

**HOW DO PEOPLE WITH LEARNING DISABILITIES EXPERIENCE AND MAKE SENSE OF THE
AGEING PROCESS?**

Gayle Ellen Newberry

Submitted in accordance with the requirements for the degree of
Doctor of Clinical Psychology (D. Clin. Psychol.)
The University of Leeds
Academic Unit of Psychiatry and Behavioural Sciences
School of Medicine

March 2013

The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

© 2013 The University of Leeds and Gayle Ellen Newberry

ACKNOWLEDGEMENTS

Thank you to the participants for giving up your time and sharing your experiences.

I would like to thank my supervisors, Dr. Carol Martin and Dr. Lorna Robbins for all their support and guidance throughout this process.

Finally, thanks to my family for supporting me through this research project and the rest of the doctorate. Special thanks go to Dan, for your endless patience, support and encouragement, and to Molly for helping me to remember the most important things in life.

ABSTRACT

Not enough is currently known about how people with learning disabilities experience and understand the ageing process. This is particularly important as the population of older people with learning disabilities is growing due to increased life expectancy. This study aims to fill this gap in the literature by exploring how people with learning disabilities experience and make sense of the ageing process and old age.

Seven people with learning disabilities aged 60 or over were interviewed, and their accounts were analysed using Interpretative Phenomenological Analysis. An individual analysis of each participant's account is presented, followed by the group analysis. The master themes arising from the group analysis were: quality of relationships is central to enjoyment of life, including sub-themes on the importance of affection and companionship, distress at lack of closeness, and anxiety about ability to satisfy others; powerlessness; needing a sense of purpose; and making sense of getting older, including sub-themes on reactions to changes with age, life review and looking to the future.

The findings of the study are discussed in relation to the existing literature. Clinical implications of the findings include the need for services to support older people with learning disabilities in maintaining friendships and meaningful activities. This study demonstrates that some older people with learning disabilities can engage in a process of life review and learning disability services could play a useful role in facilitating this process. Understanding of the ageing process varied between participants, and tended towards a negative, stereotypical view of ageing. The findings suggest that people with learning disabilities could benefit from psychoeducation on the ageing process to aid them in making sense of the changes they experience as they get older.

TABLE OF CONTENTS

ABSTRACT.....	4
TABLE OF CONTENTS.....	5
LIST OF TABLES.....	8
ABBREVIATIONS	9
INTRODUCTION.....	10
Literature review.....	10
Older people with learning disabilities	10
Ageing in the general population.....	12
Identity.....	14
Ageing and identity in the general population	15
Identity and people with learning disabilities.....	16
Identity and old age in people with learning disabilities	17
How might ageing for people with learning disabilities differ from the general population?	19
Attitudes towards older people with learning disabilities.....	20
Conceptualisation of old age among people with learning disabilities	21
The experience of ageing and old age in people with learning disabilities	22
How does this study aim to add to the literature?.....	25
Research aims	26
Research questions	26
METHOD.....	27
Rationale for the use of Interpretative Phenomenological Analysis	27
Rationale for using a qualitative method	27
Selecting the most appropriate method.....	27
Interpretative Phenomenological Analysis (IPA)	28
Ethical approval.....	28
Sample and recruitment	29

Sample size.....	29
Inclusion and exclusion criteria.....	29
Recruitment process.....	30
Ethical considerations: Consent.....	31
Data collection.....	32
Rationale for the use of semi-structured interviews.....	32
Design of interview guide.....	32
Interviews.....	33
Transcription.....	33
Ethical considerations: risk, payment and confidentiality.....	34
Risk.....	34
Payment.....	34
Confidentiality.....	34
Data analysis.....	35
Quality checks.....	37
Reflexivity.....	37
RESULTS.....	39
Participant demographics.....	39
References to ageing.....	39
Individual analyses.....	41
Audrey.....	41
Frank.....	47
Harry.....	51
Dorothy.....	55
Joyce.....	60
Peter.....	64
William.....	69

Group analysis.....	73
Quality of relationships is central to enjoyment of life	73
Powerlessness.....	76
Needing a sense of purpose.....	77
Making sense of getting older	78
DISCUSSION.....	81
Summary of findings	81
How do people with learning disabilities experience the ageing process and old age?	81
Quality of relationships is central to enjoyment of life	81
Powerlessness.....	86
Needing a sense of purpose.....	87
How do people with learning disabilities make sense of the ageing process?.....	89
Making sense of getting older	89
What meaning does the ageing process have for people in terms of their identity?	95
Strengths and limitations.....	97
Clinical Implications	99
Future Research	101
Conclusions	102
REFERENCES.....	103
APPENDIX A - Ethical approval.....	114
APPENDIX B - Study information for recruiters	119
APPENDIX C - Participant information sheet	122
APPENDIX D - Consent form.....	127
APPENDIX E - Interview schedule	129
APPENDIX F - Transcriber confidentiality agreement.....	131
APPENDIX G - Extract of transcript demonstrating data analysis process.....	132

LIST OF TABLES

Table 1 - Participant demographics	39
Table 2 - Participants' references to ageing and death	40
Table 3 - Characteristics associated with ageing by participants	41
Table 4 - Individual themes for Audrey.....	42
Table 5 - Individual themes for Frank	48
Table 6 - Individual themes for Harry	52
Table 7 - Individual themes for Dorothy.....	56
Table 8 - Individual themes for Joyce	61
Table 9 - Individual themes for Peter.....	66
Table 10 - Individual themes for William.....	70
Table 11 - Master themes.....	73

ABBREVIATIONS

CLDT: Community Learning Disability Team

DoH: Department of Health

IPA: Interpretative Phenomenological Analysis

INTRODUCTION

This chapter introduces the characteristics and service needs of the increasing population of older people with learning disabilities. It outlines background literature relating to ageing in the general population, before explaining why the experience of ageing may differ for people with learning disabilities. The chapter summarises the existing literature on how people with learning disabilities conceptualise and experience the ageing process. A gap in the literature is identified, to be addressed by this study. Finally, the research aims and research questions of this study are outlined.

Literature review

Older people with learning disabilities

A learning disability is a significantly reduced ability to understand new or complex information and a reduced ability to cope independently, beginning before adulthood with a lasting effect on development (DoH, 2001b). Emerson and Hatton (2008a) estimate that there are 985,000 people in England with learning disabilities, including 174,000 aged over 60.

Life expectancy has improved for people with learning disabilities (DoH, 2001b; Holland, 2000; Janicki et al., 1999; Patja, Iivanainen, Vesala, Oksanen & Ruoppila, 2000; WHO, 2000). Life expectancy for people with learning disabilities in general remains lower than the general population, but greater numbers of older people with learning disabilities now survive into later-life and some, particularly those with mild learning disabilities, live as long as age peers in the general population (Janicki et al., 1999; Patja et al., 2000).

People with learning disabilities have more difficulty accessing health services than the general population due to factors including communication difficulties, and lack of understanding of learning disabilities among healthcare professionals (Mencap, 2004, 2012; WHO, 2001). The combination of poor access to health services, and elevated risk factors for ill-health, such as diet, exercise and socioeconomic status, results in people with learning disabilities approaching the ageing process from a disadvantaged position in terms of health (Bigby, 2004).

People with learning disabilities experience many of the same biological changes with age as the general population, and in general rates of age-related conditions among people with learning disabilities are comparable to or higher than the general population (Evenhuis et al., 2001). Some older people with learning disabilities may also have health risks from associated developmental disabilities, or syndrome-specific conditions (Evenhuis et al., 2001). People with Down's syndrome are at increased risk of early development of age-related difficulties with hearing and vision and Alzheimer's disease as well as having a higher risk of difficulties such as cardiovascular problems (WHO, 2001). Older adults with learning disabilities without Down's Syndrome are also at higher risk of developing dementia compared to the general population (Cooper, 1997; Strydom, Hassiotis, King & Livingston, 2008), although not to the same extent as those with Down's Syndrome.

Emerson and Hatton (2008a, 2011) predict a rise in the number of people aged over 50 with learning disabilities. This will combine with factors reducing the capacity of informal support networks, for example an increased percentage of older people with learning disabilities whose parents may be frail or deceased, increasing the demand for social care services (Emerson & Hatton, 2008b).

Older people with learning disabilities fall between two services. Some older people with learning disabilities experience physical and mental deterioration with age, which may overshadow the needs associated with their learning disability, being best served by services for elderly people (DoH, 2001a; DoH, 2001b). Other older people with learning disabilities are misplaced in services for older adults as they are significantly younger than other residents and services may lack suitable activities and training around learning disabilities (Thompson & Wright, 2001). These people may be better served by a combination of residential support and occupational and recreational activities taking account of the ageing process and their learning disability (DoH, 2001a; DoH, 2001b).

Older people with learning disabilities live in a range of settings including the family home, supported living, specialist learning disability provision, or older person's residential care. Changing support needs or increased frailty of family carers may result in people having to move as they grow older (Mental Health Foundation, 2002). People with learning disabilities may be inappropriately placed in older adult's provision because of a shortage of places in learning disability provision, and a lack of forward planning (Mental Health Foundation, 2002).

It is important to protect friendships and activities, and services such as day-centres are a key part of this as they may form someone's main source of social contact (Mental Health Foundation, 2002). Retiring from a service can have a large impact on an individual's social network. The health of older family carers could also have an impact, for example if they become too frail to accompany the person to activities, or become unable to care for the person, resulting in them moving away from their social network in the local area (Mental Health Foundation, 2002).

Ageing in the general population

Physical and cognitive changes with age. As people grow older, they experience a number of changes. The onset of 'old age', commonly assumed to begin at around 65 years of age, is a time when changes that have been occurring gradually through adulthood become more apparent. There are age-related declines in vision and hearing, and changes in perceptual processes meaning that older people have more difficulty integrating sensory information (Stuart-Hamilton, 2000). In general, older people retain their crystallised intelligence, or knowledge, but show a decline in fluid intelligence, having more difficulty processing information quickly and solving novel problems (Rabbitt et al., 2004; Singer et al., 2003). There is also a decline in memory in later-life (Stuart-Hamilton, 2000), particularly in working and episodic memory (Marcoen, Coleman & O'Hanlon, 2007). Many people manage to adapt to age-related changes, and maintain a relatively high level of wellbeing despite the challenges they face (Marcoen, Coleman & O'Hanlon, 2007).

Successful ageing. Bowling (2005) summarises some of the definitions of 'successful' ageing, which have included concepts such as achieving social, psychological and physical wellbeing, and being able to adapt to meet the challenges of later-life. If successful ageing is based on dominant norms including criteria such as the absence of disability, or high cognitive capacity, people with disabilities could be excluded from the possibility of successful ageing (Bigby, 2004). According to Bowling (2005), older people include social activities, interests and goals in their definition of successful ageing. Bowling (2005) found that the majority of people reported that they had good quality of life in old age. They identified enjoyable things about getting older such as independence and freedom, as well as disadvantages such as worsening health resulting in loss of independence. Bowling found that older people's perception of quality of life was similar to that of younger people, but older people experienced more challenges in

life, such as bereavement, health problems and reduced income, which affected their priorities. Bowling concluded that the main components of quality of life are: an optimistic outlook and psychological wellbeing, good health and physical functioning, good social relationships, maintaining social roles, living in a safe community with good services and transport, adequate income, independence and control.

Developmental challenges associated with ageing. Development and ageing can be thought of as co-occurring and interacting processes of change (Marcoen, Coleman & O'Hanlon, 2007). A dominant theory of human development is Erikson's (1973) eight stages of life, with a different conflict predominant at each stage. The stage relevant to later-life is integrity versus despair, where the growing awareness of closeness to death brings an evaluation with a struggle between integrity, a sense that life has been meaningful and goals have been achieved, and despair, a sense that life has been meaningless and it is too late to explore other routes to integrity.

There are developmental shifts associated with ageing. As well as experiencing physical changes in appearance and capabilities, older people typically experience changes in their social roles. Hendry and Kloep (2002) describe human development in terms of a series of developmental challenges. In late adulthood people experience a normative maturational shift as their bodies gradually change, for example diminishing physical strength and changing appearance. Another maturational shift for women is the menopause. Becoming a grandparent can be considered a quasi-normative shift as it occurs for a majority of people within the age range of late adulthood. There is another normative shift on reaching pensionable age, and many people experience the major change of retirement. Depending on the individual, this could be a pleasant experience bringing freedom and opportunities, or could lead to difficulty adjusting and psychological problems as a result of no longer feeling useful (Hendry & Kloep, 2002; Stuart-Hamilton, 2000). Leaving work can have associated effects such as financial changes, and loss of structure and social networks which may impact on wellbeing. However, retirement does not necessarily lead to a lack of engagement, and can succeed if the individual continues with their social roles and replaces work with activities relevant to their personal goals (Kunemund & Kolland, 2007).

Thompson (1993) suggests that the literature has focused on pathological ageing and neglected people's ordinary experiences, which are particularly diverse once the structure of

their life is no longer dictated by work. He reports the findings of 55 life story interviews with people aged over 60. The participants did not feel old, instead they felt that they were continuing an ongoing process of development. Thompson identified four main areas in which the participants found meaning. The first area was work. Some people continue to seek work, others maintain work habits such as getting up early or dressing smartly. Thompson reported that women were more likely to have retirement issues around the loss of their caring roles. The second area identified was leisure where there was a large degree of diversity, with some people having few activities, some maintaining old activities and some taking up new ones. In the third area of grandparenting, Thompson identified pleasure at becoming a grandparent, although an active role as grandparent is not automatic, but depends on the relationship with children. In the final area, intimate relationships, adjustments have to be made with changes such as retirement, and there may be a loss of some intimate relationships. Thompson emphasises that old age is a time of constant reconstruction and that becoming 'old' doesn't change people, instead it is the turning points such as retirement and how people respond to these challenges that are important.

Social networks in old age. Changes in social networks can be expected in later-life. Older people are likely to experience the loss of a spouse, friends or relatives. Older people seem to adjust better to being widowed, perhaps because it becomes more of a normative event (Askham, Ferring & Lamura, 2007; Hendry & Kloep, 2002). Family relationships are an important source of emotional and practical support (Askham, Ferring & Lamura, 2007; Hendry & Kloep, 2002). Friendship remains an important part of older people's lives, with friends taking supportive roles and neighbours playing a meaningful role (Askham, Ferring & Lamura, 2007). Although social networks tend to decrease in size as people reach old age, contact with closer friends is maintained and older people tend to be contented with their friendships (Askham, Ferring & Lamura, 2007; Lang & Carstensen, 1994).

Identity

One aim of this study is to explore what meaning ageing has for participants' identity. This section presents a summary of literature on ageing and identity in the general population followed by consideration of identity for people with learning disabilities in general, and older people with learning disabilities.

Ageing and identity in the general population

People use narrative memory and life story formation as a way to find meaning in their lives, and understand themselves as an individual in the context of their environment and life stage. The ability to construct narratives is at the centre of identity formation, and changes and evolves across different stages of the life span (McAdams, 2001; Singer, 2004). McAdams (2001) suggests that identity takes the form of an internalised life story, influenced by the person themselves and their cultural context. The life story integrates different roles and relationships across time to give the identity a sense of unity and purpose.

Troll and Skaff (1997) found that people maintain a coherent sense of self across time, with older adults over 85 years old feeling that they are the same person they have always been. Participants perceived changes in some of their characteristics, but these were largely positive and seemed to be incorporated into a sense of personal history.

According to Westerhof and Tulle (2007), older people identify both positive and negative aspects of ageing, and hold different age identities in different areas, such as physical functioning and social functioning. Health and fitness become more important to the way people perceive themselves in older age, and negative aspects of ageing tend to be identified in the physical domain, such as loss of mobility, whereas positive aspects tend to be social, such as relationships with grandchildren and fewer responsibilities (Westerhof & Tulle, 2007). In general, people tend to feel younger than their actual age (Kleinspehn-Ammerlahn, Kotter-Gruhn & Smith, 2008). Biggs (2005) suggests that self-perception in old age is not straightforward and there may be differences between how old someone looks, feels, and wants to be.

Ageing occurs within a social context, and the dominant discourses around ageing are largely negative, with old age typically portrayed in a stereotypical and negative way. Older people are likely to experience ageism, discrimination based on their chronological age (Blytheway, 1995; Whitbourne & Whitbourne, 2011). Westerhof and Tulle (2007) suggest that identifying with a younger age that is more valued by society may be a way to preserve self-esteem. This becomes more difficult when the functioning and appearance of the body are affected by ageing. One way to manage this would be to distance the self from the ageing body, and Featherstone and Hepworth (1991) suggest that in later-life there is a discrepancy between

the youthful inner self, and the ageing exterior which is seen by others and can be thought of as a mask of ageing. Bullington (2006) interviewed thirteen people aged between 63 and 82 in a phenomenological study of the ageing body and identity, and found that some participants disliked their ageing body and viewed it as a surface seen by others, not as a reflection of themselves. Bullington's participants reported that their bodies were a reminder that they were getting older. Some were trying to feel at home in their new situation by making the best of it, finding new goals, or lowering their level of ambition to make do with what they were able to achieve. Some were able to come to terms with the changes in their body, others gave a sense of a battle with their body, limiting them with its reduced strength. The ageing body and limitations didn't necessarily result in a negative sense of self, respondents had different ways of finding meaning in their ageing bodies. Some found that their changed appearance affected their self-perception, whereas for others it held no importance.

The changes that occur in ageing can threaten the sense of self, and according to Identity Process Theory, people maintain a dynamic balance between their sense of self and their experiences using a combination of processes (Sneed & Whitbourne, 2003). Identity assimilation involves interpreting experiences in terms of the schemas held about the self, and maintains a sense of self-consistency. Identity accommodation involves changing the identity in response to new experiences. Experiences that do not fit with the identity are first processed using identity assimilation, and if this is unsuccessful then identity accommodation is used. Finding a balance between identity assimilation and accommodation allows changes to be made when the identity is challenged while still maintaining a consistent sense of self. This is associated with successful adaptation to the changes of ageing (Sneed & Whitbourne, 2003).

Identity and people with learning disabilities

Beart (2005) argues that many people with learning disabilities do not see the label of learning disabilities as salient to their identity, partly because of confusion over the definition of the term, and partly because of the emotional impact of the label. However, despite this lack of salience to some individuals, the label of learning disabilities powerfully influences how an individual is viewed, leading to negative perceptions and stigma, and can determine access to services and opportunities, affect people's treatment through diagnostic overshadowing, and over-ride other aspects of identity (Beart, Hardy & Buchan, 2005).

