

**Life in the Later Years:
An Exploration of the Meaning of Retirement to Ageing Self-Advocates**

by

Sarah Diane Baumbusch

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SOCIAL WORK

in

The Faculty of Graduate Studies

THE UNIVERSITY OF BRITISH COLUMBIA
(Vancouver)

November 2010

© Sarah Diane Baumbusch, 2010

Abstract

The purpose of this study was to explore the meaning of retirement to adults with an intellectual disability in older age. *Background:* Seven adults between the ages of 50-60 years old participated in in-depth semi-structured interviews on the subject of retirement. All participants lived independently in the community, three participants were male and four participants were female. *Method:* An interview guide was used to address topics related to retirement. Interviews were approximately one hour in duration. Data was analyzed to find content themes. *Findings:* Three key themes came out of the data; the economics of retirement, desire for choices in retirement, and changing relationships with ageing parents. *Discussion:* Rethinking the term “retirement” in order to be more inclusive to the experience of populations who may not have participated in the paid workforce, acknowledgement of the transition from a “person with a disability” to a “senior citizen”, and education in regards to retirement and the issues that arise at this time of life are areas of discussion that came forward in this study.

Preface

This research, *Life in the Later Years: An Exploration of the Meaning of Retirement to Ageing Self-Advocates* has been approved by the University of British Columbia Behavioural Research Ethics Board certificate H09-03194.

Table of Contents

Abstract.....	ii
Preface.....	iii
Table of Contents	iv
Acknowledgements	vii
Dedication	viii
Introduction.....	1
1.1 Background and Significance.....	1
1.2 Research Question.....	2
1.3 Theoretical Framework	3
1.3.1 Social Constructivism.....	3
1.3.2 Anti-Oppressive Practice.....	4
1.3.3 Modern and Post-Modern Collaboration.....	5
1.4 Importance of Research.....	5
2 Literature Review	7
2.1 Definition of Retirement	7
2.2 Pre-Retirement Planning	8
2.3 Leisure as an Aspect of Retirement.....	9
2.4 Adult Day Programs.....	11
2.5 Working with the Concept of Retirement	13
3 Research Methods.....	15
3.1 Design.....	15
3.2 Declaration of Self	15
3.3 Sampling.....	16
3.4 Study Participants.....	18
3.5 Data Collection.....	21
3.5.1 Pre-Contact.....	21
3.5.2 Initial Contact.....	21
3.5.3 Interview.....	22
3.5.4 Content Analysis	24

3.6	Ensuring Quality	24
3.6.1	Rigour	24
3.6.2	Protection of Participants' Rights.....	25
4	Findings.....	26
4.1	Theme 1: “You can’t build a sizeable nest egg really”	26
4.1.1	Retirement Savings.....	27
4.1.2	Precarious Financial Situation.....	27
4.1.3	Apprehension.....	28
4.1.4	Desire for Information.....	30
4.1.5	Summary	30
4.2	Theme 2: “There’s more to life than just going to a day program...”	31
4.2.1	Choices	31
4.2.2	Self-Determination	32
4.2.3	Relationship to Community Living.....	34
4.2.4	Friendships	36
4.2.5	Summary	37
4.3	Theme 3: “I’ve got to start helping [my parents] and it’s not easy”	37
4.3.1	Caregiving	38
4.3.2	Witness to the Ageing Process	39
4.3.3	Summary	41
5	Conclusion	42
5.1	Research Summary.....	42
5.2	Comment on “retirement”	42
5.3	Community Living and Social Work Practice	44
5.4	Social Work Education.....	46
5.5	Policy.....	47
5.6	Strengths.....	47
5.7	Limitations	48
5.8	Future Research.....	49

5.9 Final Thoughts.....	50
References.....	51
Appendices.....	54
Appendix A: Letter of Consent	54
Appendix B: Interview Questions	57
Appendix C: Demographic Form.....	58
Appendix D: Recruitment Poster	61

Acknowledgements

I offer my appreciation to my committee members, Paule McNicoll, Tim Stainton and Rachelle Hole for your time and interest in facilitating my success. In particular, my advisor Paule McNicoll who has helped me endure the graduate student process with reassurance and ongoing support.

Special thanks to my family members who have provided me with numerous opportunities in life that have led to this point.

Dedication

To all the individuals I have met who have been labeled as “developmentally delayed” or as having an “intellectual disability” - you are more interesting, funny and outgoing than the majority of people I meet.

“The world acts as if what a person with a disability
has to offer is a secret,
for those of us who are family members and friends
we know what that secret is”.
- John O’Brien

1 Introduction

1.1 Background and Significance

The purpose of this study was to explore what retirement means to ageing self-advocates. The desire to look at this topic came from a culmination of personal experience both as a professional working in the community living sector, my involvement as a research assistant on projects on the health of this population, and my personal investment in this topic area as a family member. As a professional in the field, I have heard many service providers stress how important they feel it is for the older adults with an intellectual disability to “be allowed” to retire. Knowing that any time people who are viewed as “other” and, in this case, a group that is “cared for” by service providers, are vulnerable to paternalistic decision-making, it was important for me to pursue research which would provide direct voice of this population themselves. It was of interest to me to find out whether the discourse being created by service providers reflected the experience and desires of this population. Bigby’s (1997) research regarding later life for older adults with an intellectual disability supports the need to further explore the desires of this population, as the majority of participants in her study were “retired” from their adult day programs because the staff had initiated it, not because it was the individual’s choice to retire. This research is particularly pertinent now since this is the first cohort of older adults living in the community in large numbers, post de-institutionalization, and who are living into much older age, outliving their parents who are often their caregivers (Bigby, 2002).

The majority of research that has been done in this area does not involve direct

interviews with persons with an intellectual disability about later life planning and retirement. Rather, the majority of literature involves surveys and interviews of service providers and family members on behalf of persons with an intellectual disability (Ashman, Suttie & Bramley, 1995; Bigby & Baladin, 2005; Bigby, 1997; Lawrence & Roush, 2008; Mahon & Goatcher, 1999). It is problematic that there is a general lack of research in this area that directly represents the voice of people with an intellectual disability. The majority of what is available about this topic is mainly out of Australia and the United Kingdom (Ashman et al., 1995; Bigby & Baladin, 2005; Bigby, 2002; Bigby, 1997; Cordes & Howard, 2005; Lawrence & Roush, 2008). I was only able to find one Canadian academic article that looks specifically at retirement and implications for people with an intellectual disability (Mahon & Goatcher, 1999). This demonstrates a need for more research in a Canadian context about this topic area, and for more research that involves persons with an intellectual disability directly. My study will respond to both of these needs; to contribute to Canadian research and make place for the direct voice of persons with an intellectual disability.

1.2 Research Question

The research question that I will address is, what does retirement mean to ageing self-advocates? A “self-advocate” is a person who identifies as a member of the population with an intellectual disability and actively participates in the empowerment of persons with an intellectual disability to fulfill their rights as citizens (Miller & Keys, 1996).

1.3 Theoretical Frameworks

1.31 Social Constructivism

I have chosen to use social constructivism to provide a theoretical framework for this research study. Social constructivism allows for the exploration of complex meanings of experiences and relies on the participants' viewpoints to come to an understanding about the subject matter. It considers how an individual's point of view is constructed through their interactions with society, and considers present, as well as, historical interactions between the individual and society (Creswell, 2007). Social constructivism is based on the presumption that there is no absolute objective truth; an individual's experience is subject to the influences of the community and culture in which the individual lives. This context must be considered when individuals are relaying their experience of the world (Grossman Dean, 1993). This paradigm acknowledges that the researcher's own relationship with the subject matter inevitably interacts with the participants in shaping the outcome of the information collected (Creswell, 2007). The interview process is an interactive social exchange in which the interviewer and interviewee together construct the conversation, and ultimately the knowledge, that comes out of this process (Holstein & Gubrium, 1997).

In exploring notions of retirement and their relationships to people with an intellectual disability, social constructivism provides a strong basis for analysis. It will provide a unique analysis of the constructs of both disability, as experienced by the participants in this study, as well as the construct of retirement, as a social ideal. The outcomes of this

research will consider historical and current constructs as important components of the evolving relationship of intellectual disability to retirement.

1.32 Anti-Oppressive Practice

This research incorporates anti-oppressive structural social work practice theory. Structural social work situates itself within critical theory with a focus on how certain sub-groups within the population experience oppression (Mullaly, 1997). The goal of structural social work is to alleviate this oppression; one method to achieve this is to provide a collective voice to members of the sub-group who may not otherwise have a platform to bring their viewpoint to the larger community (Mullaly, 1997). As stated in the in the introduction, there are few studies in which people with an intellectual disability are interviewed firsthand when the subject matter is directly related to their experience (Ashman et al., 1995; Bigby & Baladin, 2005; Bigby, 1997; Lawrence & Roush, 2008; Mahon & Goatcher, 1999). Although this research is limited to persons with an intellectual disability who are verbal, it maintains itself in the foundation of anti-oppressive social work practice by making a point to seek out and include members of this subgroup and speak directly to them, instead of risking oppressing them further by seeking out secondary informants to speak on their behalf. Mullaly (1997) writes “people are subjects, human beings with inherent dignity and worth” (p. 170), a philosophical statement that Mullaly (1997) believes can be operationalized in social work practice. Following this philosophy, a conscious decision was made to give a monetary honorarium of twenty dollars to the participants. Although minimal, this sum makes a statement regarding the fact that the participant’s time and contribution are valued.

