The experience of retirement for individuals with an intellectual disability

Megan Flowers

Edith Cowan University

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The Experience of Retirement for Individuals with an Intellectual Disability

Megan Flowers

A report submitted in Partial Fulfillment of the Requirements for the Award of Bachelor of Science (Occupational Therapy) (Honours)

Faculty of Computing, Health and Science

Edith Cowan University

October 2010
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Title:
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Name:
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A report submitted in Partial Fulfillment of the Requirements for the Award of Bachelor of Science
(Occupational Therapy) (Honours)
Faculty of Computing, Health and Science,
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The Experience of Retirement for Individuals with an Intellectual Disability

Megan Flowers
Abstract

Retirement is a significant life transition that affects all workers; it is therefore important that individuals in the workforce are aware of the issues that can occur during the retirement years. The retirement experience has been researched in depth, however studies into the experience of retirement for individuals with an intellectual disability is severely lacking. Robert Atchley researched the factors that facilitate successful retirement adjustment for individuals in the normative population; this narrative review discusses these factors in relation to the barriers that individuals with an intellectual disability face in achieving a smooth retirement adjustment. The results found that: individuals with an intellectual disability are more likely to be obligated into early retirement; have an increased chance of experiencing health difficulties; experience financial limitations and have disparities with appropriate accommodation. Individuals with an intellectual disability have also been found to have little comprehension of the retirement notion and subsequently lack retirement pre-planning. In addition it was also found that there are problems in governmental policies which can result in inappropriate and inadequate services for individuals with an intellectual disability.

Key Words: Retirement, (intellectual) disability, ageing process, Atchley Model of Retirement

Author: Megan Flowers

Supervisors: Dr Janet Richmond, Ms. Elaine Ledgerwood & Dr. Sonya Girdler

Date Submitted: 20th October 2010
Background

In Australia 3.6 million people have a disability and around 600,000 of these individuals have an intellectual disability (Australian Bureau of Statistics (ABS), 2003). In order to be diagnosed with an intellectual disability a person will have deficits in three key areas; low levels of intellectual performance, difficulties in adapting behaviour and increased support needs to live independently. Intellectual disability can be mild, moderate or severe ("Disability Services Act," 1991).

A mild intellectual disability refers to individuals who have an intellectual quotient (IQ) score between 50 -70. These individuals require minimal assistance to participate in the community and with extra support they can learn to read, write and find employment in the open market. They may find it difficult at times to understand and adhere to the more complex rules of social conduct (Xingyan, 1997). An individual with a moderate intellectual disability will have an IQ between 35 and 50, they may be able to read basic words and have the ability to be independent in personal care, it is common for these individuals to be employed in business services as they often require extra support in daily scheduling (Xingyan, 1997).

Severe intellectual disability refers to individuals who have an IQ score below 35. They often have limitations in verbal communication and require high levels of support throughout their lives. Employment for individuals with severe intellectual disability is currently uncommon however this may not always be the case as employment for people with a disability is an emerging concept (Xingyan, 1997).

In the last 20 years extensive efforts have been made to expand employment options for individuals with a disability. They can now find work in Australian disability enterprises (formally called business services) which cater for individuals with higher support
requirements, or be employed in the open market and contend against the general population for paid work (Ashman, Suttie, & Bramley, 1995; Centreink, 2008a).

Australian disability enterprises employ over 20,000 people with a disability nationwide, 19% of this workforce is over 50 years of age and predictions show it will increase to 50% by 2050 (Australian Institute of Health and Welfare (AIHW), 2008c; Department of Families Housing Community Services and Indigenous Affairs. (FaHCSIA), 2007). The ageing workforce is a result of enhanced longevity and survival rates of individuals with a disability and is associated with improvements in health care, technology and science (Janicki, 2009; Kelly, Kelly, & Craig, 2007). It is therefore important to consider the long-term implications of this sector of the ageing population after they have retired.

Retirement is usually defined as the time at which people leave the paid workforce and receive finances from a pension scheme (Ekerdt & Diveney, 1990; Savishinsky, 1995) and is a significant transitional stage in human society that affects all workers. Research in the field of retirement and intellectual disability is scarce. There is therefore a requirement for further research on the topic to ensure that these individuals are appropriately supported during this significant life period.

Methods

This literature review examines the experience of retirement for individuals with an intellectual disability. It evaluates the current research that has been conducted on patterns of retirement adjustment and the factors that affect a smooth transition from the role of employee to retiree. The review also examines the barriers that individuals with intellectual disabilities face during their daily lives and as they age. The key terms searched include;
intellectual disability, retirement, (occupational) use of time and the Atchley Model of retirement. The terms were truncated, adjusted and exploded in order to meet the criteria of the database that was being searched.

Four databases that contain relevant information on the topic of retirement and disability were searched. These are CINAHL, MEDLINE, PsychInfo and ISI Web of Science. Due to sparse literature on retirement and intellectual disability all information from the 1990s was searched, however the focus was on literature from 2000. The inclusion criteria consisted of studies that were conducted in western countries with a preference to research performed in Australia. These inclusion criteria will ensure that the literature review has direct relevance to the proposed research. All reference lists were manually searched for applicable information.

Frameworks

The Model of Human Occupation

The literature was reviewed using the Model of Human Occupation (MOHO) as a framework. The MOHO is a framework used within occupational therapy which examines the ways in which occupations are "motivated, patterned and performed" (Kielhofner, 2008, p. 10). It is comprised of three components; volition, habituation and performance capacity.

(Kielhofner, 2008, p. 22)
Volition refers to the motivation for occupation, it has three sub parts; personal causation (awareness of own abilities and capabilities), values (what the person considers to be right and good) and interests (what one enjoys doing). Habituation refers to an individual’s habits and routines which are an important aspect in the development of a person’s internalized roles, or expectations of one in a particular situation. Performance capacity refers to the physical and mental attributes that are associated with a skilled occupational performance (Kielhofner, 2008, p. 10).

The MOHO emphasizes the physical and social environments in which the occupations take place, as these factors play an important role in the influence of activities that are chosen and their overall accomplishment. The MOHO deems that a person displays function when they are able to choose, organize and perform occupations that are personally meaningful (Kielhofner, 2008). The model is holistic and will be used in conjunction with the Atchley Model of Retirement to examine the experience of retirement for individuals with a disability.