People define and evaluate themselves in terms of the social comparisons available to them (Festinger, 1954) and the social groups they belong to (Tajfel, 1978). It has been found that self-comparison plays an important role in the self-esteem of people with learning disabilities (Crabtree and Rutland, 2001), with strategies including making downward comparisons to compare the self favourably with people who are less able, and making lateral comparisons emphasising similarity to people without learning disabilities helping to maintain self-esteem (Dagnan & Sandhu, 1999; Finlay & Lyons, 2000). As older people in the general population seem to engage in self-enhancing social comparisons (Rickabaugh & Tomlinson-Keasey, 1997; Sherrard, 1998), it seems reasonable to assume that the findings of studies such as Finlay and Lyons (2000) could be applicable to older people with learning disabilities although the studies have not focused on older people specifically.

Finlay and Lyons (2000) make the point that someone who may seem to observers to have a stigmatised identity may not actually experience their identity in this way. The stigmatised identity depends on a certain set of comparisons being made, and the individual may view different comparison dimensions as salient, and make a different set of comparisons that are more useful to them and represent them in a more positive way.

Identity and old age in people with learning disabilities

Life story work helps develop understanding of past life events and contributes to a sense of identity (Atkinson 2005), linking back to the idea of identity as a narrative (McAdams, 2001). A life story research project (Hamilton & Atkinson, 2009) collected the life stories of people with learning disabilities over the age of 60. Their narratives included perceived deficiencies and being labelled as having a learning disability with resulting exclusion from family and community life, and placement in institutional settings. The stories included examples of both resistance to and compliance with institutional life, with details of people's struggles in difficult living conditions as well as examples of kindness and positive interactions.

Brown, Dodd and Vetere (2009) carried out a narrative analysis of the life stories of six older people with Down's syndrome. They point out a lack of research into identity in this population. This group has lived through changes such as the closure of institutions and exploring their experience gives us an insight into how the historical, social and cultural context has influenced their sense of themselves.

The group of people with learning disabilities who are currently in old age have lived through immense changes in learning disability services, as well as changes in the way people with learning disabilities are labelled and viewed by society. People currently in their 60s or older would have grown up during a time when large numbers of people with learning disabilities were housed in institutions, which became long-stay hospitals when the NHS was established in 1948. Following the 1913 Mental Deficiency Act there was an emphasis on segregation and control of people with learning disabilities intended both to protect them and to protect society from them (Fido & Potts, 1997; Welshman, 2006). The institutions also admitted “moral defectives”, people who challenged society’s view of correct behaviour but may not have had a learning disability by today’s definition (Fido & Potts, 1997; Walmsley, 1997; Welshman, 2006). Institutions commonly housed large numbers of people in dormitory style accommodation segregated by gender (Stevens, 1997). Many residents worked within the institution carrying out tasks essential to the running of the institution such as maintenance, gardening and laundry (Mitchell, 2000). Some people have shared their memories of life in institutions, which include accounts of hard work, with little privacy for residents, little choice or autonomy and in some cases, experiences of abuse (Andrews, 2000; Barron, 2000; Cooper, 1997; Cooper, Ferris, Coventry & Atkinson, 2000). Some older people with learning disabilities will not have had any access to education when they were young, as many were deemed “ineducable” and excluded from school, while some others were placed in special schools. This was addressed when the 1970 Education Act gave all children the right to an education, but people with learning disabilities who are now over 60 will have missed out on this provision (Welshman, 2006). Around the same time there was a shift towards community care, shown by the 1971 white paper “Better Services for the Mentally Handicapped” which reflected changing attitudes to learning disabilities and advocated a large reduction in hospital places. This resulted in large numbers of people leaving long stay hospitals in the 1980s and 1990s, a process referred to as deinstitutionalisation (Walmsley, 2006). The philosophy of services for people with learning disabilities shifted to incorporate the principles of normalisation (Wolfensberger, 1972) and later Social Role Valorisation (Wolfensberger, 1983), with a recognition that people with learning disabilities have a right to be treated as individuals, to participate in their community and hold valued social roles. Service provision has moved towards people with learning disabilities living in small group homes or taking on supported living tenancies, with community based day services providing leisure activities and skill training (Walmsley, 2006). There is now a focus on the key principles of rights, independence, choice and inclusion as set out in the 2001 white paper “Valuing People” (DoH, 2001b). This

historical context will have had a large impact on people's experiences, so the experiences of people who are currently older may differ from the experiences of people who reach old age in future, having grown up with very different services.

Brown, Dodd and Vetere (2009) included people aged over 50 with relatively good language skills. They used a semi-structured interview format, using open-ended questions along with some more concrete questions relating to participants' current life. The narrative themes that emerged were: loss, abuse while in long-stay hospitals, transition between different homes, health, attachment figures, resilience and identity. None of the participants talked about themselves in terms of having Down's syndrome, or being old. Instead people talked about themselves in relation to gender, social roles, physical characteristics and personal strengths and difficulties. Participants were asked about whether they were the same or different to other people, and half of them were able to compare themselves to others using factors such as age and physical attributes. The findings of this study corresponded with the idea that many people with learning disabilities do not identify with the label as part of their social identity (Beart, 2005). The label of 'old' also appeared not to be salient, although the participants were aged between 50 and 56, which is at the young end of 'older' and it would be interesting to see whether this finding would have remained if older participants had been included.

How might ageing for people with learning disabilities differ from the general population?

Many aspects of old age are shared between people with learning disabilities and the general population. However there are some potential differences that make it worthwhile studying the experiences of people with learning disabilities specifically. Marshak, Seligman and Prezant (1999) suggest that people who have grown up with disabilities may lack some of the resources that other older people are able to draw on, as their opportunities for developing such resources have been limited. However, they also point out that people with disabilities may already have come to terms with some problems that other people face for the first time in old age, such as a loss of power and independence. This argument was based on people with disabilities in general but seems applicable to people with learning disabilities as they face a lack of opportunities and loss of power in common with people with other types of disability, with the added difficulty of cognitive impairment. People age within the context of their environment, and this can have different implications for people with learning disabilities in comparison to the general population. Older people in the general population tend to have an

informal support network including neighbours, extended family and contacts from community or religious groups, whereas people with learning disabilities are less likely to have spouses and children or to have built up reciprocal support relationships with neighbours over time. As a result they may be more reliant on formal services for support (Bigby, 2004). People with learning disabilities may also receive less formal support as they grow older if they fall between the remit of specialist learning disability services, and services for older adults. The wider environment in terms of policy and culture can also affect people with learning disabilities differently, as they will be affected by policy relevant to people with disabilities as well as that relating to older adults. Adjustment to changes in old age is affected by factors such as whether retirement is voluntary (Kimmel, 1990), and the extent of planning for residential transitions (Heller & Factor, 1994), and this choice and planning is less likely to be available to people with learning disabilities (Bigby, Wilson, Balandin & Stancliffe, 2011; McDermott & Edwards, 2012).

Attitudes towards older people with learning disabilities

The principle of normalisation suggests that people with learning disabilities should be able to have similar life experiences to their peers in the general population. This assumes that these 'normal' experiences are desirable, when in fact life experiences for older people may be restricted by society's attitudes to ageing (Walker & Walker, 1998a; Walker & Walker, 1998b). Older people with learning disabilities may be viewed as being in double jeopardy, as they may experience the effects of stigma related to learning disabilities as well as negative societal attitudes towards old age (Bigby, 2004). Walker and Walker (1998b) found that care workers treat older and younger people with learning disabilities differently and have different expectations of their abilities. They found that service providers tended to overstate levels of dependency for older people, concentrating on the need for care, rather than supporting them in independent living as they did for younger people. Care staff felt it was less important to help older people develop new skills or maintain existing skills. Workers with the older group were less likely than those working with the younger group to think they were capable of learning a new skill, although the older group was actually more able than the younger group (Walker & Walker, 1998b). Care workers tended to report that older people prefer indoor activities whereas younger people enjoy going out. Older service users reported that they enjoy a mixture of activities inside and outside the home, and complained they could not go out as often as they would like. Older people in the study were twice as likely as younger

people to have no regular structured activities outside the home, and to take part in fewer regular organised activities overall (Walker & Walker, 1998b). Many care workers assumed that older people have more sedentary lives, and thought that less effort was necessary in developing activities for older people. Walker and Walker (1998a) suggest that this assumption may become self-fulfilling and lead to disengagement. This has important implications for service provision for older people with learning disabilities. Family carers did not show the same age discriminatory attitudes, possibly because of a different construction of old age between formal and informal care relationships, and more reliance on a chronological definition of old age in services.

Conceptualisation of old age among people with learning disabilities

Lifshitz (2002) investigated cognitive, affective and behavioural components of attitudes towards old age in people with learning disabilities. The sample comprised 32 people with learning disabilities: 12 young people, 16 middle-aged people and 4 elderly people. The small sample of elderly people is a limitation of this study. Participants used mostly concrete and physical characteristics to define an old person. All the younger participants used negative characteristics in their definition, compared to around two-thirds of the middle-aged participants and only a third of older participants. Most participants were able to arrange pictures of people of different ages in age order, with all of the elderly participants doing this correctly. Around a third of the participants aged over 60 defined themselves as elderly. When asked whether they wanted to be an old person, the majority of the young and middle-aged participants gave negative answers whereas all of the older participants gave neutral answers. Lifshitz concluded that people with learning disabilities are influenced by stereotypes in the way they view old age, and focus on physical and practical aspects of old age. Old people were generally seen in a negative way although awareness of positive aspects of ageing was greater among older participants. Lifshitz concluded that the stereotypical view of old age can be understood in the context of social identity theory (Tajfel 1978), suggesting that negative intergroup attitudes may develop as people tend to assign people to age groups based on physical appearance and may underestimate variability within age groups and overestimate differences between groups.

Erickson, Krauss and Seltzer (1989) interviewed 47 people with learning disabilities with an average age of 62 to find out about their perceptions of old age. They carried out a content

analysis of responses and identified six categories of perceptions of old age. The most common categories were anticipated physical health changes, and general acknowledgement of one's own ageing, including some expressed desires to be young again. Further categories were anticipated work-related changes, anticipated social life changes and denial of ageing, for example participants saying that they are not old yet. The final category identified was associations with death, which included references to the death of others and awareness of participants own mortality. Participants in the study were able to consider ageing in terms of how it would affect their life in a range of domains, and their conceptualisation of ageing seemed more rounded than the stereotypical and largely physical view presented by Lifshitz (2002). This could be because Erickson et al.'s (1989) participants were older adults, and Lifshitz (2002) suggests that older people have a more balanced view of ageing than younger people. Alternatively, the difference may be due to variation in the style of questioning between the two studies.

The experience of ageing and old age in people with learning disabilities

Bigby (1997) interviewed older people with learning disabilities who had left parental care after 40 years of age, as well as informants with close long-term relationships to the people concerned, and service providers. She found that people had experienced personal development in later-life. They had greater control over their everyday lives, and participated in new activities, facilitating development of skills and friendships. After leaving parental care, participants experienced different attitudes from others, being treated as adults rather than children, and given more freedom and control. Some people had been sharing their parents aged lifestyle, or caring for their parents, and leaving the parental home changed this and provided new opportunities. Bigby (1997) found that these opportunities in later-life were balanced by vulnerabilities. People often left the local area they had lived in, and lost contact with the local community. Over half of the participants retired from their day-centres, often at the suggestion of services rather than by choice. Friendships are often context specific, so losing services leaves people vulnerable to losing their social contacts. Bigby (1997) found that as people aged they often lost their key advocate from their informal network, and became more likely to live in larger accommodation, often provided for older people rather than people with learning disabilities. These environments were often criticised for fostering dependence and not providing sufficient stimulation, as staff were not attuned to the needs of people with learning disabilities. Being older was a barrier to accessing specialist learning

disability services in some cases. Bigby (1997) noted that many of the losses people experienced could be avoided by providing more flexible services, and considering the effect of changes in service on the individual's social networks.

Thompson (2002) also found that the majority of difficulties for older people with learning disabilities were related to the support they received rather than ageing itself. Thompson used questionnaires to collect information about 161 people with learning disabilities aged over 40. Participants generally felt positive about their living situation, although they were least positive about living in large residential services. Living with friends and having contact with family were both valued. Participants were generally positive about their day-services although carers were more critical and the amount of access to services varied. Day-services had changed or ended for some people either because of person-centred planning or through being excluded by service age limits. More than two thirds of respondents mentioned physical and emotional aspects of ageing, including slowing down and feeling sad about being older, but the wording of responses suggested that participants needed help from carers to do this. About a fifth of respondents mentioned the death of friends or family. Thompson (2002) suggested that change is a difficult concept for some people with learning disabilities, but respondents to the study were able to identify ways that their lives had changed as they got older. This study provided useful information about older people with learning disabilities' opinions of their lives in old age, but it was not able to provide an in-depth exploration of participants' experiences as responses were questionnaire based. Some respondents were assisted to complete the questionnaire by carers, raising questions over whether some responses were the participants' own views or those of their carer.

Buys et al. (2008) conducted semi-structured interviews with 16 people with learning disabilities aged between 52 and 80. They explored participants' experiences of older age and expectations for the future to find out about the meaning of active ageing for this group. Analysis of participants' accounts followed an inductive process, using a constant comparative process involving developing, comparing and regrouping categories. Eight key categories seemed important in active ageing: Being empowered, including being involved in decision making, having a meaningful role and feeling valued; Being actively involved, working or engaging in meaningful activities; Having a sense of security, including financial security, emotional needs being met, and feeling secure in their environment; Maintaining skills and learning; Having congenial living arrangements; Having optimal health and fitness; Being safe

and feeling safe; Having satisfying relationships and support. This study suggested that while people with learning disabilities want the same things from older age as the rest of the population, their ability to achieve this may be impeded by a lack of appropriate support. This paper provided a useful insight into how people with learning disabilities experience old age, and identified some of the changes that they had experienced in recent years. However they did not cover how participants experienced and made sense of the process of growing older. Buys et al. (2008) note that the majority of their participants were in their fifties and sixties, and it would be interesting to know whether the experiences of people in their fifties, who could be considered relatively young, differed from the experiences of older people.

Studies to date have focused on what people with learning disabilities like and dislike about their life, and how their situation has changed with age. This is important to help services maximise people's opportunities in later-life, and minimise vulnerabilities which are often related to inflexible service provision, and other people's attitudes. Less attention has been paid to how people with learning disabilities experience and make sense of changes in themselves and their environment. Lloyd, Kalsy and Gatherer (2007) conducted the first published study of the subjective experience of people with Down's Syndrome living with dementia. They conducted semi-structured interviews with six people with Down's Syndrome. Participants were aged between 49 and 59 and met the diagnostic criteria for Alzheimer's Disease. Interviews covered participants' perception of their current life situation, changes they experienced as they grew older, their perception of ageing as a concept, life satisfaction and views about the future. Participants' accounts were analysed using Interpretative Phenomenological Analysis (IPA). They found five themes, the first being self-image. People tended to perceive roles and jobs as defining factors in their self-image. Jobs were seen as signs of independence and usefulness which may be threatened as dementia progresses. The second theme was the relational self. It was important to people to maintain consistent attachments, and staff often took the place of family and friends. An increasing need for assistance from others conflicted with the need to maintain their self-image as independent. The third theme concerned making sense of decline. Participants acknowledged some level of decline either explicitly or implicitly. There was a sense of physical slowing, and a perception of growing old. Some people had a passive and accepting attitude to decline or change, and a few were reluctant to accept the process of growing older. Some participants did not feel old, and in fact some of them would not be considered old in the general population. The fourth theme involved coping strategies. Strategies were not explicitly described, but participants mentioned

minimisation of difficulties, maintaining a routine and keeping active. The final theme identified was emotional expression. Participants showed a limited ability to express their emotional reaction to dementia related changes, but some gave a clear indication of distress. One person expressed fears about ageing and a generalised sense of loss was present in several accounts. This study provided a useful insight into the subjective experience of ageing for people with dementia and Down's syndrome. Participants in this study were all under 60, so the findings may not reflect the experiences of older people. There remains a gap in the literature on the experience of ageing for older people with learning disabilities who do not have dementia.

Jenkins (2010) attempted to use IPA to understand how people with learning disabilities view the ageing process. Jenkins collected case studies on six older people with learning disabilities which included inviting them to give their views on the ageing process, as part of a study into nursing's role in meeting the healthcare needs of older people with learning disabilities. Only two participants were able to express their views verbally. The paper gives very little information on the interview process and how data was analysed. Jenkins states that in-depth discussion of age-related physical changes was difficult. Very little information is given on participants' accounts and how the principles of IPA were applied. Given the authors statement on the difficulty of achieving any in-depth discussion it is not clear that the interview data was rich enough to conduct a meaningful analysis. Jenkins drew a tentative conclusion that the transition to old age might be less difficult for people with learning disabilities as they are already accustomed to having a label which brings discrimination, having limited opportunities, and dealing with cognitive difficulties. Jenkins argues that having had difficulties throughout their life, people with learning disabilities may have less to lose through ageing and the impact of old age may be lessened. It was not clear how these conclusions were grounded in participants' accounts.

How does this study aim to add to the literature?

While studies such as Buys et al. (2008) and Thompson (2002) have begun to investigate the experience of old age for people with learning disabilities, there has been a focus on determining the factors that seem to be important to people's experience of old age rather than on the nature of the experience itself. The contribution of current studies to understanding the experience of old age has also been compromised by the fact that they

have included participants aged over 40 (Lloyd, Kalsy & Gatherer, 2007; Thompson, 2002) or 50 (Buys et al., 2008) so the experiences of older people have been combined with those of middle-aged people. I hope to address this by looking at the experiences of people aged over 60. Other studies have explored how people with learning disabilities conceptualise old age (Erickson, Krauss & Seltzer 1989; Lifshitz, 2002), but have not linked this to a detailed exploration of their own ageing process. Jenkins (2010) attempted to take a phenomenological approach to exploring older people with learning disabilities' views of ageing but the study did not successfully capture how participants viewed and experienced ageing. Lloyd, Kalsy and Gatherer (2007) used IPA to look at people's experiences of old age and how they made sense of the experienced changes, but this was limited to people with Down's Syndrome and dementia. There is a lack of work exploring the subjective experience of ageing for people with learning disabilities, taking into account their perceptions of the concept of ageing, how they experience and make sense of their own ageing process, and what meaning this has for their identity. This study aims to fill this gap in the literature, and create knowledge that will be useful for health professionals working with and planning services for older people with learning disabilities.

Research aims

The aim of this research is to find out about the subjective experience of ageing for older people with learning disabilities. It will explore their experience of the ageing process: experience of their current life situation, their perception of the concept of ageing, what changes they have noticed as they have grown older, what sense they make of these changes, and what meaning the changes have in terms of their identity.

Research questions

This study aims to answer three research questions:

- How do people with learning disabilities experience the ageing process and old age?
- How do people with learning disabilities make sense of the ageing process?
- What meaning does the ageing process have for people in terms of their identity?

METHOD

This chapter introduces the rationale for the method used in this study. Each stage of the study is explained, with discussion of the ethical considerations. The chapter ends with a reflexive statement explaining my position in relation to this study.