The findings from this study will aid in the empowerment of this group, by providing direct voice on a subject matter that directly affects their lives, another goal of anti-oppressive practice (Mullaly, 1997). The findings from this research will be shared with the self-advocates who participated. If they want, participants may also present the findings to service providers in an effort to enhance their self-determination. It is a hope that service providers will accept the results of this study as a contribution to future planning, and that it will provide self-reflective insight about power and the decision-making process. Anti-oppressive social work practice must infiltrate every aspect of professional involvement, from frontline clinical interactions to choices made as researchers in the field.

1.33 Modern and Post-Modern Collaboration

It is acknowledged that these theoretical perspectives derive from both a modern and post-modern standpoint which may be seen as a contradiction of sorts. Although, as a researcher, I am coming from a space of mind that there is no objective truth, the findings indicate that the lived experiences of this population have commonalities that structure the truth of experience in context. An anti-oppressive perspective allows for my personal and philosophical need to come from a position that is in line with my beliefs, the social constructivist perspective places the participants' experience at the forefront, rather than my political agenda.

1.4 Importance of Research

This research gives insight into how people with an intellectual disability view their later years and provides voice to a population that often has decisions made on their

behalf by service providers and/or family members. The aim of this study is to explore how this population sees their life changing as they get older, what they want to be doing with their day to day lives in their later years, and how they might see their experience as being different than the experience of those in the general population. This research has major implications for services providers who are currently reframing their programming to meet the needs of those with an intellectual disability who are now living well into their later years. Of equal importance, this study adds to the body of knowledge that currently exists in this area and the discourse that surrounds later life for persons with an intellectual disability.

2 Literature Review

When I reviewed the literature, I used the terms “intellectual disability”, “developmental delay”, and “mental retardation” to find background research regarding this population. For the purposes of this research, I will be using the term “intellectual disability” to encompass all three terms. I have reviewed literature that looks at retirement directly as well as later life planning, work, and leisure.

2.1 Definition of Retirement

The term “retirement” in itself can be difficult to define. The conventional definition found in Websters Dictionary states it is, “ an act of retiring; the state of being retired; withdrawal from one’s position or occupation or from active work life; a place of seclusion or privacy” (Merriam-Webster, m-w.com, 2010). Statistics Canada considers an individual over the age of 55 years, out of the labour force and receiving at least half of their income from retirement sources, as retired (Bowlby, 2007). According to the 2006 Participation and Activity Limitation Survey by Statistics Canada only 30% of the population with a developmental disability had any level of participation in the labour force (Galarneau & Radulescu, 2009). This indicates that the majority of individuals with an intellectual disability have not participated in the labour force, and therefore, will not experience retirement in the traditional sense, as defined by Statistics Canada.

I have chosen to still use the term retirement to provide a reference point for the life transitions that are impinged upon an individual, either through decisions by outside forces such as a service provider, or self imposed, because of age related changes. In my experience in community living and from speaking to various service providers, the term

“retire” has been used most frequently to describe the transition of clients; to more age appropriate day programs, out of sheltered workshop situations, and to discontinue a more active lifestyle. This literature review makes evident that retirement, and its multiple implications, is unique for this population, and therefore, there is a need for more intensive research from this population’s viewpoint.

2.2 Pre-Retirement Planning

A number of studies focus on interventions leading to retirement. Lawrence and Roush (2008) explored pre-retirement planning services for persons with an intellectual disability in Ireland. They surveyed 122 service organizations with a response rate of 59%, and provided insight into policy, services, decision-making and education about retirement for service users. The survey questions were framed using two overarching principles that were identified by the researchers as essential for a successful transition into retirement; one, that the transition is a result of active and knowledgeable planning, and two, that the individual has been the one making the choices leading up to the transition. The results showed that service providers identified service users only half of the time as the primary decision-maker of when to retire, followed by professionals, and least often, family members. This study focused on gaining information from service providers rather than service users in regards to their involvement in retirement planning. The voice of service users in this case was not addressed. Only four of the service providers surveyed indicated that their workplace had any formal policy related to retirement for service users, and five respondents indicated that they offered some type of education program, although this involved information about a change of service rather

than education for individuals about retirement (Lawrence & Roush, 2008). The results of this study did raise an important question; what kind of planning is being done to prepare people with an intellectual disability for retirement?

Mahon and Goatcher (1999) conducted a study that involved providing education about retirement directly to persons with an intellectual disability. An experimental and control group were used to assess whether the experimental group member's participation in education for later life planning would result in increased life and leisure satisfaction, sense of autonomy, and corresponding lifestyle changes. Mahon and Goatcher (1999) found that the experimental group did report an increase in leisure and life satisfaction, yet external forces, such as lack of access to funds, were reported by both the experimental and control groups as major factors that constrained participation in desired leisure activities. In regards to autonomy, the researchers found that people who participated in the later life planning education either made major life changes, or articulated a conscious choice not to make changes (Mahon & Goatcher, 1999). This research shows that people with an intellectual disability may not have the same opportunities for learning about later life planning as the general population. Moreover, even with education, the life circumstances of this group provide unique challenges in fulfilling retirement goals.

2.3 Leisure as an Aspect of Retirement

The participation in leisure activities as the dominant aspiration of a desirable retirement is present in both popular culture representations and the everyday discourse of larger society. This aspiration may take on a different form in the context of the lives

of people with an intellectual disability. Bigby (1997) used a purposive sample seeking out people with an intellectual disability who were not connected to disability services, in order to reach the older adults who were in isolated living situations. The purpose of the study was to look at the prospects for later life of individuals with an intellectual disability who were over the age of 55 years, had lived with their parents until at least the age of 40 years and were currently living independently. The data were collected using a semi-structured interview with a primary informant who had a long-term close relationship with the participant. The interview sought to gain a detailed account of all aspects of the individual's life since leaving his/her parent's care. The study reported that middle aged people with an intellectual disability often shared their parent's life, either by caretaking for their ageing parent, or because the parents acted as their closest social contacts, resulting in the individual engaging in activities that were geared toward a significantly older age group. Bigby (1997) found that once participants were no longer living with their aged parents they often began taking part in new activities that they had never engaged in before, and that they expanded their social network. Though these aspects of later life for older adults with an intellectual disability were viewed as positive, they often came about as a result of unexpected circumstance, such as the death of a parent, rather than active planning (Bigby, 1997). These findings reinforce that planning for a lifetime that includes living into older age for people with an intellectual disability is not always addressed. Also, people with intellectual disabilities' history of leisure activity when they are living with their ageing parents is not the typical experience of the general population. The study also suggests that this population may not desire the same

leisure activities that are typical in retirement; if they have been living their parent's lifestyle, they would be used to activities at least 20 years beyond their own generation's experience.

Rogers, Hawkins and Eklund (1998) had similar findings in regards to the individual's experience of older age. The theme that was most prevalent in their study, of leisure options was an absence of self-determination. All participants in their study indicated that leisure activities were determined by others, formal and informal care providers, on whom the participants were dependent to access activities. In conjunction with this dependence, Rogers et al. (1998) describe persons with an intellectual disability being regarded as "child-like" by care providers who disregarded their decision-making capacity. This presents a different experience of leisure access for this population, unlike the "freedom" to participate in desired leisure activities in retirement at one's discretion, which is represented as the ideal for the larger population. These findings contribute to the purpose of the proposed study which is to elicit the direct voice of older adults with an intellectual disability to explore what they want for themselves as they age.

2.4 Adult Day Programs

Often people with an intellectual disability, particularly those who live in a supported environment, are involved in day programs that involve recreation or work-related activities. Rogers et al. (1998) showed that options for people with an intellectual disability are limited once they are no longer in traditional sheltered workshop style employment situations or recreation-based day programs. Participants in their study expressed concern regarding life after sheltered workshop closure, particularly in regards

to what would happen to their social network. Results from this study showed that participants feared retirement, instead of looking forward to it in a positive way (Rogers et al., 1998). Ashman et al. (1995) also found that participants who were employed reported a positive attitude towards work but had negative or mixed feelings about stopping work and retiring.

In relation to the proposed study, this indicates that, for numerous reasons, people who have experienced the life-course as a person with an intellectual disability may perceive retirement differently than the larger population. Opportunities to see one's social network, for example, may not be as large a concern for people in the general population who have easier access to things like transportation and who are not as dependent on others to facilitate their social life. This has implications for imposing retirement on this population, when service options and other activities are not available.

Bigby and Baladin (2005) surveyed service coordinators of day care programs and leisure services for older people, looking at the integration of persons with a life long disability into mainstream programs for older adults in the larger community. Although over half of the programs in the survey served people with a life long disability, that population only accounted for a small number of participants in each program. Many agencies were funded by the government to provide programming to people with a lifelong disability, but they served a population with various disabilities, notably brain injury, not necessarily people with intellectual disabilities. Bigby and Baladin (2005) also found that half of these programs reported having trouble accommodating people with a life long disability due to lack of staff to help facilitate participation, resulting in times

when these people were not able to participate at all. This further exemplifies that the experience of persons ageing with an intellectual disability is unique and activities that the larger population may participate in during retirement, such as attending a seniors' centre, may not be an option older adults with an intellectual disability can take for granted.