*The Atchley Model of Retirement Adjustment*

Robert Atchley (1976) theorized that there are eight stages of retirement adjustment. As all people are unique in their experience of retirement, individuals do not necessarily experience all of the eight phases, however research has shown that there is a pattern of emotional adjustment as individuals take on the new role of retiree. This model is intended to be used as a framework in understanding the emotions that can occur during retirement.
Based on the Atchley Model of Retirement (Atchley & Barush, 2004)

The first stage is the pre-retirement stage where individuals form a plan for their retirement years and have a perception of the manner in which it will occur, these perceptions will be gained from role models, friends, family and education. The individual may then experience the honeymoon stage wherein the person begins their retirement; they have feelings of high contentment and also enjoy their new found freedom. The honeymoon stage is often when retirees take advantage of this free time to go travelling, however not all individuals will experience the honeymoon phase particularly if they view their new found role as a retiree in a negative manner or if they have financial limitations (Atchley & Barush, 2004). Studies have shown that there is efficacy in the models pattern of retirement adjustment as it has been found that there is an initial increase in positive attitudes towards new retiree status in the first six months of retirement during the honeymoon phase (Ekerdt, Bosse, & Levkoff, 1985; Reitzes & Mutran, 2004).

For those who do not experience the honeymoon phase, retirement begins with retirement routine during which individuals will develop daily schedules. Retirees that participated in a
range of activities outside of employment prior to retirement are more likely to settle into retirement routines with ease as they are already involved in activities that are personally meaningful and valued and thus also satisfy the holistic MOHO approach (Atchley & Barush, 2004).

The fourth stage of retirement is related to a decrease in activity, this stage is called the rest and relaxation stage. Retirees will go through a phase where they desire a slower pace of life in which to reflect on their past lives. This time is distinctively opposite to the honeymoon phase of heightened activity. This stage has a limited duration as retirees will become restless due to reduced participation in interests (MOHO) and begin to partake in their routine activities once more (Atchley & Barush, 2004).

The disenchantment stage is a difficult phase of retirement. In this time the reality of retirement is realised. If an individual’s experience of retirement does not correlate with their pre-retirement expectations than feelings of disappointment, emptiness and possible depression can arise due to a lack of personal causation. This often occurs after the honeymoon stage when their fast paced life comes to an end, it can also occur when there is a sudden unexpected change in living circumstances such as the death of a partner. The negative emotions felt during this stage are associated with the prospect of changing their idea of their retiree role, however only a few individuals will experience this difficult phase of retirement adjustment (Atchley & Barush, 2004). Reorientation is a state of mind that can occur within the rest and relaxation or disenchantment stage. During this phase individuals assess their options in life in terms of their use of time and the available resources that will enable future choices in retirement. The retirees may start to participate in new community activities or begin to interact with their family and friends more often. In this period they
evaluate the way in which they intend to live their life during the retirement years (Atchley & Barush, 2004). Research has shown a decline in positive attitudes towards retirement at twelve months post retirement, this is the time in which retirees establish their retiree role identity and evaluate their volition and habituation (Ekerdt, et al., 1985; Reitzes & Mutran, 2004).

The seventh stage is retirement routine where the person is at peace with his/her retirement routines and roles. Appropriate coping mechanisms have been developed which helps him/her to adjust to difficult situations and this assists in retirees feeling safe and protected in their surroundings. Retirement routine can happen at any time in the transitional process, be it after the employment, honeymoon or disenchantment stage however some individuals will never experience this stage at all (Atchley & Barush, 2004). Research has shown that there is a pattern of increased positive attitudes towards retirement after 24 months post employment this increase in positive attitudes has been associated with the seventh stage of adjustment to retirement routines & roles and the redevelopment of habituation skills (Ekerdt, et al., 1985; Reitzes & Mutran, 2004).

As a person ages he/she may suffer from ill health which can result in the last stage: termination of retirement. This occurs when the role of retiree ceases to exist and is substituted by the disabled role as the individual becomes dependent on others to assist with activities of daily living.

Atchley has identified several key concepts that assist an individual in gaining a smooth transition from full time employment to retirement, these include:

- *Ability to give up one’s job gracefully*
Experience of Retirement

- Sufficient income
- Good health
- Minimal changes in an individual’s life apart from the job loss
- Realistic views about the retirement role

(Atchley & Barush, 2004).

This literature review examines the factors that facilitate or hinder a smooth retirement adjustment for individuals with an intellectual disability, it is important to consider how individuals who are already born with the “disabled role” react to the transition from other life roles of employee to retiree. Atchley’s key concepts of smooth retirement transition will be discussed in addition to how individuals with an intellectual disability adapt and cope with change and the social and institutional policies that affect these individuals during retirement.

Ability to give up ones job gracefully

Retirement can occur in a gradual manner as individuals slowly phase out the amount of hours that they work, which is often the preferred method for individuals in the general population (Australian Institute of Health and Welfare, 2000). Gradual retirement is beneficial as it enables individuals to retain an income whilst altering their normal habits and routines in preparation for the retirement years (De Vaus, Wells, Kendig, & Quine, 2007). However individuals with an intellectual disability may be hesitant to begin gradual retirement as they may be anxious about the possibility of immediate job loss due to the limited job positions available in the business services (Hodges & Luken, 2006).

Retirement can also occur very suddenly which may be planned or obligatory. Although gradual retirement is often favored, sudden retirement can be beneficial to the individual if
Experience of Retirement

this was their plan. Research has indicated that the speed of retirement has little effect on the individual’s happiness during retirement, as long as retirement was planned and voluntary (Esteban, 2009).

Health difficulties and job loss

Numerous studies show a link between voluntary retirement & good health whereas health is adversely affected when retirement is involuntary and unanticipated (Gallo, Brand, Teng, & Leo-Summers, 2009; Harkonmaki et al., 2009; Marshall, Clarke, & Ballantyne, 2001). The reasons for retirement in the normative population has been examined in depth, the Australian Bureau of Statistics found that most people stopped working when they reached the age of retirement or when they became eligible for superannuation (Australian Bureau of Statistics, 2009). However, a person with a disability may be required to leave the workforce due to declining health. Reports show that retirement often occurs when health problems no longer permit participation in work activities (Sterns, Kennedy, Sed, & Heller, 2000). The relationship between physical health decline and ageing is a phenomena that occurs in all human beings, however the natural progression of ageing impacts the population with a disability to a greater degree as they are already disadvantaged with health problems (Bigby, Webber, Bowers, & McKenzie- Green, 2008). Individuals with multiple disabilities and intellectual disabilities such as Down Syndrome are at a greater risk of premature ageing and the associated health difficulties. These health issues may compel an individual with a disability into early, unanticipated retirement (Janicki & Dalton, 2000; Zigman & Lott, 2007).

Situational changes and job loss

A person with a disability may also be obligated to retire if their living circumstances change.
Individuals with a disability are frequently required to move out of the family home to other forms of accommodation when their main family carer passes away, this often happens in the later years of the person’s life as they and their carer age (Bigby, et al., 2008). The change in accommodation location can result in early retirement as a person may no longer be able to access transport to work. A qualitative study conducted by Bigby (2008) examined the characteristics of adults with intellectual disabilities in residential aged care facilities in Victoria. The results indicated that residents with intellectual disabilities were admitted to the nursing home when their main carer passed away or when they required an increased need for support (Bigby, et al., 2008). Changes in accommodation may therefore be a cause of unplanned retirement for individuals with a disability, the unintentional nature of the retirement can have severe impacts on the persons psychological adjustment to the new found situation of retirement (Sterns, et al., 2000).

