

Aging with Developmental Disabilities: Implications for Long-Term Care

Kristin Dorrance

Interdisciplinary School of Health Sciences
Faculty of Health Sciences

University of Ottawa

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ABSTRACT

Background: Persons with developmental disabilities (DDs) represent about 1-3% of the total population in Canada; however, very little statistical data exists regarding this population in the context of long-term care (LTC). As the life expectation of these individuals increases, the distinct needs they have that are associated with aging should be addressed in LTC to help improve the quality and relevancy of the care they receive.

Methods: An exploratory qualitative study. Semi-structured interviews were conducted. Open coding of interview transcripts, and content analysis was completed. Descriptive statistics of the sample were calculated using Excel.

Results: All participants had experienced earlier functional decline which resulted in changes in their care needs. Often this meant needing to change their assistive devices. Many participants feared losing their independence as they aged.

Conclusion: There is insufficient understanding of the unique needs that face people aging with DDs or how they access LTC. The preference for these individuals is to age in place, their independence must be maintained in order for this to be successful. Three factors help to facilitate this: assistive devices, attendant care and accessibility of health care services.

Contexte: Les personnes ayant un handicaps developmental représentent environ 1-3% de la population totale au Canada. Cependant, très peu de données statistiques concernant cette population existent dans le contexte de soins de longue durée. L'espérance de vie de ces personnes augmente, les besoins distincts associés au vieillissement devraient être

examinés pour aider à améliorer la qualité et la pertinence des soins qu'ils reçoivent dans les soins de longue durée.

Méthodes: Une étude qualitative exploratoire. Des entrevues semi-structurées ont été menées. Les transcriptions d'entrevues ont été codées en utilisant un style de codage ouvert et l'analyse de contenu a été accomplie. Les statistiques descriptives des participants ont été calculées.

Résultats: Plusieurs thèmes sont devenus apparents. Tous les participants avaient connu un déclin fonctionnel à un jeune âge qui a entraîné des changements dans leurs besoins de soins. Souvent, cela signifie avoir à changer leurs appareils et accessoires fonctionnels. De nombreux participants craignaient de perdre leur indépendance en vieillissant.

Conclusion: Il y a une méconnaissance des besoins uniques auxquels font face les personnes vieillissant avec un handicap développemental et la façon dont ils accèdent aux soins de longue durée. La préférence pour ces personnes est de vieillir en place, leur indépendance devant être maintenue pour que ce soit un succès. Trois facteurs contribuent à faciliter ceci: les appareils et accessoires fonctionnels, les soins auxiliaires et l'accessibilité aux services santé.

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CHAPTER 1- Introduction

Persons with developmental disabilities (DDs) are living longer and they are requiring long-term care (LTC). In Canada, very little statistical data exist about this population in LTC. This population has distinct needs as it ages, for example minimizing functional decline and management of co-morbidities, and should be addressed in LTC; however, we do not have an adequate understanding of what care these persons require and receive. There are serious, safety-related needs which may be addressed using a variety of strategies and technologies. It is important to assess the lived experiences of persons with DDs so that society can better design and implement care strategies and technologies that fulfill their unique needs and address their preferences. A specific subset of this population was examined; this included individuals with Cerebral Palsy (n=9) and Spina Bifida (n=1)

Research Objective

To conduct an exploratory qualitative research study of the perceived barriers and facilitators to providing effective long-term care for persons with a DD, and the role for technologies in this process.

Research Questions

1. What are the unique functional and psychosocial needs of individuals aging with DDs?
2. What are the desires and preferences of persons with DDs in access to LTC and assistive technology (AT)? How well are these needs being met in LTC?

3. What are the perceived barriers and facilitators, challenges, and experiences of a person with DD accessing ATs and other resources in LTC?
4. What theory or model may best explain the perceptions of care needs of persons who are aging with DD?

Significance of Research

As the life expectancy with persons with DD continues to increase and approach that of the general population, it is important that the knowledge of LTC in this population improves also. Aging with a DD is a complex process that is a unique experience to this population. It is essential to understand the barriers and facilitators of accessing LTC and AT so that they can receive appropriate care that meets their unique needs. With a deeper understanding of the experiences of aging with a DD, appropriate changes that need to be made can be identified.

CHAPTER 2

Background - Literature Review

Literature Review - Methods

A full scoping review was performed in order to see what information on this topic exists; a broad net was cast. The following five databases were searched: Ageline, CINAHL, Embase, MEDLINE (Ovid), and PsycINFO. The search terms that were used included: Developmental Disability, Spina Bifida (SB), Cerebral Palsy (CP), Down Syndrome (DS), Aging, Long-term Care, Assistive technology/devices. These search terms were MeSH headings in the MEDLINE database, and were also subject headings in all the other four databases.

Specific criteria was used in the review, they are as follows. The population of interest included individuals aging (over the age of 50) with developmental disabilities; such as CP, SB and DS. Articles published between January 1998 to October 2013 were included in the review. The following parameters were also used; items with full text, and English language only.

Initial results produced a total of 851 articles. Amongst these articles were many that focused on the health of the parents of individuals with DDs, were specific to children or adolescents with DDs, these were excluded. Book reviews, and studies with animal testing were also excluded. A search selection process flow can be found in Appendix A. A total of 114 articles were reviewed.

Developmental Disabilities

Developmental disabilities (DDs) are complex and heterogeneous; they are defined as chronic impairments that appear before age 18 that will continue indefinitely (Parish, & Lutwick, 2005).

The Developmental Disabilities Act in the United States further defines a DD as a mental or physical impairment that results in considerable functional limitations in at least three of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency (Connolly, 2001). In Ontario, the definition of a DD was created in Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act in 2008 and is based on reduced capacities in one or both of the following ways:

- “adaptive functioning” means a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills in his or her everyday life
- “cognitive functioning” means a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences.’2008, c.14, s.3 (2).

For the purposes of this research and recruitment, DDs will refer to Cerebral Palsy (CP), Spina Bifida (SB), and Down Syndrome (DS). In Canada, it is estimated that approximately 1-3% of adults above the age of 15 have a DD (Kim, El Hoyek, & Chau 2011). In Ontario, it is estimated that 0.8% of adults between the ages of 18-64 have a DD (Lunsky, Balogh, Cobigo, Isaacs, Lin, & Ouellette-Kuntz 2014). Estimates of incidence of DS are about 1/800-1000 live births (Kim, et al., 2011).

In the past 20 years, the life expectancy for persons with DDs has greatly increased; it is about the same as the general population for most DDs (NACA, 2004). Approximately 12% of individuals with a DD are over the age of 65, a similar proportion to that in the general population (Connolly,

2001). The life expectancy for persons with DS is not as high as that of other DDs, but it is also increasing over time (Kim, et al., 2011). This increase in life expectancy results in a need for geriatric care and LTC. However, geriatric care and disability care have evolved on two separate tracks; meaning that geriatric care is ill-equipped to treat persons aging with DDs, and disability care is not equipped to treat the complications of aging with a DD (Temkin, 2009). A study in the United States surveying recent geriatrician graduates, rated 74% of them as ill-equipped to provide competent care to persons aging with DDs. (Tyler, Rader, Campbell, Zyzanski, S. & Panaite, 2009).

It has been recognized that these epidemiological statistics need to be regarded with caution. Freedman (2014) identified several gaps that contribute to the discrepancy in the numbers. For example, Freedman (2014) illustrates how the prevalence of individuals with a disability greatly changes depending on which methods you use to calculate this prevalence. According to Temkin (2009) there are many reasons that assessing this population is difficult, they include:

- i. inconsistent definitions of disability
- ii. varying definitions of aging
- iii. likely systematic under-reporting of disabilities in survey-based estimates
- iv. the large number of people with developmental disabilities living entirely outside the formal service system, rendering prevalence estimated on the basis of service statistics unreliable

- v. widely varying estimates of the general prevalence of developmental disabilities

This gap in care has stemmed from earlier transitions in care. The transition from child-centered care to adult-centered care for persons with a DD has been well documented. There is a multitude of resources targeted at children with DDs; treatment clinics, or child rehabilitation centres, have access to a multi-disciplinary team of health care providers (HCPs) that have specific disability knowledge (Young, 2006). Once a person with a DD enters adulthood they are no longer eligible to receive pediatric care, and when they transition into the world of adult health care, there is a lack of expertise by HCPs as well as few resources to educate on how their dynamic disabilities change as they age (Binks, Barden, Burke, & Young, 2007). Adults with DDs often have poorer health outcomes that may result from this. They often lack basic education about healthy life choices, are often not the targets of health promotion programs, and do not receive many of the preventive health measures as the general population, for example mammograms as a screening tool for breast cancer (NACA, 2004). This lack of expertise continues throughout the transition into geriatric care, where persons with DDs still do not have access to disability-specific care (Temkin, 2009). Glew (2011) reports the possible consequences of inadequate care:

“A vicious cycle of decreased activity, deconditioning, and loss of muscle mass leads to contractures, fatigue, pain, and less ambulation in many people with CP. As activity decreases, musculoskeletal tightness and muscle tone increase and the consequences of

contractures accumulate. This results in decreased functional ability in numerous activities of daily living.”