2.5 Working with the Concept of Retirement

When discussing retirement with older adults in this population it is important to consider that it is common for people with an intellectual disability to have difficulty with conceptual ideas (Cordes & Howard, 2005, Lawrence & Roush, 2008; Rogers et. al, 1998). Rogers et al. (1998) report that respondents have a hard time discussing time, future, and feelings. The researchers suggest that an unstructured interview that adapts to the individual's understanding can be useful with this population because it allows for rephrasing of questions multiple times during the interview in order to accommodate interviewees' comprehension. Lawrence and Roush (2008) add that people with an intellectual disability often lack the education and conceptual ideas about retirement that are prevalent in larger society. Cordes and Howard (2005) directly query the issue of the level of understanding of conceptual ideas in their study, which aims to understand the existing concepts that people with an intellectual disability have about work, leisure, and retirement. The researchers used pictures that showed different work and recreation activities to interview middle-aged adults about what they associated with "work" and "play", and, how they felt about retirement, and, what they thought their life would look like as a retired person. Cordes and Howard (2005) found that of the three concepts,

work, play and retirement, participants knew the least about retirement; they attributed this to a lack of education and previous knowledge base. The researchers acknowledge that the majority of participants belonged to the same organization and, therefore, may have had similar experiences with education about retirement so these findings cannot be generalized (Cordes & Howard, 2005). Still, it suggests that people with an intellectual disability may not be included in discussion about retirement as part of their prospective life-course or as a decision that they will have to eventually make for themselves. It also emphasizes the need to collect more information in regards to how people with an intellectual disability view retirement.

Although Cordes and Howard (2005) looked directly at retirement, it was placed in relationship to work and leisure, with the intent on exploring whether the concept itself was understood by this population. This is different to the efforts of this study; rather than using already established ideas of retirement and seeing whether this population understands them, I propose to have a broader discussion about how people will choose to spend their later years. Mahon and Goatcher (1999) found that participants in their study were adamant that they did not want to leave their work which they equated with retirement; therefore, the researchers suggest using the term “later life planning” as opposed to “retirement planning” to discuss this phase of life. These previous studies have provided insight for the approach to the current study.

3 Research Methods

3.1 Design

This research followed a qualitative descriptive design (Sandelowki, 2000; Maxwell, 2005). The analysis of the data was represented as accurately as possible to reflect what has been presented by the participants. Field notes and memos were also used to record data while the researcher was in the field in order for in-depth data collection. This design method is particularly useful when addressing questions where the answers are of special interest to practitioners (Sandelowski, 2000). In this case, the design of the study provided an opportunity to explore the meaning of retirement for a specific sub-group, which will have practice implications in regards to service provision. Data was analyzed using content analysis, where codes are derived from the transcripts, field notes, and memos through ongoing analysis. This design method resulted in a summary of findings organized around themes that fit with the data (Sandelowski, 2000).

3.2 Declaration of Self

I became involved in the community living sector as a professional about four years ago. However, I became personally vested in this community seven years ago when my niece was born with a developmental delay. I have always had a desire to work with this population, although my chosen area of geriatrics did not provide much opportunity. After deciding to break from health care and geriatrics, I was given new insight into service provision for people with intellectual disabilities when I began working as a family support worker at a local community living organization. Shortly after, I began my Masters Degree, and was given the opportunity to work as a research assistant in two

research studies involving families and their children with special needs. More relevant to this research, was the study, “Ageing Together: A Critical Analysis of the Healthcare Needs of Adults with Intellectual Disabilities and their Families” through the University of British Columbia’s School of Nursing. It was through the many interviews of service providers, family members and adults with an intellectual disability, coupled with my own experience in geriatrics and community living, that the idea for this research was derived.

3.3 Sampling

The sampling approach that I used was availability and snowball sampling (Schutt, 2008). I used this approach because I interviewed a specific sub-group of people, self-advocates, which can be a difficult population to locate. In addition to being a self-advocate, there were a number other criteria that will be necessary in order to participate. First, the participant had to be verbal and English-speaking since the primary means of collecting data is through an interview. If the individual had used American Sign Language or other methods to communicate, such as a sign board, I would have made my best efforts to find a translator so that the individual could have participated. In this case, all participants were able to communicate using verbal language. Another logistical criterion was that the participant live in the Lower Mainland. It was particularly important with this population that there was the ability to meet face-to-face in order to ensure understanding of the consent letter and demographic form and in order to pick up any non-verbal cues that may indicate that the participant needed the questions to be rephrased.

I chose the criterion age range of 50-60 years in order for participants to be under the typical retirement age of 65 years, yet far enough into adulthood that they might ponder how they will spend their later years. Bigby (1997) states that persons with an intellectual disability are considered older at a younger age than the general population. Bigby (1997) states that the age of 55 years in a person with an intellectual disability is generally accepted as comparable to 60-65 years of age for a person in the general population. It should also be considered that, even though people who have an intellectual disability are living longer than in the past, their chances of developing health problems are two and a half times higher than the general population (van Schrojenstein Lantman- De Valk, Metsemakers, Haveman, & Crebolder, 2000). The indication is that persons with an intellectual disability can be more medically complex and compromised, as being born with a developmental delay often includes physical, as well as cognitive delays, and therefore pre-existing life-long health issues, combined with the chronic conditions of an ageing body, result in bodies ageing at more rapid rate.

The sample size was between six and eight people, with a maximum of ten participants. At completion a total of seven participants were interviewed. This sample size was chosen in order to ensure that adequate data was collected to allow for review of data for themes. The goal of this study was exploratory in nature, after seven interviews there was enough data to identify emerging themes and was the beginning of saturation (Schutt, 2008). Although it was unlikely that an individual who does not experience life as a person with an intellectual disability will express interest to participate in this study, the demographic form (see Appendix C) acted as an additional screening tool.

3.4 Study Participants

A “self-advocate” is a person who identifies as a member of the population with an intellectual disability and actively participates in the empowerment of persons with an intellectual disability to fulfill their rights as citizens (Miller & Keys, 1996). I have chosen to interview self-advocates because it is less constrictive in regards to a definition of intellectual disability. It allows for any person who feels that they are a member of this population to participate. This follows an anti-oppressive framework, to provide voice (Mullaly, 1997), and to not have to set strict guidelines in relation to who is a member of this population. In British Columbia, services for persons with an intellectual disability are determined by the Community Living Authority Act which utilizes the Diagnostic and Statistical Manual of Mental Disorder 4th Edition, and mainly the intelligence quotient score of 70 or below as the qualification to be labeled with an intellectual disability and qualify for government funded support (Community Living British Columbia, www.communitylivingbc.ca, 2009). This ignores individuals who, for various reasons, self identify as a member of this population. Historically, self-advocates are active participants in a larger movement for the rights of people with intellectual disabilities and represent the interests of this population collectively (Miller & Keys, 1996). Although, these characteristics indicate self-advocates may be a specific segment of the population who have an intellectual disability at the moment they are the most direct voice in relationship to the goals of this study.

Detailed information was gathered on the participants using a demographic form (see Appendix C). The following paragraphs describe each of the participants, using pseudonyms:

April was a female in her early fifties living in the community with her husband. She attended high school until the senior grades but did not obtain a high school diploma. She had created a few self-employment opportunities for herself which she worked at intermittently. At the time of the study she was not working but spent many hours doing volunteer work mainly in the community living sector. Her income was a government disability cheque that she received every month.

May was also a female in her early fifties who lived alone in a co-op housing situation. May was very active doing volunteer work in the community living sector and had not worked in the mainstream workforce since her early thirties. May had most of her high school education but did not graduate with a high school diploma. After living off the income from an inheritance for a number of years, May was again receiving a government disability cheque as her source of income.

June was a female in her mid-fifties who lived alone in a subsidized apartment in the community. June did contract work, less than 10 hours a week, for a community living organization. She had a high school completion certificate and had attended some classes at a community college. She had multiple sources of income, a government disability cheque, personal savings, employment income, inheritance and a trust fund. The sources of income outside of the government disability cheque were set up in a way that did not threaten the loss of her government disability income. This meant that what she received

from these other sources did not exceed the allowable maximum additional income.

July was also a female in her mid-fifties, she lived with her mother and extended family members her entire life. She had participated in an employment program for people with disabilities up until the past few years when a major decline in her eye sight made it impossible to do the work. July had a high school completion certificate although she has minimal literacy skills. She source of income is her monthly government disability cheque , but she did not feel as much of a financial restrain due to the fact that she continued to live with her mother and extended family who provided basic needs.

August was a male in his late fifties who lived alone in a subsidized apartment. August's main source of income was his government disability cheque, although he also had a casual position, less than 10 hours a week, at a community living organization to supplement his income. He had an elementary school level education.

