they leave the Ontario Disability Support Program (ODSP) at 65 and transition to Old-Age Security programs (OAS). They described how they worry about how they will continue to have choice and maintain their dignity and quality of life with little support.

Disability as an emerging problem

Participants described another attitude within the focus groups: disability as an emerging problem. Some individuals noted that they are only now beginning to identify as a person with a disability, despite living with disabilities for many years. These participants spoke about their ability to navigate in their everyday lives up until they started aging. These participants were generally distant from the disability community and unaware of disability supports until recently. They described how they were often perplexed by the various systems they have to now navigate to receive supports.

Participants expressed that there were similarities between them and others who are aging, but note that their aging is happening at a faster rate. In these cases individuals described struggling to find resources or supports. A few individuals also identified their concern that their spouse or partner is now taking on a lot of extra work to support them. In some cases, they described how a breakdown of a marriage or not being able to work because of a physical issue also triggered a shift in their abilities to cope with their disabilities.

Professionals' attitudes

Professionals' attitudes became a central discussion in many of the focus groups. Often participants, regardless of their perceptions of disability, expressed a desire to be taken seriously by doctors, nurses, and personal support workers. It appears there are a number of attitudinal issues in the interactions between people with disabilities and medical staff and support services. Specifically, many participants expressed concern that contracted and/or third party personal support workers (PSWs) are not as effective in their service provision, noting that some show negative attitudes towards their clients and the types of services that people with disabilities require.

One focus group participant disclosed that she was denied life-saving surgery for the removal of a cancerous tumour, because the doctor felt it was not worth it to save her. Participants also discussed difficulties when trying to replace equipment and in accessing increased care from care coordinators and case managers. Participants spoke about a lack

of knowledge among health care providers in regards to the fluid and shifting nature of people's experience of disability; people expressed having both good and bad days.

Attitudes of the general public

Although the issue of the general public's attitude was not a central theme, some participants spoke about having to negotiate ignorance in interacting with the general public. Some disclosed that they tried to carry themselves with pride, be assertive, and dress well as a way of communicating their value to the general public. We argue that these efforts to demonstrate worth are telling of how much work is still needed in breaking down barriers for individuals with disabilities — not just in terms of employment — but also in terms of the worth and value of older individuals with disabilities and their experiences.

Social Class

As mentioned we determined information about the social class of participants based on how they self-identified. We noted four groups among participants: those with a middle-class income; those living in poverty or on a fixed income; those who were working poor; and those with episodic employment. We argue, as did many participants, that an individual's economic position directly impacts their experiences of disability and aging, with those living in poverty, or working poor finding it very difficult to age with dignity as a person with a disability.

Middle-class

We argue that individuals who self-identified as middle-class have easier access to financial resources, including financial management and procurements strategies. Middle-class participants spoke about frustrations in not having more options for leisure travel. Some were concerned about returning to work or negotiating long-term disability benefits. We observed that people who are financially stable are able to be more reflective about their disability experience. They often framed disability as an asset given their established connections and knowledge of community resources.

Middle-class participants expressed frustration that in many cases their income excludes them from funding programs for necessities such as home renovations or vehicle modifications. These exclusions often cause a lowered quality of life for these individuals as they lose out on personal travel and living in their homes for a longer period of time. These participants also expressed that they are often fatigued by trying to find resources and funding for services or supports. Again individuals who could afford goods beyond basic necessities (food and shelter) reported that they often struggle to attain aspects of life that a non-disabled person in a similar financial situation would be able to attain. On this point, one participant argued, "I have enough money to live, but not enough to be disabled."

Often recreational and social opportunities are limited because of the built environment and access to supports. For example, participants reported that finding hotels that have Hoyer lifts or restaurants with accessible bathrooms was difficult, which limited

their ability to enjoy retirement. Moreover, individuals spoke about their free time being taken up by doctors' appointments and managing their supports. There was also discussion about the exclusion of higher income earners accessing accessible housing in community housing. Of the people who we interpreted as being financially stable, many could still not afford the added expenses of disability.

These participants present an interesting contradiction in that they are not living in poverty, but they are restricted systemically for not being absolutely destitute. These people expressed anxiety about what would happen as they age and as they spent more of their monthly income on securing resources for their added disability needs. Many expressed anxiety as to their future health and finances — two significant components of their lives that are dependent on each other, yet completely unpredictable.

Lower socio-economic status

A number of people with disabilities who either self-identified as Ontario Disability Support Program (ODSP) recipients or who were attending a focus group in a common area of a community housing building or apartment building which had rent geared-to-income spoke adamantly that they did not plan for the future, because the task of existing and surviving in the present was a challenge. One participant argued, "I don't plan for the future…. I live for today; it's all I have." People who disclosed living on a low or fixed income expressed how difficult it was to acquire basic needs such as warm food or food in general. Participants in this situation also identified that they felt lucky to live in apartments with subsidized rents, because wait lists are long and there is a shortage of space. However, even while acknowledging their "luck", individuals expressed deep frustration and the desire to live in locations that were cleaner, safer, and less isolated.

The working poor

There were participants in the focus groups who spoke about being employed or having jobs. Again, because we did not collect employment statistics, the research team did not have access to specifics. This group was in a similar position to middle-class participants, but had less financial stability and usually no savings. These participants were also often excluded from means-tested programs or supports such as repairs to mobility devices or housing retro fits. Many of these participants described these consequences of their employment, as "punishment". And yet, many individuals expressed gratitude for acquiring and sustaining employment. They expressed anxiety about aging and how they would afford retirement. Many individuals also identified they had been forced to leave their jobs early due to disability-related complications and a lack of accommodations at their place of employment.

Precarious employment

A few people identified that they worked in real estate, had direct marketing businesses, or were planning to do something independent such as take up writing. Often these people had the support of a spouse or family. These jobs did not yield a lot of income,

but often provided participants with needed activity, a positive self-image, and respect amongst their peers. Many of these people were proud of their ingenuity, but again, struggled to plan for the future. They also identified that these were lines of work that do not offer disability benefits or workplace support.

General notes on social class

The connections we have made between an individual's income, social class, and quality of life should come as no surprise given the numerous academic and community-based projects that have clearly demonstrated a connection between these issues (Russell, 1998). Our participants' responses to these issues and aging, however, are novel and should be taken into consideration within future research. For instance, participants argued that employment was an important and substantial component in their lives, not solely because it provided income, but also because employment meant daily interaction, possibilities for expanding social networks, and access to social connections. Access to social networks also meant access to a variety of friends outside of their care networks, who could support them when needed. This also led to an easier time with service navigation, because people with natural support networks or who were attending support group meetings were often put in touch with resources faster than those who were disconnected. Academic research (Gillies, 2013) shows that people with disabilities are often under-employed for their level of education. Participants who had post-secondary education disclosed more knowledge and life experience of things they may need as they age.

The stories that emerged from the focus groups suggested social class and disability were interlinked. Most people were not frustrated because they have disabilities; rather, they expressed frustration that disability prevented them from easily gaining access to the resources and social experiences they desire and in many cases, require. When people were able to easily access resources that improved their quality of life, aging became an exciting possibility and planning for their "next chapter" became a reality.

Structural and Institutional Concerns

Poverty

Most participants who attended the focus groups were experiencing poverty. While no one disclosed their exact income, a large number identified that they were living in poverty and surviving with funds provided by ODSP. Recipients of the program receive a monthly income determined by calculating basic needs, which include the family size, age of dependents, geographic location, mandatory disability or medical necessities (such as transportation or medication), and additional benefits like the Special Diet supplement[1] (Shantz, 2011; Tarasuk & Vogt, 2009; Vozoris, Davis, & Tarasuk, 2002). Participants consistently described ODSP income as insufficient, and many argued that an increase was necessary. Poverty, or a lack of resources, was a constant topic during focus groups. Participants often expressed that they are struggling to survive in the present. When asked about how they thought their lives would change as they aged with a disability, many suggested that their quality of life would improve because their income would increase. Issues such as struggling to find funds for proactive health care such as massage or physiotherapy were linked with a lack of funds and living in poverty. Participants often identified that lack of money, even for inexpensive items, often escalated into a crisis or hardship. Consumers reported in the surveys that financial support and access to income were one of the five most important issues, both in regard to current needs and anticipated needs in the future.