Aging with a DD has been noted to have unique differences than aging without disability. There are secondary conditions, or co-morbidities, that have been associated with aging with a DD. For example, there is a higher incidence of osteoporosis in women with CP (Temkin, 2009). Persons aging with DDs also have higher rates of thyroid diseases, heart diseases and sensory impairments (Temkin, 2009). Each subgroup of disability also has complications that can arise: persons with DS are more likely to develop dementia or epilepsy than the general population; persons with CNS-related DDs, such as CP and SB, are more likely to develop acute respiratory diseases and vision disorders (NACA, 2004). These health outcomes are highlighted in Table 1 below. Additionally, it has been found that persons aging with DDs often experience functional decline earlier in life by comparison to the general population (Glew, 2011). Persons with DDs may experience signs of aging up to 20-30 years earlier than the general population (Hirst, Lane, & Seneviratne, 2013).

Common Health Outcomes	Developmental Disability		
	CP	DS	SB
Early functional decline	X	x	x
Acute respiratory disorders	X		x
vision disorders	X		x
Alzheimer's Disease		x	
Congestive heart failure	X	x	x
Hypertension	X	x	x
Coronary disease	X	x	x
Epilepsy		x	
Urologic issues			x
Osteoporosis	x		
Obesity			x
Musculoskeletal deformities	X		
Thyroid conditions	X	x	x
Gastro-Esophageal Reflux Disease (Chronic Heartburn)	X	x	x

Table 1: Common health conditions and outcomes in individuals aging with DDs by disability type

Co-morbidities in persons with DDs are very common. The National Advisory Council on Aging (2004) suggests that this is in part due to:

“Few health professionals have expertise in treating persons with developmental disabilities, and communication between the professionals and the patient can be difficult. For these reasons, many older persons with developmental disabilities develop chronic conditions or diseases that could have been prevented or treated earlier, if they had been detected.”

Additionally, Alexander, Bullock, and Maring (2008) stipulate that health care providers are unfamiliar with these specific health needs, they may be apprehensive to provide services to

older adults with DDs. Moreover, it may be difficult for these individuals to access care due to physical inaccessibility of the equipment and/or examination room (Hirst, et al., 2013). When a person with a DD does receive care, these co-morbidities are often misdiagnosed and are wrongly attributed to the DD (Kim, et al., 2011). Persons with DDs are estimated to have 5.4 medical conditions; which can include congestive heart failure, hypertension, and coronary disease (Kim, et al., 2011). An individual with a disability is 6 times more likely to suffer mortality from a preventable disease than the general population (Alexander, et al., 2008).

The health status of an individual with a DD is generally lower than both the general population and the population with other disabilities (Alexander, et al., 2008). Close to 50% of individuals with DDs rated their health status as “fair or poor” (Shooshtari, Naghipur, Zhang, 2012). Persons with DDs also access health care services more frequently than individuals with other disabilities (Shooshtari, et al., 2012). An emphasis on prevention of secondary conditions can be achieved with proper health screening and maintaining a healthy lifestyle (Alexander, et al., 2008).

Long-term Care Setting

Long-term care is often considered to be exclusively linked with aging and older adults. However, the basic definition of LTC is not dependent on the age of the individual receiving services. For the purposes of this research, the following definition of LTC will be used:

“Long-term care is the system of activities undertaken by informal caregivers and/or professionals to ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible

degree of independence, autonomy, participation, personal fulfillment, and human dignity.” (Fahey, 2003)

In the past 40 years, there has been a shift from persons with DDs living in large institutions to a more community based setting (Parish & Lutwick, 2005; Kim, et al., 2011). The community based setting consists of group homes, care provided in individual apartments by community service agencies, and supported living units (Kim, et al., 2011; Temkin, 2009; Glew, 2011). Other community- based services may include: respite, community participation supports – day, employment, and vocational supports, and specialized home care. However, there is little data about how/where LTC is delivered to persons aging with DDs (NACA, 2004). According to Parish and Lutwick (2005) LTC is provided to a relatively small number of persons with DDs (~15%). Temkin (2009) suggests that LTC facilities do not provide a successful care environment for persons with DDs. Further, he suggests that this may in part be due to the lack of disease-specific skills of the care providers. However, training to provide appropriate care in the community setting is also lacking. Community settings offer more social opportunity and participation. (Kim, et al., 2011)

Technologies to Assist Care

Assistive technologies play an important role in the life of an individual with a disability. Assistive technology (AT) can be defined broadly as applied knowledge; this definition encompasses the wide range of applications that AT provides. AT ranges from mobility and safety devices to educational or exercise programs. This broad definition of AT facilitates the ability to encompass all ranges of AT that a person can receive, not only those that are used to assess physical or mobility issues. The atypical nature of aging with a DD has been highlighted above. However,

there is very little research on the intersection of aging with a DD and the use of AT. Wilson, Mitchell, Kemp, Adkins, and Mann (2009) note that this atypical aging leads to declines in functional and physical abilities, and that an appropriate solution to this issue is the use of AT.

In a study performed by Wilson, et al. (2009), they attempted to examine the effects of AT use over time in persons aging with DDs. What they discovered was that the number of pieces of AT used by participants increased over time (based on the need of it by the participants.). Also, that functional decline was delayed in the treatment group as compared to the control group. The results of this study indicate not only that there is an increased need for AT as persons with DDs age, but also this increase in use of AT can help to delay the functional decline common to aging with a DD. However, fewer pieces of AT are used to manage more functional limitations in nursing homes than in the community (Hammel, Lai, & Heller, 2000). Hammel, et al. (2000) states that the use AT as well as environmental interventions can help to delay or prevent functional declines, health conditions, dependent care placements as well as increase social participation.

Wilson, *et al.*, (2009) also suggested that appropriate implementation of AT includes: identification of appropriate AT, adequate education on the use of each specific AT, and proper environmental modifications. It is important to also consider the individual's environment in which the technology or device is being introduced, integrate the AT into their everyday life habits and routines and provide long-term support for both the consumer and their caregiver (Hammel, et al., 2000).

Hammel, et al. (2000) identified the following most common barriers to accessing AT: funding, information on how to access services and products, long-term training, device complexity, limited availability, and few qualified service providers. Wilson, et al. (2009) identified that there

were few other studies in which they could compare their results. The article that they used as a comparison measured similar outcomes in the frail elderly, not individuals aging with DDs. This further emphasizes the gap in the literature about the uses of AT in persons with a DD.

Further research on the intersection of AT uses and aging with a DD needs to be completed. Research should be focused on gaining an understanding of this intersection by the exploration of the lived experience of those aging with DDs. This type of exploratory study would help to identify the specific needs of this population as they age with these complex disabilities. The knowledge gained would be useful for LTC planners and policy makers as they try to address the increasing complexity of needs of people who are aging with disabilities and chronic conditions.

[Environmental Review](#)

The following resources were also discovered by conducting an environmental scan. The Ontario Partnership on Aging with a Developmental Disability (OPADD) is an organization that partners with LTC service providers, academic sources and the government. The OPADD has eight regional committees across Ontario that attempt to improve the quality of life of older adults with DDs particularly by the use of transition planning. The OPADD is actively involved in applied research, caregiver education, service delivery and policy development.

One of the major and most influential partners of the OPADD is the Ontario Provincial Ministry of Community and Social Services (MCSS). As a ministry of the provincial government, they have the power to influence changes in policy which could greatly benefit persons aging with DDs. The MCSS created Developmental Services Ontario which is a centralized location that list information on all the current supports for an individual of any age that has a DD and allow these

individuals to apply for these supports and services. MCSS also implemented new legislature in 2008, the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act. This legislation aims to improve services and supports and services to adults with DDs and their families. (*Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*) Additionally, the MCSS recently announced that they would be investing more funds in order to try to improve services and enhance supports of older adults with DDs. The creation of new legislation and the investment of more funding emphasizes the importance of further investigation into the needs of persons aging with DDs. Similar resources and organizations have been located in the United States.

In Ontario, there are several options for residential supports and services. These include supervised group living (or group homes), long-term care facilities, assisted-living units, community outreach attendant services and direct funding services.

CHAPTER 3 - METHODOLOGY

Research Design

In this study, a qualitative approach was used. By using this approach, an understanding of the person with a DD's perceptions and experiences with LTC was gained. Using this approach, it was also possible to identify opportunities for improving experiences through technology. A qualitative approach provides a means of viewing an event through the eyes of the population being studied as they experience it (Barriball & While, 1994). Using detailed descriptions of an experience can be used to further our understanding, and gives us the ability to analyze the experience. Additionally, it provides insights to their attitudes, experiences and behaviours (Rowley, 2012).

To date, there is no effective conceptual framework that has been identified in the literature for persons aging with developmental disability in LTC. Therefore, a grounded theory approach to content analysis was used for this research. This approach is a research method that enabled the development of a framework relating to the findings of this research (Charmaz, 2006).

Research Objective

To conduct an exploratory qualitative research study of the perceived barriers and facilitators to providing effective long-term care for persons with a developmental disability (DD), and the role for technologies in this process.

Research Site

Data collection was completed at the participant's place of dwelling (e.g. home, group home, LTC facility, etc.). All data analysis occurred in Dr. Jutai's lab, located in Annex B at Saint Vincent's Hospital.

Sample

Inclusion Criteria

Participants included persons aging with DDs over the age of 50 that may be accessing either formal or informal LTC services in facilities or at home. Due to the nature of DDs, the inclusion criteria for cognitive function was the ability to understand the informed consent form ((Appendix C) which is written at a grade 8 level) and the ability to communicate their needs or issues.