Rationale for the use of Interpretative Phenomenological Analysis

Rationale for using a qualitative method

The research questions that form the basis of this study are concerned with understanding how participants experience and make sense of the ageing process. Qualitative research methods are suited to looking at how people experience events and make sense of the world. They aim to explore and describe participants' experiences (Willig, 2008). The aim of the study was to explore rather than quantify participants' perceptions and experiences, so it was clear that a qualitative approach would be most suitable.

Selecting the most appropriate method

I explored a number of methods of analysis before choosing one and will briefly summarise these. Grounded theory involves identifying and integrating categories of meaning from data to understand a phenomenon. It is more suitable for use in explaining social processes, rather than exploring the nature of experience (Willig, 2008). The grounded theory method could be used to map the categories of concepts that people use to make sense of their experiences of ageing, to understand the structure of their experience (Willig, 2008). However grounded theory is geared towards the development of theory, and as I aimed to describe people's experiences rather than explain them, a phenomenological approach seemed more appropriate.

People's experiences are likely to be influenced by how the concept of ageing is constructed. Discursive Psychology and Foucauldian Discourse Analysis (FDA) are both concerned with the role of language in the construction of social reality. Discursive Psychology looks at how people use their discursive resources to achieve interpersonal aims, and how particular versions of reality are produced through the use of language (Willig, 2008). This did not seem to fit with

my research questions. FDA considers the relationship between discourse and how people feel and act (Willig, 2008). I could have used FDA to look at how older people with learning disabilities construct meaning in relation to ageing, and how different discourses about ageing affect participants' experiences. However my main interest lies in how people experience ageing, rather than how this experience is affected by discourses, and so Interpretative Phenomenological Analysis seemed to be the most appropriate method to use.

Interpretative Phenomenological Analysis (IPA)

IPA looks at how people make sense of their world, by examining the meanings that experiences hold for them. IPA is informed by phenomenology, the study of experience, and focuses on lived experience, attempting to capture what an experience is like (Smith, Flowers & Larkin, 2009; Smith & Osborn, 2008). IPA researchers explore the participant's lived experience in detail, and are interested in how each person perceives an event, rather than trying to produce an objective description of the event. IPA is underpinned by hermeneutics, the theory of interpretation. IPA acknowledges that it is impossible to directly access the participant's experience, and that the researcher brings their own view of the world to the process (Willig, 2008). IPA researchers are interested in how participants make meaning out of their experiences. IPA involves a 'double hermeneutic' (Smith, Flowers & Larkin, 2009; Smith & Osborn, 2008), as the participant is interpreting and making sense of their own experience, and through analysis the researcher is attempting to make sense of the participant's account, adding a second layer of interpretation. IPA seemed to be the method that would best suit my research. There is a gap in the literature for a study exploring what getting older is like for people with learning disabilities, and what meaning they make of the changes they experience. IPA allowed me to explore how people experience ageing, their reflections on what is happening to them and how they make sense of the ageing process.

Ethical approval

Ethical approval was granted by Leeds Central Research Ethics Committee. A copy of the approval letter is shown in Appendix A. Approval was also granted by the Research and Development Department of Leeds Partnerships Foundation Trust and South West Yorkshire Mental Health Trust. The research was approved by Leeds, Wakefield and Kirklees Councils to enable recruitment through council-run day-services. The approval letter for Leeds Partnerships

Foundation Trust is shown in Appendix A. The other organisations were not used in the recruitment process.

Sample and recruitment

Sample size

IPA uses small sample sizes as it involves detailed case-by-case analysis. Five or six participants has been suggested as reasonable for student projects (Smith & Osborn, 2008), and four to ten for professional doctorates (Smith, Flowers & Larkin, 2009). Clinical psychology postgraduate programmes have converged on six to eight as a suitable number of participants for an IPA study (Turpin et al., 1997). On this basis I planned to aim for eight participants. I actually recruited seven participants, but interviewed two of them twice to produce a total of nine interviews.

Inclusion and exclusion criteria

The main inclusion criteria were that participants must have a learning disability and be over the age of 60. Earlier research involving older people with learning disabilities has used participants as young as 40, but there is a trend towards using the more conventional age of 60 to counter the stereotype of premature ageing in people with learning disabilities (Bigby, 2004). Including participants younger than 60 would risk mixing the experiences of older people with the experiences of middle-aged people. An age limit of 60 seemed reasonable as it would allow me to explore experiences of old age while also being feasible in terms of recruitment.

The focus of this study was experiences of healthy ageing so I excluded anyone with a diagnosis of dementia. Due to the method chosen, it was necessary for participants to be able to take part in an in-depth interview. This required a certain level of verbal communication, which unfortunately meant that people with severe learning disabilities could not be included. The decision about whether participants were included or not was made on the basis of recruiters' opinion of their ability to make an informed decision to participate and ability to take part in an interview rather than on their diagnosed level of learning disability.

Recruitment process

I contacted Community Learning Disability Teams (CLDTs) and day-services for people with learning disabilities, and provided them with information about the study, shown in Appendix B. I asked them to discuss the study information with any suitable service users. After finding out from the services whether any service users were interested in taking part, I made arrangements through the services to meet with potential participants to give them more information about the study.

Contact with CLDTs identified a total of thirteen possible participants. I contacted the staff involved to explain more about the study and to arrange to meet the participants if appropriate.

Of these thirteen:

- Six were accepted as participants
- One was found to be under 60 years old
- Two had no current involvement with the CLDT and staff were unsure whether they would be interested or suitable
- Two were not currently able to participate due to physical ill-health
- Two people took part in a meeting to discuss the study, along with a worker from the CLDT, but did not have sufficient understanding of the study to give informed consent. They were therefore not used as participants

Contact with a day-service for people with learning disabilities identified four possible participants and I met with them as a group to discuss the study. Two people did not seem to have sufficient understanding of the study to give informed consent. Two people understood the study, but one of them did not wish to take part. One person was keen to take in the study and was accepted as a participant. This gave a total of seven participants.

IPA studies benefit from a relatively homogenous sample, as using a group of participants who are fairly similar in terms of social situation and other factors relevant to the topic of the study allows a detailed examination of the variety in the way they experience the phenomenon in question (Smith, Flowers & Larkin, 2009). Achievement of a perfectly homogenous sample is limited by practical factors. The participants used in this study were all over the age of 60,

appeared to have mild to moderate learning disabilities and were in contact with learning disability services. All participants lived in settings where they were supported by staff to a greater or lesser degree. This seemed to be a sufficiently homogenous sample given the limitations of recruiting from a limited population through third party recruiters.

Ethical considerations: Consent

Obtaining informed consent to participate in research can present ethical challenges when working with people with learning disabilities (Cameron & Murphy, 2006), and it is important for researchers to overcome this barrier to obtain information from people with learning disabilities (Finlay & Lyons, 2001). It was important to ensure that participants had capacity to decide whether to participate in the study. The concept of capacity is important in protecting vulnerable people from harm, while protecting people's right to make decisions (Dye, Hendy, Hare & Burton, 2004). In order to decide whether to participate, participants needed to understand and retain certain information about the study, such as what it would involve and the risks and benefits of taking part. They also needed to weigh the information up to reach a decision, and communicate their decision (DoH, 2001c; Department for Constitutional Affairs, 2007).

It is important to provide information in a form that the person can understand, and their understanding should be checked (DoH, 2001c). Cameron and Murphy (2006) emphasise the importance of providing accessible information as part of the recruitment and consent process, with a face-to-face explanation to gauge participants' response to the information. They recommend that researchers allow increased time for the consent process, and ensure that information sheets and consent procedures are adapted appropriately. I worked with a Service User Involvement Group to develop an accessible information sheet (Appendix C). I met with each participant to go through the information sheet and answer their questions. I asked participants to tell me about the information I had provided to ensure that they had been able to understand, retain and use the information to reach a decision.

In order for consent to be valid the person must be acting voluntarily, not making a decision under pressure (DoH, 2001c). The information sheet made it clear that participation in the study was voluntary, and participants' care would not be affected if they chose not to take part. I gave participants at least a week to think about the information, before visiting again to

recap the information sheet and give them the consent form. The consent form, shown in Appendix D asked participants to communicate their decision by ticking yes or no to taking part in the study.

Data collection

Rationale for the use of semi-structured interviews

IPA requires a rich and detailed account of participant experiences, and this is usually gained by interview, although other methods such as focus groups are sometimes used (Smith, Flowers & Larkin, 2009). I chose to use interviews to collect data as I felt that this would enable me to build up a good rapport with participants and ensure that each participant was given sufficient time and support to articulate their experiences to the best of their ability. This seemed particularly important as I was aware that some participants may have communication difficulties and may need additional support and time to understand the questions and to respond. Semi-structured interviews are often used in IPA studies (Reid, Flowers & Larkin, 2005). I chose to use semi-structured interviews to achieve a balance between structuring the interviews beforehand and allowing participants to take the lead in focusing on the areas they felt were important. Using semi-structured interviews enabled me to ensure that interviews covered topics which seemed likely to be of interest, and enabled me to word questions and prompts carefully to make them accessible to participants.

Design of interview guide

I designed an interview guide based on topics of interest that had arisen from my literature review. The interview guide is shown in Appendix E. I used open ended questions, beginning with a general question about what getting older meant to participants before moving on to questions about participants' own experiences. I included a number of prompts for each question to be used if participants struggled with the open questions. Writing questions in advance of the interview allows them to be carefully constructed to be open and non-directive, but there is also an advantage to incorporating participants' terms and comments into questions during the interview (Willig, 2008). I aimed to strike a balance by having questions and prompts prepared in advance, but adapting them to match participants' vocabulary where appropriate.

I discussed the interview guide with a Service User Involvement Group and with my field supervisor, a Clinical Psychologist experienced in working with people with learning disabilities, and acted on their suggestions to make the wording of questions as accessible as possible. I included an exercise where participants were asked to look at five pictures showing people of varying ages. Male participants were shown pictures of men and females were shown pictures of women. This exercise was intended to make the topic of ageing more concrete for participants as well as giving me additional information on participants' awareness of ageing. I also invited participants to bring their own photographs to the interview. Three participants (Audrey, Frank and Joyce) brought photographs of themselves over the years, which were used to facilitate discussion of changes with age.

Interviews

Participants were given the choice of being interviewed at the University of Leeds with travel expenses paid, or being interviewed in a location of their choice. Most participants chose to be interviewed at home, and one interview was carried out at a day-service. The shortest interview lasted 40 minutes and the longest was 75 minutes with most lasting around an hour. At the end of each interview I discussed with participants whether they felt that they had covered everything they wanted to talk about. For two participants it was clear that there was more to say, so a second interview was arranged. All interviews were recorded on a Dictaphone. Participants were made aware of the Dictaphone and consented to the interview being recorded. Most participants seemed to ignore the Dictaphone once it was recording and it did not appear to affect the interview process. Participants were made aware that the recordings would be stored securely. Participants were also informed that the recordings would be heard by a transcriber, and that the transcriber would keep the information confidential. I made notes after each interview to record my initial impressions of participants' accounts and my reflections on the interview process.

Transcription

I transcribed one interview myself, but due to time constraints it was necessary to employ a professional transcriber to transcribe the rest of the interviews. Transcription produced a verbatim record of the interviews, and captured pauses and non verbal content such as laughter. I checked the accuracy of all of the transcripts by reading them while listening to the

recording. Participants' speech was not always clear and there were a few instances where some words could not be understood from the recording. This was indicated in the transcript by "..." in place of the missing word. This occurrence was not frequent enough to have an adverse effect on the overall quality of the interview data.

Ethical considerations: risk, payment and confidentiality

Risk

The interviews involved discussion of sensitive topics, and I was aware that participants may find this distressing. I used my clinical judgement as a Psychologist in Clinical Training to decide when a topic should not be pursued to avoid causing unnecessary distress to participants. In order to manage the risk of distress to participants I monitored participants for signs of distress, and talked to each participant at the end of the interview to find out how they had found the interview process. I had prepared for potential distress by ensuring that I had contact details for the Samaritans and I was aware of how to make referrals to the Community Learning Disability Team if further support was needed. I was also prepared to support participants in accessing a member of their support staff if needed. In the event, none of the participants reported any distress following the interviews.

Payment

I gave each participant a £15 gift voucher to thank them for taking part in the study. Participants were not made aware of this payment until the end of their involvement so that it did not influence their decision about whether to participate.

Confidentiality

Interview recordings were transferred directly from the Dictaphone on to the University of Leeds' secure drive. Recordings were sent for transcription on an encrypted memory stick which met the University's standards for the encryption of data. The transcriber signed a confidentiality agreement, shown in Appendix F. Each participant was given a pseudonym and identifying information was removed from the interview transcripts. Identifiable information such as participants' names and addresses are in locked storage at the University.

Data analysis

Data analysis was carried out within an IPA framework, following the steps suggested by Smith, Flowers and Larkin (2009) in their guide to carrying out IPA studies. The steps are outlined below with an explanation of how they were applied in this study. An extract of coded transcript is shown in Appendix G.

Step 1: Reading and re-reading. I read each transcript while listening to the interview recording to help me recall the interview experience and get an overall sense of the structure and content of the interview. I then re-read each transcript twice, paragraph by paragraph to immerse myself in the data and engage with the participant's account.

Step 2: Initial noting. On the next reading I began making notes in the left hand margin of the transcript to record my initial impressions and comments on the data. These notes were largely descriptive rather than interpretative, and focused on the relationships and events participants were describing, identifying what was important to the participant and what these things were like for the participant. The initial notes also included some comments at a more conceptual level, for example identifying a sense of powerlessness after noting several instances of decisions being made for the participant and activities being restricted. At this stage I also summarised participants' responses to the exercise using pictures showing people of different ages.

Step 3: Developing emergent themes. At this stage I read through my initial notes and applied a higher level of interpretation to capture the essence of the experience or meaning that was communicated in the transcript and summarised in the initial notes. I found this process difficult at times as taking this step towards interpretation of the data felt as though I was moving away from the participant's account and this felt uncomfortable. I dealt with this by using supervision to check the credibility of my emergent themes, and referring back to methodological texts which recognise that this stage of analysis can be uncomfortable (Smith, Flowers & Larkin, 2009).

Step 4: Searching for connections across emergent themes. This stage involved mapping how the emergent themes fitted together. I did this by printing out the typed list of themes and cutting each theme out. I laid them out on the floor and grouped themes together if they

seemed similar or related. I continued moving the themes around until I was happy that the arrangement reflected how the themes related to each other. It became clear that some themes fitted together as related concepts and it was sometimes possible to identify a super-ordinate theme at a higher level of abstraction. I included a selection of extracts for each emergent theme, making a note of the line number so that I could easily relate themes back to the transcript. I checked the super-ordinate themes against the extracts to ensure that they were grounded in the data and accurately captured the meaning of the extracts.

Step 5: Moving to the next case. The same process was repeated with each transcript. I tried to treat each case separately and keep an open mind to the themes emerging from each transcript. It was inevitable that I would be influenced to some extent by the ideas from previous transcripts, but I tried to minimise this by setting aside my interpretation of previous cases and immersing myself in each new transcript.

Additional step: Focusing on experience. At this stage I realised that I was not ready to move on to the next step of analysis and first I needed to refine my emergent themes. I had taken a break from my research and on my return I was able to take a fresh look at the emergent themes I had identified. I felt that my themes were still too descriptive and concerned with the detail of participants' lives rather than capturing the essence of how participants experienced life as an older person and what meanings the ageing process held for them. I returned to the transcripts and repeated the process of initial noting but this time focusing more on the experiential and meaning making aspects of participants' accounts, in light of the understanding I had developed from the previous analysis. I then repeated the steps three to five. I then felt more satisfied with the themes I had identified for each participant, and ready to move on to the final step.

Step 6: Looking for patterns across cases. I printed the list of themes for each participant, including extracts to illustrate the themes, and looked at all of the themes to gain a sense of the overall picture. I then cut each theme out and laid them out on the floor. This allowed me to cluster the themes together to reflect similarities and related concepts. Some of the themes could be grouped together as examples of a higher order theme. Following this process I was left with a list of master themes for the group. I produced a table showing the super-ordinate and sub-ordinate themes illustrated by extracts.

Quality checks

I was keen to ensure that my themes were credible and remained grounded in participants' accounts. I shared several pages of a coded transcript with another researcher carrying out an IPA study. My colleague reported being able to make sense of my analysis and agreed that the themes I had identified seemed to reflect the participant's experience. I also used supervision to discuss the process of analysis and shared numerous extracts with my supervisor to check the credibility of my coding and emergent themes.

Reflexivity

Reflexivity is important in qualitative research as the researcher shapes the research process and it is necessary to acknowledge the assumptions and beliefs the researcher has brought to the study and how this may have influenced their interpretations. Reflexivity allows the researcher to acknowledge their personal reactions and position in relation to the research (Shaw, 2010; Willig, 2008).

My interest in this research study arose from my work with people with learning disabilities. I have worked with adults with learning disabilities in several services as an Assistant Psychologist and a Psychologist in Clinical Training. As part of my training I have also provided psychological therapy to older adults without learning disabilities. I noted that a large part of this work involved clients' reactions and adjustment to growing older. This made me realise that there had been little mention of ageing in my work with people with learning disabilities. An increasing number of older people with learning disabilities are being seen by Community Learning Disability Teams, but it seemed that age was only mentioned in terms of the risk of developing dementia. This difference in approach between the two types of service sparked an interest in finding out more about ageing for people with learning disabilities. In addition, I was aware that this is a growing area of interest due to the growth in the population of older people with learning disabilities. As a 30 year old woman, I feel far from old age, but I am already aware of physical changes occurring as I grow older.

My own attitudes towards ageing have been shaped by images of ageing in the media, watching family members grow older, and working with older adults in a range of care roles. This has left me with mixed feelings about ageing. On one hand I look forward to later-life as a time of freedom with retirement bringing increased leisure time to spend with loved ones. On

the other hand I have been influenced by negative views of ageing in society, and working with many older people who were experiencing physical health problems and dementia has increased my awareness of the downsides of ageing, and perhaps skewed my perception of the likelihood of encountering these conditions in old age. My own experiences led me to expect that participants would also have been affected by negative stereotypes around ageing, and I wondered whether participants' exposure to images and messages about ageing would be any different to my own.

RESULTS

This chapter sets out the findings of the study. It includes an overview of participant demographics and their responses to the topic of ageing, followed by the phenomenological analysis of participants' accounts. Each participant is introduced with a pen portrait followed by the analysis of their account. The group analysis is then presented, with a description of the super-ordinate themes found across participants' accounts.

Participant demographics

Table 1 - Participant demographics

Pseudonym	Age	Living situation
Audrey	60	Living alone in a flat with visits from support workers, and staff available on site
Frank	81	Residential accommodation
Harry	64	Supported living with 3 other men
Dorothy	74	Residential accommodation
Joyce	68	Residential accommodation
Peter	77	Supported living with 3 other men
William	62	Supported living with 3 other men

References to ageing

Six of the participants were able to talk about what ageing involves in general, not necessarily related to themselves; this included physical changes such as increased pain, going grey,

getting wrinkles, and slowing down, as well as other changes such as being able to retire, becoming forgetful or developing increased tolerance. Only one participant (Dorothy) was not able to say anything about what happens as people get older.