High monthly expenses prevented many participants from saving money. Often participants were aware of savings programs such as the Registered Disability Savings Plan (RDSP)[2], but said that they could not take advantage of them because their incomes were so low and geared towards everyday living expenses. Many participants were not aware of grants[3] available to them that could help contribute to RDSP.

Again, participants highlighted that they believed that there is an institutionalized cycle of poverty, in which the system that provides income also limits individuals from seeking income through their own means. Participants disclosed that there were many disincentives that prevented them from working while receiving ODSP, such as losing coverage for repairs of mobility devices. Currently, ODSP provides a transitional health benefits plan for those who are employed. This benefits plan covers the cost of drugs and

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[1] For more information on the Special Diet supplement please visit: http://www.mcss.gov.on.ca/en/mcss/programs/social/special_diet_apply.aspx

[2] To learn more about the Registered Disability Savings Plan (RDSP), please visit: http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/rdsp-reei/menu-eng.html

[3] To learn more about the grants available to people with disabilities in relation to RDSP, please visit, http://www.esdc.gc.ca/eng/disability/savings/grants_bonds.shtml

other medical necessities, but does not cover the cost of repairs. Repairs can be expensive and create severe financial restraint. Many participants suggested that exclusion from coverage for repairs prevented them from accepting employment opportunities, especially if the employer could not offer comprehensive health coverage through private insurance.

In addition, it became apparent after facilitating multiple focus groups in different areas, that there was significant contradictory information about ODSP. Often participants would correct, argue about, or share information with other participants. Our findings suggest a varied client experience, and it appears that there are multiple interpretations of the policies and regulations both among clients and caseworkers. Finally, participants often expressed that they experienced "bureaucratic fatigue" when trying to negotiate government programs that were in place to help or support them.

Some participants disclosed they were either formally or informally not controlling their own money. A number of participants disclosed that family or a trustee were managing their money. In some cases, people were unsure about their arrangements regarding their money. This made it hard for people to comment on whether they were saving for the future.

In conclusion, the focus groups revealed that poverty stemmed from institutionalized system issues, specifically with provincial support programs and affordable city housing. Participants who live in poverty expressed deep concern about their future, especially regarding the cost of their support (equipment, medication, hours of service, etc.) as they aged. For some, poverty was considered either a lifelong sentence or something that would catch up to them in old age.

Gaps in Policy

Participants identified several gaps in policy that were directly related to aging. Their concerns were as follows: the transition off of ODSP; directing services as one ages; expanding care as one ages; aging in place; and maintaining supported decision-making.

ODSP transition

A major concern, which was discussed in almost every focus group, was the fear of transitioning from ODSP to Old Age Security (OAS). At the age of 65, individuals with disabilities are no longer eligible for ODSP and must apply for OAS. This means a reduction in income, loss of dental coverage, and a reduced drug plan. Further, whereas ODSP covers the 25% co-payment to the provincial Assistive Devices Program for equipment, the federal program, OAS does not. Many participants expressed a high level of anxiety about what they were going to do once they were no longer eligible for ODSP. Other participants who were already living on OAS described a reduced quality of life and increased hardship. One participant advised others in the focus group to "get what they need before turning 65." She argued, "People don't know that they need to get what they need before they turn 65, because that's the cut off for ODSP." Such statements, which we heard often, reveal that

participants fear leaving ODSP and the benefits of the program. The impending transition from ODSP to OAS has many planning out their care provisions well in advance. We consider this matter a serious gap in policy that has yet to be addressed by policy-makers.

Self-directed services

Participants also raised concern regarding their ability to self-direct their service needs in their old age. Many worried they might lose the ability to do so or that their ability to direct their services would change. There appeared to be a lot of confusion and misunderstanding regarding policies or protocols for programs like Self-Managed Direct Funding. Participants were worried that an inability to direct their own services would automatically exclude them from receiving Direct Funding. Often participants worried about losing Direct Funding, as the alternative for many was living in an institutional setting. Further, participants expressed concern and difficultly with being able to change or expand their services regarding many different programs (e.g., supportive housing, attendant outreach, and direct funding).

While no one directly expressed that "supported decision-making" should be considered a best practice, many participants alluded to the idea. Participants expressed frustration in not having support for planning as they age. For example, participants were interested in finding support for managing money, writing a will, and negotiating better care. These all seemed to be critical.

Aging in place

Participants expressed concern about "being allowed" to stay in their current homes as they age, particularly people who lived in congregate care settings. Participants of higher socio-economic status were often more capable of navigating programs of support for renovating their homes to make them more accessible. Some participants were planning on moving to, or had already moved to more accessible homes, such as a bungalow, apartment, or condominium. Others were planning on living in seniors' residences and had booked their stay years in advance. For participants with lower socio-economic status, living at home is much less likely without significant changes to policies on home renovation. As with many other themes discussed throughout this report, social class or an individual's socio-economic status truly impacted their way of living[4] (Harrison & Walsh, 2013)

These policy gaps and limitations create hardship and a lower quality of life for people with disabilities as they age. If these gaps were addressed, they may improve individuals' quality of life.

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[4] For more information please see: the American Psychological Associations fact sheet on aging and socioeconomic status: http://www.apa.org/pi/ses/resources/publications/factsheet-age.aspx

Gender, Sexuality, and Race

Women's Health

A number of women in the focus groups disclosed predominantly negative experiences of trying to access gender-specific health care services, for example, gynecological care and breast cancer screening. For the most part, there were issues with support with transfers, and how to physically examine someone who is not "able-bodied". A large number of women also disclosed that they had been refused general medical treatment from a doctor at some point in their lives. One participant had been refused a life-saving operation (cancer surgery) because she has a disability. One participant disclosed she could not get her assistive device into the doctor's office. Many women said they had searched to find a good doctor or a doctor who understood them. Based on what these women shared, we argue that health care services and supports are not set up to accommodate the needs of women aging with disabilities.

A clear exception to this experience was the Anne Johnston Health Station. Many of the participants had positive experiences or positive stories to share about the Station. Some people shared a concern for privacy since so many in the "disability community" shared the same doctor at this facility. Still, participants were more critical of the limited number of doctors available to them outside the Station and urged that all doctor's offices be accessible and welcoming to a variety of different body types, including aging female consumers. Female participants, in particular, wanted more meaningful support from their doctors throughout this next phase of their lives. Finally, participants pointed out that as the population continues to age and more women with disabilities need access to health care, it is going to be exceedingly more difficult to support them within segregated, specialized medical units like the Station. Therefore, expanding and properly enforcing the Customer Service mandate under the AODA would mean more accessible doctors' offices in areas all across the city.

Relationships and Sexuality

Sexuality was a topic in a few focus groups. Participants identified that they were married or wanted a romantic relationship and whether they had children or wanted children. One participant jokingly commented that she wants to have more sex both now and as she ages, and many echoed her sentiment saying they worried about isolation. Sexuality, when discussed in the focus groups, focused on heterosexual and monogamous relationships. There was little to no discussion of surrogate sex, sexual support, or exploring different kinds of sexualities. When people talked about sex it was mostly described in opposition to loneliness or in the context of having children.

Regarding disability, sexuality, and aging three main topics came up: 1) those with partners feared that the role of their partners will shift to that of caregiver more so than that of a lover; 2) others feared isolation as they age; and 3) those with children feared they would burden their children with their care.

LGBTQ Communities

Missing from this research are the experiences of individuals with disabilities who are part of the LGBTQ community. This population was not actively sought out in the research. No participants self-disclosed their sexual identity or discussed issues related to the LGBTQ community during any focus groups; that is, everyone who participated in the focus groups presented with normative gender. People seemed to be enacting cis-gender roles rather than trans or genderqueer identities. However, it is an interesting parallel that there is research emerging such as the Ontario Public Health Association's Trans Health Project (Gapka & Raj, 2003) that shows those who identify as queer or with "atypical" gender presentation are also struggling to negotiate care as they age. This work also suggests people with disabilities often struggle to find supports or staff that is open to supporting individuals from the LGBTQ community. Homophobia and transphobia continue to be pressing issues within the disability support structures (Erickson, 2007).