Recruitment

In order to recruit the participants, contact was made with various organizations in Ontario that either provide services to this population or that have information on this population. Once contact was made, the agencies were informed that ethical approval had been received for this research from the Bruyère Research Institute and the University of Ottawa Research Ethics Boards. The agencies that agreed to be included were as follows:

- i. The In Community
- ii. Visiting Homemakers Association
- iii. Ontario Federation for Cerebral Palsy
- iv. Ottawa Foyers Partage
- v. Ontario Cerebral Palsy Sports Association

vi. Direct Funding – Centre for Independent Living Toronto

Recruitment was done following the ethics and recruitment policies of each respective agency. This would mean that in some cases, the agency would provide contact information for potential participants, which in turn would be contacted by telephone. In other cases, the agency would contact the potential participants themselves, in which case a script would be given to the agency so they could properly inform potential participants what the research entailed. In addition to contacting these agencies, a purposive sampling approach was used to identify potential participants. Specifically, a snowball or chain approach was employed; this approach identified additional participants through others who may have known an individual who meets the criteria for this study.

Description of the Sample

Initially, a goal of 20 participants was set, yet fewer participants were needed because saturation was achieved after 10 participants were interviewed (Mason, 2010). Saturation of the data occurred when no new themes or codes emerged from the transcripts after the 8th participant.

The following table provides a brief description of the population:

Sample:	N: 10
	CP: 9
	SB: 1
	DS: 0
Age	Mean: 60.4
	Min: 52
	Max: 84
Sex	M: 5
	F: 5
Comorbidities	Mean: 2.7
	Min: 0
	Max: 5
Number of ADs:	Mean: 5.2
	Min: 4
	Max: 7

Table 2: Description of Participants by Disability, Age, Sex, Number of Comorbidities and Number of Assistive Devices.

Data Collection

A semi-structured interview format was used to collect data. These interviews were conducted face-to-face at the participant's residence. This type of data collection method is useful when trying to understand the lived experience of an individual (Rowley, 2012). That is to say that interviews are useful for research that is interested in gaining insights about the participant's thoughts, ideas and perceptions (Bolderston, 2012). By comparison to a questionnaire or survey, an interview is the preferred method for this research as it has several advantages. One advantage is that it can facilitate comparability; the interviewer can ensure that all questions are answered (Barriball & While, 1994). Further, interviews are useful when the interviewees may be open to answering questions in a private setting (Bolderston, 2012) and can ensure that participants are not being influenced by others while answering a question (Barriball & While, 1994).

A semi-structured interview guide (Appendix D) was developed as this type of interview is well-suited to an exploratory approach as is used in this research (Barriball & While, 1994). This style of interview is sensitive to the individual's perceptions, and allows for clarification and elaboration of answers (Barriball & While, 1994). A semi-structured interview is particularly useful because it allows the researcher to have a specific set of questions common to all participants and the flexibility to adapt the line of questions to any themes that may be emerging in the interview (Bolderston, 2012; Crooks, Williams, Stajduhar, Allan, & Cohen, 2007). The interview consisted of both open-ended and close-ended questions which allowed us to gain insights of the participant. Open-ended questions encouraged participants to discuss important aspects of their lived experiences, perceptions about aging, and also about their history with AT. Close-ended questions asked about demographic and lifestyle factors which the literature suggests may be important for LTC care for persons with DD. The full interview guide is provided in Appendix B.

Probing is an important part of the semi-structured interview format. It is a good tool in ensuring reliability of the data; it allows the interviewer to explore and clarify inconsistencies in the participant's responses and ensuring that all topics are explored thoroughly (Barriball, & While, 1994). Probing is also valuable in developing the rapport between the participant and the interviewer (Barriball, & While, 1994). Specific to this research, probing was particularly useful in ensuring that specific topics are addressed in relation to needs (e.g. of aging with DD) that have been identified in literature. For example, the interviewer will have a list of needs that must be explored in the interview. As the interview progresses, items that have been discussed will be checked off and at the end of the interview, the interviewer will address the remaining items.

Piloting

The full interview guide was piloted to ensure that the interview guide was understandable and that questions were clearly covering the topics that were being asked. Additionally, the interview was piloted to ensure that there was sensitivity to disability culture. The piloting was completed with two colleagues/peers, and three members of the community (all had Cerebral Palsy and were not the correct age but have had experiences that allowed them to provide insight for the interview guide).

The interview was first piloted with two colleagues which motivated changes such as: rewording and reformatting some of the questions; more examples of specific health issues to be added; and, more probes for the interviewer. The piloting of the interview guide with members of the community provided insights into how to better word questions to be more specific to DDs and be more sensitive to disability culture. These individuals were able to provide some more examples of assistive devices and also suggested to have formal definition of accessibility in hand. Overall there was a general re-ordering of the interview questions, some reformatting and further probes were discovered as necessary to be included in the interview guide.

A similar methodology was used in a study by Horsman, Suto, Dudgeon, and Harris (2010) that explored the psychosocial needs of individuals aging with Cerebral Palsy. This study had a similar objective, with a goal of exploring the individual's perspective which helps to validate the methodology selected for this research. Moll and Cott (2013) also used a qualitative methodology, including semi-structured interviews and content analysis for their study whose participants had cerebral palsy.

Interviews

The interviews lasted approximately 45-90 minutes. This extended time range took into consideration possible communication barriers that may have arisen throughout the interview.¹

Participants with communication difficulties were invited to use any assistive technology that they use to communicate or a facilitator. Prior to the interview, participants were asked to complete a consent form, which can be found in Appendix C. The participants had the opportunity to review the form with the interviewer and ask any questions at that time. After receiving verbal consent, they then were asked to sign the form.

Interviews were conducted in the place of dwelling of the participant. The location assured privacy and facilitated an environment where participants felt comfortable discussing their experiences. Prior to the commencement of each interview, the consent form was reviewed with the participant. Throughout the interview, participants had the opportunity to ask questions and ask for any clarifications. They also had the option of not responding to questions if they preferred not to answer. With the participant's consent, the interviews were audio-taped. To ensure anonymity, the participant's data was coded. To protect privacy and confidentiality, all electronic files were password protected and all paper documentation (demographic questionnaire and consent form) was stored in a locked cabinet in Dr. Jutai's laboratory.

¹ It is common in persons with DDs to have speech impairments. This timeframe considers that it may for example, take a bit longer for a person with a speech impairment to use an assistive device to communicate.

Data Analysis

Audio tapes from all interviews were fully transcribed. Accuracy checking was done on all transcriptions; after the transcripts were complete, the researcher listened to the interview again while reviewing the transcription. After the interview was transcribed, data analysis began by using coding to organize the data set. Coding is the method of choice for this research as it imposes structure on the data set and helps to categorize themes or patterns that emerge from the data (Rowley, 2012). In particular, an open coding style, was used (Charmaz, 2006). Open coding is the analysis of the data concerned with identifying, naming, categorizing and describing phenomena found in the data. Content analysis was the method of choice in this research as currently, there is no framework that adequately describes the intersection between aging with a DD and AT. The data analysis followed a grounded theory approach that helped to facilitate the construction of such a framework (Charmaz, 2006). By comparison, a phenomenological approach would have provided insight to the life experiences but not facilitated the creation of a framework. As the themes/patterns arose from the data, specific codes were given to each theme/pattern. The codes were then applied to the rest of the data. The primary and secondary themes/patterns was organized in a hierarchical structure that has the theme, the sub-theme and the code; this helped to conceptualise the themes (Saldana, 2009). As the data were coded, memos were used to capture the development of relationships between items (Charmaz, 2006). Memos are an important component of content analysis, they are essentially code notes for the researcher. The close-ended questions had numerical answers; these were coded and analyzed using Microsoft Excel.

Content Analysis

Conventional content analysis was used for the open-ended questions in order to identify primary and secondary themes that arose from the data. The conventional content analysis was facilitated by the use of probes to explore predetermined categories; it allows for the supporting and extension of a theory (Hsieh & Shannon, 2005). Microsoft Excel was then used to do basic descriptive statistics on both the open- and close-ended questions. The descriptive statistics include: frequency counts of themes and sub-themes from the open-ended questions; measures of central tendency and dispersion.

Codes

A list of preset codes were created based on the types of questions in the interview guide. Emergent codes were also created using an open coding style. The initial set of codes was used to analyze one transcription of an interview. The emergent codes were created to cover the information that was not accounted for in the preset codes. The first transcript was then re-coded using the new codebook. This process was repeated whenever new codes were created as described by Taylor-Powell and Renner (2003) and Saldana (2009). This approach, derived from grounded theory, enabled an additional level of rigor within the data analysis. The complete codebook can be found in Appendix E.

Themes

The content analysis revealed several themes from the interviews. The themes can be defined as follows:

1. **Accessibility:** Refers to the accessibility of their homes, almost all believe their homes are fully accessible and would not make any changes to their homes.

2. **Assistive Devices:** All participants use assistive devices, most are able to have good training, and good access to these devices. The only concern is the wait time on receiving the device.
3. **Effects of aging on the body:** This refers to the physical effects of aging that the participants had and how their disability was affected specifically. Often the participants began to experience this at a young age. One common outcome that was described was an increased need of personal support care as they were unable to do as many ADLs.
4. **Health Care:** This includes three subthemes:
 - i. The **health care system** and health care practitioners are not well suited to the needs of individuals with these disabilities. Practitioners are not well educated on the effects of aging on an individual with a DD and often treatment and diagnostic tests are not accessible.
 - ii. **Long-term Care facilities:** This refers to the feelings expressed by participants about the potential to move into a facility; many negative feelings, such as distress.
 - iii. **Attendant Care:** Refers to the structure of care provision, and the relationship between the attendants and the participants.
5. **Independence/autonomy:** This was an overarching theme that was found in each aspect of the other themes. Many felt that their independence was

threatened or not respected in a health care setting, in a long-term care setting or if they were to be removed from their current living environments.