The involuntary nature of retirement produces discordance in volition and performance, individuals are not internally motivated to retire and they lack the physical ability to work (Kielhofner, 2008). They may therefore experience emotions from the disenchantment stage of the Atchley model whereby the individual is not stable in the reality of their retirement environment (Atchley, 1976).

**Sufficient Income in retirement**

Much research has shown a correlation between financial stability and smooth retirement adjustment (Gallo, et al., 2009; Reitzes & Mutran, 2004; Smith, Langa, Kabeto, & Ubel, 2005). Specifically Marshall et al (2001) who found that the odds of reporting dissatisfaction in retirement were reduced by 20% for each $10,000 earned per household.
Limited finance is a common issue that individuals with an intellectual disability endure throughout their lives (Dalton & Ong, 2007). They are at a financial disadvantage to the normative population as high paid employment opportunities are extremely rare, their lower intellectual performance and lack of extended education opportunities means that individuals with an intellectual disability are unable to compete with the general public for job positions (Ashman, Suttie, & Bramley, 1993). The average wage for a person in supported employment is around A$21-$60 per week compared to A$725 for an average Australian. Even allowing for income from the disability support pension this limited wage results in a restricted ability to save for the retirement years ahead (Australian Bureau of Statistics, 2003b). Thus, an individual may not experience certain stages of the Atchley model due to financial limitations, phases such as the honeymoon stage are associated with participation in recreational activities such as travel which require funds that individuals may not be able to gain (Atchley, 1976).

**Good health in retirement**

Financial stability is vital in sustaining livelihood for basic household requirements but more importantly for sustaining health (Gallo, et al., 2009), individuals with a disability face barriers in terms of finance and health. As previously discussed, individuals with intellectual disabilities often suffer from additional health complications. A study in the Netherlands showed that individuals with intellectual disabilities had 1.5 more doctor appointments than the normative population (Van Schrojenstein Lantman de Valk et al., 2004). The Australian health care system has been found to have limited capacity to meet the needs of individuals with a disability as they age (Goodard, Davidson, & Mackey, 2008). Reports have shown that individuals with intellectual disabilities have difficulties in accessing appropriate treatment. This is due to limited comprehension of when to seek medical advice, difficulties in
expressing their health problems and problems with understanding doctor’s instructions (Adlin, 1993; Ashman, et al., 1995). As individuals age their general health deteriorates and individuals with an intellectual disability face a higher likelihood of health complications during their retirement years. These complications can result in a particularly stressful retirement due to costly medical treatment demands and lack of finance, this will affect the way in which they adjust to their retirement. This stress is integrated in the environmental factors of the MOHO and the last stage of the Atchley model whereby independence is decreased due to declining health and financial limitations (Atchley, 1976; Kielhofner, 2008).

Minimal changes in an individual’s life apart from the job loss

Continuity is a way in which individuals adapt to new situations (Atchley, 1976). Old experiences provide a basis for the way they react to new found changes, continuity can be in the environment in which they live, the relationships they have around them or the activities in which they participate (Atchley & Barush, 2004). Environmental continuity in retirement is a facilitator that often does not occur for individuals with an intellectual disability who live in the family home. This is due to the issue of accommodation relocation as individuals and their carers age (Bigby, et al., 2008). They may therefore experience a significant barrier in adapting to retirement as they could lack environmental continuity whilst undergoing vast changes in their usual lifestyle due to their newfound retirement. However, individuals with an intellectual disability who reside in shared accommodation have a greater likelihood of experiencing environmental continuity as they are encouraged to age in place (Fyffe, Bigby, & McCubbery, 2006).

Individuals with an intellectual disability may also face a barrier in adapting to new situations due to their lack of relationship continuity; these individuals have a disparity to the normative population in terms of the types of relationships they form. Those in the general
population often gain lifelong support from a marital relationship, however this is not the case for most individuals with an intellectual disability (Schoenman, 1995).

It has been found that 45% of people with a disability have informal carers, with 72% being parents to these individuals (AIHW, 2008c). Individuals with an intellectual disability therefore often rely on their family as the main form of social, financial and emotional support (Fujiura, 1998; Heiman, 2002). This main form of support is lost when the family member passes away (Bigby, et al., 2008).

The MOHO framework and the Atchley Model of Retirement emphasize the importance of participation in activities that are personally meaningful (Atchley, 1976; Kielhofner, 2008). However, partaking in meaningful activities can prove to be difficult for individuals with an intellectual disability for reasons such as poor physical health, financial restraints and changes in accommodation (Australian Bureau of Statistics, 2003b; Bigby, et al., 2008; Van Schrojenstein Lantman de Valk, et al., 2004). These factors can affect the individual’s ability to continue participating in their normal activities post retirement and will therefore affect the way in which they adapt to the changes of retirement.

Realistic views about retirement role

Atchley (1976) deemed that having a realistic view of retirement roles assisted a person in experiencing a smooth retirement transition. This is supported by Marshall (2001) who found that lower life satisfaction occurs when the reality of retirement does not meet people’s expectations. A realistic view of an individual’s retirement roles requires foresight of the transition ahead. Individuals with an intellectual disability have been shown to have deficits in their ability foresee their retirement future. Research has shown that individuals with an
intellectual disability have little comprehension of their own ageing process (Cordes & Howard, 2005), the eventual need for retirement and how they will occupy their time after the termination of their employment (Cordes & Howard, 2005; Hawley, Fethney, Gopalan, & Hodges, 2005). Deficits in retirement comprehension may be due to the lack of retirement culture and role models within this population (Hodges & Luken, 2006).

Future plans for retirement are not frequently discussed and there is clearly a great need to educate individuals with an intellectual disability on the matter of retirement (Heller, Factor, Sterns, & Sutton, 1996). Statistics show that individuals with a disability are seldom aware of their ability to make choices, it has been found that 60% of individuals had no choice about the type of work they accomplished and 25% of individuals had no input into their daily routine (Heller et al. 2000). Advising individuals of the implications of retirement empowers them to make informed decisions that will assist in developing realistic retirement roles.

Retirement preparation programs are one way in which individuals can be educated on the patterns of retirement and plan ways in which they will overcome difficulties during this period of their lives. Programs provide information on ways in which to plan for; financial difficulties, health issues, housing issues, career development, relationship difficulties and productive use of time (Dennis, 1986). Retirement preplanning has shown to be beneficial in assisting individuals in their retirement years as individuals are informed of what to expect during the retirement years (Marshall, et al., 2001). Retirement preparation programs for individuals with an intellectual disability are currently scarce. Lawrence and Roush (2008) analysed the pre-retirement services that were available for individuals with intellectual disabilities in Ireland. Out of 72 organisations only five had retirement education programs, and the majority of places only offered support in the form of referral to residential services.
and day programs. However the Australian government has identified the deficiency in retirement planning and are developing retirement resources to overcome this issue (McDermott, Edwards, Abello, & Katiz, 2010).