All of these factors, as well as fear of self-identifying within a group of strangers, may have contributed to a lack of discussion regarding the experiences of LGBTQ people with disabilities in relation to aging. Although there may not have been any self-identified members of the LGBTQ community in the focus groups, there will be LGBTQ people who age into disability. We are suggesting, therefore, that we consider their experiences when making policy.

Racial Tensions

In describing their experiences with different care providers, participants recounted stories of discrimination based on race. Participants shared stories of being treated differently than others and they assigned this difference to racism. Often these experiences are pushed aside as incidences of individual intolerance. However, this leaves unexamined the historical and structural issues that allow for discrimination to persist (Kirkham, 2003). Racial tensions in particular, affect people of colour, especially people of colour with disabilities, and their access to appropriate and comprehensive care. Unattended issues such as racism, ableism, poverty and other systemic forms of marginalization lead to experiences of discrimination. Attention must be paid to addressing these underlying issues in order for substantive change to occur.

Participants also experienced discrimination outside their homes with nurses, doctors, Wheel-Trans drivers, and with other individuals in their everyday lives. To address racial tensions in everyday incidences, we advise service providers to hold comprehensive anti-oppression training sessions for both staff and consumers. When issues of racial tension arise, they should be taken seriously and addressed immediately by management staff. Management staff should be aware of the underlying issues involved in these incidences and consider this in their investigation of the situation. Each organization should have guidelines and consequences clearly written down for when either staff or consumers experience discrimination. Failure to take experiences of racism seriously only further perpetuates harmful stereotypes and leads to further experiences of abuse.

Risk of Abuse

Abuse or the risk of abuse is a major concern for some participants. Participants fear future experiences of abuse as older people with disabilities. Specifically, participants are concerned with changes in care if their cognitive abilities were impaired. The research team had not initially identified the issue of abuse for discussion.

Witnessing abuse

Some participants feared experiencing abuse in the future, because they witnessed abuse in either their home or in hospital settings. Abuse often goes unreported in these facilities because people with disabilities fear retaliation from care providers. Maintaining and increasing dedicated funding for abuse prevention training for direct service staff is essential for identifying, documenting, and mitigating the risk of abuse. Training should be implemented specifically to highlight the needs of aging consumers. Training modules must take into consideration physical and cognitive impairments of people aging with disabilities. The suggestion of implementing a helpline or other means of communication alone is not satisfactory.

Abusers

Abusers of people with disabilities can be children, spouses, other family members, care providers, PSWs, attendants, nurses, doctors, accessible transit drivers, etc. We are not suggesting that people with disabilities are vulnerable to abuse. Rather, this list highlights the number of individuals people with disabilities come into contact with every day as they navigate space. Preventing abuse means comprehensive training for individuals and adequate staffing and resources in many sectors, including those not listed above.

Types of abuse

Participants highlighted that there are also different types of abuse, including physical abuse, verbal/emotional abuse, financial abuse, sexual abuse, and neglect. There is already extensive literature describing these different types of abuse (Krug, Mercy, Dahlberg & Zwi, 2002). However, we would like to highlight another form of abuse participants raised in the focus groups. Participants argued that isolation and lack of general stimulation are also forms of abuse. Neglect from care providers and family is a major concern for participants as they age. Participants are concerned about how they will be treated and what their everyday experiences will be like as they age. These questions continue to be unanswered for people aging with disabilities.

Abuse prevention training

Participants suggested that more training is needed for professionals in acute care facilities — those most likely to help consumers report abuse. One participant argued that doctors and nurses often asked people with disabilities if they were being abused in front of the individuals who were the most likely abusers, including family, care providers, etc. It

should be common practice that questions about abuse be conducted with the person alone.

Working conditions and abuse

Stressful working conditions for care providers can lead to people with disabilities experiencing abuse. Participants argue that currently care providers have only a limited amount of time to assist with tasks like bathing, toileting, dressing, etc. However, participants feared that as they age and their care needs become more complex, that the numbers of hours allotted per consumer would not meet their changed needs. Participants expressed fear that frustrated and stressed staff may take out this aggression on them or neglect their needs to meet their deadlines. Some participants in the study justified future experiences of abuse by arguing that the aging disabled body would be frustrating to manage. This underscores the value attributed to disabled bodies — which decreases as they age — so much so, that consumers are willing to justify, and therefore potentially experience abuse in the future in order to have their care needs met.

Gaps in Services

Focus group participants identified a number of gaps in services in a variety of sectors including attendant services and supports, services for care providers with disabilities, access to proactive health professionals, and mental health services. Overall these areas are highlighted as having significant gaps in services for people aging with a disability.

Attendant/Personal Support Workers, Services and Supports

Focus group participants described accessing many different services to live. These services are delivered either formally by Community Care Access Centres (CCACs), Attendant Outreach programs, Supportive Housing programs, and the Self-Managed Direct Funding program or informally through family and friends. According to our consumer surveys, nearly 30% of respondents received formal supports, while another 47% received a combination of formal and informal support.

Restricted attendant services

Participants expressed concern that the aging process would leave them less independent, and therefore in need of more hours of attendant services. Increases in services were denied to participants either because of budgetary constraints and/or lack of staffing. In fact, participants shared with us stories of services being cut back either because the individual was not incontinent or had family members living with them. Many participants described instances in which they went without services. Participants described how they relied on family members to support them. Some described accessing consumer advocacy groups, social service agencies, medical/occupational therapy documentation, or legal assistance to advocate for maintaining or increasing their hours of attendant services.

Participants on Self-Managed Direct Funding seemed to have the fewest issues. Their concerns centred on providing a living wage to their staff as a means to attract quality support and to decrease staff turnover. They also expressed concern over being able to negotiate more care hours if and when their needs change as they age. In the same vein, participants had concerns over what would happen if they lost the ability to manage their services due to age, because direct funding managers are required to manage their own support.

CCAC-funded personal support workers

Participants expressed a number of frustrations and concerns with service from CCAC-funded PSWs. The issues we heard repeatedly were workers missing shifts; workers being rude or acting inappropriately, (such as talking on the phone); improperly trained workers; workers' expressing their unsolicited opinions on the client's lifestyle; workers leaving early or refusing to do certain tasks; and difficulties contacting case managers.

Furthermore, CCAC- funded PSWs are contracted to do some personal care and light housework. This means that many participants struggled to arrange support with complex bowel/bladder routines, transfers, ventilator support, cleaning, meal planning/preparation, communication assistance, and other tasks that fell outside of the CCACs scope of services for PSWs. Many of the stories participants shared illustrated a strong disconnect between the education and training PSWs receive and realities of the work involved in support services. Many PSWs are trained to work in medical settings and have very little knowledge of disabilities in everyday settings. Participants using Attendant Outreach programs or staff in a Supportive Housing program had varied experiences, depending on whether support was restricted to personal care, or if it included other services such as cleaning, meal planning, etc. If people were able to get support for services outside of the traditional definitions of personal care, they often expressed higher satisfaction with their living situation.

Finally, many participants, with the exception of those on Self-Managed Direct Funding. discussed the difficulty in accessing support outside of the home. For example, attendant care at work, at school, on vacation, or during a medical appointment was described as unlikely, if not, impossible.

The many gaps regarding attendant services were apparent throughout our focus group sessions, and attention to this area is needed. Participants expressed the desire to maintain the current number of support options, but also argued for increasing services overall, not simply to meet the current demands, but to ensure sustained growth that will match growing numbers of people aging with disabilities.

Caregivers with Disabilities

Many of our participants, in addition to having disabilities themselves, were caregivers to older family members or to spouses, partners, and/or children with disabilities. One participant argues, “People don't think disabled people are caregivers, we don’t get credit for that…. [W]e aren’t viewed as caregivers; the caregiver is a non-disabled person caring for a disabled person or an ill person.” The same participant goes on to argue that, as a person with a disability, she understands how the system works and can navigate the system to get the support she needs as a caregiver. Still, it is evident from this story that support for caregivers who have disabilities is non-existent. Often these supports are geared towards non-disabled individuals. Being a caregiver takes a tremendous amount of time. Caregiving for a loved one can swallow up a consumer’s allotted time with a PSW managing another’s care (such as making phone calls for arranging support services). Increasing the hours of support for people with disabilities who are also caregivers would help alleviate some of the burden on these families, especially as they age alongside with those who they are caring for.