CHAPTER 4 – RESULTS

Participants

Education

The figure below shows the highest level of education completed by the participants. Four participants completed a high school education or higher, only one participant did not attend school at all.

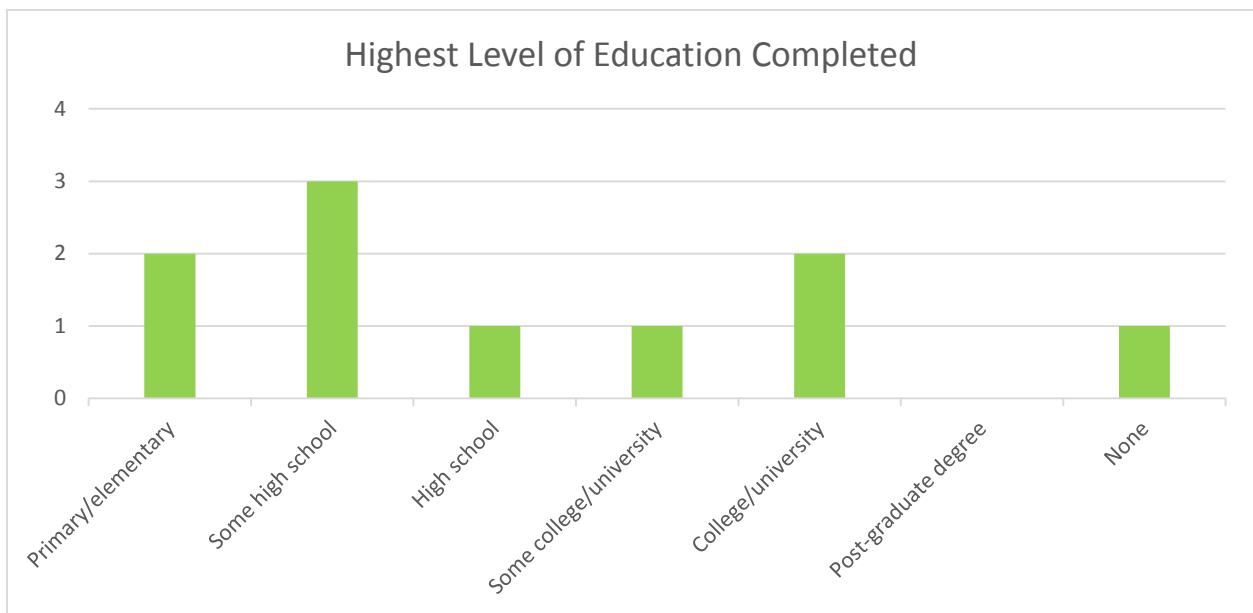


Figure 1: Participants level of education.

Living Environment

All the participants lived in an environment where they were able to access a more informal LTC service. None of the participants currently lived in a LTC facility or nursing home. The chart below shows the distribution of the participants by the type of housing they live in and what resources that they access.

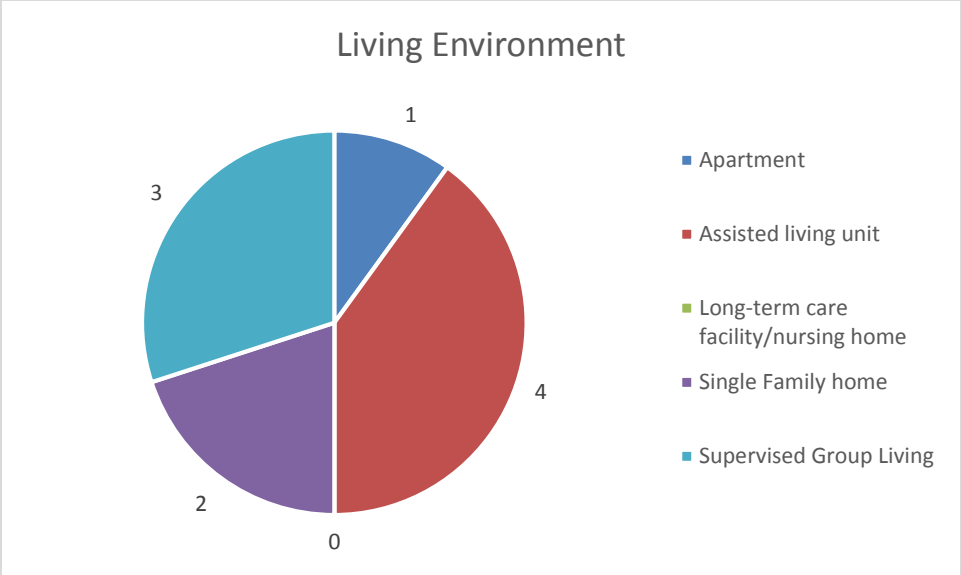


Figure 2: Distribution of participant’s living environment.

Themes

After analysis of the transcripts, there were several themes that emerged from the data. They are described below. The following table shows statistics that describe the number of times that a theme came up during the interviews. The theme that was discussed the most at length was Health Care and then second was the Physical Changes that the participants experienced in association with aging.

	<i>Physical Changes</i>	<i>Accessibility</i>	<i>Assistive Devices</i>	<i>Health Care</i>			
				<i>Total Health</i>	<i>Health Care System</i>	<i>LTC</i>	<i>Attendant Care</i>
Mean	9.8	4.5	5.4	16.7	7.6	2.7	6.4
Standard Error	1.53	0.45	0.81	2.07	0.76	0.97	1.09
Median	9.5	5	6.5	16	8	1.5	5.5
Mode	4	6	7	17	9	1	8
Standard Deviation	4.85	1.43	2.55	6.53	2.41	3.06	3.44
Sample Variance	23.51	2.06	6.49	42.68	5.82	9.34	11.82
Kurtosis	-1.44	-1.00	-0.96	6.72	-0.18	0.79	4.55
Skewness	0.21	-0.57	-0.76	2.35	0.11	1.35	1.95
Range	13	4	7	24	8	9	12
Minimum	4	2	1	10	4	0	3
Maximum	17	6	8	34	12	9	15
Sum	98	45	54	167	76	27	64
Count	10	10	10	10	10	10	10

Table 3: Descriptive statistics of themes found in the data.

Skewness and Kurtosis should range between -2 and 2, if they are greater than this, it is outside the accepted range of normality (symmetry and normal distribution of the data) (Vincent, W. & Weir, J., 1994). The Health Care theme has a value that exceeds 2 for both skewness and kurtosis, this means that the health care theme is not normally distributed and is not symmetrical. This is in part due to two participants who spoke at length of their health care experiences by comparison to the other 8 participants.

Physical Changes and Aging

Comorbidities

Each individual had on average 2.7 health conditions aside from their disability, the most by any one participant was 5, and one participant reported no health conditions. The table below summarizes how many participants reported specific health conditions.

Health condition	# CP	# SB
arthritis	4	
diabetes	1	
epilepsy	1	
hypertension	3	
memory problems		1
orthopedic impairment	4	
osteoporosis	1	
respiratory disease	2	
sensory impairments	2	
spinal cord injury	1	
edema of lower extremities	4	1
cranial dystonia	1	

Table 4: Number of participants per disability reporting health conditions.

"I think in terms of aging, there is just generally more wear and tear on the body when you have CP"

In addition to chronic health conditions, the participants reported additional age-related changes (as listed in table 4) in their bodies that were believed to be directly affected by their disability. Most of these changes affected their mobility. The table below summarizes the changes in their bodies as they aged with their disabilities.

Self-reported effects of aging due to disability	# CP	# SB
Increased falling	3	-
Increased spasticity	7	1
Decreased dexterity	2	-
Changes in ability to walk	3	-
Loss of ability to do self-transfers	5	-
Muscle weakness/change in muscle tone	7	1
Decrease in overall mobility	9	1

Table 5: Self-reported disability and age related changes.

Many of the participants reported that they began experiencing age-related changes in their bodies in their early 30s and 40s, or they would experience a great decrease in their abilities in a very short time.

"My whole body is just changing. I can't even do 10% of what I was able to do 2 years ago when I renovated my apartment"

Due to these changes, the participants often:

- i. Needed more assistance with daily activities
- ii. Had to adapt method of transfers (i.e; from wheelchair to toilet)

"I used to be able to transfer myself, but now I need to use a lift"
- iii. Had to rely on new ADs (i.e; transitioning from a manual wheelchair to a power wheelchair)

"I just can't walk anymore, my legs slowly started giving out, more and more"
- iv. Had to request additional attendant care support to deal with changes in care

The following excerpts are from the interviews and provide examples of some of the changes experiences by individuals aging with DDs.

"I can really feel my aging"

"I can't control my hands like I used to, it is one of the reasons I don't work anymore... I need help to fill in forms, I have more spasms and less dexterity."