September was a male in his mid-fifties who lived alone in a market rental apartment. September had part-time employment at a community living organization, where he received benefits, but his main source of income was his government disability cheque. September had an elementary level education.

October was a male in his late fifties, who lived with his spouse in an apartment in the community. October had a high school level education. He had worked intermittently throughout his adult life; his response to employment status, was "forced retirement". His main source of income was a government disability cheque.

3.5 Data Collection

3.51 Pre-Contact

The potential participants were contacted through a third party, service providers who worked with self-advocates in the community living sector, who gave potential participants a brief verbal description of the study and a copy of the poster advertising for the study (see Appendix D). I spent some time giving the third parties some background on the study so that they could give the potential participants a sense of the goal of the study. The third parties were given a flyer for the study to give out to those who were interested in participating in the study (Gochros, 2008). My telephone number was provided so that potential participants could contact me to express interest in participating in the study and get further information. I reviewed the letter of consent and interview questions with a self-advocate before using them in the study. The self-advocate gave feedback in terms of using plain language and changes to some of the questions that were harder to understand.

3.52 Initial Contact

The initial method of contact was most often via telephone, or being approached by participants when they saw me at community events or meetings. I gave potential participants a brief description of the study, went over the letter of consent verbally (see Appendix A), and gave the participants an idea of the types of questions that would be asked if they chose to meet for an interview. I offered to mail a copy of the letter of consent and interview questions (see Appendix A and B) could be mailed to the potential participant for review. Potential participants were asked if they had any questions at this

point. They were given the option to participate in the interview either over the phone or in person at a time and place that was convenient with them. Face-to-face interviews were emphasized as the preference, and all interviews did take place face-to-face. Participants were offered the choice to think about whether they would like to participate and call me back, or set up an interview time at the initial contact (Gochros, 2008).

3.53 Interview

The participants were only asked to do one interview. The interview was recorded by a digital recorder turned on after the participant signed the consent letter and understood that the recorder was picking up what was being said from that moment. The consent letter was read and explained and any questions regarding the study were addressed before recording (Gochros, 2008). Participants were informed that if anything was said during the interview that they did not want transcribed they could state that they would like it deleted either within the interview or contact me after the interview and I would take it out when cleaning the transcript (Ivanoff, Blythe & Walters, 2008). The demographic form (see Appendix C) was included in the recorded portion of the interview. This was done so that that important information that may have come up while going over the demographics was recorded. For most participants I read and filled in the demographic form with the participant because literacy can be an issue with this population.

A semi-structured interview was used in order to address areas of importance to the research, but it allowed for an open enough platform that other questions could come up during the course of the interview, depending on the participant's answers, in order to get

more depth on a specific issue or to clarify (Maxwell, 2005). In two cases, two participants were interviewed at the same time, at the request of the participants. In one of the cases it was clear that being interviewed together provided an increased comfort level for at least one of the participants. In the other case, the two participants being interviewed were a married couple who experienced the world as a unit. Social constructivism concentrates on how the individual makes sense of their everyday life and world and recognizes that this is always influenced by the context. It emphasizes providing an atmosphere in which the participants feel most comfortable, which in some cases, may mean the presence of another individual (Grossman Dean, 1993).

The interview guide (see Appendix B) acted as a reference tool in order for the interview to stay on topic. The participants had some discretion in how they chose to answer questions, but the main content area of retirement was the focus. At times when the interview content lost its focus I referred back to a question on the interview guide, or rephrased the last relevant statement made by the participant, and asked a question to further the statement in order to move the interview forward. I employed active listening throughout the interview, paraphrasing important statements that were made, checking-in with the participant for clarity and encouraging the participant to elaborate on ideas (Gochros, 2008; Holstein & Gubrium, 1997). At the end of the interview I asked the participant if there was anything that had not been addressed that they felt I should know for the purpose of this study. I allowed the participant to make a final statement regarding the topic area, and if the participant did not feel that there was anything else to be said on the subject, I closed the interview. I reminded the participant of the phone

number at which I could be reached in case they wanted any part of the transcript removed after the interview. At the end of the interview I thanked the participant for their time and gave them twenty dollars for participating.

3.54 Content Analysis

I made field notes and memos that were of interest and in relation to the subject being studied throughout data gathering. Recordings were sent to a professional transcribing agency, and data analysis occurred simultaneously to data collection. The interview was transcribed verbatim, sent back to me and I cleaned the transcript to get rid of any identifying information and any information that the participant indicated that they wanted removed. I coded the transcripts for themes. Coding was done by reading the verbatim transcripts and developing coding categories. The information in the code categories were compared in order to establish overarching themes (Maxwell, 2005). The three overarching themes that will be further explored in the findings chapter were; the economic implications of retirement, the desire for choices, and the impact of having ageing parents during this time of life.

3.6 Ensuring Quality

3.61 Rigour

In order to maintain validity constant reflection of my own ideas around the subject matter was collected through memos and field notes. Direct interviews with the population which the research question identifies, as opposed to secondary informants, contributed to the validity of the results (Maxwell, 2005). The recorded interviews were transcribed verbatim to ensure that the participant's voice was directly considered.

Selective recording was avoided by taping the entire interview, starting from the demographic form to the last question of the interview. The transcripts provide details and accuracy that field notes and memos cannot provide and can be accessed by others in order to further assess accuracy (Perakyla, 1997). Direct participant quotes were used to support the data and avoid misinterpretation and researcher bias affecting the conclusions drawn from the interviews (Maxwell, 2005).

3.62 Protection of Participants Rights

Approval of this study was obtained from the University of British Columbia (UBC) Behavioural Research Ethics Board. Participants were made aware that if they had questions about the study or their rights as a participant that they could call the UBC Research Subject information line and were given the phone number and time of day the office was open. Participants were provided with a copy of the letter of consent which outlined the purpose of the study, assured the voluntary nature of the participants, and the participants' ability to withdraw at any time. Audio-taped interviews were kept in a secure location and deleted after transcription. Transcripts were cleaned to discard of any identifying information and pseudonyms were used in the findings. A confidentiality agreement was signed by the Principal of the company used to transcribe the interviews. A copy of the cleaned transcripts and signed consent forms will be given to the School of Social Work to be kept secure in the archives room and will be kept for at least 5 years and then destroyed.

4 Findings

The findings will be described in three key themes that came out of the interview data. These themes address the economic implications of retirement, the desire for choices, and the impact of having ageing parents during this time of life. Pseudonyms will be used in quoting the participants in the findings.

4.1 Theme 1: “You can’t build a sizeable nest egg really”

The majority of participants either did not participate in paid employment at all or had minimal involvement at the time of the study. Don and Lisa, a married couple, had brief engagements in self employment in the past, Lisa was still self-employed, through a mail order cosmetics company, at the time of the interview. Mary and Rose both worked about three hours a week, Rose worked for a neighbour in her community and was paid when the neighbour was able to afford it. Larry and Mark both worked part time at separate community living associations. All of the participants received a disability income from the government ministry meaning that they could only earn an extra \$500 a month before having money deducted from their disability cheque. The participants faced inconsistent employment opportunities during the course of their adult lives. During their adulthood, none of the participants had secured a job that had lasted an extended period of time. The four sub-themes of retirement savings, a precarious financial situation, apprehension about transferring to old age pensions, and, the desire for information become apparent when discussing the economics of retirement for participants.

4.11 Retirement Savings

All participants were receiving disability income from the government which did not allow an accumulation of savings in their bank account without losing this income. A number of participants noted that they were unable to participate in the process of building funds for the future. The ability to accumulate savings heading into retirement was one of the biggest concerns for Don:

And being disabled, it's so much harder for the disabled community anyway. If we keep a job, if we're lucky enough to keep a job for 20 years then it would be great, but the fact of life is, usually they last about 5 years if even that, and then it's gone. So the fact that you can't build a sizeable nest egg really... The only thing is that I know, the one thing that I'm going to have problems with, is the fact that there's not enough money to really... like I've got no retirement [savings] that I know of at all, so that's going to be the biggest problem

Mark had also found himself out of the workforce for a number of years until his recent employment at a community living organization where he worked eight hours a week:

Well the first thing, it'll be very interesting to see, because since I haven't worked for a long time 'til I worked for (community living organization), is to find out the years I put in because I've been there just over, I think it'll be three years since this past year... but the thing is to see what I understand basically about when I come to retirement is to see do I have a pension from work, how that works and that because I don't understand how that works really...

Christine spoke about the context of not being able to save for retirement: "Because I know a lot of seniors, they... even seniors that don't have a disability, the way the government is right now, it's really hard to put any money away for your old age".

4.12 Precarious Financial Situation

The financial situation of dependence on government support for basic needs created a situation where participants lacked the ability to plan into the future.

Mark described the realities of his financial state:

...recently I had run out of a pair of pants, so I had to buy some, so thanks to somebody, show me about the Sears Clearance Centre, so I got some new... these pants that I got on right now and another pair, and I always look at prices of things too because you don't know what's going to be the cost of places where they have a clearance centre, or maybe some places I might be looking around before I buy the product too, because men and ladies go through clothes and... they didn't fit me and I'm trying to work...