Proactive Health

Access to proactive health care services was a substantial concern for participants. Examples of proactive health care include exercise, healthier diets, and access to allied health professionals. However, proactive health care services were generally inaccessible to participants because of a variety of barriers, including financial limitations, structural or environmental barriers, and also attitudinal barriers from health professionals.

Access to proper equipment and healthy eating

Many participants expressed frustration at the limited number of spaces that they could visit to find out their weight. Besides the Anne Johnston Health Station, and some hospitals in the city, there were no other options for weighing individuals who used mobility devices. This was considered by many participants to be a serious barrier to keeping track of their weight — and their overall health.

Participants also expressed a desire to eat healthier to maintain their health through better nutrition. The cost of a healthy diet prevented many participants from eating more nutritious meals. Restricted incomes, either from ODSP or other support programs, could not cover the costs associated with a healthy and complete diet. Many participants therefore relied on artificial supplements as a way to eat healthy foods within budget. An increase to the food allowance for people aging with disabilities — including covering the cost for travel associated with visiting grocery stories — would allow for a better diet, potentially preventing health complications in older age.

Access to allied health professionals

Accessing the services of allied health professionals and other practitioners, such as massage therapy, occupational therapy, physiotherapy, acupuncture, naturopaths, and other non-traditional medicines were important to aging consumers as a way to maintain their present health. Often during conversations about massage therapy, participants began exchanging information with each other, such as phone numbers and names of health professionals who they had seen and who had accommodated their particular needs. Moments like this demonstrated how little information there is available regarding allied health services. In addition, it demonstrates the importance of access to therapies of all kinds, as participants often considered them essential for aging well.

In addition to the lack of information, participants noted that many therapy clinics didn't have the appropriate lifts or other technology to accommodate them. One participant argues, "Massage therapy is really hard to go to because there's no assistance for lifting, and you can't get any technology over there, that could help you have better quality of life as you move into your aging." Another participant shared the same concern about access to health services, but argues that access goes beyond the physical, suggesting that these services should be covered under existing health care plans. She states, "I do get naturopath treatment, I do get massage therapy…. [T]hese things need to be covered under

the health system…to me, chiropractor, massage therapy—all of that needs to be covered— and doctors need to be able to write a prescription and to refer you. This is preventative health. This is health care that helps us maintain what we have…."

Similar to the restraints regarding nutrition, income and financial barriers were often cited as key reasons why individuals did not or could not participate in different types of proactive health care. Poverty and lower social class, as in many other situations, greatly contributed to participants' inability to engage in these activities.

Mental Health

The topic of mental health came up many times during the focus groups. Participants had many complex thoughts and ideas on mental health. Many participants struggled to connect to traditional mental health services; whereas, others struggled against being pathologized or controlled by the mental health system. Many participants identified as having major and minor (situational) depression. At times people disclosed having suicidal thoughts, usually in the context of expressing how isolated they felt, or how they were feeling depressed about their exclusion from various events (often because of systemic barriers, such as unreliable transportation). Many participants also expressed deep concern about the future, which they pointed out increased their anxiety, depression and other experiences of mental health issues. The precarious nature of their futures caused many participants to experience distress in the focus group setting.

Many participants disclosed that they sought out mental health services and had either been rejected by the service provider or could not afford the service. Many participants identified fatigue from living in poverty or constantly having to advocate for services over a long period of time. Participants described depression and burn out as conditions that developed as they aged in a society that actively marginalizes people with disabilities. The issue is two-sided—the need to access mental health services and simultaneously address the social and economic positions of people with disabilities in society.

Transportation

While the issue of transportation may not seem intimately connected with aging and disability, it was one of the major topics discussed in every focus group we conducted.

Access to public transportation

In many major Canadian cities, the general public transportation system is only partially accessible (Malhotra & Rowe, 2014). Typically, when accessibility is considered, it is geared towards wheelchair users. This often leaves people with other disabilities, such as sensory disabilities, to use their own individual strategies to navigate general transportation. In Toronto and many other cities, a separate transit system was developed in place of the inaccessible transit system, specifically to meet the needs of people with physical disabilities. In Toronto this system is called "Wheel-Trans". Mississauga also has an accessible transit system called TransHelp and York Region has Mobility Plus, to name a few.

A systemic perspective on transportation

In the focus groups, many participants reported systemic issues with navigating both general public transit systems as well as the parallel accessible transit systems. Their chief complaints were that the accessible transit system limits spontaneity, is not user-friendly, that they are not treated like valued customers, and staff can often be unfriendly and unkind. There were individuals within the focus groups who really like and said positive things about services such as Wheel-Trans; however, most of these individuals identified that they did not use the services regularly or had assumed that as a person with a disability they would have no access to independent transportation. Therefore, if you are an occasional user, the service would appear to be comprehensive; however, if you use the service regularly, there are systemic problems with the service.

People also reported that access to accessible transit is available only if they were able to provide verification of their needs. This often excluded people with invisible disabilities, cognitive disabilities, those who have learning disabilities, or people who fatigue quickly. As routes are not direct, people talked about trips taking longer than what would be typical, thus creating a "time poverty". Long trips also meant that people with bladder issues, often had to forgo the services or compromise their health or comfort. The current systemic and individual negotiations become a concern given the growing aging population. As individuals age, many of them will "age into" disabilities, so more people will be using these parallel transit systems just as people with disabilities will also be aging and in need of the transportation. It would be in the best interest of all involved to address the access issues of the general public transportation system, creating meaningful access for all citizens.

There are a number of issues with Wheel-Trans. First, it is hard to book rides on short notice. If individuals are unable to transfer to cars, then they are only able to take

accessible buses or accessible taxis, which restricts when they can get rides. Second, Wheel-Trans is often late and on occasion fails to pick up customers — without notice. If customers miss more than four rides in a month they are temporarily suspended from the service as a "punishment". Their practice of suspending riders who often have limited options for travel causes many individuals stress and forces them to leave events early to avoid penalties. Third, it often takes too long to get to any desired location with Wheel-Trans. Some participants shared that they spend 4 hours every day on Wheel-Trans to get to work and back home. Fourth, participants urged for the implementation of a new system that would allow for pick-up times closer to when they are ready to leave. Often, participants argued, that they waited around for hours just to catch their return ride. This left many participants feeling frustrated and disrespected by the company as it conveyed the little value attributed to the time of people with disabilities.

Private vehicles

Participants that were using private vehicles also had concerns as they age and their disabilities/needs changed. A primary frustration was locating funding for adaptions to vehicles. Many participants who were able to drive or who had driven prior to acquiring a disability discussed that funding was either not available at all or the means test to qualify for funding was so low, that one would likely not be able to afford a car if they qualified for the funding. A few participants also disclosed that often finding a close parking spot is key to managing fatigue. Much like parallel transits systems, as the general population ages into disability, there are going to be more drivers with disabilities. It is important that the number of designated spots required for one business reflect the growing number of disabled drivers.

Transportation infrastructure will need to adjust to accommodate the increased number of people with disabilities accessing the service. The city and province must immediately address the issue of transportation services to better support people with disabilities to access safe, affordable, and efficient transportation.

Housing

The housing situation for people with disabilities in the Greater Toronto Area is dire. Currently in Toronto, the Toronto Community Housing Corporation controls the vast majority of accessible rental units. As of 2014, 165,069 households were on the wait list for housing, a steady increase in demand since 2006 (Monsebraaten, 2014). Participants expressed significant frustration at the length of time they were expected to wait for accessible housing. However, participants also raised many other concerns.

In addition to the pressing shortage of accessible rental units, there is also a shortage of rental housing that includes attendant services. Of the accessible rental space available, many are located in underserved areas of the city and in poorly maintained buildings[5]. Participants often complained that the location of their current home was determined by a lack of accessible apartments with subsidy and service, rather than by personal choice. Of the focus groups we conducted in the suburbs, people disclosed they felt trapped in their current living setting, as there were few activities within walking distance of the building.