"I am starting to fall more, and now it is getting more and more difficult to get back up"

Accessibility

Home

All participants reported living in an accessible/barrier-free home and were satisfied with the design of their homes. Participants described accessibility as the ability to move around easily in their homes, having wider doorways, automatic door openers, and appropriate grab bars and ramps. A few of the participants reported having wheelchair accessible kitchens with lowered counters, and some reported having roll-in showers in their bathrooms.

Living in an accessible home promoted the feeling of independence in the participants. There was more sense that they would be able to stay longer in their homes. And not need to go into a LTC home. Already having the accessibility in their homes means that even if their mobility needs change, they will still be able to age in place

"my home is accessible so I would like to stay here as long as I can."

Accessibility of Health Care Services

"What they call accessible is accessible, but not for everyone.... A lot of people don't get that"

There is a lack of access to health care services that was reported by this population. For example, one participant reported that they had two dentists refuse to treat him because he had CP. Two female wheelchair users were unable to get mammograms because the mammogram machines were not wheelchair accessible; this meant they were unable to get adequate diagnostic imaging.

"I once was asked to get a mammogram... they can't get the machines low enough to fit the wheelchair... so I just never got one."

In areas of Ontario where the population is slightly more dispersed, it is difficult to access rehabilitation therapists such as physiotherapists or occupational therapists.

"I wish I could connect with a physiotherapist or occupational therapist just to ask questions but it is very hard to get something like that set up without having to go through a lot of hoops"

Health care

Physicians and the Health Care System

The majority of the participants reported that their primary health care provider, their general practitioner (GP), treated them with respect and respected their autonomy. Participants reported that their GPs were often willing to try to learn more information on an as needed basis with regards to how a DD affects a person who is aging; one participant expressed:

"I had to get a mammogram done, obviously I can't get a mammogram, so I talked to my doctor and she arranged to do an ultrasound done instead.... If your doctor is open-minded then they can find different ways to do stuff"

However, reports of experiences with physicians that were not their regular practitioner were often traumatic and upsetting to the participant. The table below summarizes some of these experiences:

Reported Issue	Participant's Experiences:
Lack of Knowledge of DD	<i>"Doctor's don't know how to treat for different things because of the CP."</i>
No consideration for specific needs of disability	<i>"Like when I had my wisdom teeth out and they put in the IV in my arm, I have not much control over the muscles in my arms, they have a mind of their own. I kept telling them not to put the needle where the arm bends, but they did. So when I wake up, the arm starts to flex and the needle goes straight through the vein. They don't listen"</i>
Physician being uncomfortable around disability	<i>"...whenever I have gone in for another medical situation, they look like terrified rabbits when I come in. They don't want to deal with anyone with a disability in a hospital setting..."</i>
Lack of respect	<i>"[Doctors] treat me like I am nothing, or that I am retarded or stupid"</i>
Assumptions made about the individual's needs	<i>"[when I broke my leg] I heard the attending surgeon say 'let's not worry about so and so because she is in a wheelchair anyway, we won't bother casting it'"</i>

Table 6: Issues in health care affecting persons aging with a DD.

The summary above describes unsettling experiences that these participants had in health care settings. These issues indicate that there is a lack of disability awareness and a clear lack of training of health care professionals on proper disability etiquette and what role these disabilities have in the aging process.

Attendant Care

The Ministry of Health and Long-term Care (2014) defines attendant care as: “homemaking and personal support services to people over the age of 16 with permanent physical disabilities who require assistance with activities of daily living and have the ability to direct an attendant to carry-out pre-determined tasks that they cannot physically do for themselves”

All of the participants had self-directed care. This means that they were able to direct the attendants in how they provided their care. Participants were more satisfied with the care when they were able to ensure that the care was tailored to their own needs. Each individual prefers different techniques when receiving assistance. For example, transferring can greatly vary from individual to individual. It was reported that they were much more satisfied when the attendant was open to adapting to their needs. Every person should be treated as an individual with different preferences, the same applies to the care that is received by an individual with a disability.

Each participant expressed that they felt the majority of their attendants understood their disability and had a good rapport. For promoting good relationships between the individual and their attendant, communication was described as the most important component for receiving a higher quality of care from the attendants. Additionally, participants who were able to hire their

own attendants (i.e.; they were on the Direct Funding program) reported better relationships with the attendants.

Participants that were able to schedule their own care schedules and had the flexibility of changing that schedule reported feeling more independence. Being able to self-direct care, schedule care services and being able to have a role in the selection of the attendants allowed participants to have the greatest sense of independence.

Long-term Care Facilities

None of the participants currently live in a long-term care facility. However, three participants had previously lived in a LTC institution as adolescents and young adults. All three participants described the experience as unpleasant.

"...you know it isn't living. You can't really enjoy life"

Most participants felt that LTC facilities were associated with adults that were much older than they were. In general there was a stigma and fear that accompanied thoughts of living in a LTC facility. The primary reason for this fear was that all participants associated living into a LTC facility with a complete lack of independence. What the participants described as a lack of independence was the:

- i. inability to direct their own care and have a say in how care is provided,
- ii. inability to leave and return as they wish,
- iii. inability to schedule their own care, and
- iv. possibility of losing their motorized mobility devices.

Not being treated as an individual and not having individual preferences be considered when living in a LTC facility was a major concern for all individuals. There was a fear that the staff of long-term care facilities would not consider their preferences.

"...they treat everyone with the same brush, it is a very hard thing to handle"

Since all their homes are fully accessible, all participants expressed a desire to continue to age in place; that is to stay in their current home as they continue to get older. However, a few participants expressed that they were concerned that they would not be able to.

"I am a little scared. I worry that if my health takes a turn for the worse that I won't be able to stay here and I will have to go back to an institution type setting."

"I'd rather stay where I am... Because if you in a nursing home, you rot and die"

Assistive Devices

The most commonly used ADs were mobility devices such as power and manual wheelchairs and scooters; all participants had one or more mobility device. Both lifts and commodes were commonly used by participants for showering and toileting. Other devices that were mentioned included: grab bars, ramps, automatic door openers, adapted kitchen appliances, adapted computer accessories, and communication devices.

Most participants were satisfied with the access to these devices and the ones that they had in their possession. However, there were some difficulties faced by the participants in getting these

devices in a timely fashion; it was expressed that it could take anywhere from 1 year to 2 years to get a new wheelchair after they visited with an occupational therapist. Additionally, 9 of the 10 participants used the Assistive Devices Program to obtain their mobility devices; the Assistive Devices program provides funding for people with long-term disabilities to purchase assistive devices.

Participants expressed that these devices allowed them to live more independently.

"[My scooter] gives me a lot more freedom that I never really had before... more independence."

Assistive devices were key to living independently:

"[If I didn't have my assistive devices] it would be a disaster. I would be limited to my bed or a chair. Transferring from my bed to a toilet would be impossible. Without all of these devices, life would be a nightmare"

Independence

The preference for maintaining independence was prevalent throughout all of the other themes. And the preference to age in place is apparent. Being independent and maintain that independence was considered to be the most important thing for this population. The fear of losing independence was expressed by all participants.

"If you don't have your independence, you don't have very much at all"

Some participants were resistant to changes in their care as they felt it threatened their ability to maintain independence.

"I'm still doing things [for my care] they don't want me to do. I have been told not to do it but I am scared to lose my independence"

Everyone able bodied or disabled wants to be independent. The important thing to consider with this population is that there are several more factors that must work together to allow them to have that independent lifestyle.

"Despite the fact that I had to switch to a power chair from a manual, and despite the fact that I need more staff than I did before, I am still very independent."

These factors are summarized in the framework below, Figure 3.