The urgency of living in the moment was clear in Lisa's description of how she saw her financial situation: "...it's trying to work around what we got and do it when we have the money to do it, because we know as we get older, it's going to be even worse". This was echoed by her husband Don: "The funding isn't really there, you have to live day to day sort of and that's the other problem too". These participants lived their adult lives in the midst of ever-changing government rules and regulations regarding their financial security. Christine described how important the benefits attached to government support were to her economic survival: "Yeah, I'm lucky mine is covered, mine is covered right now, because between – I'm not a senior yet – my medical and my dental and my bus pass, that's what was making me so broke before".

4.13 Apprehension

The uneasy reliance on the economic stability embedded in the label of "persons with a disability status" to the unknown label of "senior citizen" created apprehension in many of the participants. For Lisa it was not knowing what would happen to the benefits she was currently receiving:

So, you know, what things can you do? And what things can get covered on your medical and everything else? And do you get a new... probably a new medical card and all this, so there's changes too that come into it. So I don't know, I'm not looking forward to turning 65.

Mark feared an already difficult financial situation may become worse with this transition:

...but just to know what it's going to be like... my money, is it safe? So be careful when I retire, you have to do all types of things all over again when you're single and not working, then you got to pay for bills by yourself, you have to make sure... if you don't pay your bills, you're going to be a little bit struggle, but it might be less, I don't know what it's like to be out of... is it less than we get, or is it a bit more than we get? That's the thing I don't know about.

Larry was concerned for his peers in regards to meeting their basic needs:

...what happens when they get to be 65? Are they aware of their area's groups? That are resourceful, because I know most places they have dinners at [community living organization], but the community kitchens... I think it's going to be a problem of, where there's going to be not so much funding available, so that's why they have to get you to know there's a back up and having these centres.

The potential loss of benefits once a person becomes a senior was a major concern for Christine as well, who described her interaction with her optometrist after getting her disability benefits back:

And as soon as I said that, his attitude was... and it could affect seniors too, his attitude went [snaps] from night and day, "Oh, what can I do for you (Christine)?" And I said, "Well they told me that I'm entitled to an eye test and I might be able to get new glasses because I've been off the system for seven years." And as soon as they know that you have your medical coverage back, it's like night and day, you went from being mean to nice.

Don spoke about the deprivation of resources for the senior population in more general terms:

...and it's ridiculous, they keep putting the emphasis on seniors and that and yet they don't divert any funds towards the seniors program whatsoever and it's crazy really. They know the population's getting older and yet they don't really want to do anything about it which doesn't make any sense really at all.

4.14 Desire for Information

Participants expressed a desire for a better understanding of the financial implications of receiving a pension. Larry was the only participants who said that he was given information on saving for retirement, which was at his place of work, from a manager who spoke to all employees about their pension plan and personal savings. Lisa described the confusion she felt in trying to understand how her and husband's finances would work when he turned 65 years old and received old age pension and she was still getting her disability income: "I mean, you see all these tables, but that's not explained, 'cause I get some and he'll get some, where does the money...? How much will it come to? Will it come to the same? Will it come to different?".

The desire to better understand his future finances was echoed by Mark:

Well, yeah, I'm just wondering so I can prepare myself to know because once I know what I get in my pension, will be that less, or do you still work, or do you have to collect... do you have to be on a pension first, or you can't work anymore? That's the thing I've been confused about right now. I'd rather wait 'til somebody can help me with that, to understand that.

Don described his confusion in regards to information he had been given:

When they were on say, the GAIN or whatever, yeah it was covered, but then when you're on the senior, it's not covered, "Why not?" Especially when you have an operation, if you're on GAIN, it might be covered, but with OAP it might not be covered. So there's all this, "What is covered? What isn't covered?" Can we get the funding to do...? And that's all I've been hearing for the last little while, "I'm 65 and I can't get this, and why can't I get that?"

4.15 Summary

The economic instability experienced throughout adulthood resulted in a situation in which participants did not have a solid financial situation heading into retirement years.

A dependency on the government placed participants in an economic climate subject to the continuous threat of change, while their economic security was dependent on decision-making outside of their power. There was a feeling that their situation could get worse after they turn 65 years old and had to transfer from disability income to seniors' pension.

4.2 Theme 2: “There’s more to life than just going to a day program...”

As participants headed into their retirement years they reflected on how their choices were dictated by their circumstances. Some participants felt they were left out of decision-making and discussion about their retirement years. There was a sense that these later years may bring changes in the participants' relationships to the community living entity, as well as, their friendships. These topics will be discussed in the four sub-themes of choices, self-determination, relationship to community living and friendships.

4.21 Choices

The absence of participation in the workforce and lack of savings limited the options for leisure and dream fulfillment in retirement.

As Don expressed:

Well what I wanted to start doing when I turned 65 was to start traveling, but I don't know... like I said, all that hinges on the money factor and it's just whether I'd have the funding to go traveling or that would be a problem as well too. It's nice to think about it and to dream, but in reality I don't think it probably is going to turn out the way I want it to really.

Mary had a similar outlook:

if you've been living in a group home and say, you're sixty and all of a sudden you're retired, your life isn't... you won't be taking trips like the average person, or you won't be taking trips and you won't be doing... maybe I'm wrong, but that's the way I look at it. I don't see myself going, like my brother and his wife are probably going to be traveling in a few years and I don't see myself doing that or getting a new house or a new car.

Although there were possible limitations in leisure activities Mary still had strong feelings about having choices: "...But if you're just saying to retire just for the sake of you just think we should retire and go into another day program, I'm not going to retire. I want to be given some choices".

4.22 Self-Determination

Self-determination was a central element in living the life that participants wanted in older age. Mary had strong concerns when discussing watching an older friend interacting with service providers who were moving the friend to a new housing arrangement and she felt her friend's wishes were not being taken into consideration:

Mary: "Yeah, and I don't want that to happen. I want you to respect me for what I'm saying, or anybody, but that's really hard. I don't think people are used to having people talk back to them sometimes."

Interviewer: "When you talk back to them?"

Mary: "No, no I mean if any self-advocate talks back to someone usually we're told, "Everything is fine, so you don't want to rock the boat, so..."

Interviewer: "You've had that experience your whole life?"

Mary: "Most of it."

When asked if there was anything she wanted to be different about her life when she got older, Rose responded: “Well I’d like to be independent and make sure everybody lets me do what I want to do and make sure I can do it on my own”. The sentiment of being part of a population that is not treated equally was expressed by Don: “The people with the chronic disabilities are even getting further and further behind. There should be a way around it, but nobody’s found it yet”.

The everyday discourse of planning for retirement was notably absent in a number of participants. Discussion about the basics of retirement, such what life changes a person may want, was not common. Rose, a 54 year old woman, who had lived at home with her mother her whole life, and was active in community living organizations, was never spoken to about retirement:

Interviewer: “During your life, did people talk to you about retirement?”

Rose: “Not really, no.”

Interviewer: “So people didn’t really talk to you about planning for retirement or saving money?”

Rose: “No.”

Interviewer: “Do you wish that people did?”

Rose: “I wish they did, spoke up and say, “What do you want to do when you want to retire?” Say, “I don’t know.”

Christine, a 51 year old woman, had a similar experience of not having engaged in discussion about the idea of retirement in her life:

Interviewer: have people talked to you about retirement?

Christine: No.

Interviewer: So people don't say, "What are you going to do when you retire?"

Christine: No they haven't.

Mary spoke to the issue of wanting engagement: "That's the other thing, if people can help people plan for their retirement more".

4.23 Relationship to Community Living

There was some conflict expressed from all participants in regards to how they viewed their relationship to community living organizations into their retirement years.

Numerous comments were made that expressed feelings of loyalty to the community living organizations, in which the participant had been involved with for many years, juxtaposed to a desire to expand their network to include more mainstream services, by attending local community seniors centres. The label of "intellectual disability" gave participants access to community living organizations as adults, while the upcoming label of "senior citizen" gave the potential to access new activities and organizations. This was clear in Larry's thoughts on where he wanted to spend his time in his retirement years.

Larry was already involved with an integrated seniors centre through his work where he supported the seniors with disabilities. Larry described his experience having involvement in both community living and mainstream seniors programs:

Well from what I've seen it looks fun, it's like the community I'm involved with, it's nothing to with wrong about disability and that, but I think I've seen other centres that have been more strong feeling about it, integration. But we'll still be visiting friends at times too. We will still be going to the [community living centre] dances and things like that.

The desire for inclusion in typical senior's activities while maintaining a relationship with community living organizations was also expressed by Mary:

If I want to go to [the community living association], that's fine, but if I say, want to go to [local seniors centre], or [other seniors centre], you know I should be able to say, "This is where I want to go." I don't want to be going where just my peers are going, I want to go where I want to go, and I should be given that choice instead of saying, "This is where you're going to go."

Mark who became involved with community living in the middle of his adulthood was not interested in expanding his network to mainstream seniors' centres: "...I want to do my best to stay around here, because this is my life now." Although, Don also expressed that he would like to become more involved with mainstream seniors activities in his community, he emphasized the important role community living would play in his life as he got older:

...we're probably going to be leaning on the agencies quite a bit more when we do reach 65 because there won't be a lot of the services that we can get. And I think that's one of the things I could see happening, is the associations are going to have to take a more active role in the seniors and in planning for the care that the seniors get, the quality of life that the seniors get too.