Congregate living

There are limited options for people with disabilities to live in congregate settings. Most of these settings are geared to those with a label of intellectual disability. People who do not have an intellectual disability, but cannot direct their attendant care services or require their care distributed in another format other than episodic bookings, often fall between the cracks. Further, people who wish to live in community-based, as opposed to institutional, congregate settings, lack options. North Yorkers for Disabled Persons remains a stand-alone model of service and housing. However, we discovered a growing need amongst participants with intellectual disabilities for similar housing arrangements to North Yorkers, but across the city. In addition, similar housing like that provided by North Yorkers for Disabled Persons could also benefit people with physical disabilities who may struggle to quickly and reliably direct their own care. The long wait lists for housing, in addition to the lack of diverse housing and care options for people with disabilities, has led many people with disabilities to age in their parent's home or go into costly long-term care facilities. This phenomenon has meant families are more likely to experience crises as parents age and start to experience age-related illnesses. The result is adults with disabilities are robbed of the opportunity and choice to cultivate lives independent of their parents and families (Kelly & Kropf, 1995).

[5] For an exact list of rent geared-to-income housing the Toronto Community Housing Corporation has a list available on their website. It is noted that the corporation is working to remove the stigma of community housing.

Community and Culture

Community

Participants expressed the importance of strong community connections. Many participants described aging as lonely and scary, and therefore argued that community support —ways to socialize and engage in public life— was very important as they aged. However, participants also highlighted that there were many barriers to their participation in the community, including transportation, structural, and environmental barriers.

Barriers to community participation

Barriers to community participation included transportation, specifically for participants who were drivers, and who, because of age-related changes, have been forced to rely on public transportation. For these participants, public transportation was a significant barrier to their continued movement in and around their communities. Participants also expressed that bad weather also played a significant role. Many participants expressed frustration over sidewalks in the winter that were not shovelled or salted. Participants were also concerned about slippery conditions and mobility devices breaking down from rain or other water damage. The concern was often that the time and money it took to repair mobility devices was too much of a risk to venture outside. Weatherproof devices are considered a necessity.

Community as care

One participant expressed the importance of community for preventing further disabilities — community as a source of care. She argues, "I had a stroke 4 years ago, and now I am in an (electric wheelchair). When I had a stroke, no one found me until 2 days later, and it was too late for them (the doctors) to do anything." Having people around, community to call on, and support staff nearby was considered by some participants essential to preventing accidents. Care, participants suggested, is not just a matter of meeting individual needs. Rather, it's a process that requires strong bonds between people with disabilities and the other people in the places they are living in. There appears to be a clear distinction here between, "being taken care *of*" and "caring *for*"— in that the latter allows an understanding of care that is interdependent.

Difficulties changing communities

Often people with disabilities will be forced to leave their homes and enter into new communities as they age. Some participants expressed anxiety about this process, suggesting that leaving one's home and entering into a new community was often difficult. Some expressed the fear that it might be impossible to recreate a sense of community in a new place. One participant argues, "You create resources for yourself in a community. When you're relocated, you can't just re-build that. Each family has different needs." This suggests that moving when you are an older person with a disability is a complex, difficult process. Many participants therefore advocated for more supports in the home as they

aged, so that they could continue to live within their preferred communities for as long as possible.

Access to Culture

We have described, in some detail, the importance of community as a way of combating isolation and other forms of neglect that can lead to secondary impairments. Still, we would like to make a distinction between access to community and access to culture. By community we mean the spaces and places where consumers live and those who live with them. Culture, however, means being able to move around the city, participate in cultural activities, and engage with fellow citizens. Festivals, movie events, theatre shows, concerts, ethnic events, food events etc. are different examples of cultural events that people with disabilities are often excluded from because of access issues. The City of Toronto, specifically, hosts thousands of these events throughout the year, and participants expressed interest in attending many of these events. However, barriers described elsewhere in this report — transportation, financial limitations, structural barriers — must also be addressed in relation to accessing cultural spaces and events.

Assisted Dying

It is not without significance that we are ending the Analysis section of this report with this controversial and timely issue. The Supreme Court of Canada's decision in *Carter vs. Canada* was delivered after we concluded most of the focus groups. Still, many participants shared their opinions with us about assisted suicide or assisted dying.

Within focus groups the topic of assisted dying evoked strong participant responses. Upon analysis, we determined that social class or economic status are markers that shape participants' opinions. For instance, participants who presented or self-identified as living in poverty argued that there is a growing fear that assisted dying would become a systematic way of disposing of older individuals with disabilities, especially those that could not find space in palliative care or hospice facilities or could not afford private support at home. Their arguments are powerful and poignant, and they follow closely the official stance of the Council on Canadians with Disabilities. The Council argues:

> In the final stages of a terminal illness, at the time when grief and fear may be most powerfully present in our lives, Canadians must now decide for themselves whether life is worth living. Among them are the most vulnerable Canadians, those who are dependent on others, and who are relegated to the margins of social and economic participation. We must not allow them to be diminished again in the coming discussions about their own end of life options.

On the other hand, individuals from higher socio-economic statuses argued in favour of the right to die, citing that this was a matter of individual choice. Participants who supported assisted suicide often also had degenerative disabilities, in addition to economic security. When asked if they had prepared wills or other formal legal documents that stipulate their wishes, more individuals from a higher socio-economic status responded in the affirmative. This was not true for many of the participants who disclosed that they lived in poverty. The fear of the unknown, especially concerning decisions of life and death, left many uneasy about assisted dying. Moreover, those without families or those with estranged families feared that the state would inevitably decide these matters for them, rather than one who knew their wishes.

Assisted dying is a complex issue that is met with both joy and utter fear. Poverty and social class further complicate this issue, like many other issues we have discussed throughout this report. Further exploration and study of people with disabilities' thoughts and ideas concerning assisted dying is strongly recommended. While choice is essential, it must always be examined in relation to the social and political contexts within which individuals are living and making those choices.

Recommendations

Based on the findings from both the survey material and focus groups, we recommend the following:

Policy and Regulatory Measures

- Enforce the *Accessibility for Ontarians with Disabilities Act (AODA)* and ensure compliance across all sectors in the province.
- Extend Ontario Disability Support Program (ODSP) coverage to the end of life.
- Ensure health and wellness offices (hospitals, medical offices, massage therapy offices, etc.) are accessible and have appropriate equipment with properly trained staff to support consumers to access healthcare services
- Develop and revise policies to take into consideration the experiences of people aging with disabilities who also belong to the LGBTQ community.
- Develop and revise policies to take into consideration the experiences of women aging with disabilities.

Funding

- Expand programs such as Attendant Outreach, Supportive Housing. and Self-Managed Direct Funding to meet the growing demand for support for people aging with disabilities.
- Establish a contingency fund to meet increased service demands to support consumers to age in place, including during critical health events.
- Increase the available funding for home renovations and other minor and major structural home changes so that people aging with disabilities can continue to live in their homes.
- Increase dedicated funding for abuse prevention training for direct service staff.
- Increase hours of support for people with disabilities who are also care providers.

Service Delivery

- Meet the growing demand for accessible and affordable housing with support services for people aging with disabilities. This includes maintaining current accessible and affordable housing services.

- Increase service hours for personal support workers so consumers can age in place.

- Develop and implement mandatory and comprehensive anti-oppression training for both service provider staff and consumers.

- Improve access to a variety of mental health services.

Education and Information

- Establish further opportunities for people aging with disabilities to learn about disability and the experiences of disability from diverse perspectives and through different mediums.

- Develop and distribute educational materials that detail the rights and responsibilities of people aging with disabilities in connection to attendant services and other support services in a wide range of accessible formats.

- Develop and distribute educational materials that detail information regarding the Registered Disability Savings Plans (RDSP), including training and information to major financial institutions.

Conclusion

This yearlong project, funded by the Ontario Trillium Foundation in 2014, organized 18 focus groups with 128 participants. The goal of the project was to gather consumer's responses and compile this report, which highlights and annotates the barriers people aging with disabilities face. The project endeavoured not only to explore the experiences of people with disabilities, but also to create an opportunity for consumers to contribute their thoughts and ideas in a way that would inform policy and create positive change. Furthermore, the project intentionally engaged with consumers who are at times left out of academic and policy-based research, such as AAC users.