Due to the lack of retirement comprehension and deficiencies in awareness of ability to make decisions, pre-retirement programs designed for the general population may prove ineffective for individuals with a disability. By educating individuals with a disability on issues that meet their specific requirements and by providing support in making informed decisions, successful planning for retirement has proven to be possible (Heller, et al., 1996).

Pre-retirement planning is important as it promotes personal causation through increasing the individual’s awareness of their abilities and capabilities in making their own retirement choices. Educating individuals on issues such as health, finance, support networks and use of time enables them to plan for their retirement in a way that produces healthy valued habits that promote successful age ing (Kielhofner, 2008). Forming plans to address difficult times ahead enables a person to have a positive experience of smooth retirement transition (Atchley, 1976).

Intellectual disability and adapting to new changes

Retirement is a life transition that affects an individual’s usual habits and routines, social integration and financial stability, it has been found that individuals with a disability are reluctant to depart from their established work routines and commence the transition to retirement (Ashman, et al., 1995; Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004; Buys et al., 2008; Hawley, et al., 2005; Jonsoon, Borrell, & Sadlo, 2000). The Atchley Model of Retirement Adjustment shows that individuals will experience a range of emotions during
this transition, as changes in habituation and internalized roles can result in dysfunction (Atchley, 1976; Kielhofner, 2008). It is therefore imperative that people who are about to experience retirement are able to adapt to the changes that retirement brings.

An individual’s aptitude to adjust to retirement successfully will be greatly influenced by the ways in which they cope with the stressors that retirement imposes on them. Coping has been defined as “the cognitive and behavioral efforts employed to manage the demands (external and/or internal) of a stressful situation and/or the emotions surrounding the situation” (Atchley, 1976, p. 13). There are currently two primary forms of coping strategies, active coping and avoidant coping. Active coping refers to the individual attempting to gain control over a stressful situation/emotion whilst avoidant coping is where an individual attempts to ignore or disengage in a stressful situation. Individuals have been found to have less psychological distress when they use active coping strategies. Avoidant coping has been found to have a negative impact on psychological distress (Ayers, Sandler, West, & Roosa, 1996; Conner-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000).

Extensive literature has shown that individuals with an intellectual disability experience stress from negative social interactions and use ineffective avoidance strategies to cope with social interactions (Bramston, Fogarty, & Cummins, 1999; Fogarty, Bramston, & Cummins, 1997; Hartley & Maclean, 2008). It has also been found that individuals with an intellectual disability will use active coping strategies if they believe that they have control in the situation (Bramston, et al., 1999). These findings have implications on the way in which individuals with an intellectual disability cope with retirement, as they may be faced with situations such as a change in accommodation where they have little control and autonomy of the environment around them and may therefore have difficulty in coping with the situation.
Retirement is also associated with an increase in free time where individuals are able to participate in new activities in the community, however few individuals with a disability participate in mainstream groups for retirees (Hall & Hewson, 2006). If these individuals utilize avoidant coping strategies they may be at an increased risk of social isolation during retirement. The use of avoidant coping strategies will affect the way in which an individual adapts to retirement; if a person is having difficulties in social interactions they may experience the disenchantment stage whereby they experience problems in developing roles and routines in a healthy manner (Atchley, 1976).

Policies

In Australia there is a void in the services available for aged individuals with an intellectual disability, as it is not clear if aged care services or disability services are responsible for providing for the needs of these individuals (Leveratt, Bowers, & Webber, 2005). This has occurred for the reason that aged care facilities are funded at a national, state and local level whilst disability services are funded by the state, resulting in policies that are unclear to local service providers (Leveratt, et al., 2005). Aged care services are therefore not trained to work with individuals with an intellectual disability and disability services do not possess the expertise to work with the issues that can arise with old age (Bigby, 2008a; Buys & Rushworth, 1997).

Individuals with an intellectual disability often have health difficulties such as premature ageing which results in premature retirement. These individuals are not appropriately supported by the government as they are considered too young for aged care services and are a low priority for disability services (Bigby, Fyffe, & Ozanne, 2007). Consequently,
individuals are being placed in aged care facilities at a very young age, this increases the probability of an individual experiencing social isolation (Bigby, et al., 2008).

The discrepancy between disability services and aged care facilities has also had an impact on the ways in which individuals spend their time once they have retired. There is currently a lack of social engagement and community participation opportunities for individuals with a disability during retirement (Clement & Bigby, 2009; Hall & Hewson, 2006; McDermott, et al., 2010). Community groups have been found to be willing to support individuals with a disability during retirement but are ill equipped to provide appropriate services to these individuals (Balandin, Llewellyn, Dew, & Ballin, 2006). Day centers have also been found to be inadequate in providing services for aged clients as just 34% of centres nationwide offer programs aimed at the elderly (Bigby, et al., 2004). In addition, day centres will only accept individuals with a disability into their day programs if they have previously been a part of that services; this excludes individuals who worked full time prior to retirement (Bigby, 2002; Bigby, et al., 2004; Hodges, Luken, & Hubbard, 2004).

The array of physical, cognitive, environmental and social difficulties experienced by individuals with an intellectual disability in daily life affect the way in which they adjust to retirement. There is therefore a requirement for governments to put in place policies and supports that meet the needs of these service users during the retirement years (Hogg, Lucchino, Wang, Janicki, & Working group, 2000).

Conclusion

Retirement is a transitional period when an individual will experience change in their lives. Each person is unique in the way in which they adjust and cope with change however several
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key factors such as good health, sufficient income and ability to give up a job gracefully have been found to assist in facilitating a smooth transition from worker to retiree. These key factors have been discussed in relation to individuals with an intellectual disability and several important issues have been highlighted.

There is currently a need for improved healthcare policies as individuals with intellectual disabilities experience difficulty in accessing appropriate treatment. This is especially important for older adults with intellectual disability, as they will require additional treatment as they age. Healthcare policies should include education to all healthcare professionals on the suitable treatment strategies for clients with intellectual disabilities.

Discrepancies in appropriate institutional policies for individuals with an intellectual disability have also been found. These individuals currently have limited support from aged care services and disability services. In order to overcome this, a new service is required that caters specifically for aged individuals with disabilities by having staff that are trained in aged care and disability as well as providing support to community retirement services.

Education is not only vital for healthcare workers but also for the families of individuals with an intellectual disability as they are often responsible for making decisions on behalf of their family member. It is therefore important that they are empowered to make informed choices on issues such as accommodation and retirement so appropriate strategies can be put in place that assist in overcoming any difficulties that occur as they and their family member age.