When asked about the differences for people with a disability in regards to getting older in comparison to older adults without an intellectual disability Larry responded:

"there are supports both inside of our [community living] associations and I think when people get to be recognized about who they are, they will get the supports elsewhere too."

4.24 Friendships

The connection to community living provided a source of friendship and support.

Christine found the benefits of being involved in community living in both her friendships with peers and professionals:

Oh yeah, that's what keeps me going. Yeah, it's not just a... it's meeting all my friends that are not only self-advocate friends, but (names) that used to be the president of (organization) and meeting all my friends, it's very important to stay involved. It's so easy to get depressed, you know?

On the other hand, Mary, felt conflict in these friendships and struggled with the fact that some of her friendships were with community living professionals:

Instead of say, when they get to say, 60 and then they retire and they don't want to have anything to do with me. Because I think that's what happens, I think people forget that people need people still. I think that there's people that are sixty that are living in a group home for example and there's just paid staff to be around them, and they go to their day program and that's all they have is their day program. And they don't see them outside of the day program and they just see the staff at the group home or their roommate...they want to be there for me, but then... they're not, they're working

Both Christine and Mary expressed strong emotional reactions to why these friendships were so vital. When asked what she thought was different for people ageing with a disability than for the general population and what are some concerns she had for her peers, Christine responded: "My peers, that they'll be isolated and they'll feel alone and depressed and feel like nobody wants them or loves them anymore". Mary had similar worries about isolation: "A friend of mine said, "Getting old isn't for the weak of heart." And to me, thinking about it makes me kind of sad because I think, "I live alone.". Larry brought up the importance of making friends outside of community living with people who do not have a disability:

You know what I mean, I don't believe in being prejudiced, I like to meet people and I've always had the nature, since I was in upbringing. I remember the first time getting involved with a community group... I remember his thing was he wanted me to be happy and try to enjoy myself more, and I was always hanging around with people, and that's how I know my mom's a very much a strong support mother, you know? Saying, "You need to hang around with people than just your self-advocacy group. You need to socialize with people in the public".

4.25 Summary

Although the retirement years brought the possibility of new opportunities participants experienced multiple layers of complexity in fulfilling these broader prospects. Dream fulfillment was hampered by limited savings and income, cumulated by an absence of participation in discourse about retirement, and feelings of disempowerment.

An adulthood of being involved and supported by community living organizations, now included a possibility of being involved in the mainstream seniors community, presenting mixed feelings for many participants. Some participants became acutely aware of the importance of the connections they had in community living organizations with professionals, who also acted as friends, while others struggled with these relationships and saw the importance of expanding outside of these circles.

4.3 Theme 3: "I've got to start helping [my parents] and it's not easy"

As participants aged, they faced their parents ageing and death, meaning an end to both emotional and financial support. Many participants also reciprocated this support for their aged parent. These relationships faced change, including death of the parent, and desire for open dialogue on these issues. The sub-themes of caregiving and bearing witness to the ageing process will be presented.

4.31 Caregiving

The potential loss of emotional and financial support was a concern to Don who felt he was not able to reciprocate support to his parents to the extent that he would like:

I keep looking at my parents, they're in their nineties, so it's like, how are they going to help me when they're...they've lived it all, they don't really need to keep living my life as well as their own, so in a way, I've got to start helping them, and it's not easy.

Rose who lived with her mother who was in her mid-eighties provided support with day-to-day activities:

Rose: "Well now she's taking puffers, there's a lot of things she can't do, and reach up and her arms are out. She can't walk, if she goes out she has to have her walker or one of us holding her and stuff like that, she's very unsteady".

Larry: "And going up and down to do the laundry and..."

Rose: "Yeah, I mostly do that, 'cause it's hard for her to come back up and do that".

Interviewer: "So she relies on you a lot right now for help".

Rose: "Yeah, that's right. Yeah, 'cause I'm always there..."

Christine had lost her mother a number of years ago but described her experience after her mother needed increased help due to failing health:

...out of my whole family, my sister and I were the only ones who took my mom out. We took her on the bus, we took her on the sky train, that took a lot of balancing with my mom ...sometimes my sister and I kind of felt alone, like we were taking it on ourselves because they all were busy with their own lives and their own stuff.

Lisa described this changing relationship with her own parents: "You see, it's like we have to start being the parent to the parent and you know, that's kind of... we've got to do that, right? It's kind of hard when the roles are reversed".

4.32 Witness to the Ageing Process

Many participants were seeing their parents, and their peers' parents, getting older. Larry described his mother in regards to her ageing: "Well her health condition is getting down, she's ignoring it, she's a real fighter you know. I remember hearing my mom, she's a real procrastinator, she would never think of getting old, "I'm never going to think about getting to 82, and here I'm fighting it." Lisa had concerns for her peers who still lived with their elderly parents: "And their parents are ageing too, so that brings up the ageing because their parents are over 65 and they're about 65 then so they're getting at that age, so then what's... where do they go from there?". Mark also commented on the changing relationship between his peers and their parents as they got older: "...I work with people before they come older about what we're doing with their sons and daughters to help their lives, because sometimes after they become senior they don't get to see them and they change...".

Participants talked about the intimate support that they got from their ageing parents even as older adults. Larry commented that his mother sends him care packages, calls to check in on him frequently and goes over his budget with him on a regular basis. He commented that his mother had always filled the role of a lifeskills worker in his life. Other participants commented that their parents help them financially by buying groceries and giving them gift cards for shopping.

Mary had recently faced the death of her father and was still experiencing grief at the time of this study. She had helped care for her mother as well, in the years before her death. Mary felt that education and support in relation to the issues of ageing parents and death and dying was not being provided for people with intellectual disabilities:

“I think that people need to have a workshop for helping people with their parents getting older...And people need to talk about it, and not be afraid that we don't understand. But if we don't understand it... explain it in a way we understand. That's garbage when people say, “I don't want to rock the boat.” But if you don't explain it to us, I'm going to be more upset, so tell me... How else can we cope if you don't tell us? That's the way I look at it. I'm just telling you how... I might be different, but I don't think I'm that different than people. I think most people would want to know.”

The emotional toll of an aging parent is particularly acute when the parent has played an intimate role in the individual's life throughout their lifespan, which risks being ignored in regard to people with an intellectual disability. At times the perceived capability of persons with an intellectual disability to understand the physiological changes of the ageing process and to experience emotions on the same level as the typical population may exclude this population from receiving information that they deserve. Mary had suggestions for how this situation might be avoided:

...And there's a lot of [older] people I know still living at home. And I think that people need to talk... I've said for a long time that people my age be able to have a group of people that you can... just talking about how you're feeling about it...

4.33 Summary

Facing the ageing and death of their parents was a significant issue for participants at this time in their lives. Many participants provided care for their parents as they were still intimately involved in each others' day-to-day lives. Providing space for discussion on how to deal with emotional toll of this changing relationship and gain information on the ageing process was suggested as a way to alleviate some of the strain during this time and acknowledge the capacity and involvement of this population.

5 Conclusion

5.1 Research Summary

The findings from this study give some insight into what retirement means to ageing self-advocates. For the participants in this study, retirement meant: an increase in challenging financial times and retiring their economic status as “persons with disabilities”, retiring from close and supportive parental relationships due to the parents’ health decline and/or death, and retiring from exclusive involvement in community living organizations to becoming involved in mainstream seniors’ community centres. These areas are significant life changes that occur with retirement for these adults with an intellectual disability. To the participants of this generation of persons with an intellectual disability this shows unique experiences of retirement.

Although previous research has explored the areas of later life planning, education, and leisure activities in older age, an extensive academic literature review did not find any research specifically on the issue of retirement and older adults with an intellectual disability. The majority of literature in the general area of ageing with an intellectual disability is based in countries outside of Canada, which is also limiting (Ashman, Suttie & Bramley, 1995; Bigby & Baladin, 2005; Bigby, 2002; Bigby, 1997; Cordes & Howard, 2005; Lawrence & Roush, 2008).

5.2 Comment on “retirement”

These findings require an expansion of the term “retirement” as a noun with implications focused on economics, to a noun that includes important life changes that are not a direct result of disengagement from the workforce.

The term retirement is tied with the context of capitalism. The quote, “you can’t build a sizeable nest egg really”, exemplifies the common goal of being able to save money for retirement and having enough funds to live comfortably, a sign of having been successful in the workforce. Our society is organized around the labour market, which places people who do not have the opportunity to participate in the labour market at the bottom of the hierarchy. The participants in this study had minimal or intermittent engagement in the workforce, with the threat of the loss of disability income if they did find employment that would provide funds beyond the allowed maximum additional income, placing them in a subordinate position to the general population.