Finally, this project explores a topic not yet widely researched or discussed by service providers, health care professionals, and to a certain extent, people with disabilities themselves. This ground-breaking research, therefore, calls attention to the experiences of people aging with disabilities. It asks that policy-makers and service providers begin to develop and review existing policies to include this fast growing population. The work ahead is exciting as it points to the success of past initiatives, campaigns, and policies that have extended and enhanced the lives of people with disabilities, so that aging is now a primary concern. As the life expectancy of people with disabilities is improving, so too is their expectation that society will include them in meaningful ways. It is the hope of the research team and all those that have supported the project that together we can aid in ensuring all people with disabilities live full lives.

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Appendices

Appendix 1 - Consumer/Client Survey Results

Centre for Independent Living in Toronto (CILT) Inc.
Aging With a Disability: Consumer Survey
Summary of Results (Numerical Data Only)

Number of Responses: 332

Demographics:

1. Age of respondents:

16-29 = 5.7%
30-40 = 13%
40-55 = 36.8%
55-65 = 25.1%
65+ = 19.4%

2. Nature of disability:

Cerebral Palsy	24.2%
Multiple Sclerosis	19.5%
Spinal Cord Injury	14.6%
Muscular Dystrophy	12.3%
Arthritis	11.6%
Stroke	5.6%
Post-Polio	5.3%
Spinal Muscular Atrophy	5.0%
ABI	4.0%
Spina Bifida	3.3%
Amputation	2.3%
Guillain-Barre Syndrome	1.7%
Osteogenesis Imperfecta	1.7%
Amyotrophic Lateral Sclerosis (ALS)	1.3%
Friederich's Ataxia	1.3%
Parkinson's	1.0%
Other	4.3%

3. How long have you been living with your disability?

Whole life	35%
Less than 10 years	12%
10-25 years	20%
25-50 years	33%

Current Supports and Services:

4a. Do you currently receive support?

Yes = 84.8%
No = 15.2%

b. If yes, what supports are you receiving?

Home with help from family and friends	24%
Home with formal supports	29%
Other	47%

Other:

- CILT
- Direct funding
- Bellwoods
- Both family and formal supports
- Apartment and CILT
- Independent Living
- Caregiver
- PSW & CCAC
- Retirement assistive living
- Volunteers
- Group home
- MS Society

5. Have you ever thought how aging will affect you?

Yes = 76.3%
No = 23.8%

Current Needs:

6. What supports are you currently receiving?

The five most important supports and services consumers are currently receiving:

Attendant services/PSW	9.3%
AAC/Communication Assistance	8.8%
Financial support	4.7%
Equipment needs	4.6%
Access to health and dental care	4.6%

The five <u>least</u> important supports and services consumers are currently receiving:

Systems Navigation	4.3%
Allied Health Professionals	4.4%
Nurturing Assistance	4.4%
Palliative Care	4.4%
Speech Therapy	4.4%

7. How important are the following needs to you at the present time?

The five <u>most</u> important needs to consumers at the present time are:

Attendant services/PSW	9.3%
AAC/Communication Assistance	8.8%
Access to income	4.7%
Access to Health and Dental Care	4.7%
Emotional Well-being	4.6%

The five <u>least</u> important needs to consumers at the present time are:

Palliative care	4.4%
Nurturing assistance	4.4%
Socialization	4.4%
Employment/volunteering	4.5%
Advocacy	4.5%

<u>Future Supports and Services:</u>

8. What supports do you anticipate needing as you age?

The five <u>most</u> important supports and services consumers anticipate needing as they age are:

Attendant services/PSW	9.2%
AAC/Communication Assistance	8.5%
Equipment Needs	4.5%
Access to Health and Dental Care	4.5%

Financial support	4.5%

The five <u>least</u> important supports and services consumers anticipate needing as they age are:

Nurturing Assistance	4.2%
Speech Therapy	4.2%
Systems Navigation	4.2%
Palliative care	4.2%
Allied Health Professionals	4.3%

9. Thinking about your needs in the future, how do you think your prioritization of those needs will change?

The five <u>most</u> important needs to consumers in the future will be:

Attendant services/PSW	9.2%
AAC/Communication Assistance	9.0%
Access to income	4.7%
Financial support	4.7%
Access to health and dental care	4.6%

The five <u>least</u> important needs to consumers in the future will be:

Subsidized/supportive housing	4.3%
Peer support	4.4%
Advocacy	4.5%
Employment/volunteering	4.5%
Nurturing assistance	4.5%

10. In which of the following areas would supports/services make the aging process easier?

In order of significance (from highest to lowest), the following supports/services would make the aging process easier for consumers:

Maintaining independence	10.9%
Accessible health care	10.8%
Financial security	10.4%
Directing your own care	9.6%
Access community resources	8.4%
Mental health/wellness	7.5%
Social networking	7.3%
Social inclusion	7.0 %
Education about aging process	6.7%

Future planning	6.4%
Adaptive/communication equipment	4.9%
Maintaining healthy sexual relationships	4.9%
Increased support to parent/grandparent	2.8%
Communication assistance	2.4%

Anticipation of Future Barriers

11. As you age, which of the following do you feel will be of most concern to you?

Changing health service requirements	29.1%
Changing physical service requirements	28.3%
Changing social service requirements	20%
Changing mental health service requirements	16.6%
Other	6.0 %

Appendix 2 - Service Provider Survey Results

Centre for Independent Living in Toronto (CILT)
Aging With a Disability – Service Provider Survey #2
Summary of Results (Numerical Data Only)

Number of Responses: 35

Demographics:

1. Age group of clients/consumers served:

16-29 = 17.0%
30-40 = 17.9%
40-55 = 17.9%
55-65 = 24.1 %
65+ = 23.1%

2. The most common disabilities seen are:

Stroke	13.8%
MS	13%
Arthritis/Rheumatic conditions	10%
Cerebral Palsy	10%
Spinal Cord Injury	9.2%
Acquired Brain Injury	8.5%
Muscular Dystrophy	6.9%
Parkinson's	6.1%
Spina bifida	6.1%
Other	3.8%
Huntington's Disease	3.1%
Amputation	2.3%
ALS	2.3%
Friederich's Ataxia	1.5%
Osteogenesis Imperfecta	1.5%
Polio	0.8%
Guillain-Barre Syndrome	0.8%

3. Do you see signs of aging in your clients/consumers under the age of 55?

Yes = 83.3%
No = 16.7%

If yes, what are the signs?

Key Themes (number indicates frequency of responses):

Physical Decline – (13)
Increase in Services – (7)
Slips and Falls – (6)
Depression – (6)
Equipment needed – (5)
Cognitive Decline – (5)
Fatigue – (2)
Join Pain – (2)

Current Supports and Services:

4. Indicate what type of supports/services you currently provide most often to your clients:

Attendant services	21.1% (attendant services + PSW)
Communication assistance/AAC	9.1%
Case management	7.9%
Information	6.8%
Socialization	5.7%
Escort/accompaniment outside the home	5.1%
Systems navigation	4.5%
Equipment needs	4.0%
Palliative care	4.0%
Allied Health Professional	3.4%
Other	4.5%
Mental health	3.4%
Nutrition	3.4%
Physical therapy	2.8%
Nurturing Assistance	2.8%
Employment/volunteering	2.3%
Housing	2.3%
Transportation	2.3%
Health/dental care	1.7%
Occupational therapy	1.7%
Speech therapy	0.6%
Financial support	0.6%

Current Needs:

5. **The five most important current needs to clients/consumers are:**

PSW/Attendant services	8.8%
Communication assistance/AAC	8.8%

Transportation	4.7%
Equipment needs	4.7%
Systems navigation	4.7%

The five <u>least</u> important current needs to clients/consumers are:

Allied health professionals	3.8%
Socialization	4.3%
Financial support	4.5%
Physical therapy	4.5%
Escort/accompaniment outside the home	4.5%

<u>Future Supports and Services:</u>

6. **The 5 <u>most</u> important future supports and services to clients/consumers as they age:**