Framework for Aging with a Developmental Disability

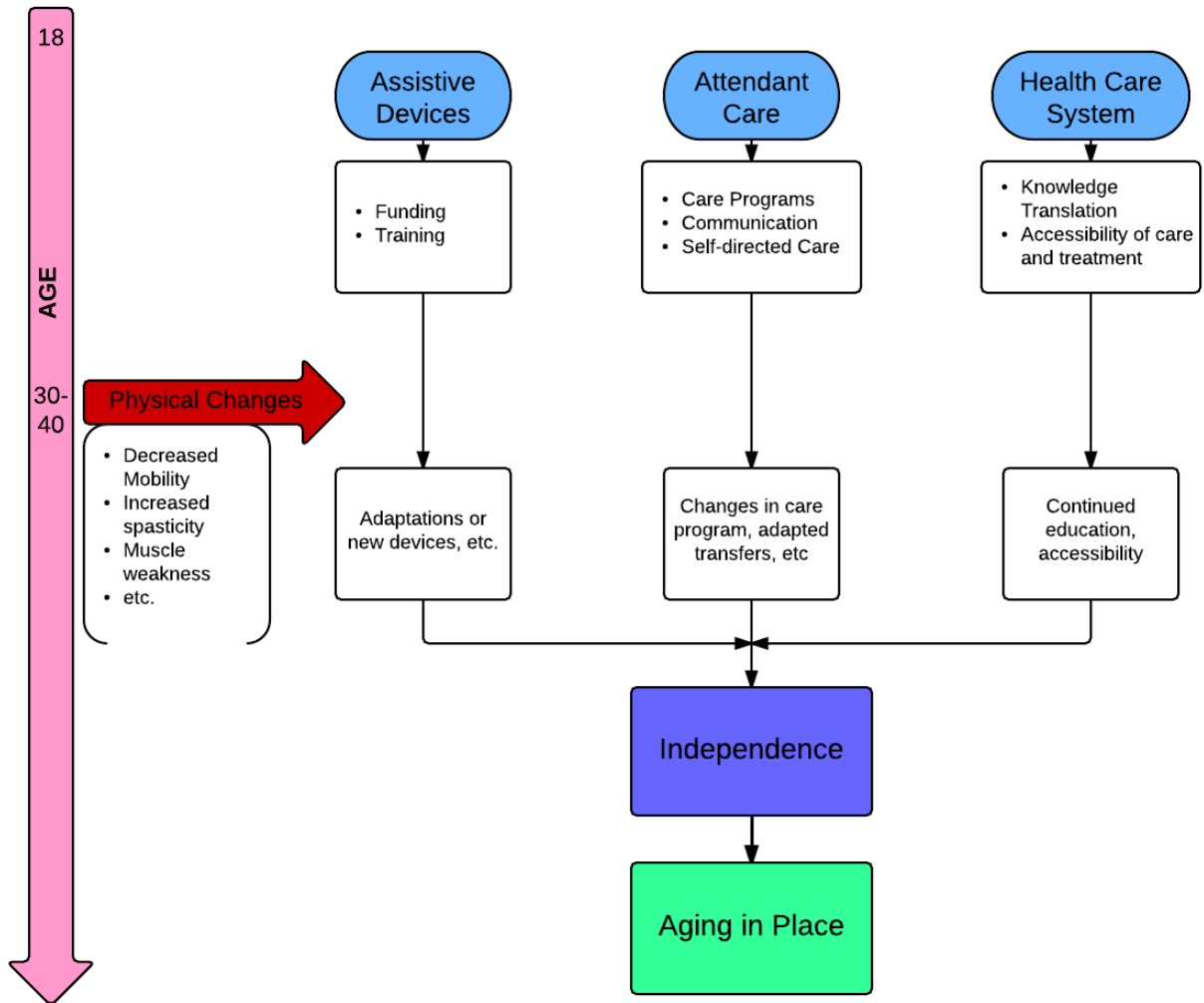


Figure 3: Factors that facilitate aging in place for individuals aging with DDs.

This framework emphasizes the preference for individuals aging with DDs to maintain their independence so that they are able to age in place. Assistive devices, attendant care and accessibility of health care services are the three most important factors in facilitating this.

Assistive devices help to allow the individual to be more mobile, transfer more easily and help to facilitate toileting and showering. Mobility devices specifically allow the individual to feel independent as they are able to get around with limited assistance. In order to ensure that these devices are accessible to this population adequate funding of these devices (i.e.; the Assistive Devices Program) is critical. It is also important that resources for proper training of these devices are also in place.

Attendant care is also significant in maintaining independence in this population. The ability to self-direct care or at least be able to have their care preferences considered is critical. Additionally, care programs (i.e.; Assisted Living Units, the Direct Funding program, or Supervised Group Living) need to be in place and maintained so that individuals with DDs can have access to attendant care. These care programs need to be able to be adapted as the individual who is aging with a DDs' needs change. Good communication across the care program helps to facilitate a good care environment. This communication should include the individual, the attendant and the care director/manager.

The third factor revolves around the health care system. It is important that health care practitioners are well informed of the health outcomes of individuals aging with DDs. This knowledge should be explained to this population so that they are able to make appropriate plans for their futures.

As the physical changes associated with aging with a DD occur, each of these areas need to adapt to meet the changing needs of the individual. If, for example, an individual with CP loses some of their dexterity and are no longer able to propel a manual wheelchair, a power-assisted wheelchair could be considered. Additionally, the decrease in dexterity may result in the

individual requiring more assistance with their hygiene, as these sorts of changes occur, the care program should reflect these additional needs. All of these factors need to continue to adapt and work together to best facilitate these individuals both maintain their independence and aging in place.

CHAPTER 5 – DISCUSSION

Conclusion

Individuals aging with DDs want to age in place and maintain independence as their bodies and disabilities change. On average the participants noted that they see more changes in their bodies at an earlier age than the average population. They face many changes in their disabilities that affect their mobility, ability to complete day to day activities and how they manage their care.

In order for this population to be able to maintain their independence and be able to stay in their current homes as they age there are three factors that help to promote it.

- i. Accessibility and health care services: home needs to be barrier free with a universal design. Health care services such as diagnostic imaging and preventative care need to be accessible to everyone in the population
- ii. Attendant care: self-directed care with flexible scheduling promotes the most independence.
- iii. Assistive devices: are critical in promoting and maintaining independence; adequate access and training of these devices should be a priority.

LTC facilities are feared by this population as they are associated with a loss of their independence and individual preferences. Therefore, for a more successful experience in a LTC facility, specific measures should be considered. Primarily, the personal support workers or attendants in the facility should consider the individual preferences of the person receiving care.

For persons with DDs, this is incredibly important as they have been accessing and managing their own care for several years. This means that they have adapted care to meet their specific needs and preferences. To take away their ability to manage and direct their care threatens their sense of independence.

As noted above, according to Kim, *et. al*, (2011) noted that individuals with DDs have on average 5.4 medical conditions in addition to their disability. However, the participants in this research only had an average of 2.7 co-morbidities. This discrepancy may be attributed to the relatively young age of this sample (mean age= 60.4) and/or insufficient reporting by the participants. It was noted that some participants reported no health conditions but were taking several different medications. These findings are consistent with Lunsky, *et al.*, (2014) findings of high medication use in individuals with DDs.

Aging with a DD differs from process of aging without a DD or with an acquired disability. As was described by the participants, the aging process seems to exacerbate their physical disability. These individuals begin to experience a overall functional decline 20-30 years earlier than the average population, a finding consistent with the literature (Hirst, *et. al.*, 2013; Glew, 2011). Some of the physical changes experienced by persons with DDs as they age are as follows (but not limited to):

1. Decreases in overall mobility (i.e.; walking, transferring)
2. Increased spasticity
3. Muscle weakness, change in tone and musculature

While many of these changes may be considered a normal part of the aging process in the entire population, it is important to remember that these changes occur on an accelerated timeline. As these physical changes occur in these individuals, their needs for AT may also change.

An important consideration with assistive devices and their use by individuals with DDs is that the usage is often lifelong. From a very young age, these individuals use or have exposure to varying types of assistive devices. Their experiences with AT differs from someone from the average population as they have had much more exposure. A specific consideration for the intersection of AT and aging with a DD is that there is a certain familiarity and acceptability of AT due to this exposure. For able-bodied individuals, the reliance on ATs or having to use further devices may be seen as a loss of independence, however, for many individuals with DDs, these devices are seen as a tool towards independence. As the physical needs of individuals with DDs change, the devices need to adapt with them. HCPs and health care services need to support these adaptations as these changes will help to promote and maintain independence, a priority of this population.

Implications/Future Considerations

"I realise.... in a sense ... I am probably the first generation of disabled that are getting older in today's society...never really happened before...they were in the closet before; kept at homes, in institutions, and now we are out there in the world...nobody knows what is going to happens next"

This anecdote paints a very good picture of the current state of knowledge of health care professionals. It illustrates the significance of this research and that more research needs to be done with this population.

An exploratory study was helpful in learning of the past experiences of this population and what their preferences are in the future. As the life expectancy of persons with DDs continues to increase, it is important that the specific needs and preferences of this population are considered in LTC settings.

Education and Knowledge Translation

Health care practitioners need to be educated about the experiences of this population and how their experience of aging differs to the experiences of the average population. Additionally, as physicians are more educated about what sorts of things they can expect as they age, this information needs to be disseminated to individuals with DDs.

It is critical in LTC settings that care expectations are clearly explained by the individual with the DD and that care preferences are taken into consideration. Communication between the care provider, or physician with the person with DD is essential in maintaining independence.

Additionally, it would be helpful to have individuals who are aging with DDs to inform younger adults with DDs of their experiences. This knowledge translation would be very helpful for younger adults to know what kinds of questions they should ask when seeking LTC services.

"If I had to give advice to anybody else who is aging with a disability, I would say: don't give up. Keep your independence, don't let anyone else tell you what you can and can't do."

Limitations

There was a good distribution of participants living in different housing, however, there were no participants who lived in formal LTC facilities. Therefore, this study is only representative of the population that lived in what are considered informal LTC settings. It is not surprising that no participants were recruited from LTC facilities as this population is in fact difficult to track. Additionally, this is consistent with what was reported by Parish and Lutwick (2005) and Kim, *et al.*, (2011); there has been a shift from living in LTC facilities to living in the community and accessing services and supports from the community.

To increase the reliability of the study, using two coders would have made the results more reliable. However, for this study there was only one coder used, the primary researcher.

Sample

The sample was not representative of all individuals with DDs, it focused primarily on a specific subset of the population (individuals with CP). The findings of this research can help give insight to the experiences of individuals with DDs, however, they are more directly relevant to individuals with CP. It is important to consider that the experiences of an individual with DS may produce different findings.

While the sample size was adequate for this type of research (Mason, 2010), a larger sample size would be more representative of the population. Unfortunately, there were no participants with DS and only one participant had Spina Bifida. Due to the nature of the study, the interview guide was written at a grade 8 comprehension level, this unfortunately limited the participants that would be eligible to partake in the study, especially those with DS.