Of these six participants, five described themselves as old, or reported noticing changes related to ageing for example William said *“On account of me being very old I have to hold on to the staff’s hand”*. One participant, Audrey, did not think of herself as old and talked about ageing as something that will happen to her in the future *“Now I can get about more ‘cause I’m only 60 but other people can’t”*. Table 2 shows which participants described themselves as old, noticed changes with age in themselves or others, or referred to their own or other people’s death. Table 3 shows which characteristics participants referred to as part of ageing, including references to their own ageing process and their beliefs about aging in general. This is intended to illustrate participants’ understanding of what happens as people get older.

As part of the interview participants were asked to look at five pictures showing people of a range of ages. Participants were asked to say which of the people looked youngest and oldest, and arrange the pictures in age order. Four participants (Audrey, Joyce, William and Harry) arranged the pictures in an order which matched my own perception. Peter did not take part in this task. Frank chose pictures from the middle of the age range for both oldest and youngest. When asked about his choices his comments were based on the clothes worn by the pictured people. Dorothy also picked pictures from the middle of the age range as youngest and oldest, and she was not able to elaborate on how she had made her decision.

Table 2 - Participants’ references to ageing and death

Participant	Described changes in self with age	Described changes in others with age	Referred to own death	Referred to death of others	Described self as old
Audrey		✓		✓	
Frank	✓	✓			✓
Harry	✓	✓	✓		✓
Dorothy					
Joyce	✓	✓		✓	✓
Peter	✓			✓	✓
William	✓	✓	✓	✓	✓

Table 3 - Characteristics associated with ageing by participants

Participant	Characteristics associated with ageing												
	Loss of mobility	Incontinence	Grey hair	Wrinkles	Pain	Memory loss/forgetfulness	Vulnerability	Sadness/feeling down	Increased patience and understanding	Change in taste or style (music/clothes)	Retirement (voluntary)	Unable to work	Moving towards death
Audrey	✓	✓	✓			✓	✓	✓		✓		✓	
Frank			✓			✓					✓		
Harry				✓					✓	✓			✓
Dorothy													
Joyce					✓			✓			✓		
Peter								✓			✓		
William	✓						✓						✓

Individual analyses

Audrey

Audrey was 60 years old and lived alone in a flat, with weekly visits from support workers and support staff available on site for Audrey to access when necessary. Audrey lived with her family as a child, but went into foster care as a child when her mother became unwell. Audrey lived in a “mental hospital” for a while, and then moved between several hostels and carers. Audrey described a very difficult past with a number of abusive experiences. She moved to England to stay with a sibling over 20 years ago, and then lived in residential care for a while before moving to her current flat a few years ago.

Audrey enjoyed living in her flat and took pride in keeping it clean and tidy. Audrey was an active member of her religious community. She enjoyed helping out at meetings there and had made some good friends through her religion. Audrey also had a wide circle of friends in the local community and saw herself as a sociable person. She enjoyed attending college and was

proud of learning to read and write. Audrey had a close relationship with her brother and sister in law, and missed her other brother who had died. Audrey did not see herself as old. She believed that getting old involves mental and physical deterioration and her view of ageing was based on watching family members getting older.

I visited Audrey at her flat for the interview and we talked for seventy minutes. At the end of the interview we agreed that there was more to cover so I returned for a second interview which lasted an hour. Audrey was friendly and talkative. She was able to give a detailed and coherent picture of her history and her current life. Audrey had clearly had some very difficult experiences in the past but her circumstances have changed for the better over time and my overall sense was that she felt fulfilled by a full and active lifestyle. Audrey had strong negative beliefs about ageing, and saw ageing as something that will happen to her in future but she asserted that she is not old yet.

Table 4 - Individual themes for Audrey

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Life is better now • Growing in confidence • Fulfilment from new experiences and learning new skills • Importance of feeling useful • Valuing independence • Vulnerability and protection • Importance of feeling liked and wanted • Importance of support and companionship • I'm not old yet • Fear of ageing 	<ul style="list-style-type: none"> • Getting older involves deterioration • Fear that life will be less enjoyable in future

Life is better now

Audrey reported feeling happier than she has ever felt before. She described an extremely difficult past with numerous abusive incidents and a lot of sadness. Audrey's life has improved greatly in many ways and this has helped her to feel much happier, although Audrey also felt that psychological therapy had played an important role in enabling her to cope with her past and feel happy.

*"Not a happy person back then. No back then I was never a happy person"
"I'm more happy now than I've ever been"*

Growing in confidence

Audrey described a marked change in herself over time. She has become much more talkative and sociable, and has generally grown in confidence. Audrey was proud of this change. She felt that psychological therapy had enabled the change to take place, but in more recent years she has continued to build her confidence by learning new skills such as learning to read and pushing herself to talk to new people.

*"She's more talkative now than she..than I used to be"
"I didn't used to do it because I used to be a lot shy until I really got into knowing people and then I started helping out"
"Ever since I went to college I've been going into a shop, asking somebody about this and about that but before I went to college I would never do that to anybody"*

Fulfilment from new experiences and learning new skills

Audrey described a sense of fulfilment from learning new skills, and learning to read has also helped her to feel more confident. She seemed open to new experiences and had recently started new courses at college.

*"IT skills, and music on a Friday....I only recently started going on a Friday. 'Cause I wanted to learn how to play all the different instruments"
"They're helping me to read and write at college and that's helped me a lot. That I'll go into a shop now and ask people something"*

Importance of feeling useful

Audrey described helping at Salvation Army coffee mornings and she valued feeling useful. She seemed proud when talking about her role as a helper and it was clearly something she enjoys doing.

"I make sure...the officers get their cup of coffee in a morning. Take two cups in, one in each hand"

"I make sure C gets a weak coffee, P gets a tea...it feels quite nice. This Sunday it's me that's on teas and coffees"

Valuing independence

Audrey described having a lot more independence now than she had in the past, and her independence seemed extremely important to her. She was proud of her ability to keep her flat clean and tidy, and determined to do this independently.

"I like it 'cause it means you're more independent for yourself and that now"

"I do it all meself. I wouldn't let anybody touch it. I do the flat on my own. The only thing they help me is with the duvet cover 'cause I struggle with that but they never help me with anything else"

Vulnerability and protection

In the past Audrey has felt alone and unprotected. She described repeatedly being let down by people she relied on for protection. More recently Audrey described feeling well protected by her family, who view her as a vulnerable adult in need of protection. In general Audrey seemed to share this view and their efforts to protect her made her feel secure. Audrey felt that her family can be overprotective and she seemed to find this stifling at times although this was outweighed by pleasure in her feeling of security. I wondered whether Audrey initially felt that her family's protectiveness was a welcome change from previous insecure and frightening situations, but now she has become more confident and independent and feels less in need of their protection, meaning that what was previously perceived as security now feels like overprotection.

"They said...she's a vulnerable sister...if they're not going to look after her we're not going to let her go"

"Well at first it felt alright but it feels as though they sometimes get too protective of you"

Importance of feeling liked and wanted

Audrey felt popular and well liked, in contrast to her past where she felt unwanted and this made her unhappy. Audrey valued being wanted and it was important to her to feel that people like her. Audrey felt that becoming a happier person had made people like her more, but also that having people like her had made her feel happier.

"That was one bit that made you feel really down. At that time you felt nobody wanted you"

"Well now I feel that everybody wants me. That feels nice that everybody wants you now. When you're smiling and that they all want you now"

"When you're giving them their teas and coffees and that, they smile to you and that means, if they're smiling, that they like you"

Importance of support and companionship

Audrey had a wide circle of friends including some close friends. She described gaining pleasure and companionship from spending time with her friends. Audrey particularly valued the support she received from her friends and this seemed to give her a sense of being cared for. I wondered whether feeling alone and unsupported in the past may have contributed to Audrey now feeling that support from her friends is very important to her.

"It means that you've got a lot of people there that you could talk to. On a Sunday, you've got a lot of people you could really talk to"

"If you went down and something was wrong, one of them would come over and say "what's wrong today" and you'd be able to tell them"

"If anything's wrong and that they're able to help you"

I'm not old yet

Audrey did not view herself as old because she felt active and able, and she had not noticed any age-related changes in herself. Audrey conceptualised ageing as a process of physical and mental deterioration that happens when someone reaches old age. She did not feel that ageing was relevant to her as she is not old yet, but she has given thought to the ageing process and expects it to happen to her in the future.

"Now I can get about more 'cause I'm only 60 but other people can't"

"Not at the moment I've not noticed any [changes] in me yet"

"I've never forgot things yet but through time that could happen"

Fear of ageing

Getting older involves deterioration. Audrey seemed scared of getting older, because she expects her health and wellbeing to deteriorate when she reaches old age. This fear is based on her negative views of old age, which are based on her experience of watching family members deteriorate in old age. This has given Audrey a negative perception of old age including the following beliefs:

Audrey believes that people find it more difficult to get around when they reach old age and are at risk of falling.

"They can't get about as much"

"Well some older people fall about and that and have to get sticks and that"

Audrey believes that memory loss and Alzheimer's disease are common in old age because she has watched family members become confused as they grew older.

"They get that Alzheimer's disease. As they get older"

"When my granny got older you knew that she was forgetting things... When she got to 100 you knew she was forgetting things, where she'd put them and that"

"'cause that's sometimes what older people do. They walk out and forget where they're going. Forget where their home is"

Audrey believes that people become vulnerable in old age, and may become more fearful.

"As you get older it might start to change 'cause you might be vulnerable on the buses and that"

"If the bus is crowded and you're standing you'd be frightened to stand if you were older"

Audrey described older people becoming unhappy in old age due to deterioration related to ageing.

"When I saw my granny deteriorating. Really before she died I knew she was getting sadder"

"It's when they get to about 80 or 90, you see them not smiling and that"

Audrey believes that these areas of deterioration are common in old age, and as a result she believes that they are likely to happen to her in future when she reaches old age. She seemed to feel scared at this prospect.

"That really happens to a lot of them as they get older. They forget where they're putting things"

"Well I could forget where I put things and that, as I get older"

Fear that life will be less enjoyable in future. Linked to her negative perception of old age, Audrey expected her life to become less enjoyable in a number of ways as she gets old and this was a frightening prospect.

Audrey described enjoying her life, with an active lifestyle providing her with a sense of wellbeing and fulfilment. She expects deterioration in a number of areas when she reaches old age, and she seemed worried that this will affect her lifestyle and reduce her quality of life in

future. Audrey expects that changes with age will mean that she is no longer able to take part in the activities she currently enjoys.

"My life is alright at the moment because I can get out and about and do things.

There's some other folk can't"

"As you start to get older it [going to college] might change. 'Cause you might be vulnerable on the buses and that"

"I just keep knitting. At the moment yeah, but not as you get older it probably won't"

Audrey reported that she has a good circle of friends and sees them often but she lives alone. She was happy with this and content to spend time alone. Audrey thought that this would change as she gets older, and that she will begin to feel lonely and less able to manage independently. She viewed this as a negative change, but did not seem too worried as she seemed to feel confident that company and help would be available if required.

I think as you get older it will...well you might get sad and that or lonely"

"I think as I got older I wouldn't like to do it on my own. I probably would like to have company as I got older...And you'll probably not forget things 'cause if you've got somebody there they'll probably, if they're younger, they'll remember you".

Frank

Frank was 81 years old and lived in residential accommodation. Frank lived with his family in childhood. He was unable to remember when he left his family home and entered residential care, but he remembers living in one previous group setting before his current home.

Frank attended a day-centre one day a week. He had been attending the centre for a long time and enjoyed being familiar with the people and routines there. Frank was gregarious and enjoyed friendly banter with staff and other service users. He had chosen not to retire from the day-centre because he enjoyed going there and had no plans to stop attending. He had previously enjoyed drawing and going out on his own, but was no longer able to do this. Frank was aware that he was getting more forgetful with age

The interview took place at the day-centre Frank attends and lasted 40 minutes. Frank was very talkative, but he often jumped between topics and I found him very difficult to follow. At some points Frank also had difficulty understanding my questions. I found it difficult to get a clear picture of Frank's life outside the day-centre, for example his home and how he spends the rest of his time. This was partly due to Frank finding it difficult to understand and answer some of my questions and partly because of my difficulty in understanding Frank as I found his

speech fragmented and confusing. Having some knowledge of Frank's day-centre helped me to interpret his speech and it was more difficult to interpret his responses relating to his home because I lacked this contextual knowledge. Frank had couldn't remember much about his past or details such as how long he had lived at his current home, he didn't seem to have a coherent sense of his own history. Following the interview I felt that I had not understood Frank's experience in as much depth as I did with other participants, because I had been focused on trying to understand his speech, and struggling to get a coherent picture of how he spends his time and what is important in his life. I was also left with a sense of sadness, perhaps because Frank was so keen to present himself as knowledgeable and an important member of the day-centre and I developed the impression that this was an attempt to bolster his self-esteem against feeling that he is increasingly struggling with life.

Table 5 - Individual themes for Frank

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Struggling with life • Wanting to prove himself by showing knowledge and being in charge • Feeling embarrassed at changes with age • I can't do it now: Frustration at lost abilities and independence 	<ul style="list-style-type: none"> • Life is hard • Feeling stuck • Life is unpredictable • Dismay at being unable to get it right • Taking on the valued role of teaching others • Importance of knowing and enforcing rules • Importance of having a useful role • Importance of ability to do things well

Struggling with life

Life is hard. In my interview with Frank there was a general sense that he has found life difficult, and that it has been a struggle for him to achieve his goals, or perhaps that he has been unable to achieve them.

“It don’t come easy does it”

Feeling stuck. Linked to the theme of finding life hard, it seemed that Frank’s experience of difficulty in achieving goals such as finding a job had left him feeling stuck.

“Not easy going to find a job is it?”

“So I’d be stuck wouldn’t I?”

Life is unpredictable. Frank seemed to feel that life is unpredictable, saying *“You can’t tell can you from one day to the next”*. There were a number of confusing exchanges in the interview, where Frank found it difficult to understand my questions, and I found it difficult to understand his responses as he seemed to jump between topics. I wondered whether Frank might have a similar difficulty in understanding and being understood in his everyday life, which could leave him feeling that the world is a confusing place.

Dismay at being unable to get it right. Frank seemed to have an awareness that he is not always able to understand and fulfil other people’s expectations and he seemed dismayed by his inability to get things right and satisfy others. This feeling may have been exacerbated by Frank’s awareness that he is becoming more forgetful over time, making it even more difficult for him to get things right.

“If they gave me a job they’d say “who’s been ringing up”. How do I know? Can’t write number”

“They ring up and say “who’s been today?” How do I know which doctor’s been”

Wanting to prove himself by showing knowledge and being in charge

Frank seemed to be struggling with his awareness that he is not always able to satisfy others and get things right, and that this is getting even more difficult as he becomes more forgetful with age. I got the impression that Frank’s self-esteem was threatened by this perceived inability to satisfy others, and he reacted by focusing on the areas where he feels capable and valued in order to protect his self-esteem.

Taking on the valued role of teaching others. At several points in the interview Frank pointed out that he was giving me ideas. I felt that Frank was keen to place himself in the role of teacher. This seemed to enable him to feel that he was the one holding and giving knowledge. This role seemed to be one that Frank valued highly and was keen to emphasise.

“That’s what I do. Give you some ideas”

Importance of knowing and enforcing rules. Frank was aware of rules and procedures at the day-centre, such as the fire alarm procedure and the importance of washing hands before meals. He seemed to want to show me the extent of his knowledge, and he also described reminding other service users of the rules. It seemed valuable for Frank’s self-esteem to view himself as knowledgeable and to have other people acknowledge this. Helping to enforce rules and procedures also seemed to allow Frank to feel that he is performing a valued role by helping the staff, and he seemed to feel that this gave him a higher status than some other service users.

“You can’t have your dinner unless you wash your hands”

“Hey there’s a fire. Outside, girls over there, boys over there. Stand there. Well that’s a good idea”

Importance of having a useful role. Frank was keen to find ways of being useful, such as helping staff to enforce the rules and helping me by giving me ideas. It seemed that feeling useful was important for Frank’s self-esteem.

“So I’ll be on that for you”

“I’m just giving you some ideas”

Importance of ability to do things well. Frank emphasised things that he felt he had done well, and it seemed that it was important for him to maintain a sense of himself as capable, possibly in an attempt to protect his self-esteem and reduce his feeling of dismay that he is sometimes unable to get things right.

“I’m doing well aren’t I. You won’t beat this one”

“So I’ve done well”

Feeling embarrassed at changes with age

Frank has noticed himself becoming more forgetful with age *“I’ve forgot...Do it all the time”*. At times it seemed that he was embarrassed by his forgetfulness and he used several strategies to manage this embarrassment. At some points in the interview Frank seemed to gloss over details that he had forgotten, possibly attempting to disguise his forgetfulness. He also tended

to assert his strengths, for example saying *"I'm very good at showing you some stuff"* which seemed to be a way of reducing his embarrassment and protecting his self-esteem. At other points he seemed to view forgetting as a normal part of ageing, for example saying *"I've forgot her name with being old"*. I wondered whether normalising forgetting was another way of reducing his discomfort at noticing this change in himself.

I can't do it now: Frustration at lost abilities and independence

Frank had noticed his abilities changing as he has got older. He now finds it difficult to draw, which was previously one of his main hobbies. Frank also seemed to feel that he had lost some of his independence because he now needs more staff support, and he is no longer able to go out alone. Frank seemed to feel frustrated at the loss of independence, and at being unable to do things he previously enjoyed.

"I can't draw now"

"I usually...I can go on my own. But I've got to go with staff now in case I slip"

"I used to walk but now I can't. I've been down to the bakers. Can't now"

Harry

Harry was 64 years old and lived in supported living accommodation with other men of a similar age. Harry was abandoned by his parents in infancy and lived in an orphanage before attending several different special schools. Harry then lived in a hospital for people with learning disabilities for over 20 years. After leaving the hospital he lived in several group homes, spending a few years in each place. He had been in his current home for over 10 years and was contented there.

Harry enjoyed a close friendship with one of his fellow residents. He described spending a lot of his spare time studying. He enjoyed learning and self improvement and was learning to read. Harry did voluntary work as a caretaker and working in a charity shop and saw this as a good way to occupy his time.

I met Harry at home and the interview lasted for fifty minutes. Harry came across as a very calm and thoughtful person. When I first met him to introduce myself and the study Harry seemed quiet and reserved and I anticipated that he might need prompting to elaborate on his answers. When we began the interview I was surprised to find that Harry spoke freely and

gave an eloquent account of his beliefs and experiences. I was struck by Harry's philosophical outlook on life and death and after the interview I was left with a sense that Harry has moved on from a difficult past and now feels at peace with himself.