PSW/Attendant services	9.2%
Communication assistance	9.2%
Case management	4.7%
Employment/volunteering	4.7%
Equipment needs	4.7%

The 5 <u>least</u> important future supports and services to clients/consumers as they age:

Nurturing Assistance	3.8%
Allied Health Professional	4.5%
Housing	4.5%
Occupational therapy	4.5%
Palliative care	4.5%

<u>Future Concerns:</u>

7. What services/supports do you feel would make the aging process easier for your clients/consumers?

Maintaining independence	10.2%
Access community resources/alternatives	9.3%
Financial security	9.3%
Mental health/wellness	9.3%
Accessible health care	8.8%
Future planning	8.3%
Social inclusion	8.3%
Awareness/education of aging process	7.3%

Social networking	6.8%
Directing own care/attendant services	6.3%
Adaptive/communication equipment	5.8%
Increased support to parent/grandparent	4.4%
Communication assistance	3.9%
Maintaining healthy sexual relationships	1.9%

Appendix 3 - Partner Organizations

Access Independent Living Services
ARCH Disability Law Centre
Birchmount Bluffs Neighbourhood Centre
Centre for Independent Living in Toronto (CILT)
Multiple Sclerosis Society
Muscular Dystrophy Canada
North Yorkers for Disabled Persons
Ontario Federation for Cerebral Palsy
Spinal Cord Injury Ontario
Tobias House Attendant Care

Appendix 4 - Community Organizations

March of Dimes
Participation House Markham
Huntington Society of Canada
PACE Independent Living
Anne Johnston Health Station

Appendix 5 - Focus Group Questions

We are asking you to do 2 different things in this focus group: 1) is to reflect on your past experiences; and,2) is to think about future experiences. We are asking you to do this because aging is a process that takes place across time - and so thinking about the past and into the future will be necessary.

1) What are some words that come to mind when you think about aging?
2) These are a list of services and supports: Does anyone use any of the support services listed?
    a. Allied health professionals (i.e. naturopath, massage therapist)
    b. Attendant services
    c. Case management
    d. Communication assistance
    e. Employment/volunteering
    f. End of life/Palliative care
    g. Equipment needs
    h. Health/dental care
    i. Housing
    j. Information
    k. Mental Health
    l. Nurturing assistance (i.e. attendant service support with parenting tasks)
    m. Nutrition
    n. Occupational therapy
    o. ODSP/Financial support
    p. Personal Support Worker
    q. Physical therapy
    r. Socialization
    s. Speech therapy
    t. Systems Navigation (i.e. support in coordinating services)
    u. Transportation

3) What support services do you use?
4) How do you anticipate these support services changing as you age?
5) What is the number one issue that you feel you may face as someone aging with a disability?
6) What about these issues makes them so important?
7) Do you plan for the future?
    a. If yes, what do you plan for?
    b. If no, why don't you plan for the future?
8) What do you think about when you think about aging with dignity?

Appendix 6 - Sample Call for Participants

Aging with a Disability[6]

What: The Ontario Federation for Cerebral Palsy is looking for ten (10) interested participants to attend one (1) Focus Group

Where: Ontario Federation for Cerebral Palsy – Community Room
1630 Lawrence Avenue West
North York, Ontario M6L 1C5

Date: Wednesday, August 20, 2014

Time: 12:00pm – 3:00pm
(Note: if you are taking Wheeltrans, please schedule your arrival for 11:30am and your departure at 3:30pm)

Access Independent Living Services, in partnership with a multiple-disciplinary group is embarking on a **research project looking at the experiences of people with disabilities and the aging process.**

People with disabilities are generally living longer and healthier lives, due to advancements in medicine, improved living situations, and care practices, and continued funding for disability supports, among other things. However, the current support systems in place are not equipped to handle the growing number of people aging with disabilities. One of the reasons for this shortfall is lack of understanding about the aging process among people with disabilities. This study intends to address this lack of understanding by connecting with and engaging members within the community who have disabilities. This will be done through a series of focus groups during the month of August 2014.

Some of the questions we will be asking during the focus groups include:

- What is the aging process like for people with disabilities?
- How do services change throughout the aging process, and how can they be improved so that the aging process is respectful and dignified for people with disabilities?
- What unique challenges do people with disabilities and their care providers encounter throughout the aging process?

[6] Calls for Participants always included Access's logos, in addition to Trillium's logo and the participating organization.

The information that we collect from the focus groups will be used to compile a report about the aging process for people with disabilities. This report will be available to all participants and to the public by the Summer of 2015.
If you are interested in taking part in a focus group on 'disability and aging', we encourage you to **follow this link and sign up** to attend one of the focus groups:
https://www.eventbrite.com/e/aging-with-a-disability-the-ontario-federation-for-cerebral-palsy-tickets-12298859219

You can also register to attend the focus group on August 20th, 2014 at OFCP by either emailing (awad@accessils.ca) or calling us (416-780-1650, ext 226). Please indicate in your message your name, your affliation (OFCP), any dietary restrictions, and accessiblity needs you may require in order to participate (along with a phone number). Attendant services will be provided. Light refreshments will be served.

You will receive a call back confirming your attendance.

If you are unable to attend the focus group at OFCP on August 20th, 2014, but are still interested in contributing to the study, please email (awad@accessils.ca) or call 416-780-1650 ex 226. Please leave a return email or phone number (and appropriate time to call back) and we will contact you to arrange your attendance at a different time and place.

Project Coordinator: Fady Shanouda

Facilitators: Chelsea Jones
Mary Jean Hande
Samantha Walsh
Terri-Lynn Langdon

Funding for this project is provided by: Ontario Trillium Foundation

Appendix 7 - Introduction and Welcome

Hello everyone. My name is Fady Shanouda and I am the Project Coordinator for the Aging with a Disability Project. On behalf of all the partner organizations, the peer-facilitators, Chelsea Jones, Mary Jean Hande, Samantha Walsh, and Terri-Lynn Langdon, and myself we would like to welcome you to the Aging with a Disability Project and thank you in advance for your participation and contribution today. This focus group is one of twenty we will be conducting in and around the GTA between now and January.

Access Independent Living Services is the lead organization on this project. The purpose of this study is to learn about your understanding of aging, and the aging process for people with disabilities. In this focus group, we want to understand how disability and aging are related generally, and we also want to understand how aging as a disabled person will impact services/supports.

The format today is as follows:

Your facilitators are Mary Jean, Chelsea, Sam, Terri-Lynn and myself. _____ will be asking the questions and facilitating the discussion. _____ will also be keeping track of time and ensuring we take breaks and that the focus group finishes on time. We will break at _____ am/pm for 30 minutes and resume at _____ am/pm. The focus group will end promptly at_____ am/pm. Before you leave, please be sure to sign a consent form. You are welcome to come up to us after the focus group has ended to ask us any questions or to clarify a point you made during the discussion. _____ will be taking notes throughout the focus group. _____ will be ensuring that the discussion is being recorded. _____ will be in charge of the flip chart.

Before we go any further, we would like to start by making a few acknowledgements:

- I would like to acknowledge the attendants who will be working with us today, _____ and _____. They will be around during the focus group and the breaks to assist individuals in any way.

- I would also like to acknowledge the Sign Language Interpreters/Communication Facilitators here today, _____ and _____.

This focus group will strive to be a positive, anti-oppressive, accessible space. This means:

- We welcome you to share or not share your thoughts, opinions, and experiences as we move through the questions.

- You will be sharing experiences, stories, and opinions that others in the group may share, while others will disagree. Please share if you agree or disagree with another participant's ideas, but do so in a respectful manner.

- In this space everyone can speak or express their ideas in different ways. In the same regard, please be mindful that we all have differences in the room, including different ways of communicating, different languages, and the different levels of knowledge. Please be aware of how much you are sharing and allow for others in the group to share as well.

- We welcome you to share all experiences, including experiences that may be considered negative. You are welcome to swear, get mad and express yourself with using your preferred language style. Please feel free to answer a question with a question.

- As this is an accessible space, please speak one at a time and introduce yourself before you speak every time. We have provided you with materials in your packages for people who want to jot down their ideas, key words, and images/pictures. If you are comfortable and willing, please share these with the group or the facilitators either during or after the focus group.