Recruitment and Having a “Developmental Disability”

In society, the term developmental disability is often used interchangeably with the term intellectual disability (ID). While a number of individuals with a DD also have an ID, not every individual with a DD has any sort of intellectual issue. For example, only 25-40% of individuals with CP have any cognitive impairment (Odding, E., Roebroek, M. E., & Stam, H. J., 2006). Since these two terms are used synonymously, the term DD is associated with a stigma of ID, and often times individuals who have, for example Cerebral Palsy, and have no ID, will not self-identify as having a DD. After 2 months of recruitment yielding few participants, the members of the community that had helped pilot the study were contacted to discuss any potential issues with the recruitment documents. These individuals stated that they believed changing the term developmental disability to the three specific disabilities may prove to yield more participants.

Additionally, using agencies that provide services for individuals with DDs was a limitation to recruitment. These agencies were able to identify potential participants but due to staffing limitations they were unable to pass along the recruitment poster and information sheet.

An important consideration is that there is a different definition of living independently for an able-bodied person than there is for someone who lives with a lifelong disability. An able-bodied person may not think that having to rely on an AD and attendant care is an independent lifestyle. However, people with DDs are still able to feel independent and they assert this independence by having the ability to control these aspects of their assistance. They are able to direct the care they receive, have a say in what Ads they need. Additionally, attendant care is seen more as a tool to independently living as opposed to a barrier to it.

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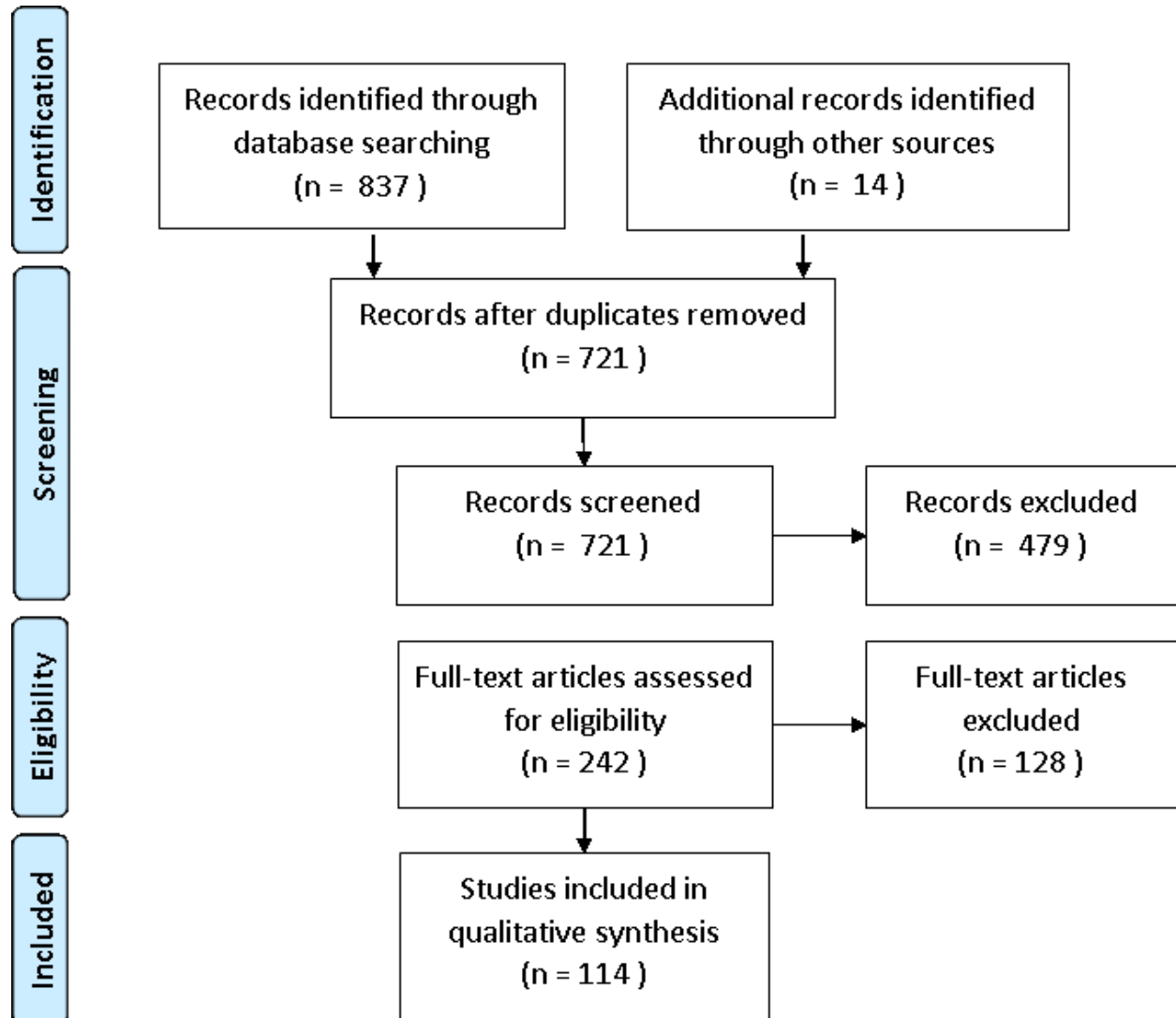
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APPENDIX A – FIGURES

Search Selection Process Flow:



APPENDIX B – RECRUITMENT DOCUMENTS

Participant Information Sheet

Institut de recherche
Bruyère

Bruyère
Research Institute

Project Title: **Aging with Cerebral Palsy, Spina Bifida and Down Syndrome:
Implications for Long-term Care**

Thank you very much for considering taking part in our study. This information sheet will help you understand what will be involved if you take part in the study. It will also help to explain why this research is being done.

Why is this study being done?

People who have Cerebral Palsy, Spina Bifida, and Down Syndrome are living longer. However, very little is known about experiences with long-term care and assistive devices as they age. Some examples of these devices are grab bars in bathrooms, canes and walkers, and pill dispensers.

We are inviting people who have Cerebral Palsy, Spina Bifida, and Down Syndrome that are over the age of 50 to take part in this research project. The goal of this research is to learn about your experiences and thoughts about long-term care and assistive devices.

What will I be asked to do?

If you agree to take part in this study, you will be asked to meet with a researcher in person. The meeting can be at the place of your choice, most likely where you live. At this time, you will fill out a questionnaire about yourself. The questionnaire will ask questions about your month and year of birth, where you live, your education, etc.

After the questionnaire is done, there will be an interview which will last about 45-90 minutes. The interview will be about your experiences and thoughts on long-term care and assistive devices. The meeting, including the questionnaire and interview will be audio recorded.

Additional Questions?

If you have any addition questions about this study, please contact
the primary researcher. That person is:

Kristin Dorrance

Master's Student, University of Ottawa

DO YOU OR SOMEONE YOU KNOW HAVE CEREBRAL PALSY, SPINA BIFIDA OR DOWN SYNDROME?

Volunteers are needed to take part in an interview for a research study about the experiences of people aging with Cerebral Palsy, Spina Bifida and Down Syndrome.

To qualify, you must:

- Have a disability such as Cerebral Palsy, Spina Bifida or Down Syndrome
- Be over the age of 50



For more information, please contact:
Kristin Dorrance at:



INSTITUT DE RECHERCHE
BRUYÈRE
RESEARCH INSTITUTE

*Affilié à l'Université d'Ottawa
Affiliated with the University of Ottawa*

APPENDIX C – INFORMATION/CONSENT FORM

Information/Consent Form

PROJECT TITLE: Aging with Developmental Disability: Implications for Long-Term Care

INVESTIGATOR:

Kristin Dorrance
MSc in Interdisciplinary Health Sciences (candidate)
Faculty of Health Sciences
University of Ottawa

CO-INVESTIGATOR/SUPERVISOR:

Jeffrey Jutai: Faculty of Health Sciences, University of Ottawa and Scientist, BRI

Funding Organization: BRI (CLRI)

Dear Madam or Sir,

We would like to invite you to take part in a research project being done by the Bruyère Research Institute. The goal of this research is to learn about your experiences and thoughts about long-term care and assistive devices. However, before agreeing to take part in this research project and providing your consent, please take the time to read, understand, and consider carefully the following information.

The informed consent form may contain words that you do not understand. We invite you to ask any questions you have to the researchers, in order for them to explain any words or information that does not seem clear.

Why is this study being done?

People who have Cerebral Palsy, Spina Bifida, and Down Syndrome are living longer. However, very little is known about experiences with long-term care and assistive devices as they age. Some examples of these devices are grab bars in bathrooms, canes and walkers, and pill dispensers.

We are inviting you to take part in a research project that will collect information on the unique experiences of someone aging with Cerebral Palsy, Spina Bifida, and Down Syndrome.

This project includes of people who have Cerebral Palsy, Spina Bifida, and Down Syndrome that are over the age of 50.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will be asked to meet with a researcher in person. The meeting can be at the place of your choice, most likely where you live. At this time, you will fill out a

questionnaire about yourself. The questionnaire will ask questions about your month and year of birth, where you live, your education, etc.

After the questionnaire is done, there will be an interview which will last about 45-90 minutes. The interview will be about your experiences and thoughts on long-term care and assistive devices. It will include open-ended questions that will let you tell us your thoughts. The meeting, including the questionnaire and interview will be audio recorded and the recordings will be transcribed.

What are the benefits and risks or inconveniences of the study?

You may not directly benefit from this research. However, we hope that you taking part in the study may help to give us important information about the experiences of someone aging with Cerebral Palsy, Spina Bifida, and Down Syndrome. This information may help improve these experiences in the future.

Apart from giving your time, there are no other inconveniences linked with taking part in this research project.