Table 6 - Individual themes for Harry

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Fulfilment from continued learning and self improvement • Valuing the opportunity to do something useful • Friendship as a source of affection and enjoyment • Dismay at being unable to get things right • Anger at a difficult life • Acceptance of changes with age • Regret at lost opportunities • Acceptance of ageing and death aided by religious belief 	<ul style="list-style-type: none"> • Importance of keeping occupied • Pride in being useful

Fulfilment from continued learning and self improvement

Harry was very interested in studying and learning. He described finding learning enjoyable and seeing himself as someone who is well informed and committed to self improvement. This seemed to be an important part of Harry's self-image.

"I'm more interested in lessons than I am in pictures"

"I've always been studying. All my life, I've always all my life"

As well as being an enjoyable hobby, learning was also a source of pride for Harry. He was learning to read and felt proud of his achievement.

"I started reading lessons about a couple of years ago and I'm getting there. I'm getting there"

Harry was keen to improve himself, and felt that he was achieving this by learning to read and continuing to study and increase his knowledge. Self improvement seemed to be something that Harry valued highly and formed an important part of his life.

*"I'm still learning to read. I'll be able to improve myself. I want to read fluent"
"All I do is just study, study, study. I believe that you learn something all the time"*

Valuing the opportunity to do something useful

Importance of keeping occupied. Harry described voluntary work in two roles, working as a caretaker and helping in a charity shop. He seemed to feel that it is important to keep busy, and saw his work as a way of filling his time and keeping occupied.

*"it gets you out"
"summat to do"*

Pride in being useful. Harry seemed to value having a useful role at work, and described his duties with pride.

*"Set the tables out. Do the bathrooms and toilets"
"I go there and do tables and chairs. Put toilet paper in the toilet, put soap in the box. Put hand towels out if they want me to"*

As well as feeling useful at work, Harry also seemed to feel needed by his co-workers, which added to his sense of pride in his useful role.

"They said don't leave because, you leave the work'll suddenly come"

Friendship as a source of affection and enjoyment

Harry enjoyed spending time with his friend and the companionship from this relationship seemed to add to his sense of contentment with his life. Harry was very close to one longstanding friend and clearly felt a great deal of affection for him.

"I'm fond of 'im, just fond of 'im. Yeah, I like 'im very much. I almost love 'im. Maybe it is love, I don't know what it is"

Harry valued his relationship with his friend very highly. He described making changes in order to protect his friendship.

"I used to be very interfering, a busy body. I'm not now. I've stopped that.....I nearly lost S so I stopped.....I wanted to keep S as a friend"

Dismay at being unable to get things right

Harry expressed difficulty in satisfying others and getting things right. He seemed to be struggling to understand what other people require of him, and there was a sense of dismay that he is unable to get it right.

"You wonder if you've been good enough. You can't tell. If somebody says to you that's wrong, two minutes later they say that's right"
"I don't know. I just don't get it right"

Anger at a difficult life

Harry expressed anger at a number of events in his past where he had been mistreated or betrayed.

"They found me abandoned somewhere. I was left. They left me"
"Even my best friend went against me"
"He should be struck off, he had no mercy"

In addition to the feeling of betrayal from these events, Harry seemed to feel a sense of injustice that people had been allowed to get away with mistreating him.

"She's getting away with it and I can't do owt about it"

Harry's anger at how he had been treated in the past contrasted with his contentment in his current home. There was a sense that he has moved on from a difficult past to his current situation where he is treated well and feels contented and fulfilled.

Acceptance of changes with age

Harry had noticed a number of psychological changes in himself as he has grown older. Harry appeared to view this type of change as being a normal part of ageing. He was accepting of the changes in his outlook and seemed to view them as changes for the better.

"You understand more and you get more patience and you get more understanding of other people"
"I used to be very interfering, a busybody. I'm not now. I've stopped that"

"I've changed, having bad moods I'll walk away and come back"

Regret at lost opportunities

Harry commented that he was too old to get married, and said *"I would if I'd been younger. I'd like to've had kids but I never met anybody"*. This gave me the impression that Harry had a sense of opportunities passing him by, and felt regret that he had missed out and that some opportunities were now closed to him because of his age.

Acceptance of ageing and death aided by religious belief

Harry talked about getting older and eventually dying with a sense of acceptance. He seemed to view getting older as something that is neither good nor bad, and he spoke about it without any sense of fear or resistance.

"I suppose it's natural, you just accept it. You know it's going to happen. You can't avoid it"

"Just growing old. I'm not worried about it, I don't mind"

It seemed that Harry's religious belief played a large part in helping him to face death as he believes that death will bring him closer to God.

"As you get older you get nearer to heaven...step by step"

"God'll say Harry come here"

Dorothy

Dorothy was 74 years old and lived in residential accommodation with a small group of people with learning disabilities. She grew up living with her parents and her two sisters. Dorothy was unable to remember where she had lived in between her parents' house and her current home.

Dorothy attended a day-centre two days a week and she planned to continue attending in the future. She enjoyed going there and she especially liked the food and the staff there. Dorothy had mixed feelings about her home. She liked most of the staff but at times she found it difficult to get on with the other residents. She enjoyed helping around the house although she did not feel that the others do their fair share. Dorothy reported that her sister took her out

regularly and she looked forward to these visits even though she doesn't always get on with her sister. Dorothy was very fond of her sister's dog and her own collection of cuddly toys.

I visited Dorothy at home for the interview and we talked for an hour. I found Dorothy's speech difficult to understand and had to concentrate hard to understand what she was saying. I was not able to get any sense of Dorothy's understanding of what ageing means or how she has experienced the ageing process. She did not seem to understand my questions about ageing, but it was not clear whether this was because Dorothy is not aware of ageing, or whether my questions did not connect with her understanding of ageing. Dorothy could not remember what had happened in between living with her parents as a child and living in her current home. She suggested that I ask a member of staff and I got the sense that she relies on others to hold her life story for her.

Table 7 - Individual themes for Dorothy

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Powerlessness • Anger • Suffering • Seeking affection • Values having a useful role 	<ul style="list-style-type: none"> • Feeling bossed around and powerless • Feeling unheard • Feeling powerless to get her needs met • Resentment • Defiance • Unhappiness • Pain • Gaining affection is complicated by ambivalent relationships • Valuing uncomplicated affection • Pleasure from spending time with people she likes • Staff not able to provide enough closeness • Seeking affection but being limited by others • Importance of feeling useful • Pride in doing her job well • Importance of being independent

Powerlessness

Feeling bossed around and powerless. Dorothy felt that she was bossed around by her sister and staff at her home. She felt that others held all the power and controlled what she was allowed to do.

*“Too many bosses”
“I’d do it but they won’t let me”*

Feeling unheard. Dorothy described feeling that people don’t listen to her, and that her views and needs are not taken to account which seemed to leave her feeling powerless.

“Ee won’t listen to me”

Feeling powerless to get her needs met. Dorothy felt reliant on other people to meet her needs. This included relying on staff to meet her practical needs, and relying on her sister to visit. She did not feel that her needs are being met, but felt powerless to change this.

*“I want a new bed. Nobody will buy me one. It’s a shame in’t it”
“They won’t go to the doctors and ask for some cream”*

Dorothy felt that other people held all the power to make decisions, and she was left in uncertainty, for example waiting to find out whether or not her sister would visit. This seemed to add to her sense of powerlessness.

“I don’t know if she’s coming tomorrow. She rings up sometimes, tell ‘er I’m not coming or summat”

Dorothy expressed a lot of dissatisfaction with her current situation but felt powerless to make any changes, which left her feeling stuck.

“I cannot get on with her. No, I’ll have to stay here”

Anger

There was a very strong sense of anger running through Dorothy’s account. This seemed to be largely related to her sense of powerlessness, and her feeling that her life is not satisfactory but she cannot do anything to improve it. Her anger also seemed to be fuelled by a sense of injustice at the way things are.

“She goes out and she doesn’t take me. That’s not fair”

Resentment. Dorothy felt a strong sense of injustice that she did a lot of work around the house and did not feel that the other residents did their fair share. This had left Dorothy feeling extremely resentful.

“Why should I work hard in this house, can’t he help?”

“I always do it. Why me? Can’t X help me?”

“All the kitchen this morning I did it all. After that I said I’m not doing it while you mess about”

Defiance. Dorothy responded to her powerlessness and resentment with defiance and she has challenged the people she feels angry and resentful towards.

“I’m not going to put up with it”

“I can get on fine here without ‘er”

“After that I said I’m not a servant to you X”

Unfortunately Dorothy’s powerlessness meant that her defiant statements were hollow and she was unable to follow them through. She was aware that she would have to “put up with” her situation because she had been unable to change it, and she could not “get on fine” without the people around her because she depended on them for support and affection. The awareness that she could not act on her feeling of defiance seemed to contribute to Dorothy’s feelings of powerlessness and anger.

Suffering

Unhappiness. Dorothy described a great deal of unhappiness. She seemed unhappy with her current living situation, and gave a general sense of being dissatisfied with life but unable to make any changes which left her feeling angry and resentful but also very unhappy.

“I don’t like it. I want to leave this house altogether”

“Awful. Terrible this is”

“I want to leave it. I’ve made up me mind. Not ‘appy in it”

Pain. Dorothy was in pain, which seemed to be affecting her quality of life and contributing to her sense of suffering.

“My legs ache a lot”

“It’s awful. When I got up this morning it was swollen. I don’t want to have it all the time again”

Seeking affection

Gaining affection is complicated by ambivalent relationships. Dorothy's main source of affection and closeness was her sister and her sister's dog. Dorothy's feelings towards her sister were ambivalent, she expressed a wish that she could spend more time with her sister but it was also clear that Dorothy doesn't always get on with her sister. It seemed that Dorothy felt a lack of closeness and affection because her closest relationship is a difficult one.

"Me and B can't get on together"

Valuing uncomplicated affection. Dorothy had a collection of cuddly toys which were very important to her. She enjoyed looking after them and showing them affection, and she felt that she received affection from them in return. It seemed that Dorothy valued the uncomplicated closeness and affection she felt from her cuddly toys because she lacked this in the rest of her life.

"This white one he loves me"

"That cat of mine, he's lovely. That white one kiss me on a morning. So does the one after"

Pleasure from spending time with people she likes. Dorothy took a great deal of enjoyment from spending time with staff at her day-centre. She seemed to value this relationship very highly and spoke about the staff with a lot of affection. Dorothy's extreme pleasure at spending time with someone she feels fond of suggested to me that she did not feel she had enough of this type of interaction, and so valued it even more highly.

"Well you see I can get on with S...I have a cup of coffee with her.....And I love every minute"

"I love 'er to death. Makes me a cup of coffee or biscuit"

Staff not able to provide enough closeness. Although Dorothy spoke about staff at the day-centre with affection and clearly enjoyed her time with them, there was a sense that this relationship did not provide the closeness and sense of connection that Dorothy required.

"She's lovely. But I can't talk to her properly"

Seeking affection but being limited by others. Dorothy clearly felt a need for more affection, and felt that her access to sources of affection was controlled and limited by other people. Dorothy relied on her sister to visit and did not feel that she was given enough time. She was extremely fond of her sister's dog and did not feel that she was allowed to see him often

enough. This restriction of her main source of affection seemed to leave Dorothy feeling lonely, but also angry at the injustice of her contact being limited.

"Well I wanted to see C don't I. Oh he's lovely"
"She always cuddle him but she won't let me. That's not fair is it?"
"She doesn't let me see much of him"
"She says it's time to go 'ome. I say you don't give me a chance"

Values having a useful role

Importance of feeling useful. Dorothy helped around the house and she seemed to value feeling useful. There was some ambivalence about doing housework as Dorothy sometimes felt that she does more than her fair share which made her feel resentful.

"I like a job what can put things in dishwashers. Or polish the table"
"What I do I clean all up. Clean all the table. All the kitchen this morning I did it all"

Pride in doing her job well. Dorothy took pride in doing her jobs to a high standard, and seemed to enjoy knowing that she had done a good job.

"I like to set the table lovely"
"I set the table with glasses on and everything"
"Today I set the table properly for breakfast. I do it"

Importance of being independent. It seemed important to Dorothy to do her jobs without assistance, which gave me the sense that she valued her independence.

"I want to do it by meself"

Joyce

Joyce was 68 years old and lived in residential accommodation. Joyce lived with her parents as a child, and went to live in a hospital for people with learning disabilities as a teenager. She found it noisy and full, but had lots of friends there. Joyce moved to a smaller group house, before moving on to her current home, another small group house, because she was having difficulty managing the stairs at her old house. It was unclear how long she had lived in her current home.

Joyce was still in touch with several friends from her previous home and enjoyed spending time with them. Several people who were important to Joyce had died in the past, including her boyfriend and a close friend from the hospital she lived in, and her parents. Joyce had fond

memories of them, but missed them very much and felt sad when she thought about this. Joyce had two younger brothers who visit her on birthdays and at Christmas.

Joyce had pain in her face and shoulder, and had been told this was because she was getting older. She had filled her bedroom with objects and photos which remind her of family and friends, and these memories were very important to her. Joyce liked going to the shops, playing dominoes with her support staff and knitting. She was pleased to have retired from her day-service because she disliked going there.

I visited Joyce at home for the interview, which lasted for 75 minutes. Joyce was friendly and talkative, and she proudly showed me her bedroom. At times Joyce replied to questions at a superficial level, giving replies suitable to a polite social exchange, for example at one point when I asked what it was like living somewhere, Joyce responded "*alright love thanks*". Joyce was happy to give more detailed answers when I asked follow up questions. During and after the interview I felt sadness for Joyce and I interpreted this as a response to the strong sense of grief and sadness present in the interview.

Table 8 - Individual themes for Joyce

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Sadness • Ageing involves unpleasant physical and mental changes • Things are better now (but not good enough) • Retirement as freedom • Valuing friendship • Disappointment that access to friends is restricted 	<ul style="list-style-type: none"> • Missing the closeness and affection of past relationships • Grief • Keeping the past alive • Pain is a normal part of getting older • Feeling down is part of getting older • Contentment • Unhappiness at times

Sadness

Missing the closeness and affection of past relationships. Joyce talked a lot about the loss of important relationships from her past. Joyce was close to her mother and missed both her parents since their death. Joyce had a close and affectionate relationship with her best friend and her boyfriend. They both died some time ago, and Joyce described missing them very much and feeling very sad about the loss of these relationships. In particular it seemed to be the affection in the relationships that Joyce missed and she did not seem to have any relationships in her current life which provided the same level of closeness and affection.

"I used to put me arms round 'im 'cause I loved 'im that much. I was sorry when I got to know he'd gone. I do miss 'im though"

"she used to put her arm round me and give me kisses and so did B. They both used to put their arm round me and kiss me. I miss all that now they've gone"

"I still get upset about them both really. Well I miss 'em both"

Grief. Joyce described crying and feeling very upset over the deaths of her parents, her best friend and her boyfriend, and it was apparent that she was still going through a process of grieving for the people and relationships she had lost.

"Many a night I 'ave a cry about me mum"

"I still keep thinking of her in me memory. I still think about her. Even though she's gone"

"I certainly would cry over her though. I was this morning a bit. Crying a bit this morning over 'er"

It seemed that Joyce needed reassurance that her sadness was a normal reaction to loss. She made a number of references to other people saying that her sadness is understandable and seemed to be using these statements to reassure herself that it is normal to feel sad over the losses she has experienced.

"They all say oh you're bound to. You're bound to feel it they says. Well I will feel it for a bit really won't I?"

"They say oh you're bound to miss 'er. She'll be looking over you they says"

Keeping the past alive. Joyce talked a lot about important people from her past, and she had surrounded herself with memories in the form of her mother's possessions, and photographs of her parents, best friend and boyfriend. This seemed to be a way of keeping the past alive, and reminding herself of a time when she was happy and had the closeness and affection that she lacks and misses in her current life.

"That's E up there...At least I've got some good memories of theirs. 'Cause them two were me mum's there. Pepper pot and music box"

*"I've got them pictures of 'er..I do miss 'er"
"Got me a little plant to remember 'er by"*

Ageing involves unpleasant physical and mental changes

Pain is a normal part of getting older. Joyce had experienced increasing levels of pain as she had grown older. She thought of pain as a normal part of ageing, and this meaning had been developed on the basis of Joyce being told by others that her pain is to be expected as she is getting older.

"I've still been getting these shoulder pains though lately. That's cause, they said, you get all these pains as you get older"

Feeling down is part of getting older. Joyce believed that feeling down is a normal part of getting older. This belief seemed to be based on the fact that she feels down herself as well as hearing others describe older people as "grumpy". The meaning that she has developed from this is that people feel down as they get older.

*"They [meaning older people] feel down"
"Cause they say oh you all get grumpy as you get older"*

Things are better now (but not good enough)

Contentment. Joyce described a sense of contentment with her current accommodation, saying *"I've settled lovely 'ere"*. Joyce clearly felt that moving to her current accommodation was an improvement and had given her more freedom, and she described feeling better since moving there.

*"It is better for me 'ere. Am quite alright 'ere now"
"I can do what I like. Get up when I like and go out when I like"*

Unhappiness at times. Despite feeling that things had improved since moving to her new home, Joyce clearly felt unhappy at times. The overall sense was that although things were better, they were still not good enough to overcome Joyce's unhappiness.

*"I feel better. But I still get a bit down in meself. I still feel down in meself"
"Many a time I have a good cry. But I do like it better 'ere though"*

Retirement as freedom

Joyce chose to retire from a day-centre that she disliked. She seemed to feel relief that she no longer has to go to work, and described feeling that she has more freedom now that she is retired.

*"I don't 'ave to get up and go to work now. Now that I'm retired. About time an all"
"I used to hate going there every day. Hated when I used to have to go but now I've retired now. So I'm free to do what I like"*

Valuing friendship

Joyce enjoyed visits from a friend she lived with in a previous home. She clearly gained a lot of happiness from these visits, and she described an affectionate relationship with her friend.

*"Makes me happy when I've got M coming"
"We both tease each other, 'Ee teases me and I tease 'im"
"Still torments me, ha ha, 'ees always been a good friend of mine as well, M"*

Joyce had lost a number of people who were important to her, and felt very sad about this. As result she valued her remaining relationships very highly.

"Ah've still got friends 'ere. Still got friends"

Disappointment that access to friends is restricted

Joyce was reliant on staff to bring her friend to visit. She was accepting of the limitations caused by staffing levels, saying *"Oh they still bring 'im when they can"*. However there was a sense of disappointment that her friend can't visit more often. Joyce's relationship with her friend was clearly very important to her and formed one of her main sources of affection and enjoyment, and she seemed to feel disappointed that contact with her friend is restricted by their reliance on staff.