Empowerment of all individuals with an intellectual disability is of uttermost importance; in order for this goal to be accomplished all individuals with an intellectual disability should be
educated on the notion of ageing and retirement. The suitability of pre-retirement planning programs for individuals with an intellectual disability run by supported business services requires further research.

The findings suggest that individuals with an intellectual disability have the motivation and values to participate in habits and routines they deem important, however experience barriers in personal causation/or ability to participate in these activities due to financial limitations, health difficulties, accommodation issues and inadequate governmental policies. These factors will play an important role in determining the emotional stages that an individual experiences during the process of retirement adjustment.
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Author Guidelines

Journal of Intellectual and Developmental Disability
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The Journal of Intellectual & Developmental Disability (JIDD) is the official journal of the Australasian Society for the Study of Intellectual Disability (ASSID). JIDD is an international, multidisciplinary journal in the field of intellectual and developmental disability. The Journal publishes original qualitative and quantitative research papers, literature reviews, conceptual articles, policy analysis papers, brief reports, case reports, data briefs, and opinions and perspectives. JIDD also publishes book reviews written at the invitation of the Book Review Editor.

This journal is of interest to researchers, academics and professionals concerned with people with disabilities and holds an important place in university, hospital, educational and service libraries. The journal is published on behalf of ASSID by Informa Healthcare

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The Experience of Retirement for Individuals with a Lifelong Disability

Megan Flowers
Abstract

The life expectancy of individuals with a disability has significantly increased in the last century. Organisations that cater for the population with a disability face the challenge of providing appropriate services that meet the changing needs of their clientele throughout the ageing process. There is currently a paucity of research on the topic of disability and retirement. This qualitative study explores the experience of retirement of ten individuals with a disability. The data was analysed in a framework approach using the Atchley Model of retirement. Overall the findings from this study show that participants experience a range of health complications throughout retirement and have limited community integration however were found to have increased financial stability during this time. A greater knowledge of the experience of retirement for individuals with a disability will assist service providers in identifying voids in policies and systems to better serve the needs of retiring individuals.

Key words: Retirement, (intellectual) disability, ageing process, Atchley Model of Retirement
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Literature review

The life expectancy of individuals with a disability has significantly increased in the last century, this longevity is related to the advancement of science, technology and health care services (Kelly, Kelly, & Craig, 2007; World Health Organization, 2000). Organisations that cater for the disabled population face the challenge of providing appropriate services that meet the changing needs of their clientele throughout the ageing process, individuals are considered to be ageing at 65 years of age which coincides with the age of normal retirement (Fyffe, Bigby, & McCubbery, 2006).

Retirement is a significant component of the ageing process as it is a transitional time where alterations occur in an individual’s customary habits, routines and lifestyle. It can be an exigent phase for the individual if they do not have the aptitude to cope with the stressors that are imposed on them during the transfer from paid work to retirement. Currently there is a paucity of research exploring retirement for individuals with a disability however ample studies have been conducted on able-bodied individuals finding five key concepts that assist an individual in achieving a smooth adjustment to retirement (Atchley & Barush, 2004). The five concepts include; the ability to give up a job gracefully, good health, financial stability, minimal changes in the individual’s life apart from the job loss and having realistic views about the retirement role (Atchley & Barush, 2004).

The first key concept of giving up a job gracefully can be difficult for individuals with a disability as retirement often occurs when their health problems no longer permit participation in work activities (Sterns, Kennedy, Sed, & Heller, 2000). These health issues obstruct the person’s capability to play the role of a retiree and they subsequently take on a disabled role, retirement is considered to be terminated at this stage of life (Atchley, 1976).
Good health is therefore another important concept that aids a smooth transition from work to retirement. The correlation between physical health decline and ageing is a well documented phenomenon that occurs in human beings, however the natural progression of ageing impacts the disabled population to a greater degree as they are already disadvantaged with health problems (Bigby, Webber, Bowers, & McKenzie-Green, 2008). This is further hindered by restricted access to appropriate medical care as individuals with an intellectual disability often have problems with seeking, expressing and comprehending health treatment and are consequently at a disadvantage compared to able bodied individuals during retirement (Adlin, 1993; Ashman, Suttie, & Bramley, 1995).

The matter of financial stability in retirement can be a concern for individuals with a disability as limited funds is a common issue that arises throughout this population group (Dalton & Ong, 2007). Individuals with a disability are at a financial disadvantage to able-bodied individuals as high paid employment opportunities are extremely rare, their lower intellectual performance or lack of extended education opportunities means that they are unable to compete with the general public for job positions (Ashman, Suttie, & Bramley, 1993). This limited wage results in a restricted ability to save for the retirement years ahead.

Sustaining minimal changes apart from job loss can prove complicated for individuals with a disability if they are required to relocate to other forms of accommodation. This frequently occurs when family care givers age and pass away or become too frail to continue looking after them in the family home (Bigby, et al., 2008). However individuals who live in group homes are less likely to experience these environmental changes as ‘ageing in place’ is
encouraged; a transfer to alternate facilities occurs only when health problems require professional aged care (Fyffe, et al., 2006).

The final concept of retirement deems that an individual is more likely to experience a smooth conversion to the new found lifestyle if they have realistic views regarding the retirement role (Atchley & Barush, 2004). A realistic view of an individual’s retirement roles requires foresight of the transition ahead. Individuals with an intellectual disability have been shown to have deficits in their ability to foresee their retirement future. Research has found that individuals with an intellectual disability have little comprehension of their own ageing process (Cordes & Howard, 2005), the eventual need for retirement and how they will occupy their time after the termination of their employment (Cordes & Howard, 2005; Hawley, Fethney, Gopalan, & Hodges, 2005). Deficits in retirement comprehension may be due to a lack of retirement culture as there is currently limited retirement preparation programs and role models existing within this population (Hodges & Luken, 2006).

The existing literature illustrates a variety of barriers that can affect an individual throughout retirement; this paper aims to explore these barriers in relation to the subjective experience of retirement for individuals with a disability.

Methods

Design

The aim of the research was to describe the experience of retirement for individuals with a disability, a qualitative paradigm was utilised to accomplish this research aim. Qualitative research is beneficial to use as it provides rich subjective data that enables the exploration and understanding of a unique phenomenon (Pope & Mays, 1995). This is the favourable
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As there is a dearth of research into the area of retirement and disability. The research process was guided with the use of the Atchley Model of Retirement. The model was used to provide a source of reference throughout the data collection and data analysis stage (Atchley & Barush, 2004).