This creates a situation of exclusion from the ability to share in the common goal of having a “nest egg” and in the discourse that surrounds it. This exclusion overlooks the contributions of older adults with an intellectual disability to society during their adult lives that are not solely economic in nature. In that, they are not unique; there are many others who cannot work or cannot find work. This requires a reconsideration of a broader discourse around the term retirement that is more inclusive to these populations. A reconsideration could result in branding a new term, other than retirement, that would encompass this transitional time of life for people with disabilities and honour the contributions of their adulthood. Those who work directly with this population need to facilitate discourse that involves people themselves, not only service providers who do not have intellectual disability. As it is, service providers may be at risk of imposing conventional ideas of retirement onto this population.

5.3 Community Living and Social Work Practice

Community living organizations can play an important role in providing desired education during this transition into the retirement years. Through the data, the participants provided a number of ways this can be addressed. The economic transition, from a label of “person with a disability” receiving a disability cheque, to the label of “senior citizen” receiving an old age pension, can cause a great deal of stress to adults who have belonged to the disability economy the majority of their adult lives. This transition means the possibility of even greater financial vulnerability in older adulthood and continued reliance on government decision-making in regards to financial allocations and services. One of the major concerns expressed by participants was the possible loss of the medical benefits that are provided to an individual receiving a disability income; these benefits act as a source of insurance and safety. The reality of losing these benefits is real. This past spring 2010, the provincial government stated that the medical benefits for adults receiving disability income would only extend one year beyond their 65th year, instead of continuing throughout their senior years as they had in the past. It was only due to public outrage that the government repealed this policy change. This is an example of the constant changes in government support experienced by this population. By acknowledging this fear and providing education on a person’s financial rights once they become a senior, community living can empower individuals to become active agents in their economic welfare. For instance, including discussions about changing lifestyles in retirement should be addressed so that adults with an intellectual disability have more autonomy over their own finances and leisure expenditures.

Community living organizations can also breach the issue of the ageing process and the loss of family members in older age through workshops and lectures. Providing space for adults to come together to talk about what they are going through as caregivers for their ageing family member, and their feelings around seeing their parents' health decline, is needed. This also acknowledges the reciprocal relationships in the lives of people with intellectual disabilities and their role as caregivers.

In addition, community living organizations have the opportunity to increase inclusion for older adults by seeking out partnerships and providing education to mainstream seniors' centres on supporting adults with an intellectual disability. The data from this study show an interest in increasing involvement with community seniors' activities into retirement, while still having a connection to the community living organization. Obtaining the label of "senior citizen" may mitigate the label "person with intellectual disability" and provide new opportunities for social contacts and activities.

Underlying these ideas for service provision requires the philosophical positioning that adults with an intellectual disability have the right to receive the same information as any adult in the general population. Mary spoke so poignantly to this when she stated, "...How else can we cope if you don't tell us? ...I might be different but I don't think I'm that different than people. I think most people would want to know." The presumption of intellectual and emotional capacity of adults with an intellectual disability can act as barriers in providing education. Any individual who is ageing needs information about the real-life situations that will come up in their later years.

The implications for service provision suggested can only be actualized when a truly rights-based approach, opposed to protectionist, position is taken.

Finally, an important practice issue that was raised was the unique balance between being a professional and being a friend and its impact on individuals who are receiving services. Mary spoke to this as she was describing her relationships with professionals in community living, "...when they get to say, 60 and then they retire and they don't want to have anything to do with me. Because I think that's what happens, I think people forget that people need people still....they want to be there for me, but then...they're not, they're working". There needs to be an increased attention to critically thinking about the relationship between social workers and the people they come into contact with, and the impact of this relationship from the other person's perspective.

5.4 Social Work Education

This research also has important implications for social work education. It acknowledges this population as an important sub-group, a group whose unique life experiences and placement in society is often ignored or unknown. In my experience, some social work educators deal with issues such as sexism, racism, and ageism, frequently, but fail to include ableism in their curriculum and class discussions. This research adds to literature regarding the issues facing individuals who have been labeled as having a disability and to the body of knowledge that can provide basis for discussion in the academic setting. The issues facing persons with a disability are unique and relevant, and need to be addressed in social work education, as most social workers will find themselves working with people who have a disability at some point in their career.

5.5 Policy

This research contributes to the discussion regarding social welfare policy and its relationship to this population. It provides a depiction of the lived experiences of a population that receives welfare at the bare minimum level, which is constantly in threat of further erosion. It calls into question whether the fundamental structures of welfare in Canada, “income protection, social insurance, services for meeting basic needs, and measures for preventing and relieving poverty” (Rice & Prince, 2003, p. 124), are being met with this population. Rice and Prince (2003) state that globalization is a central factor in an increase on the focus on economics and capitalism, which take priority over social welfare. This leaves this population at further risk for the actualization of their fears in the transition from “person with a disability” status to “senior citizen”. As seen previously, there is a constant risk of erosion of financial support and vulnerability to the variances of the economic climate. Therefore, practitioners need to maintain a keen awareness of these changes and protest the disintegration of policy that protects the rights of these citizens.

5.6 Strengths

The main strength of this study is that it provides the direct voice of this population, who often have their feelings and experiences relayed through secondary informants, on a subject matter that is directly related to their lived experience (Ashman et. al, 1995; Bigby & Baladin, 2005; Bigby, 1997; Lawrence & Roush, 2008; Mahon & Goatcher, 1999).

The participants themselves represented the experiences of both genders, and ranged in age from early to late fifties. This provided some variety in perspectives given during interviews.

5.7 Limitations

There are several factors that limit the results of this study. The implications from this study are limited to the responses of the seven participants. Therefore, the findings can only be exploratory in nature and cannot be generalized to all people in this population. The inability to generalize is furthered by the use of availability and snowball sampling in this study, because it relies on people to identify others they know, and likely are similar to them, which further limits the possibility of a diverse population base (Schutt, 2008). The retirement needs and concerns of self-advocate may be different from other individuals who have an intellectual disability. Self-advocates who live independently in the community experience life as persons with an intellectual disability differently than individuals who live in a group home environment. This study is from the point of view of self-advocates, it is possible and likely that individuals living with and intellectual disability may present similar findings, but this study is limited to the claims of the seven self-advocates whom I interviewed. This study was limited to those individuals who were verbal, actively engaged in the community, and had the ability to meet with me for the interview. Cordes and Howard (2005) point out that some individuals with an intellectual disability have difficulty in conceptualizing ideas such as retirement. The terms retirement and later life planning are concepts that require a certain amount of

background knowledge, based on education and discussions around these topics, which are not discussed to the same extent with people with an intellectual disability than with the general population (Cordes & Howard, 2005). This may have affected the understanding of the questions being asked in the interview and subsequent answers. I made efforts to simplify the language used, and checked in with participants for understanding, yet, the accuracy of the responses was reliant on the participants' understanding of the questions. On the other hand, many of my peers with whom I discussed my thesis also had difficulty aligning the concept of "retirement" with the lives of people with disabilities. There may be a need to reconsider the use of the term "retirement" and open discussion to the most useful term to discuss this transition in life.

5.8 Future Research

Given the limitations of a small sample size this research could be expanded to include a broader and more diverse group of adults with an intellectual disability. Each of the themes derived from the data provide a basis for further research. Core experiences such as the transfer from being a "person with a disability" to a "senior citizen", desired relationships between the adult in older age and community living organizations, and the affect of losing a parent through death or supporting a parent through illness, could all be studied more in-depth with this population. A general increase in academic literature of the direct voice of persons with an intellectual disability will ensure that the discourse that dictates their life is a discourse shaped by their own words. This also would suggest research in tools of communication that are effective with individuals who are non-verbal or have a more severe intellectual disability.

5.9 Final Thoughts

This research will give insight into how people with an intellectual disability view their later years and provide voice to a population that often has decisions made on their behalf by service providers and/or family members. The aim of this study is to explore how this population sees their life changing as they get older, what they want to be doing with their day to day lives in their later years, and any ways they might see their experience as being different than the experience of those in the general population. Service providers who are currently reframing their programming to meet the needs of those ageing with an intellectual disability can benefit from the information provided by participants in this study. This study calls for a reconsideration of the term retirement, whether that means an expansion of the current concept that focuses on participation in the labour market, or the introduction of a new term that includes the experiences of all citizens in this changing time of life, regardless of their economic positioning.

References

- Ashman, A. F., Suttie, J. N., & Bramley, J. (1995). Employment, retirement and elderly persons with an intellectual disability. *Journal of Intellectual Disability Research*, 39(2), 107-115.
- Bigby, C. (2002). Ageing people with a lifelong disability: Challenges for the aged care and disability sectors. *Journal of Intellectual & Developmental Disability*, 27(4), 231-241.
- Bigby, C. (1997). Later life for adults with intellectual disability: A time of opportunity and vulnerability. *Journal of Intellectual & Developmental Disability*, 22(2), 97-108.
- Bigby, C. & Baladin, S. (2005). Another minority group: Use of aged care day programs and community leisure services by older people with lifelong disability. *Australasian Journal on Ageing*, 24(1), 14-18.
- Bowlby, G. (2007, February). Defining Retirement. *Perspectives*, 15-19.
- Community Living British Columbia. www.communitylivingbc.ca, retrieved October 29, 2009. Eligibility for CLBC supports and services, Policy.
- Cordes, T., & Howard, R. (2005). Concepts of work, leisure and retirement in adults with an intellectual disability. *Education and Training in Developmental Disabilities*, 40(2), 99-108.
- Creswell, J. W. (2007). Philosophical, paradigm, and interpretive frameworks. In J. W. Creswell (Ed.), *Qualitative inquiry & research design: Choosing among the five approaches* (pp.15-33). London: SAGE Publications.