"It'd be nice if they do bring him again really but I do miss seeing him"

Peter

Peter was 77 years old and lived in supported living accommodation with three other men with learning disabilities. Peter described an unhappy childhood in a poor family. He was adopted by his grandparents and lived with them. He became ill and spent time in hospital as a child. Peter continued to have physical and mental health difficulties as an adult, and he

described a chaotic life moving between a number of hospitals and hostels. He had many unpleasant experiences in these settings and tried to run away several times but was forced to return. Peter continued to move between institutions into his fifties. Peter described a lot of sadness and regret about the way he was treated and his own past behaviour. It was unclear when Peter had moved into his current accommodation, but he had been there some time and felt settled there. Peter was not in contact with his family. He believed that one of his aunts was alive, but did not know how to contact her.

Peter enjoyed attending a day-centre four days a week where he did activities including karaoke. He was sad that the centre would be closing soon. Peter had worked as a gardener in the past but was no longer in employment. He had a girlfriend and he enjoyed visiting her every Sunday. He also enjoyed going into town on his own and spending time with his fellow residents. Peter had known one of the men in his accommodation for over 40 years and they were good friends.

I met Peter at home and we talked for an hour. When we began the interview Peter immediately started telling me his life story beginning from childhood. He seemed to feel the need to tell his story, and wanted to tell me about the difficult experiences in his past even though he found it upsetting to remember them. I made it clear that Peter did not have to discuss his past if he did not want to, but he chose to continue and he did not become distressed. We moved on to discuss more positive topics relating to his current life, and afterwards Peter reported that he had enjoyed the interview. I was aware that I felt uncomfortable at the possibility of Peter being distressed by the interview, and I chose not to ask for any further details when he was talking about upsetting memories. Peter talked quickly and his speech was soft and difficult to hear at some points. Peter tended to jump between details of his story and I found it difficult to follow him. At times this made it hard to get a clear picture of Peter's experience. We agreed that I would return for a second interview. Peter had been put forward for the study by a Community Nurse at the Community Learning Disability Team, and the nurse had made me aware that Peter experiences frequent episodes of depression. When I phoned to arrange a second interview, Peter's support staff informed me that he was depressed and would not feel up to talking so I delayed the interview by several weeks until staff reported that Peter's mood had lifted. When I arrived for our second interview it was clear that Peter was still low in mood. Peter chose to go ahead with the interview but he was noticeably less talkative than he had been in the previous interview and

gave very short answers which meant that the data from the second interview was sparse. As a result, most of the themes are based on the first interview. Peter's responses in the second interview appeared to be heavily influenced by his low mood. This data was included in the analysis as it represented an aspect of Peter's experience, but it is made clear in the analysis that one sub-ordinate theme was based on the second interview and may only represent Peter's experience during periods of low mood.

Table 9 - Individual themes for Peter

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Sadness • Positive change in self over time – settling down • Pleasure from friendship and companionship • Feeling ready for a rest • Feeling that some opportunities have passed 	<ul style="list-style-type: none"> • Sadness over difficult past • Sadness and anger over loss of family relationships • Sadness at anticipated loss of relationships and a source of happiness • Getting older involves feeling down

Sadness

Sadness over difficult past. Peter talked about difficult experiences in his past with a great deal of sadness. Regret over his own past actions contributed to Peter's unhappiness. It seemed that he had been unable to come to terms with the things that had happened to him

and things he had done, and sadness over his past was a big part of his current experience. Peter talked a lot about his past experiences and seemed to want to tell his life story, and this seemed to be a way of making sense of his current unhappiness.

"Oh it were terrible. You see all we'd get, we'd nobody getting paid we were poor, poor people so we couldn't do nowt"

"It comes back to you, why you were a bad person, why you done this, done the other"

"Upsets me, I start crying you know....it's sad though"

Sadness and anger over loss of family relationships. Peter had lost contact with his family and was distressed about this. His distress seemed to be a combination of anger or frustration that he was unable to contact his family, and sadness at the loss of these relationships. Although the following two extracts are fairly similar, there was a marked difference in Peter's tone of voice with the first quote sounding angry, and the second said with a sense of despair.

"I can't, he wouldn't give me address, he wouldn't give me it, how can I write, I don't know the street, I can't can I, no way. I can't do nowt"

"I can't contact 'em. I don't know where they live. How can I contact 'em if I don't know address. I can't can I? No way. Oh it's no good, you can't"

Sadness at anticipated loss of relationships and a source of happiness. Peter expressed sadness at the anticipated closure of his day-centre. The centre is a source of enjoyment and friendship. Peter was upset at the thought of losing the centre and his relationships with the friends he has made there, and this seemed to contribute to his general sense of unhappiness.

"I've had some good times there"

"I'll miss it...all my friends are there. I'll miss the centre"

"Get upset and start crying. I can't get over it. How would you feel if your centre were gonna close?"

Getting older involves feeling down. Peter expressed a sense of unhappiness throughout the interview, and this influenced his experience of ageing. Peter seemed to have made sense of his own sadness by viewing it as normal for someone of his age, although this perception of sadness as a normal part of ageing was only present in the second interview and therefore may have been influenced by Peter's low mood at the time.

"When you get old you...get a bit down"

Positive change in self over time – settling down

Peter had noticed a change in himself over time, that he was getting into trouble less. It seemed likely that this change was related to the change in Peter's circumstances over time. In

the past he had a chaotic lifestyle moving between institutions where he was mistreated, whereas more recently he had been settled in his current accommodation where he was treated well and had good friends. Peter seemed to view settling down as a positive change, and I wondered whether this change had allowed Peter to view himself in a more positive light and feel more content with his self-image, in contrast to feeling like a “*bad person*” in the past.

“I was always in trouble, I come here, I’ve changed. Well, thought it over, point of view. I could think, settle down, that’s it. Thing is, getting in trouble, I can’t explain really, just changed”

Pleasure from friendship and companionship

Peter enjoyed spending time with a longstanding friend, and seemed to gain pleasure and a sense of companionship from this relationship. He also expressed this sense of companionship in relation to his girlfriend. Peter showed respect for these close relationships, which seemed to indicate how valuable they are to him.

“He’s a good friend to me. Yeah. He’s alright. Well you can be happy and contented with people”

“On a Sunday I go and see me girlfriend, have a walk round, go to social club, that’s it”

“I wouldn’t go wi’ nobody else. No way, I couldn’t. It wouldn’t be worth it really to spoil your friendship with a girl”

Feeling ready for a rest

Peter described himself as being ready for a well earned rest. It seemed that Peter had developed a meaning of old age as a time to take things easy, when people are likely to retire from work by choice.

“Well I’ve worked all my life and I could do with a rest now”

“When you’re old you’ll want to retire won’t you”

Feeling that some opportunities have passed

Peter seemed to feel that a number of opportunities such as marriage and work have passed him by and are now out of reach due to his age.

“No I’m too old for ‘em really. Well, you know it’d be too much hassle, I couldn’t manage it no way. No, I’m better single, I like being single I enjoy it”

“I’d go back to it but you’re too old”

However, age was not the only factor stopping Peter from doing these things. He described getting married as “*hassle*”, and when talking about employment he expressed some uncertainty about whether he would be able to get a job. It seemed that Peter had been ambivalent about these opportunities, perhaps because of concern about his ability levels or feeling unmotivated when he is low in mood. I developed the impression that in some ways Peter felt relieved that his age gave him an acceptable explanation for feeling unable to do things such as getting a job.

“I’m not too old it’s just I can’t make money up properly. I could get a part time job but I might not pass”

William

William was 62 years old and lived in supported living accommodation with three other men with learning disabilities. William’s father died when he was a baby. He moved to Yorkshire with his mother and siblings as a young adult. He lived with his family until his late thirties, when his mother became unable to care for him and he was moved into supported living accommodation. William’s mother died soon afterwards. William had four siblings but two of them had died. The remaining siblings lived fairly nearby and sometimes visited. William had lived in the same supported living accommodation since the 1980s, except for a temporary move while his accommodation was refurbished.

William got on well with the men he lived with. He enjoyed chatting to them, watching television and going to the pub. William helped with cleaning jobs around the house. William was a Catholic and went to church every week, his religion was very important to him. William considered himself to be old. He was in good health but wanted to lose weight. William had noticed himself walking more slowly with age.

I visited William at home to interview him, and we spoke for just over an hour. William answered my questions carefully and thoroughly. He was able to ask for clarification when he did not understand a question. William seemed to have a strong sense of his own history and he was able to give a clear account of his life. William was clearly aware of his own ageing process and was able to talk about his experience of ageing, and his feelings about the future including getting older and dying. I found the interview with William enjoyable. He had clearly already given a lot of thought to the subject of ageing so he was able to talk about the changes he has noticed and how he feels about them without very much prompting. Although William

is struggling with some aspects of ageing, my overall sense during the interview was that he seemed contented with his life.

Table 10 - Individual themes for William

Super-ordinate theme	Sub-ordinate theme
<ul style="list-style-type: none"> • Contentment with current life • Struggling with physical changes of ageing • Negative construction of the future • Determination to maintain independence 	<ul style="list-style-type: none"> • Valuing being useful • Comfort and sense of belonging from religion • Slowing down as a normal part of ageing • Feeling vulnerable • Frustration at being slowed down • Mourning loss of mobility • Helplessness in the face of ageing • Worry about coping if life becomes a struggle • Sadness at the prospect of dying

Contentment with current life

William seemed satisfied with his current life, expressing enjoyment of his activities and companionship with the people around him, for example saying “*I like going to church. And I like going to, to pubs for meals*” and “*We chat, me and the residents chat and me and the staff chat*”. There was an overall sense of contentment in William’s experience of his current life.

Valuing being useful. William seemed to take pride in having a useful role in the house. It seemed that helping around the house had acted as a replacement for work, providing William with a meaningful role and a way of being of use to other people.

"I Hoover me bedroom and dust me cabinet and dust me cupboards and staff wipe window ledges. And I help the staff change me bed"

"I never had a job....but, but I help people to cater and I help people with all work..I help..with housework"

Comfort and sense of belonging from religion. William was brought up as a Catholic, and his religion was important to him. William seemed to gain a sense of comfort and security from the rituals of his religion.

"I like going to church. I like going to mass and receive the body and blood of Christ"

"It's important that I go to church and go to mass and it, it's important that me sins is forgiven..... Catholics go to mass, and people who are religious go to churches"

Being a Catholic seemed to be an important part of William's identity. It also seemed to give him a sense of belonging and a connection to his family, upbringing and ancestors, which he seemed to value.

"I am a Catholic. A good practising Catholic"

"My people was Catholics and I was born a Catholic. I grew up a Catholic"

Struggling with physical changes of ageing

Slowing down as a normal part of ageing. William had noticed himself slowing down with age, and he had made sense of this using his belief that a lot of people slow down as they get older suggesting that this is a normal part of ageing. However despite viewing slowing down as normal, William seemed to be struggling to come to terms with the change which had left him feeling vulnerable, sad and frustrated.

"As I've got older I've slowed down walking"

"I think that older people are slower to walk"

Feeling vulnerable. William described being anxious about being left alone, as he was finding it more difficult to keep up with his staff. This seemed to represent a sense of vulnerability resulting from the physical changes William has experienced with ageing. This view of himself as a vulnerable person seemed to be something new and uncomfortable for William.

"I can't keep up with the people that's around me and I hold people's hand. Keep an eye on the people that I don't lose staff and residents in the crowds"

Frustration at being slowed down. William spoke about walking slower with a real sense of frustration at being slowed down and held back by his age and his weight.

"Because I'm getting older, I can't keep up with the staff and residents. I can't. I can't walk that quick"

Mourning loss of mobility. William compared his current level of mobility to the greater level of mobility he had when he was younger, and seemed sad at the loss of his ability to walk quickly. It seemed that William was missing his younger and more active self, and finding it difficult to come to terms with the physical changes of ageing.

"I was young and active when I was 40 years old. I could walk quick. I was alright when I was 40 but now I'm the old age of 62"

Helplessness in the face of ageing. William's frustration at the changes he had experienced with ageing seemed to result in a desire to stay young. However, William was clearly aware of the inevitability of ageing and this seemed to leave him feeling helpless and despairing in the face of ageing and unwanted changes.

"I'd like if I was young but I don't know what I could do to be young....because it would be easier to walk if I was young"
"Nothing I can do to reduce me age. For I'm getting older"

Negative construction of the future

Worry about coping if life becomes a struggle. William experienced anxiety about the future because of a belief that his mobility might get worse as he gets older. William's anxiety seemed to be particularly focused on feeling that life might be a struggle in future, and hoping that he will be able to cope.

"I'll be 66 in 3 years time...It'll be more difficult to walk"
"Let's hope that I can still cope and walk when I'm 75"

Sadness at the prospect of dying. William was one of the few participants to mention the prospect of his own death. He talked about his sadness at members of his family dying, and seemed keen to distance himself from the thought of dying himself, expressing sadness that his life will end.

"I wouldn't want to die. Dying is sad"

Determination to maintain independence

William valued his current level of independence, and when talking about the future he expressed a fierce determination to maintain his independence as he gets older. Although William's words appear to express confidence that he will be able to continue looking after himself as he gets older, his mention of having the will power to carry on made me wonder

whether he expects to have to fight to maintain his independence in older age, and whether he feels some anxiety about this.

"I'm active enough to change and shower and get ready. I can manage the shower meself"

"I'll still be able to carry it on..I'll be able to look after meself as I get older. I still, I still have the will power to work the shower and get ready and change and get dressed"

Group analysis

Table 11 - Master themes

Super-ordinate theme	Sub-ordinate theme	Participant						
		Audrey	Frank	Harry	Dorothy	Joyce	Peter	William
Quality of relationships is central to enjoyment of life	Importance of affection and companionship	✓		✓	✓	✓	✓	✓
	Distress at lack of closeness				✓	✓		
Powerlessness	Anxiety about ability to satisfy others	✓	✓	✓				
Needing a sense of purpose		✓	✓	✓	✓	✓		✓
Making sense of getting older	Reactions to changes with age		✓	✓			✓	✓
	Life review: working out a relationship to the past	✓		✓		✓	✓	✓
	Looking to the future	✓		✓				✓

Quality of relationships is central to enjoyment of life

Importance of affection and companionship. Relationships were clearly very important for almost all the participants. They described experiencing a sense of companionship from close friendships, and in some cases a deeper sense of affection. Many of the participants had a

strong attachment to a key person in their life, often a longstanding friend. It seemed important for participants to have reciprocal relationships where they both give and receive affection.

“He’s a good friend to me. Yeah. He’s alright. Well you can be happy and contented with people” (Peter)

“I’m fond of ‘im, just fond of ‘im. Yeah, I like ‘im very much. I almost love ‘im. Maybe it is love, I don’t know what it is” (Harry)

Participants seemed to draw a great deal of pleasure from spending time with friends and enjoying their company. Friendship also gave some participants the experience of being cared about and treated well. Joyce talked about a friend “M” who was only able to visit occasionally but formed an important part of her life as she was able to maintain an internal representation of M and their affectionate relationship as a continuing presence in her life.

“Makes me happy when I’ve got M coming” (Joyce)

“We both tease each other, ‘Ee teases me and I tease ‘im” (Joyce)

“They’re very nice to me. They’re nice to me. I like them. I like them a lot” (Audrey)

“Well you see I can get on with S..I have a cup of coffee with her.....And I love every minute” (Dorothy)

Relationships were also valued as a source of support and comfort during times of need.

“If you went down and something was wrong, one of them would come over and say “what’s wrong today” and you’d be able to tell them” (Audrey)

Distress at lack of closeness. Two participants did not feel that they had enough closeness and affection in their current lives. For Joyce, there was a lack of meaningful relationships. She had lost the people who were most important to her in the past, and had not been able to develop any new relationships which provided the same level of closeness. Access to her remaining friends was limited by reliance on staff to facilitate visits. For Dorothy the issue was that her closest relationships were very ambivalent, making it difficult for her to give and receive affection as much as she would have liked to. This lack of closeness was distressing for both Dorothy and Joyce although they experienced it in different ways.

Dorothy seemed to experience anger and a sense of injustice that she was unable to enjoy sufficient closeness and affection because her relationships were ambivalent *“Me and B can’t get on together”* and others held the power to control her level of access to affection *“She always cuddle him but she won’t let me. That’s not fair is it?”*. Dorothy seemed desperate to give affection, with recipients including cuddly toys *“That cat of mine, he’s lovely. That white one kiss me on a morning”* and staff members *“I love ‘er to death. Makes me a cup of coffee or*

biscuit", but there was a sense of sadness that these relationships could not provide the closeness she seeks *"She's lovely. But I can't talk to her properly"*.

Joyce also described her access to friends being restricted as she was dependent on staff to facilitate visits *"Oh they still bring 'im when they can"*, but her experience seemed to be of quiet disappointment in contrast to Dorothy's anger *"It'd be nice if they do bring him again really but I do miss seeing him"*. Joyce's account was filled with her grief at the loss of close relationships from her past *"Many a times I still 'ave a good cry over her"*. Joyce missed the closeness and affection of these past relationships *"she used to put her arm round me and give me kisses and so did B. They both used to put their arm round me and kiss me. I miss all that now they've gone"*, and this need was not met by her current relationships leaving her with a strong sense of sadness at what she had lost *"I still get upset about them both really. Well I miss 'em both"*.

Both Dorothy and Joyce had developed ways to compensate for the lack of satisfactory relationships, Dorothy by finding a source of affection in her cuddly toys and Joyce by surrounding herself with memories of close relationships from her past, however neither of these strategies were effective in preventing the lack of close relationships from impacting on the women's enjoyment of life.

Anxiety about ability to satisfy others. There was a sense that relationships can be difficult and that fulfilling other people's expectations was a source of anxiety. Several of the participants described embarrassment or anxiety at not being able to satisfy others or get things right. For Audrey, this was embarrassment at not being able to read, *"if you go into a shop and you can't read somethin' you feel stupid to ask them"*, which she had addressed by going to college to learn to read. Harry expressed anxiety about finding life confusing and not being able to satisfy other people, *"You wonder if you've been good enough. You can't tell. If somebody says to you that's wrong, two minutes later they say that's right"*. Frank's account gave a more general sense of finding life difficult and puzzling.

"It don't come easy does it"

"You can't tell can you from one day to the next"

Frank seemed uncomfortable at not being able to satisfy others or get things right, *"They ring up and say "who's been today?" How do I know which doctor's been"*, and he seemed to react

to this by emphasising his knowledge and seeking opportunities to be in charge in order to protect his self-esteem

"That's what I do. Give you some ideas"

"I'm very good at showing you some stuff"

"I'm doing well aren't I. You won't beat this one"

Powerlessness

Several of the participants mentioned experiences which expressed a sense of powerlessness and restricted autonomy; examples included an account of being told that they would be moving house, rather than being consulted. Participants varied in how they reacted to restricted autonomy and power imbalances. Some seemed frustrated but often these incidents were mentioned in passing, with participants seeming to accept them without question. This could perhaps be because this is something they have experienced throughout their lives and become used to. Some accounts included feeling restricted by their reliance on staff to facilitate outings, or access to their friends. Participants generally seemed accepting of this, although there was sometimes a sense of disappointment.