Participant selection

Three organisations were approached to provide a pool of possible participants for the research; Activ, Identity and Goodwill Engineering. Activ is a ‘not for profit’ organisation that provides a range of services to enable individuals with a disability, and their families, to pursue a better life. These services include supported employment, respite and accommodation support (Activ, 2010). Identity aims to maximise the well-being, potential and quality of life of people with an intellectual disability (Identity WA, 2010). Participants were recruited from Activ and Identity accommodation services. The final organisation, Goodwill Engineering, is a light engineering and metal fabrication business that provides supported employment to individuals with a disability (Goodwill Engineering, 2010). Retired employees of the company were informed of the research and given the option to partake in the study.

Opportunity sampling was utilised to select participants that met the inclusion criteria where individuals are disabled and fully retired / in the process of retiring. Staff from the organisations approached possible participants to arrange an initial meeting with the researcher, in which caregivers were encouraged to attend. The initial meeting provided information on the participants rights and the research ethical obligations. Informed consent was obtained from all participants. Gaining informed consent from participants with an intellectual disability is important due to the issue of their capacity to understand what they
are agreeing to, this was ensured through the use of specifically developed questions by Arscott, Dagnan and Kroses (1998) to certify comprehension of the research (see appendix 1).

The final sample consisted of ten participants (n=10), three of whom are; diagnosed with cerebral palsy, predominantly physically disabled, fully retired and live independently in the community (n=3) and seven with (severe to moderate) intellectual disability living in shared homes in the community (n=7). Three of the participants with an intellectual disability had fully retired and have limited verbal skills (n=3) whilst four have good verbal skills and are beginning the retirement process by reducing the amount of hours they worked each week (n=4).

The final sample had an equal gender ratio and represented a variety of disabilities, with individuals in different stages of the retirement process. The standard age of retirement in Australia is considered to be 65 years of age (Mutchler, Burr, Massagli, & Pienta, 1999) however three participants with an intellectual disability and one participant with a physical disability commenced retirement prior to this time (50, 58, 54 & 56 years of age). The final two retired participants (with a physical disability) retired at 65 and 66 years of age. Ethical clearance to conduct the research was gained from the Edith Cowan Human Research Ethics Committee (code 5353).

Data collection

The method of data collection for six of the participants was an interview, however four of the fully retired participants did not possess adequate verbal communication skills to use this form of data collection, so participant observation was utilised instead.
The semi-structured interview (appendix 2) explored factors that affect an individual’s retirement experience, the participants’ verbal responses were recorded on audio tape and the non-verbal behaviour was documented in field notes. The interviews lasted an hour and occurred at a location nominated by the participant. This form of data collection was employed as it promoted free-flowing conversation in a normative environment and allowed the liberty to divulge detailed information in specific areas of interest (Opdenakker, 2006).

Participant observation is a method of inert learning where the researcher encompasses themselves into the participants' culture and adapts a role in their environment (Li, 2008). The aim of this form of data collection is to gain an insight into their practices, emotions and motivations, which is advantageous when working with non-verbal participants. The participant observation technique was applied for three of the participants who have limited verbal communication skills. The researcher played the role of a carer assistant and observed the participants for a day whilst they performed their usual routines, their surrounding carers and support workers were interviewed in order to gain an accurate interpretation of the phenomena. All of the data was collected through the use of field notes and audio tapes which was then transcribed and coded for data analysis. Pseudonyms were utilised to sustain confidentiality.

Data analysis

The data was analysed using a framework approach, this deductive form of analysis is approached in stages. The first stage is familiarisation, in this phase all textual data is studied in detail to classify themes and form ideas of the direction the research will take, a suitable thematic framework is then identified (Pope & Mays, 1995). The data is systematically indexed into categories by coding the transcriptions and selecting quotes that support the
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This information is rearranged into charts using the context of the framework approach (Pope & Mays, 1995). The charting stage requires attention to detail in regards to the way in which the information interacts and the correlations that are found within the data. Results can be drawn from mapping and interpreting the information into evidence that supports created typologies and concepts (Pope & Mays, 1995).

The Atchley Model of Retirement was utilised as a framework as it is an acknowledged authoritative source of research on the topic of retirement, the data was sorted, categorised and coded into its framework approach (Atchley & Barush, 2004). The issue of trustworthiness was addressed by a research journal, which ensured the data was credible, and also by the process of member checking throughout the interview to certify correct interpretation of the data. An audit trail was used to document the research process and certify the dependability of the findings. Three participants were member checked post data analysis to confirm correct evaluation of the data. The clear depiction of the participants' demographics and environmental context ensures correct transferability of the results.

Findings & Discussion

The roles and routines experienced during retirement were found to significantly contrast between the participants with a physical disability to those with an intellectual disability, this is due to a variety of causes, the foremost being autonomy. Participants with a physical disability were found to be independent in making decisions on their retirement lifestyle whilst participants with an intellectual disability lacked personal causation in making choices about their daily structure and rely on family members and staff to make decisions on their behalf. Participants with an intellectual disability therefore experience a very structured
retirement routine that is unique to this population group. These findings will be further discussed according to The Atchley Model of retirement.

*Ability to give up one's job gracefully*

The participants with a physical disability and those with an intellectual disability experienced similar barriers in their ability to give up a job gracefully, as they all reported to have stopped working when health issues prevented them from participating in work activities. When asked why he retired Toby responded:

"Too old, my shoulder is crook, my back is crook. I was lifting all the time."

Not one of the participants determined the circumstance of their retirement, and commenced the retirement process only when their health deteriorated. This is supportive of literature by Sterns et al (2000) who found health complications to be the greatest reason for retirement in individuals with a disability.

None of the participants in the research were given the option to retire at an age when they were in good health, instead they were encouraged by family and staff to work until they no longer possessed the capability to proceed in work activities. A mother of a participant commented:

"I think as a family here, we would love to see him going on with work as long as he can and when we feel he is too tired, then we will gradually start cutting it back"

Families therefore play a role in influencing the process of retirement for individuals with a disability and were found to be hesitant in changing the participants' work routine due to concerns over their occupational use of time. John explained:

"My family didn’t want me to retire; they said what you will do. You will be bored."
The findings show that participants were limited in their ability to give up a job in a graceful manner as they did not have the opportunity to determine the timing of their retirement and waited until they were obligated to retire due to health reasons. In order to overcome these issues it is necessary for individuals with a disability and their families to gain a positive perception of retirement and encourage its occurrence before they are constrained by health problems. This can be achieved by advocating the benefits of a retired lifestyle and by providing information on available pastime options, as education empowers individuals to have autonomy in making life decisions.

**Good health**

A variety of additional health problems were found within the sample, with the most commonly diagnosed being diabetes. In this study, the participants with a physical disability were found to have fewer health complications then the participants with an intellectual disability and consequently experience roles and routines typically found in the general population. The retired participants with an intellectual disability had impaired eyesight; poor hearing and limited verbal communication, one of the participants had been diagnosed with dementia. These participants had a greater disabled role due to their health requirements and dependency on others.