- Galarneau, D. & Radulescu, M. (2009, May). Employment among the disabled. *Perspectives*, 5-15.
- Gochros, H., L. (2008). Qualitative Interviewing. In R. Grinnell Jr. & Unrau, Y.A. (Eds.), *Social work research and evaluation: Foundations of evidence-based practice* (8th ed.) (pp.239-264). Toronto: Oxford University Press.
- Grossman Dean, R. (1993). Constructivism: An approach to clinical practice. *Smith College Studies in Social Work*, 63(2), 127-146.
- Holstein, J.A., & Gubrium, J. F., (1997). Active interviewing. In D. Silverman (Ed.), *Qualitative research: Theory, method and practice* (pp.201-221). London: SAGE Publications.
- Ivanoff, A., Blythe, B., & Walters, B. (2008). The ethical conduct of research. In R. Grinnell Jr. & Unrau, Y.A. (Eds.), *Social work research and evaluation: Foundations of evidence-based practice* (8th ed.) (pp.29-59). Toronto: Oxford University Press.
- Lawrence, S., & Roush, S. E. (2008). Examining pre-retirement and related services offered to service-users with an intellectual disability in Ireland. *Journal of Intellectual Disabilities*, 12(3), 239-252.
- Mahon, M. J., & Goatcher, S. (1999). Later-life planning for older adults with mental retardation: A field experiment. *Mental Retardation*, 37(5), 371-382.
- Maxwell, J. A., (2005). *Qualitative research design: An interactive approach* (2nd ed.). Thousand Oaks: SAGE Publications.

Merriam-Webster, m-w.com, retrieved August 11, 2010.

Miller, A., & Keys, C. (1996). Awareness, action, and collaboration: How the self-advocacy movement is empowering for persons with developmental disabilities.

Mental Retardation, 34, 312-319.

Mullaly, B. (1997). *Structural social work: Ideology, theory, and practice* (2nd ed.).

Toronto: Oxford University Press.

Perakyla, A. (1997). Validity. In D. Silverman (Ed.), *Qualitative research: Theory, method and practice* (pp.201-221). London: SAGE Publications.

Rogers, N. B., Hawkins, B. A., & Eklund, S. J. (1998). The nature of leisure in the lives of older adults with intellectual disability. *Journal of Intellectual Disability Research*, 42(2), 122-130.

Sandelowski, M. (2000). What ever happened to qualitative descriptive? *Research in Nursing & Health*, 23, 334-340.

Schutt, R. K. (2008). Sampling. In R. Grinnell Jr. & Unrau, Y.A. (Eds.), *Social work research and evaluation: Foundations of evidence-based practice* (8th ed.) (pp.135-156). Toronto: Oxford University Press.

Van Schrojenstein Lantman-De Valk, H., Metsemakers, J., Haveman, M., & Crebolder, H. (2000). Health problems in people with intellectual disability in general practice: A comparative study. *Family Practice*, 17(5), 405-407.

Appendix A
Letter of Consent for Participants

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
Tel: (604) 822-2255 Fax: (604) 822-8656
www.swfs.ubc.ca

Consent Form

**Life in the Later Years:
An Exploration of the Meaning of Retirement to Aging Self Advocates**

Principal Investigator: XXXXXXXX

Co-Investigator: XXXXXXXX

I am doing this research in order to complete a Masters thesis that will be written up and may be seen by other people. You will be told how the information that is collected will be used and where you can find that information. I will not use your real name when I write my report.

Purpose

The reason that talking to self advocates about retirement is important is because other research says that people who have an intellectual disability may think about retirement in a different way than the general population. It has only been in the past few years that retirement has been talked about with people with an intellectual disability. Right now many community living organizations are making changes to their programs to fit with an aging population. This study is trying to find out about what people with an intellectual disability want to be doing after they turn 65 years old, the typical age for retirement in the general population. What we find out from this study will give a better understanding of how people with intellectual disabilities think about retirement. We want to find out how you think about retirement and what you want to be doing with your time as you get older. The information from this study might be used in presentations and academic papers.

Participation

In the interview I will talk with you about what you want to be doing when you get older, if there are any changes you want to make in your life as you get older and what you think about retirement. I will also ask for personal information for the demographic

form, for example; how old you are, if you have a job and how much money you get every month. The interview will be 30–60 minutes long, and will be taped on a recorder. The interview will not be longer than one hour. The interview will be at a time and place that is best for you. After the interview is finished, the tape will be sent to someone who will type out what was said, word for word. Things that would identify anyone, like names of people or organizations, will be taken out. What is left is a transcript, and it is what I will look at to find information. All the information I get from you will be kept in a locked cabinet. The computer that will be used has a password to protect information, and only I will know the password.

Confidentiality

I will meet with you face to face, but will not tell other people you were interviewed. During the interview you do not have to answer all the questions. You may say that you do not want to answer a question and you can stop the interview at any time. You can ask to erase anything that you say during the interview if you do not want it in the final transcript. The information from the interview will be kept for at least five years, because that is the University of British Columbia's research policy. All copies of the information will be destroyed after 5 years.

Risks

No risks are expected. If you do not want to continue with the interview, you have the right to stop at any time.

What you get for participating

You will get \$20 for participating in this study.

Who to talk to for more information about this study

Please call the investigators, XXXXXXXX, named at the top of the first page.

Who to talk to about concerns around your rights as a research participant

If you have any concerns about your rights or treatment as a participant, you may call the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598. They are open Monday to Friday from 8:30am to 4:30pm.

Consent

By signing below you show that:

- **You agree to participate in the study**
- **Your questions about the study have been answered**
- **You have received a copy of the consent form.**

Signature: _____ Date: _____

Printed name: _____

Re: Receiving Report

1. I wish to receive a copy of the report of this study. ____ (check)
2. Address to which report is to be sent.
Name:
Address:

Phone Number:
E-mail address:
3. I do not wish to receive a copy of the report from this study. ____ (check)

Interview Guide

Interview Guide

1. What are some of the things you like to do everyday?
2. Sometimes people make changes to their life when they get older. What types of things do you want to be doing when you are 65 years old?
-when you are 75, 85?
3. Do you have a family member or friend that is over 65 years?
Have they changed things in their life as they got older?
What have you noticed about other people in your life as they get older?
Do you think things will be the same for you?
How will they be different?
4. Is there anything in your life that you want to change as you get older?
What would you need in order to do this?
Where do you live right now? Do you think that will have to change when you get older?
5. Do you think that you will need to “slow down” when you get to the age of 65 or older?
6. What do you think about the idea that most people in the general population want to stop working at the age of 65 years?
7. How do you feel about someone telling you that you have to retire?
8. Is there anything else?

Demographic Form for Participants

Demographic Form

Researcher to complete: ID# _____

1. My age is _____

2. Are you?

Male..... 1

Female..... 2

3. If you have a job, do you work:

CIRCLE ONE:

Full-time..... 1

Part-time..... 2

Self-employed..... 3

If you do not have a job, are you:

Not employed 4

Retired 5

In a Day program..... 6

Other (PLEASE WRITE IT DOWN)_____ 7

4. Where does your money come from?

CIRCLE ALL THAT ARE RIGHT:

Money from your job..... 1

Disability cheque 2

Canadian Pension Plan (CPP) disability..... 3

Personal savings..... 4

Inheritance..... 5

Trust Fund..... 6

58

Other (PLEASE SPECIFY)_____

5. About how much money do you get every month?

6. What level of school did you finish?

CIRCLE ONE:

- Elementary School 1
Grade: _____
- High School Diploma.....2
Grade: _____
- College Diploma..... 3
- Other (PLEASE WRITE IT DOWN)_____ 4

7. What is your marital status?

CIRCLE ONE:

- Common-law 1
- Divorced..... 2
- Married 3
- Separated..... 4
- Single..... 5
- Other (PLEASE WRITE DOWN)_____ 6

8. What type of housing do you live in?

CIRCLE ONE:

- Subsidized rental housing (you pay according to your income).....1
- Market rental housing (landlord does not know your income).....2
- Group home.....3
- Room and board in a family's home (Homeshare).....4
- 59
- A property that you own.....5

Live with a family member.....6

OTHER (WRITE IT DOWN)_____

9. The number of people in my house is: _____

10. Who lives with you:

Relationship to you

Age

Recruitment Poster

What does RETIREMENT mean to you?

**We would like to talk to you if you are:
A Self Advocate between the ages of 50 and 60**

What will you have to do if you want to be in the study?

If you want to be part of the study you will talk to a researcher for half an hour to an hour at a time and place that is best for you. You will be asked questions about what you want to be doing with your time as you get older, if there are any changes you want to make as you get older, and what you think when you hear about retirement.

You will get \$20
for participating

**If you would like to talk to a researcher
please call:
XXXXXXXX**



Study through the UBC School of Social Work