"They're going to try and get me out, depends on't staff you see. How many staff they've got" (Joyce)

Dorothy was the only participant who explicitly focused on her sense of powerlessness, and she spoke about this with a great deal of anger. She described feeling bossed around, unheard and left in uncertainty while others make the decisions.

"Too many bosses"

"Ee won't listen to me"

"I don't know if she's coming tomorrow. She rings up sometimes, tell 'er I'm not coming or summat"

Dorothy was clear that she did not feel that her needs were being met.

"I want a new bed. Nobody will buy me one. It's a shame in't it"

"She goes out and she doesn't take me. That's not fair"

Dorothy had challenged others about this, but she had not been able to change the situation, adding to her sense of powerlessness. She responded to this with defiance, *"I'm not going to put up with it"*, but ultimately she felt that she had little option but to live with her situation because she was dependent on the people around her for help, which left her feeling stuck, and even more powerless.

"I cannot get on with her. No, I'll have to stay here"

It seemed that levels of autonomy had increased over time for many of the participants as a result of service change. For example Harry said *“we have our own money, do your shopping, buy clothes, you didn’t do anything like that. Didn’t do it at [institution]”*. Several participants including Harry and Audrey were happy with their new found autonomy and independence but others still felt limited, ranging from Joyce’s disappointment at not being able to get out more, to Dorothy’s anger at being powerless to get her needs met.

Needing a sense of purpose

Almost all the participants talked about the importance of feeling useful. The experience of feeling wanted and needed at work or feeling that they held a useful role in the house seemed very much valued by participants, and I developed a sense that this was very important for their self-esteem.

“They said don’t leave because, you leave the work’ll suddenly come” (Harry)

“Well I help J to serve their lunch up. And then I go through and tell everybody when their lunch is ready” (Audrey)

“What I do I clean all up. Clean all the table. All the kitchen this morning I did it all” (Dorothy)

“I never had a job....but, but I help people to cater and I help people with all work..I help..with housework” (William)

For some participants, pride in doing something well, for example doing their job to a high standard or doing well at college, added to the sense of achievement from being useful.

“I started reading lessons about a couple of years ago and I’m getting there. I’m getting there” (Harry)

“I like to set the table lovely” (Dorothy)

“I’m very good at showing you some stuff” (Frank)

Meaningful activity seemed particularly important for Harry’s identity, and he seemed to value his image of himself as a hard worker and as someone who is interested in learning and self improvement.

“I don’t get paid but I work you know”

“I’ve always been studying. All my life, I’ve always all my life”

“All I do is just study, study, study. I believe that you learn something all the time”

Harry and Audrey both gained a sense of fulfilment and enjoyment through learning new skills and this focus on self improvement seemed to give them a sense of purpose and achievement.

"They're helping me to read and write at college and that's helped me a lot. That I'll go into a shop now and ask people something" (Audrey)

"I'm still learning to read. I'll be able to improve myself" (Harry)

Making sense of getting older

Reactions to changes with age. Four of the participants (William, Harry, Frank and Peter) talked about how they had experienced changes as result of ageing. Harry and Peter both described feeling that some opportunities have passed, as they now see themselves as too old to do things like get married or have children.

"I would if I'd been younger. I'd like to've had kids but I never met anybody" (Harry)

"No I'm too old for 'em really. Well, you know it'd be too much hassle, I couldn't manage it no way. No, I'm better single" (Peter)

Harry seemed to feel a sense of loss and regret about this, whereas Peter seemed more accepting. I got the impression that he had felt daunted by the prospect of things like getting married and finding a job, and almost felt relieved that his age had now given him an excuse not to pursue these things

"I can still do work, but I mean, they wouldn't employ me now, I'm too old. When you get to 65 you finish"

William had noticed himself slowing down with age, *"As I've got older I've slowed down walking"*, and this had left him feeling vulnerable and sad as he missed being more mobile.

"I can't keep up with the people that's around me and I hold people's hand. Keep an eye on the people that I don't lose staff and residents in the crowds"

"I was young and active when I was 40 years old. I could walk quick. I was alright when I was 40 but now I'm the old age of 62"

William also expressed a great deal of frustration at being slowed down. This sense of frustration was echoed by Frank who seemed frustrated at his loss of abilities and independence.

"Because I'm getting older, I can't keep up with the staff and residents. I can't. I can't walk that quick" (William)

"I used to walk but now I can't. I've been down to the bakers. Can't now" (Frank)

Life review: working out a relationship to the past. Three of the participants talked about experiences of betrayal or abuse in their past. Harry talked with anger about his past, and Audrey described sadness at a number of abusive experiences in her life. Both Harry and

Audrey placed these experiences firmly in the past and gave a sense that their lives had moved on and things had changed for the better.

"They found me abandoned somewhere. I was left. They left me" (Harry)

"He should be struck off, he had no mercy (Harry)

"I didn't like them at all because they hurt you. Well she didn't but he did...and she stood and watched him. That's the bit I hated because she stood and watched him" (Audrey)

Peter also described anger and sadness over losses and unpleasant experiences in his past.

"I went to X hostel, you see, warden, ooh he says I don't like you being here, he used to swear at clients, terrible, horrible place"

"How can I contact 'em if I don't know address. I can't can I? No way. Oh it's no good, you can't "

These feelings seemed to have a strong influence on Peter's current experience, with his anger at past mistreatment and regret over his own actions in the past seemingly making it difficult for him to enjoy life despite his improved living conditions.

"It comes back to you, why you were a bad person, why you done this, done the other"

Audrey and William both expressed contentment with their current lives, with William making comments like *"It's nice here"*. Audrey was very clear that her life had improved over time, with her current experience being better than her past. She captured this theme when she said *"I'm more happy now than I've ever been"*. Joyce also described an improvement over time, saying *"It is better for me 'ere. Am quite alright 'ere now"*. This improvement seemed more superficial and, despite a house move improving Joyce's life somewhat, her experience was still largely one of sadness.

"I feel better. But I still get a bit down in meself. I still feel down in meself"

Several of the participants noted improvements in some aspect of their life over time. Some described positive changes in their self over time, for example Peter described settling down as a positive change over time *"I was always in trouble, I come here, I've changed"*, and Audrey had noticed herself growing in confidence, *"I didn't used to do it because I used to be a lot shyer "* as well as becoming happier. Service change had resulted in increased freedom and independence for several participants, and this was greatly valued.

"I can do what I like. Get up when I like and go out when I like" (Joyce)

"I go to Leeds on me own you know" (Peter)

"I can manage me shower on me own and I can manage to choose clothes on me own" (William)

"I do it all meself. I wouldn't let anybody touch it. I do the flat on my own" (Audrey)

Looking to the future. Three of the participants spoke about their feelings about ageing in the future, and expressed very different outlooks. Harry spoke about ageing and death with a sense of acceptance and an absence of fear. This outlook seemed to be aided by his religious beliefs.

"Just growing old. I'm not worried about it, I don't mind"

"I suppose it's natural, you just accept it. You know it's going to happen. You can't avoid it"

"You die, you can't help it, can't do owt about it"

"As you get older you get nearer to heaven...step by step"

"God'll say Harry come here"

In contrast to Harry's acceptance of ageing, William and Audrey expressed a great deal of fear about what their future holds. William described feeling anxious about getting older, feeling sad at the prospect of dying, and feeling helpless in the face of ageing

"I'll be 66 in 3 years time...It'll be more difficult to walk"

"Let's hope that I can still cope and walk when I'm 75"

"I wouldn't want to die. Dying is sad"

"Nothing I can do to reduce me age. For I'm getting older"

"I'd like if I was young but I don't know what I could do to be young"

Audrey also talked about ageing with fear, her worries included expecting deterioration and unpleasant changes with age.

"Well some older people fall about and that and have to get sticks and that"

"that's sometimes what older people do. They walk out and forget where they're going. Forget where their home is"

"I don't think it would be nice to have your interests and that all changing"

Audrey was also concerned about losing valued activities with age and finding life less enjoyable in future

"As you start to get older it [going to college] might change. 'Cause you might be vulnerable on the buses and that"

"You'll probably not go about smiling as much"

Audrey was very contented with her current lifestyle and a lot of her anxiety around ageing seemed to be related to a fear of losing the wellbeing and independence she currently enjoys.

"My life is alright at the moment because I can get out and about and do things. There's some other folk can't"

DISCUSSION

This chapter summarises the findings of this study in relation to the three research questions the study set out to answer. It outlines how the themes from the group analysis fit in with and add to the existing literature around older people and people with learning disabilities. The chapter discusses the study's strengths and limitations, as well as summarising the clinical relevance of the findings and the implications for further research.

Summary of findings

How do people with learning disabilities experience the ageing process and old age?

The study found that all but one of the participants had some awareness of getting older, although they varied in how they experienced the ageing process. Some were aware of ageing in others but did not feel that the ageing process was part of their current experience. The majority of participants had experienced changes related to ageing. For one participant the changes were experienced as a natural and acceptable part of life, but others experienced anxiety and frustration at losing abilities and independence as they grew older. Participants seemed to experience old age as a time to review their lives and negotiate a relationship to their past as well as looking to the future. There were three key themes relating to participants' experience of old age. Relationships were of central importance and had significant influence on participants' enjoyment of life. Powerlessness and restricted autonomy was part of the experience of old age for the participants in this study, and finding a sense of purpose by maintaining useful roles seemed to be important to participants' self-esteem. This chapter discusses how the themes identified in this study relate to the literature on older adults and people with learning disabilities.

Quality of relationships is central to enjoyment of life

Importance of affection and companionship. Close relationships were very important to participants' sense of wellbeing. Most of the participants had some close friendships and described giving and receiving affection, companionship and support. Relationships were a source of pleasure for participants, and they described enjoying time spent with their friends, for example Joyce said "*Makes me happy when I've got M coming*".

The importance of close relationships for participants in this study is not surprising as the literature suggests that close relationships are of central importance for older people in general (Cavanaugh & Blanchard-Fields, 2006; Jerrome, 1990). Lang and Carstensen (1994) suggest that while social contact is reduced in later-life, close emotional relationships are selectively maintained. For participants, intimate relationships seemed to be meeting the same needs for personal support, sociability and emotional intimacy as they do for other older people (Jerrome, 1990). One difference was that this sample seemed to have fewer close family relationships than many other older people. In general, older people tend to have relatives they would describe as close, with siblings and children tending to be among the closest relatives (Cavanaugh & Blanchard-Fields, 2006; Jerrome, 1990). None of the participants in this study had spouses or children, as is typical of the majority of people with learning disabilities (Bigby, 2004), and some did not have any contact with family members. Some participants described warm relationships with family but in general participants referred to close friends rather than family as their main source of companionship and enjoyment. This focus on friendship rather than family as the main source of companionship does not seem to be unusual among older people, and the literature suggests that friendships are extremely important for older people, providing continuity, reciprocity, fun and emotional intimacy (Cavanaugh & Blanchard-Fields, 2006; Jerrome, 1990). The friendships described by participants included the three themes described by de Vries (1996) as underlying friendships among adults of all ages: emotional intimacy, affection and support; shared activities and interests; and sociability with friends providing a source of fun.

Friendship is recognised as important to the wellbeing of people with learning disabilities, including older people (Brown, 1993; Buys, Boulton-Lewis, Tedman-Jones, Edwards, & Knox, 2008; Knox & Hickson, 2001; Murphy, Cooney, Shea & Casey, 2009). In particular, having someone to feel close to is important (Haigh, 2013; Knox & Hickson, 2001). The important friendships described by participants in this study were mostly the “good mate” type of friendship described by people with learning disabilities in a study by Knox and Hickson (2001), being important relationships with longevity, reciprocal support and common interests. Some of the enjoyable relationships described were with staff, and it has been recognised that relationships with staff can make up an important part of the social network for people with learning disabilities (Haigh et al., 2013).

The findings of this study support the existing evidence that friendship remains important into old age for people with learning disabilities, as it does for other older adults.

Distress at lack of closeness. Some participants lacked close affectionate relationships and were distressed by this lack, reacting with either grief and sadness or anger and injustice. Joyce talked with sadness about missing the affection she got from relationships in her past, and Dorothy was angry that her access to affection was limited, saying "*I want to see C, when do I see him, never? That's not fair*".

As previously discussed, close relationships are recognised as being important for older people. Older people can experience loneliness if they are alone, or if their relationships do not meet their needs and they do not have a confidant (Jerome, 1990). Johnson & Troll (1994) identify some possible constraints to friendship in late life, such as friends of a similar age becoming more likely to be disabled or deceased, and the expected give and take of reciprocal friendship becoming harder to sustain with increasing disability. Despite these constraints they found that older people continued to maintain friendships, although they did not necessarily consider these friends as confidants. They found several factors that could facilitate or constrain the ability to maintain friendships, including ease of access to friends, level of disability and personality factors such as gregariousness. They suggested that while older people may find it difficult to maintain the same types of friendship they had earlier in life, some are able to adapt to this by changing their definition of friendship to include a wider range of acquaintances. Some older adults in the general population may face disruption of social networks due to moving to residential care (Dupuis-Blanchard, Neufeld & Strang, 2009) but when comparing experiences of normal, healthy ageing among people with and without learning disabilities it seems that the barriers are greater for people with learning disabilities.

There is considerable evidence from the literature to suggest that older people with learning disabilities may face more barriers to maintaining close relationships than other older people. Several participants, in common with many in their cohort, have lived in institutions which may have reduced their ties with family and their local community, and led to difficulties with reintegrating into the community and making friends (Amado, 1993; Bigby, 2004; Bigby, 2008). Bigby (2004) also notes that friendships of people with learning disabilities may be context specific and can therefore be disrupted by changes such as moving house or leaving a day-service. People with learning disabilities have more limited opportunities than the general

population to make and maintain interpersonal relationships (Wilson, Robbins & Martin, 2012). The literature suggests that people with learning disabilities have small social networks with few friends outside their families and staff teams (Bigby, 2008; Knox & Hickson, 2001; Krauss, Seltzer & Goodman, 1992; Robertson et al., 2001), although people in supported living settings tend to have more friends outside their family and larger social networks than those living at home (Grant, 1993). People with learning disabilities have limited choice and control over their relationships, with relationships being influenced by disempowering constructions of people with learning disabilities as dependent and different to those without disabilities (Wilson, Robbins & Martin, 2012). Knox and Hickson (2001) described how people with learning disabilities actively try to maintain their friendships through reciprocal invitations, as well as making time for each other and reminiscing but acknowledged that people's level of autonomy can have an impact on their ability to make arrangements to see friends. For some participants in this study, restricted autonomy played a part in leaving them dissatisfied with the amount of affection and closeness available to them, for example where visits to friends or family were dependent on staff or family members' availability. Nunkeosing and John (1997) identify that while people with learning disabilities are capable of forming valuable friendships based on reciprocity and acceptance, relationships can be constrained by the need for support or practical help from others. They found a frequent experience of loneliness either because people lack social contacts or because they lack any relationships with a close intimate attachment. For participants in this study it seemed to be a lack of close attachments rather than a lack of social contacts in general that caused the most distress.

While there has been an acknowledgement in the literature that close relationships are important and that social networks tend to be lacking for people with learning disabilities, there has been less attention given to how people with learning disabilities experience this lack of connectedness. Knox and Hickson (2001) described one participant's grief at the death of a good friend from her past. Her experience of missing and reminiscing about her friend was very similar to that of Joyce. This study adds to the literature by providing an account of the distressing experience of lacking close intimate relationships.

The experiences of participants in this study reflected the consensus in the literature that older people with learning disabilities face barriers to maintaining relationships in addition to those experienced by older people in the general population. Participants' experience of distress at a lack of closeness reinforces the importance of supporting people to maintain close

relationships. The findings of this study give added weight to Knox and Hickson's (2001) conclusion that it is important to give further consideration to ways of supporting older people with learning disabilities to cope with the death of close friends, particularly as they may have limited social networks and lack other close relationships to help them cope with the loss and provide alternative sources of closeness and affection. The findings also reinforce the importance of supporting people to maintain longstanding close relationships as it was clear that close relationships provided pleasure where they were present, and distress where they were absent or restricted.

Anxiety about ability to satisfy others. Several participants reported a sense of anxiety about negotiating relationships and fulfilling other people's expectations, for example Harry said *"You wonder if you've been good enough...If somebody says to you that's wrong, two minutes later they say that's right"*. For participants in this study, it seemed that anxiety about satisfying others was something they had always lived with, due to a sense of finding life difficult and specific difficulties with things like reading and writing. These anxieties seemed to be related to factors connected to the participant's learning disability rather than their age, and as such this experience seemed to have more in common with other people with learning disabilities rather than other older adults. For some participants, it seemed that this anxiety had worsened as they had encountered age-related changes, such as becoming forgetful, making it even more difficult for them to perform well and satisfy others.

Collins and Smyer (2005) suggest that self-esteem may become more variable with age, and that older adults may engage in strategies such as social comparison or disengaging from domains that threaten self-worth, to protect their self-esteem in the face of losses with age. There was some evidence of participants focusing on areas where they performed well in comparison to other people which may have been an example of this type of strategy. For example, Audrey said *"Well my life is alright at the moment because I can get out and about and do things. There's some other folk can't"*, and Frank said *"I'm very good at showing you some stuff"* and *"you won't beat this one"*.

Nunkoosing and John (1997) argue that people with learning disabilities can be anxious about social contact with non-disabled people because they have past experiences of rejection and fear being rejected again. People with learning disabilities may engage in negative social comparisons which can impact on their self-esteem (Dagnan & Sandhu, 1999). Engaging in

comparisons with non-disabled peers has been shown to lower self evaluations among adolescents with learning disabilities (Crabtree & Rutland, 2001). People with learning disabilities often do not categorise themselves using the label of “learning disabilities” (Finlay & Lyons, 2005) and may protect their self-esteem by focusing on their similarities with people who do not have learning disabilities, or on comparisons with other people with learning disabilities who are less able (Finlay & Lyons, 2000). There is some evidence that people with learning disabilities try to protect their self-esteem by making downward social comparisons to people considered inferior (Dagnan & Sandhu, 1999) or devaluing attributes on which they perform poorly (Crabtree & Rutland, 2001), but in some settings there may be limited opportunities for people with learning disabilities to make downward comparisons, and they may lack protective factors such as a range of valued roles (Dagnan & Sandhu, 1999).

This study has provided that some older people with learning disabilities feel anxious about meeting others’ expectations. This is in keeping with findings from the literature of people with learning disabilities, but has not previously been studied in older adults with learning disabilities.