Individuals with an intellectual disability have been found to experience difficulties in accessing appropriate medical care (Adlin, 1993; Ashman, et al., 1995), however this is not an issue for the participants as their group home conducts medical checks on the clients each Sunday. If a person was found to be ill, the group home would organise an appointment with a general practitioner and transport them to the clinic. Individuals with an intellectual
disability in these organisations are therefore highly supported in ensuring optimal health as they age throughout retirement.

Good health during retirement was a topic that caused concern for the participants with a physical disability. They felt that deteriorating health was a threat to their highly valued independence. Toby explained:

"I kept falling over, I was in a wheelchair and then they said that I had to go into a group home and I said that I'm not going into a group home."

Maintaining good health during retirement enables individuals to participate in valued activities, however it is difficult for aged individuals with a disability to encounter good health during retirement as they experience a greater amount of health complications (such as premature ageing) to able-bodied individuals (Bigby, et al., 2008). Individuals with a disability should therefore be informed on ways in which they can manage their physical and mental health during retirement and consider retiring at a younger age in order to experience the benefits of retirement without health complications.

**Sufficient income**

The full sample receive finance from the disability support pension. The participants living in group homes rely on staff to organise all financial matters, including funeral plans and wills. When asked about income, Sarah responded:

"The staff do all that, they go to the bank and collect the money and they do the shopping."

These participants are not responsible for budgeting their income during retirement and may therefore experience less stress then able-bodied individuals during this time, however, they
do have less choice regarding the way they spend their money during retirement to able-bodied individuals.

Limited finance was not an issue reported by any of the participants, on the contrary, participants were able to afford to travel during the retirement period. Two of the participants with a physical disability had been to Hong Kong, another was visiting Bali in October, whilst participants with an intellectual disability had been able to afford a holiday home in Hillarys and one had been to Phuket. Since travel is a typical leisure activity in retirement and often occurs in the early ‘Honeymoon’ stage, the participants are similar to able bodied individuals in this aspect of their retirement experience (Atchley & Barush, 2004).

The participants with a physical disability all commented that their income had improved since they retired. Bradley stated his financial situation as:

“A little better now to what it was..... you get more in the pension too, cause when you’re working you lose about a hundred dollars out of the pension.”

Another cause of increased financial gain was the participants’ ability to plan ahead for their retirement; Toby described how his superannuation has assisted him during the retirement period:

“Well before I retired I used to put money towards my super and I got a good super and I have been putting into a fixed term account and let it grow,..... and before I retired I made sure that I bought everything for my unit”

An increase in income has enabled the participants to engage in new activities and has relieved their stress on financial matters. When asked how this increase in finance had affected him John said:

“I can pay my electricity and phone bills”
Increased financial stability in retirement is a finding that disputes current research (Dalton & Ong, 2007) and is a phenomenon that is not often found in able-bodied individuals during the retirement period. This opposite correlation may be due to the limited wage that individuals with a disability earn throughout their lives, which results in a restricted ability to save for the retirement years ahead. Toby mentioned this topic:

"The only thing that I haven't got, I didn't have a good education, because in my day we did not do much school work, we did lots of physio and all that. What people tell me is that if you haven't got it on paper it doesn't matter. I reckon most people at (organisation name) don't have a good education because they all have different disabilities".

The statement is supportive of literature by Ashman, Suttie & Bramley (1995) who identified that financial strain occurred in individuals with a disability due to restricted employment opportunities. The participants increase in financial stability during retirement is a positive discovery, however further research using a population based sample is required to strengthen this finding.

**Minimal changes in the individual’s life apart from the job loss**

All of the participants with an intellectual disability retired in a gradual manner by reducing the amount of hours they worked each week. During their days off they attended day centres on a part time basis to become familiar with an altered lifestyle. Since retirement these participants spend the weekdays at centres where they participate in a range of leisure and recreational activities that are aimed at maintaining physical and cognitive functioning. The participants became accustomed to the day centres whilst they were employed and therefore
experienced minimal change in their life once they stopped working; this environmental consistency is beneficial in aiding a smooth adjustment to retirement.

The full sample also experienced stability in their accommodation, as their housing had stayed constant throughout retirement. The participants with an intellectual disability reside in shared accommodation where support workers are on duty and available full time. The organisations match clients in the group homes dependent on their level of function, behaviours and personality in order to encourage a positive living atmosphere. All of the retired participants with an intellectual disability had parents that were deceased, however, they were found to experience relationship stability throughout retirement as they resided with the same individuals in the group homes. Although a termination of relationship did occur when staff members changed vocation. This relationship continuity assists an individual in coping with the transition from paid work to retirement.

The group homes encourage ‘ageing in place’ as it minimises the clients need to change environments when they are elderly, though this was reported to be an issue by a staff member in one of the group homes:

“It can be difficult to provide appropriate services that meet the needs of Jane and all the other residents, as sometimes Jane can’t keep up in the activities and slows down the rest of the group, it can stop the rest of the house doing things that they want to do ....... Jane is slowing down, it would be great if we could provide activities for her to do at home, more like what they do in aged care homes, but this brings us back to the problem of limited staff.”

Group homes have been found to experience challenges in providing appropriate services for their aged residents due to limitations in; resources, staff numbers and employees with aged-
care training in disability (Fyffe, et al., 2006). In order to overcome this, one of the organisations (Identity) has developed a pioneering home that caters for aged and high medical care individuals. It is the first facility that has been built for this clientele group in Western Australia and was developed to ensure that individuals with a disability transfer to an appropriate environment when they age.

The participants with a physical disability live independently in the community. They lead a retired lifestyle that contrasts to the life of participants with an intellectual disability in a variety of manners. The main disparity within the sample is the difference in retirement routines. Participants with an intellectual disability have a highly structured routine whilst participants with a physical disability are independent in determining their daily arrangements, as they are no longer constricted by work obligations. All of the retired participants with a physical disability deemed the changes that have occurred since retirement are positive, Bradley explained:

“Well I can do things, I don’t have to get up early in the morning and I do the things that I enjoy doing”

The participants value their retirement as they can participate in activities that are personally meaningful; John described his retirement to be:

“Busier now compared to when I was working.... I talk, do public speaking at schools and I am on the Ministerial Advisory Council on Disability”

Voluntary work was a way in which Bradley also spent his time during retirement:

“I have got a job, not a paid job but I have got a voluntary job..... its working in the kitchen”
These participants had the liberty to participate in new occupations that they could not partake in prior to their retirement due to time restrictions. In addition, they reported to have developed new friendships whilst maintaining old ones during their transition to retirement.

The participants with a physical disability sustained their environmental and relationship continuity once they stopped working however experienced vast changes in the activities they participate in. These alterations were reported to have assisted them in adjusting to a retirement lifestyle.