- Your participation is voluntary. In other words, you can decide to leave the research at any time, for any reason, and your decision will not affect your relationship with Access Independent Living Services, the Ontario Federation for Cerebral Palsy or any of the researchers here.

- Please feel free to move around the room if you need to stretch or need a break. You are free to leave the room at any time.

- Washrooms are located _____.

- Finally, as the focus group is made up of a group of individuals, we cannot guarantee that your identity or participation in the project will remain confidential. However, we ask all participants to keep all comments made during the focus group confidential and to not discuss what happened during the focus group outside the focus group.

- Before we continue, does anyone have any questions?

    - If you have any questions throughout the focus group please ask them at any time. If after the focus group or even after the research is collected you have questions please get in touch with me and I will do my best to answer.

We are just going to take some time now to identify how everyone communicates and make sure that facilitators know your communications needs. Let's start with everyone introducing.

Appendix 8 - Consent Form

Trillium Research Advisory Committee: Michael Mathieson, Cathy Samuelson and Stacy Lintern

If you have any questions about this project, at any time, including following your participation, please contact Michael Mathieson at michaelm@accessils.ca or (416) 780-1650 ex. 223

The purpose of this project is to document the experiences of aging for people with physical disabilities.

People with disabilities are generally living longer and healthier lives, due to advancements in medicine, improved living situations, and care practices, and continued funding for disability supports, among other things. However, the current support systems in place are not equipped to handle the growing number of people aging with disabilities One of the reasons for this shortfall is lack of understanding about the aging process among people with disabilities**.** This project intends to address this lack of understanding by connecting with and engaging members within the community who have disabilities. This will be done through a series of focus groups in the Fall of 2014.

You have identified yourself as someone interested in participating in this project. Participation in this project means you will be available to participate in one (1) focus group lasting approximately three (3) hours. A list of questions or an interview guide will be available to those interested on the day of the focus group.

The focus group will be audiotaped. The project coordinator (Fady Shanouda) and peer-facilitators (Terri-Lynn Langdon, Mary Jean Hande, Samantha Walsh, and Chelsea Jones) will attend the focus groups. They will be taking notes, checking on recording equipment, assisting with communication, and facilitating the discussion. After the focus group, there may be a follow-up phone call in order to clarify information.

It is possible that during the focus group you will recall and ponder on past and future experiences that may make you feel uncomfortable and/or upset. If this happens you do not have to continue talking about that particular event or situation. You are always welcome to stop participation in the focus group at any time. If after the focus group you are feeling uncomfortable and/or upset, please speak with the project coordinator and/or one of the peer-facilitators and we will do our best to find the appropriate supports for you.

The information that we collect from the focus groups will be used to compile a report about the aging process for people with disabilities. We expect to be conducting focus groups until December 2014, and writing a report afterward. This report will be available to all participants and to the public by the Summer of 2015. This project will also be presented in public places and at different organizations and to government agencies.

You may choose or not choose to allow your identities to be known when quoted in the final report. If you wish to remain anonymous potential identifiers will be omitted or masked (names, countries, organizations, voice, etc.) and you will only be identified by a code name (that you can choose).

Please choose your pseudonym if applicable:_____

Audiotapes of the focus groups will be stored in a locked cabinet at Access Independent Living Services at 50 Ashwarren Drive, for seven (7) years after the report is released to the public. After seven (7) years, the data will be destroyed.

Providing additional information after the focus group is encouraged so that the experiences you shared in the focus group are presented accurately. You are also free to remove or change any information you provided during the focus group after the focus group.

The only cost to participating in this project will be the time involved in completing the focus group (approximately three (3) hours). You will be given a $10.00 gift card honorarium for participating in the project prior to the start of the focus group. Your participation is totally voluntary and you may withdraw at any time during the project, for whatever reason with no adverse consequence to you. If you choose to withdraw, you will still be paid the honorarium and your sections in the focus group data will be destroyed.

If you have questions about your rights as a participant, please contact Michael Mathieson at michaelm@accessils.ca or (416) 780-1650 ex. 223.

Yours truly,

Fady Shanouda
Project Coordinator
Access Independent Living Services

Consent Form to Participate in the Project

I, _____, have read the accompanying letter of information and/or have had the nature of this project explained to me. I agree to participate in this project. All questions about the project have been answered to my satisfaction.

_____
Name of participant

_____
Signature of participant

_____
Date

_____
Signature of Project Coordinator or Peer-facilitator

_____
Date

If you had assistance signing your signature, please include the name and signature of the person who provided the assistance.

_____
Name

_____
Signature

_____
Date

_____
Signature of Project Coordinator or Peer-facilitator

_____
Date

Participant's Copy - Consent Form to Participate in the Project

I, _____, have read the accompanying letter of information and/or have had the nature of this project explained to me. I agree to participate in this project. All questions about the project have been answered to my satisfaction.

_____
Name of participant

_____
Signature of participant

_____
Date

_____
Signature of Project Coordinator or Peer-facilitator

_____
Date

If you had assistance signing your signature, please include the name and signature of the person who provided the assistance.

_____
Name

_____
Signature

_____
Date

_____
Signature of Project Coordinator or Peer-facilitator

_____
Date

This is a copy of the signed consent form for the participant's records

Glossary of Terms

Allied Health Professionals: Allied Health Professionals are a group of professionals distinct from medicine, such as dentistry and nursing that are a part of health care teams. Other allied health professions include dental hygienists, physical therapists, occupational therapists, speech and language pathologists, dieticians, audiologists, and respiratory therapists. Allied Health Professionals have their own professional scope of practice, and regulatory bodies, and establish their credentials through diplomas, certified programs. and continuing education.

Augmentative Assistive Communications: Augmentative and Alternative Communication (AAC) refers to all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. AAC is for those who are unable to use traditional speech and require an augmented system to communicate. For example, consumers may have specific types of cerebral palsy (not everyone one who has cerebral palsy has a communication difference), Autism, Amyotrophic Lateral Sclerosis (ALS), and Acquired Brain Injury, or they may be Stroke Survivors, etc. Augmentative aids such as picture and symbol communication boards and electronic devices are available to help people express themselves. In the case of this research project, individuals who used bliss boards or voice output systems (talking computers) participated in some of our focus groups.

Cisgender: The term cisgender refers to someone who identifies socially with the gender that is assigned to them given their physical appearance (genitals). Cisgender is sometimes referred to colloquially as ones' "biological sex". For example, a person who was identified at birth as being a girl and self-identifies as such would be a ciswoman. Cisgender is used to highlight the idea that gender is fluid. This allows for people who have transitioned from their cisgender to the gender they feel fits with whom they are intellectually and spiritually to identify without creating a binary.

Cognition: Cognitive functioning includes the processes by which an individual perceives, registers, stores, retrieves, and uses information. Some conditions in which cognitive functioning are impaired are dementia, delirium, and depression. Cognition is a medical term that considers the experience of cognition only through a medical lens.

Disability Community: The term "disability community" refers to the collective of people with disabilities within the Greater Toronto area (GTA). This is not to say that all disabled people are the same, but rather that there are general trends, themes, and debates amongst people living with disabilities. Moreover, many people with disabilities within the GTA have mobilized using their disability identity to connect with others and advocate for a higher quality of life for all people with disabilities.

Independent Living: Independent Living (IL) is founded on the right of people with disabilities to: live with dignity in their chosen community; participate in all aspects of their life; and, control and make decisions about their own lives. Independent Living is a vision, a philosophy and a movement of persons with disabilities. Born on California university campuses in the 1970s, the movement spread to Canada in the 1980s, and has since reached around the globe and changed the way people view and respond to disability.

Middle-class: This is a term often used when discussing household income. This is typically a household who makes a living wage and have basic needs and some extra income for savings or entertainment.

Palliative Care: Palliative Care is a specialized health care approach that focuses on improving the quality of life of patients and their families who are experiencing a life threatening illness. A team of health care professionals such as physicians, pharmacists, nurses, chaplains, social workers and psychologists work together to create a plan of care designed to help relieve the suffering of patients and their families.

Supported Decision-making: An accommodation in legally regulated decision-making processes to protect the right to exercise self-determination for those vulnerable to losing their rights (Bach, 2006).