Can I stop being in the study and what are my rights?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no consequences of any kind if you decide that you do not want to participate.

During the interview, if there is a question that makes you feel uncomfortable, you do not have to answer it. You do not have to answer any question that you do not want to answer.

What happens to my information? Is it private?

While you take part in this study, the researcher records all information about you in a research file. This information will include your answers to the questionnaire and interview. Your file may also include other information such as your name, gender, and month and year of birth.

All of the information collected during the study will remain private, within the limits set by the law. To help keep your identity and information private, a code number will be given to your file, and that is how you will be identified. This information will be kept in a research lab located in Annex B of the Saint Vincent's Hospital, 45 Empress St, Ottawa ON.

The study researcher will use the data for research purposes only. The study data may be published in scientific journals or shared with other people during scientific discussions. No publication or scientific discussions will show any information that would cause you to be identified. Your personal information, such as your name and address, will be destroyed 5 years after the end of this project. The Bruyère Research Ethics Board may review your information. This review would be under the supervision of the Investigator for audit purposes.

You may review your research file to make sure that the collected information is true, to have incorrect information corrected or deleted, and to make copies, for as long as the study researcher has this information.

Consent

Acceptance: I, _____ (name of participant), agree to participate in this research study conducted by Kristin Dorrance, Master’s student in the Faculty of Health Sciences at the University of Ottawa and Master’s Intern at the Bruyère Research Institute.

Questions: I am encouraged to ask questions. If I have any questions about the research study, I can contact: Kristin Dorrance.

If I have any questions about the rights of a research participant or ethical concerns about this study, I can contact the Chair of the Bruyere Research Ethics Board Care at (613) 562-6262 ext. 1420 or the Protocol Officer for Ethics in Research at the University of Ottawa, Tabaret Hall, 550 Cumberland Street, room 159, Ottawa, ON, K1N 6N5, at (613) 562-5841 or ethics@uottawa.ca.

There are two copies of the consent form, one of which is mine to keep.

Signature of the Participant: _____ Date: _____

Signature of the Investigator: _____ Date: _____

APPENDIX D – INTERVIEW GUIDE

Aging with Developmental Disabilities: Implications for Long-Term Care: Interview Guide

Introduction: I am going to ask you a few questions about your experiences that you have had as you age and with assistive technology. As a reminder, if you do not understand the question, let me know and I can try to better explain it. If you feel uncomfortable answering any of these questions, you do not have to answer them.

Background Questions

1. What is your month and year of birth?
2. Please choose which disability you have
 - a. Cerebral Palsy
 - b. Spina Bifida
 - c. Down Syndrome
 - d. Other. Please specify
3. What is the highest level of education have you completed?
 - a. Primary or elementary school
 - b. Some high school
 - c. Graduated from high school
 - d. Some college or university
 - e. Graduated from college or university (Bachelor's degree or other diploma)
 - f. Post-graduate degree (Master's, PhD or other doctorate degree)
4. What kind of place are you living in?
 - a. Apartment
 - b. Assisted living center
 - c. Long-term care facility/nursing home
 - d. Single family home (house)
 - e. Supervised group living
 - f. Other: _____
5. Do you live with:
 - a. alone
 - b. family/spouse
 - c. Caregiver
 - d. Roommates
 - e. Other: _____

6. Which of the following health problems do you have? We will be going through a list of different health problems, if you have any of these health problems, please tell me approximately how long you have had it for.
- Amputation of a lower limb
 - Arthritis
 - Dementia
 - Diabetes
 - Epilepsy
 - Heart Disease
 - Hypertension – High Blood Pressure
 - Memory Problems
 - Multiple Sclerosis
 - Orthopedic impairment (joint pain) of the hip, knee, back or neck
 - Osteoporosis
 - Respiratory Disease (e.g., Chronic Obstructive Pulmonary Disease)
 - Gastroesophageal reflux disease (GERD) [Chronic Heartburn]
 - Sensory Impairments (vision, hearing, etc.)
 - Spinal Cord Injury
 - Stroke
 - Thyroid Disease
 - Vision disorder
 - Are there any other health concerns or issues that you would like to mention?
7. What doctors, specialists, PTs, OTs, physiatrists, or other health care practitioners do you see? We will call this your health team.

Interview Questions

- Think of a typical day, and tell me about how you manage your daily living needs.
PROBE: What about for your health needs, for any of the health issues you described above?
- So you mentioned you lived in _____?
PROBE: Do you consider your living environment to be accessible?
PROBE: Could you describe what you mean by accessible?
Accessible: everyone has access. Enables use of

assistive technology. Can include: an unobstructed path, ramps, powered doors, grab bars etc.

PROBE: Does the place you live impact your daily life?

PROBE: Is there anything you would change about your daily living environment?

3. Do you feel that these individuals understand your disability?

4. Do you rely on help from other people in your home?
(If they mentioned already that they receive help, say instead: "So you mentioned that you receive help for...")
PROBE: Who helps you?
PROBE: What are some of the kinds of things that you receive help with?

5. Do you receive any form of LTC services?
Long-term services: assistance and care provided over a period of time for people with chronic disabilities where the goal is maximum independence
PROBE: which members of your health team are involved in your long-term care services?
PROBE: Have you had any challenges in receiving it?

6. What are some of the things that concern you as you get older?

7. How do you think that your needs may change as you grow older?
PROBE: What are some of the changes you have already experienced? (e.g. mobility, health, etc)
PROBE: What supports do you think you may need?

8. Have you had any issues or faced any challenges receiving care that is specific to your disability?

9. Do you feel that your health team respects your independence/autonomy?

PROBE: Do you feel that they are well –educated about your disability and its effects on aging? Have you been informed about how your disability might change/affect you as you get older?

10. Do you use any equipment to help you manage your needs? **PROBE:** to see if they use any others...

Examples include

- a. Mobility devices : canes, walkers, wheelchairs (power and manual), scooters
- b. Safety devices: grab-bars, ramps, raised/lowered toilets, automatic door openers
- c. Hearing aids
- d. Communication devices – ie; AAC
- e. Adapted cutlery ie; rocker knife
- f. Computer assisted software or hardware – word prediction, speech to text

11. Have you used any other assistive devices in the past?

PROBE: What have been your experiences with it? How long have you used it for? (For each device)

PROBE: How did you get them?

12. Did you have any problems getting the help and equipment you need? Tell me about them.

PROBE: Are there any devices that you would like but do not currently have? Why do you not have access to them?

13. If you didn't have access to this help, what parts of your life would be most affected?

PROBE: What areas of your life has it most helped? (i.e; social, personal, work, etc.)

14. What impact has this help had on other people in your life? (e.g., family and friends)?

15. Do you feel that you have been well-informed of your options for your future as you get older?

PROBE: for LTC?

PROBE: for assistive devices?

16. Is there anything else you would like to tell me about the experiences you have had as you have gotten older with your disability?

APPENDIX E – CODEBOOK

Theme	Sub-Theme	Code	Description of Code
Age-related changes		BNC	Need more help with day to day activities
		BAD	Rely on new Ads
		BCY	Experienced aging related changes in 30s and 40s
		BTC	Had to adapt how to transfer
		IFL	Fear of losing independence as they age
		BMC	Changes in mood (ie; decreased patience)
		BCM	changes in mobility
		BCF	Increased number of falls
		BCE	Feeling changes all over body
		BCN	Comorbidity needs extra attention or treatment
Health Care	Health Care System	HKP	HCP does not understand how disability affects aging
		HKF	HCP has not communicated how disability will affect them in the future
		HKU	Does not know what options exist as they get older or how their bodies may change
		IHG	Good treatment towards independence in health care settings
		IHC	Health care environment, not treated with independence
		HTP	Unable to receive treatment because not adapted or refusal from physician
		HPP	Receives physio on regular basis
		HAC	concerned care programs will not always be supported by the government
		HSP	Health care system not adapted to needs of those with disabilities
	Attendant Care	CDF	Using the Direct Funding Program
		CAL	Have assisted Living support
		CSU	staff are understanding of disability needs
		CNC	as needs change, more care can be acquired
		CCA	challenges in accessing care
		CNA	no challenge in accessing care
		CSC	Staff make changes to care that are not requested by participant- difficulty in accepting in these changes
		CSD	Care is self-directed
		ICR	Resistant to changes in their care because they do not want to lose independence
		CTI	care can be scheduled at times they want

		CCC	importance of communication for good care provision
	Long-term Care Facilities	LFF	Fear of one day living in LTC facility
		LFI	fear that a LTC facility would strip them of independence
Accessibility	At home	AHS	Accessibility in home is good
		AHA	Home has universal design
		AHN	No changes needed to improve accessibility of home
		ICS	Currently feel they have independence in their environment
	External Environment	HTP	Unable to receive treatment because not adapted or refusal from physician
		ATC	frustration with accessibility and treatment on transportation
Assistive Devices		ADA	Have all Ads that they need
		ADR	Repair services
		ADT	Training of Ads is very good
		ADF	Use the ADP program to access the devices they need
		ADW	Waiting time for new AD
		ADC	Changes in AD due to age-related needs
		ADI	listing off Ads
		ANF	unable to use ADP to pay for Ads
		AWN	would like new Ads but not absolutely needed
		ADL	use at least one AD for all ADLS/losing AD would affect whole life
ADLs		ALI	identifies performance of ADL independently
		ALA	assistance needed for ADL