*Realistic views about the retirement role*

Four of the participants in the sample were in the process of retiring by reducing the amount of hours they work each week. These participants lacked understanding of the retirement notion, when asked about the timing of her retirement Mary responded:

"*When I’m old enough to retire, but I don’t know how old you have to be”*

A single participant was aware of the way in which they could spend their time during retirement:

"*There is a place in Wanneroo that takes people when they retire.*” (Tracey)

These participants showed limited knowledge on the topic of retirement and had restricted foresight on their possible retirement roles. Individuals with an intellectual disability may therefore require support in developing realistic retirement roles. This can be achieved by: setting goals, grading activities and predicting possible problems that may arise. Support workers should be wary of underestimating the individual’s capability, as this occurred to Bradley:

"*They told me that I could not learn how to use a computer when I’m sixty, they said you can’t do it and a lot of people said that to me and it made me more determined.*"
All of the employed participants highly valued their work and one participant reported that they did not want to retire:

"No thank you, because we get a lot of important jobs coming in." (Christopher)

However the fully retired participants stated to prefer their retiree role to their former worker role:

"I prefer it now when I'm not working" (Sarah)

The employed participants may be hesitant to retire, as they have no information regarding the topic. None of the participants (n=10) had experienced any form of retirement education programme or had been assisted with their retirement transition, although most of the sample believed that it would have been beneficial to them. The retired participants were therefore unaided in developing retirement roles and were responsible for their own integration into the community. When Bradley was asked how he became a volunteer at the kitchen he replied:

"I just found this out myself"

None of the participants within the sample were aware of any community clubs or groups that cater for retired individuals within their area.

The participants with a physical disability are at an advantage over the participants with an intellectual disability as they have the capability to arrange pastimes within the community, the participants with an intellectual disability experience social integration when the day centres, group home or family take them on outings to public areas. Christopher commented on this issue:

"I like to mix where they don't come from our workshop ... Because I like to talk to people I don't know and get to know them."
Community integration can be accomplished if individuals are informed of the options that are available to them during retirement and supported in implementing their desired retirement routines. The sample in this research had no assistance during their retirement transition, however this may change in the future. The government has developed retirement education resources and are currently implementing them nationwide at supported employment services (FaHCSIA, 2010). Pilot studies are being conducted to assess the appropriateness of the resources, if deemed successful the experience of retirement may be improved for future individuals with a disability.

**Limitations**

The study has a limited sample size, with participants who have difficulty in abstract thinking and communication difficulties, this makes the data that can be collected limited. Further research that includes interviews and ethnographic observation of groups of participants is therefore required in order to confirm the transferability of the results. The sampling technique can also be improved as the use of opportunity sampling resulted in a lack of retired participants with an intellectual disability who had adequate verbal communication skills to participate in an interview. This however may have been due to health complications that are often found within this population group. Two of the organisations provided participants from their accommodation services and as a consequence the sample consisted of individuals who resided in the group homes with increased support networks. The study therefore did not explore the experience of retirement for individuals living in family homes within the community. The utilisation of purposeful sampling would ensure that all disabilities are represented in a fair manner.
Participant observation was used to explore the experience of retirement for the participants with limited verbal communication skills, this form of data collection is beneficial as it provides ecological validity. However it has restricted ability to gain a subjective stance on the phenomena. A qualitative design provided rich data on the subjective experience of retirement and would be utilised in further research.

**Conclusion**

The purpose of this qualitative study was to explore the experience of retirement for individuals with a lifelong disability. It was found that the experience of retirement is significantly diverse between the participants with a physical disability to those with an intellectual disability, this occurs due to their different level of support requirements. Individuals with an intellectual disability were found to lead a very structured routine and lack autonomy in making decisions about their retirement routines whilst participants with an intellectual disability determined their roles and routines during retirement. Further research is required to determine the appropriate way of supporting these individuals’ needs during retirement.

The participants were similar in that they possessed limited ability to give up their job in a graceful manner due to health complications and lack of retirement education. They were also alike in terms of their health condition although this impacted the participants with an intellectual disability to a greater degree. An optimistic finding shows all participants experienced financial stability during retirement whilst individuals with a physical disability reported an increase in financial income, further research is required to support this finding. The participant’s experienced minimal changes in their environment and relationships since retirement however individuals with a physical disability were found to experience a vast
change in the activities they participated in during their free time; these changes were regarded as positive occurrence.

The whole sample showed unrealistic views about their retirement roles as no one had experienced any education on the topic of retirement. The retired participants showed limited integration in community programmes, which was particularly evident for individuals with an intellectual disability. Future research could examine the viability of client centred support during retirement.

A greater knowledge of the experience of retirement for individuals with a disability will assist service providers in identifying voids in policies and systems to better serve the needs of retiring individuals. Several of the requirements of ageing individuals with a lifelong disability have been identified and there has been progress in developing resources to overcome gaps in service provision. A group home designed to cater for high medical care and aged individuals will be open by the end of 2010 whilst retirement education resources are currently being implemented nationwide. The experience of retirement for individuals with a disability appears to be positive for future generations.

Overall, the results from this study show that the participants regarded their retirement as a positive and valued experience. However these findings cannot be generalised to the population with a disability, further investigation using a longitudinal study is required to strengthen the findings of this pilot study.
References


Appendices
Appendix 1 – Questions to ask to ensure informed consent:

- What will I be talking to you about?
- How many times will I want to talk to you?
- Are there any good things about talking to me?
- Are there any bad things about talking to me?
- What can you do if you decide you won’t want to talk to me anymore?

(Arscott, et al., 1998).

Appendix 2 – Semi-structured interview guide
Experience of Retirement

Code: 
Age: 
Length of retirement period:

VOLUNTARY/INVOLUNTARY RETIREMENT

Why did you retire? How do you feel about your retirement? What makes you feel this way?

HEALTH

How would you describe your physical health status now? Mental Health – how, why, when

Has your physical health status changed since retirement? How?

INCOME

Has your income changed since retirement? How?

How do you support yourself? – buy things. What do you like to spend your money on

LIVING SITUATION

Have your living arrangements changed since retirement? Who do you live with? Do you like it? Why

MOHO

How do you normally spend your day?

What activities do you participate in for fun? Have these changed since you retired? What activities would you like to participate? Why are you unable to participate in these activities? How does that make you feel?

Q4. SUPPORT SYSTEMS

Are you married? Would you like to be - relationships

Who do you spend most of your time with now? Is this different to when you were working?

How have your relationships with friends and family changed since retirement? Why?

Have you made new friends/relationships since retirement? How?

Have you joined any new community clubs/social events since retirement?

Q5. RETIREMENT PRE-PLANNING

Do you think you were prepared for retirement? Did you understand what it meant to be retired?

Were you given any information on retirement when you were still working? By who?

Did you receive help in planning your retirement? By who? How did they help you? (Would you have liked to have had assistance in planning your retirement?)

Has the retirement experience been what you expected it be? Why/ why not?
Experience of Retirement

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