Powerlessness

Several accounts included themes of powerlessness and restricted autonomy, shown in comments such as *“I’d do it but they won’t let me” (Dorothy)*. Some participants described increased autonomy as a result of moving from institutions to supported living settings, and this reflects a general pattern of service change (Caine, Hatton & Emerson, 1998). For example, Harry said *“we ‘ave our own money, do your shopping, buy clothes, you didn’t do anything like that. Didn’t do it at [institution]”*. Despite this change, participants’ accounts revealed restricted autonomy and dependence on staff to facilitate leisure activities and one participant in particular felt a great deal of anger at feeling powerless, unheard and dependent on others to meet her needs. This seemed to reflect the wider experience of disempowerment among people with learning disabilities found in the literature. For example Owen and Wilson (2006) suggest that dependence, powerlessness and restrictions in choice and control are part of life for many people with learning disabilities, and Manners, Russ and Carruthers (2006) reflect on one woman’s experience of feeling powerless as a person with a learning disability. Goble (1999) describes how disempowering it is for people with learning disabilities to be dependent on staff and services, whilst having little knowledge of staff roles and systems of working.

Halliday and Robbins (2006) comment that for people with learning disabilities, having their ideas listened to in therapy is a new and positive experience as they rarely get heard. Powerlessness has also been identified as an issue for older people with learning disabilities. Bigby and Knox (2009) found that older people with learning disabilities felt that decisions were made for them by services and family members. Strnadova and Evans (2012) interviewed 55 women with learning disabilities aged between 40 and 78. They carried out semi-structured interviews and analysed the data using grounded theory. They found that the core phenomenon influencing the women's perceived quality of life was a lack of control over their own life. This was caused by a combination of the women's disability, health problems, handicapping behaviour of their carers and limited opportunities.

There is very little discussion of powerlessness in texts on adult development and ageing suggesting that powerlessness is not a common experience for older people among the general population, or perhaps it has not been recognised and explored. Some older people experience dependency, for example as a result of physical illness or dementia, but this is not the case for all older people (Bond & Cabrero, 2007). Articles on older people living with chronic physical illness (Efraimsson, Rasmussen, Gilje & Sandman, 2003; Yu, Lee, Kwong, Thompson & Woo, 2007), or in residential care (Lee, Woo & Mackenzie, 2002) do acknowledge powerlessness as part of their experience but their findings are not directly relevant to this study, which is focused on experiences of healthy ageing.

The experience of powerlessness appears to be one way in which this group of participants may differ from older people in the general population. It seemed that participants' experience of powerlessness largely arose from reliance on others as a result of their learning disability. It is already known that powerlessness is experienced by older people with learning disabilities (Bigby & Knox, 2009; Strnadova & Evans, 2012). This study has provided an additional insight into how participants reacted to and made sense of this experience, with reactions ranging from unquestioning acceptance, through disappointment to anger and resentment.

Needing a sense of purpose

The importance of being useful was present in most participants' accounts. Some participants took part in voluntary work and others gained a sense of purpose by making themselves useful at home, for example William said *"I never had a job....but, but I help people to cater and I help*

people with all work..I help..with housework". Participants seemed to gain pride and self-worth from feeling that they held meaningful roles, and did their jobs well. Several participants were involved in learning new skills and this provided enjoyment and fulfilment.

Many older people in the general population will have worked and retired. Work can provide many benefits in addition to financial reward, such as mental stimulation, social contact, focus and meaning. After retirement it becomes important for older people to replace these benefits through leisure activities, voluntary work or other productive activities such as caring for grandchildren (Cavanaugh & Blanchard-Fields, 2006; Kunemund & Kolland, 2007; Papalia, Sterns, Feldman & Camp, 2007; Whitbourne, 2008).

The literature suggests that older people with learning disabilities want to continue working, learning and taking part in activities (Ashman, Suttie & Bramley, 1995; Benz & Kennann, 1988; Bigby, 2004). This was reflected in the findings of this study. Several participants had maintained voluntary work or continued attending day-services, those who did not work found useful jobs to do around the house and several participants expressed a continued interest in learning. This is not surprising as keeping active, being engaged in meaningful activities and having opportunities to learn and maintain skills are recognised as being important for older people with learning disabilities (Bigby & Knox, 2009; Buys et al., 2008). Helping out at work or at home seemed to provide participants with valuable roles and a sense of being useful and valued by others, which has been shown to be important to people with learning disabilities, including older people (Bigby & Knox, 2009; Haigh et al., 2013).

It has been suggested that older people with learning disabilities rarely express wanting to retire due to fear of boredom and loss of relationships in retirement, and the sense of meaning and purpose provided by work (Ashman, Suttie & Bramley, 1995; Bigby, 2004; McDermott & Edwards, 2012). This study suggests that the picture is more complex. Five of the participants described themselves as having worked at some point, either doing voluntary work or attending day-services which they referred to as "work". Three participants intended to continue working or attending day-services in the future, with no desire to retire. However two participants had chosen to retire. In one case this appeared to be because she had disliked her day-service and was glad of the chance to leave. Another participant described feeling ready for a rest, and held the belief that most people would want to retire at 65.

For participants in this study, jobs and day-services seemed to provide meaning, valued roles, self-worth and social networks. In order to feel able to retire people would need to be confident that these needs could be met in other ways. This is also true for older people in the general population, but people with learning disabilities are likely to need more support to find ways to compensate for the loss of the benefits of work (Bigby, 2004; Bigby, Wilson, Balandin & Stancliffe, 2011).

How do people with learning disabilities make sense of the ageing process?

Participants in the study used a range of beliefs about ageing to make sense of their own ageing process. For example, Audrey described experiences of watching family members deteriorate as they reached old age, but she has not noticed any deterioration in herself yet. She had made sense of this by conceptualising ageing as a process of mental and physical decline that begins when someone becomes “old” at around 80 or 90 years old. As a result she viewed ageing as something that is not yet relevant to her but will affect her in future. Harry had used his religious beliefs to help him make sense of getting older, seeing ageing and death as an ongoing natural process that will bring him closer to God. Several participants used ideas about what is “normal” as people get older to help them make sense of the changes they had experienced. For example changes such as walking slower and becoming forgetful were referred to as normal aspects of getting older. This view of normal ageing seemed to be based on a combination of watching friends and family get older, and listening to the people around them talking about ageing, for example saying that certain changes are to be expected as they get older.

Making sense of getting older

Reactions to changes with age. Four of the seven participants were aware of changes with age. This included some positive psychological changes such as increased tolerance, but the main changes described by participants were the feeling that certain opportunities are now in the past, physical slowing and loss of independence.

Participants varied in their response to feeling that opportunities had passed, from regret to acceptance and possibly relief that age had provided a socially acceptable explanation for being unable to do some things. Participants reacted with sadness and frustration to losses

with age, including physical ability and independence, and seemed to mourn the loss of their previous abilities. Jenkins (2010) suggests that deterioration with age may have less impact for people with learning disabilities who already have more problems with health, eyesight, hearing and mobility than the general population. While it may be true that the changes with age are less of a contrast for people with learning disabilities, it was clear that participants in this study highly valued their health and mobility and the changes they had experienced with age were experienced as significant losses and threats to future independence. For example, William said *“when I was 50 I could walk quick...but then I couldn’t walk quick and I was slowed down”, “I’d like if I was young....because it would be easier to walk if I was young”* and *“Let’s hope that I can still cope and walk when I’m 75”*.

Old age is a period of adjustment to change for the general population, which may include loss of job role and reduced income, loss of spouse and increased frailty as well as more positive changes such as becoming a grandparent (Coleman, 1990). Losses of various kinds are a common experience in old age, and older people appear to have an enhanced ability to adjust to change and loss (Marcoen, Coleman & O’Hanlon, 2007; Woods, 1999). The success of coping depends on a wide range of factors including personal resources, self-esteem, perceived wellbeing, protective factors such as availability of a confidant, and the subjective experience of losses (Coleman, 1990; Whitbourne, 2008; Woods, 1999). Adjusting to the changes of old age is part of a lifelong process of development and adjustment. Hendry and Kloep’s (2002) model of lifespan development suggests that development involves negotiating a series of challenges. Individuals differ in the resources they possess to help them respond to these challenges.

Ageing for people with learning disabilities involves tasks similar to those negotiated by the general population including adjustment to losses and reduced physical abilities, adjustment to changing roles and acceptance of mortality (Seltzer 1985). People with learning disabilities are less likely to experience some of the changes associated with old age in the general population, such as becoming a grandparent. The experience of this process may be different and more challenging for people with learning disabilities because of factors such as reduced problem-solving capacity, poor informal support networks and restricted life experiences leaving them with fewer resources to cope with change and loss as part of ageing (Seltzer, 1985; Thorpe, Davidson & Janicki, 2001).

My participants' conceptualisation of ageing showed some similarities and some differences to the existing literature, outlined in the introduction chapter. Erickson, Krauss & Seltzer's (1989) study of perceptions of old age among older people with learning disabilities found responses relating to anticipated physical health changes, and general acknowledgement of one's own ageing, both of which were replicated in this study. Another similarity between the findings of this study and Erickson et al. (1989) was that participants anticipated changes in their social life with some being pleased at the idea of taking it easy, while others worried about the loss of social activities. Many of Erickson et al.'s (1989) participants associated getting older with stopping work, whereas for participants in this study retirement was seen as optional rather than automatic with old age. This study did not show the same degree of denial of ageing that was found by Erickson et al. (1989), possibly because the mean age of participants was higher, at 69.43 compared to 62.38 in Erickson et al. (1989). One participant talked about ageing as something that has not happened to her yet, but she was only sixty so it was understandable that she did not consider herself old yet. Participants in this study showed some association between ageing and death as found by Erickson et al. (1989), with several participants talking about the death of friends and family members, and two participants acknowledging their own mortality. Participants mostly focused on concrete physical characteristics such as slower walking, which was consistent with previous findings on attitudes of people with learning disabilities towards ageing (Lifshitz, 2002). Participants seemed to have a stereotypical view of ageing including having grey hair, being forgetful and having difficulty, in keeping with Lifshitz's (2002) findings on conceptualisation of ageing by people with learning disabilities. Attitudes towards ageing in this study were largely negative. This was surprising given that participants were over 60, and Lifshitz (2002) found that older people with learning disabilities had a more balanced view of ageing than younger people, in common with the general population.

One participant did not seem to have much awareness of the ageing process, and only four of the participants were able to discuss changes they have experienced with age. It has been suggested that people with learning disabilities may be less aware of ageing because they lack some of the markers available to people in the general population, such as becoming grandparents and retirement, and as a result there may be little distinction between life stages apart from the changes in their own body (Dodd, 2008). One participant stated that in her understanding, the term "getting older" only applies to the deterioration that happens in very old age. There is evidence that people with learning disabilities lack information and understanding around normal changes with age such as the menopause (McCarthy & Millard,

2003). This suggests a need for psychoeducational work for people with learning disabilities to increase their understanding of ageing as a process. Dodd (2008) points out that a psychoeducational approach is already used for peers of people with Down's syndrome and dementia, and has resulted in them becoming more aware and more tolerant of the changes their peer is experiencing. She suggests that a similar approach is needed to improve the transition to old age for people with learning disabilities, and this study has added evidence to support her suggestion. Some participants were clearly aware of age-related changes and used the concept of getting older to make sense of them, so it would be helpful for them to have more understanding of the ageing process to aid them in understanding what is happening to them.

Life review: working out a relationship to the past. Several participants seemed to be going through a process of reviewing their past, negotiating a relationship with past experiences and making sense of how their past has influenced their current experience. Some participants had come to terms with their difficult past and described a marked contrast with their current experience of contentment. For others, distress over past mistreatment continues to be part of their current experience. The process that participants described seemed similar to the process of life review described by Butler (1974). Butler described this mental process as a normal activity of old age which allows older people to come to terms with the life they have lived. Life review involves reflecting on past experiences, including unresolved conflicts. This allows conflicts to be reintegrated, and allows the person to reflect on significance and meaning that past events hold for their current life. If successful, life review can enable people to understand and learn from negative experiences in their past and give a feeling of peace. This can enable older people to come to terms with the life they have lived and prepare for death. However it is also possible for people to be left with feelings of guilt or depression if certain events or actions have not been resolved (Butler, 1974). It has been suggested that reminiscence can also be useful for identity maintenance, as stressing the value of past experiences and achievements can maintain a sense of self-worth, helping to minimise the discrepancy between the life they would like to live and the reality of their life following losses with age (Coleman, 1990). The participants in this study did not seem to be using reminiscence in this way. The reminiscence described by some participants seemed to be the type termed "integrative reminiscence" by Wong and Watt (1991), which functions to achieve self-worth, coherence and reconciliation with the past in a similar way to Butler's (1974) concept of life review. In contrast Peter seemed to describe "obsessive reminiscence" (Wong & Watt, 1991),

with guilt and rumination over past actions indicating difficulty in integrating negative events from the past. For example, Peter said “It comes back to you, why you were a bad person, why you done this, done the other”.

By telling the story of their lives, participants seemed to be constructing a personal narrative, which may have been a way for them to better understand themselves and their worlds (Murray, 2003). Life story work aims to aid reminiscence, giving people an opportunity to talk about and record their past experiences in a way that may benefit their current situation. This type of approach is used with a number of client groups including older adults and people with learning disabilities (McKeown, Clarke & Repper, 2006; Moya, 2009). For people with learning disabilities who may struggle to tell their story, life story books can also serve the function of helping support staff to get to know the person and understand their history (Meininger, 2005; Moya, 2009). The literature around people with learning disabilities seems to focus on life story work as a means of producing a life story book to hold the person’s biographical history, rather than on the process of facilitating the process of life review as seen in the literature on older adults. It has been recommended that life story books be used more widely with people with learning disabilities and used as a tool to help them reflect on their life and plan for their future, not just to produce a biography (Dodd, 2008). The findings of this study strengthen Dodd’s recommendation and also suggest that there is an additional need for work to focus on helping older people with learning disabilities to come to terms with and integrate their past experiences. It is already known that reminiscence group work can be valuable and meaningful for older people with learning disabilities but research has focused on the effect on people’s wellbeing and mood rather than on the process of life review (Van Puyenbroeck & Maes, 2009). This study provides evidence that some older people with learning disabilities can engage in a process of reminiscence and life review as a way of coming to terms with what has happened in their past and how they have reached their current situation. Some participants seemed to be struggling with this process of integration, and it would be useful to give consideration to how older people with learning disabilities can be supported in the process of life review.

A number of participants described life improving over time, with changes including increased freedom, independence, confidence and happiness. It is important to remember that participants have experienced a great deal of change in learning disability services which is likely to have influenced the change in their experience. Several participants had moved from

institutions to supported living accommodation where they have a lot more independence and freedom. Support for people with learning disabilities has changed a lot during the lifetime of participants in this study, moving towards an emphasis on integration into the community, independence and choice and an increased recognition of the rights of people with learning disabilities (Abraham, Cooper & Ferris, 2010; Cadbury & Whitmore, 2010; DoH, 2001b; DoH, 2009).

Looking to the future. Several participants described their attitudes towards ageing in the future. One person was accepting of growing old and faced the future without fear. In contrast, two other participants were fearful of the future and described worries about deterioration including loss of mobility and independence. It seemed that this was related to participants' negative view of ageing as a process of deterioration. As previously discussed, one recommendation from this study is to provide a programme of psychoeducation to improve understanding of ageing among people with learning disabilities. This would leave people with a more rounded view of the ageing process and more understanding of the changes they are likely to experience, and it seems likely that this would help to alleviate some of the fear described by participants as they looked forward to a negative and uncertain future.

Most participants seemed to make an association between old age and death, with several talking about the deaths of friends and family members in old age. Only two participants talked about their own mortality, and they had different outlooks towards death. Harry accepted the prospect of death and viewed it without fear, whereas William expressed sadness at the thought of dying. The key tasks of old age, life review and developing integrity are thought to be triggered by an awareness that the end of life is approaching (Butler, 1974; Erikson, 1973). It seemed that most participants had this awareness to some extent, and some had clearly begun a process of life review as discussed previously. Erikson's (1973) concept of integrity includes the need to reach acceptance of the life that has been lived and to accept the prospect of death without fear. This forms the basis of the psychosocial crisis of integrity versus despair to be negotiated in old age. It is not always successfully negotiated, with some people being left with a sense of meaningless and despair (Erikson, 1982), and it stands to reason that some people with learning disabilities would also fail to achieve integrity and remain despairing and fearful of death. The participants who spoke about death seemed to be at different stages in the process of coming to terms with their own mortality, and other

participants were not able to articulate their thoughts about death. There is little information in the literature about how people with learning disabilities view their own mortality, and this study provides evidence that some older people with learning disabilities are aware of the approaching end of life, and are actively trying to come to terms with this. Studies of older people in the general population have found that older people think more about death than younger people do, and are more accepting and less fearful of death (Cameron, Stewart & Biber, 1973; Kalish & Reynolds, 1976; Kastenbaum, 1999; Keller, Sherry & Piotrowski, 1984). The literature does not show whether the same is true for people with learning disabilities, but Lifshitz (2002) found that fear of ageing was greatest among young people with learning disabilities and decreased with age, so it seems possible that the same pattern exists with fear of death as found in the general population. The participant who was accepting of death had a strong religious faith, which ties in with the finding that people with strong religious belief have less death anxiety (Kalish & Reynolds, 1976). The findings of this study tentatively suggest that older people with learning disabilities have begun thinking about death and going through a process of coming to terms with the idea, helped by factors such as religious faith, in the same way that older people in the general population do. However as only two participants spoke about their own mortality, it is not possible to draw any firm conclusions, and more research in this area would be useful.

What meaning does the ageing process have for people in terms of their identity?

The participants did not explicitly discuss how ageing had affected their sense of identity, but in the analysis it was clear that many of the participants were aware that they had changed with age, and this seemed to influence how they viewed themselves. The participants varied in the degree to which they accepted old age as part of their identity. One participant was very clear that she does not identify herself as “old” yet and for some others age did not seem to be a salient part of their identity, but several participants did identify themselves as old. The concept of old age had a range of meanings for participants. These meanings appeared to have been influenced by observing people around them growing old, as well as their own ageing process. It seems likely that participants will also have been influenced by discourses around ageing among their families, staff teams and wider society.

Participants’ views of ageing were largely negative and this may reflect the negative stereotypes in societal concepts of old age. The language used around old age often has

negative connotations and old age tends to be presented in a negative way in the media (Blythway, 1995). Participants may have internalised some of the negative constructions of ageing in society, affecting their own experience of ageing. Being seen as an older person could expose participants to additional discrimination from society, as older people are seen to have lower social value than younger people (Whitbourne, 2008). The multiple jeopardy hypothesis (Ferraro & Farmer, 1996) suggest that older adults from a minority group are at risk of additional discrimination, as ageism interacts with other biases such as those against women or people from minority ethnic groups. Older people with learning disabilities could be considered to be experiencing double jeopardy of discrimination as they are part of at least two groups viewed as disadvantaged in society: older people and people with learning disabilities (Bigby, 2004; MacDonald & Tyson, 1988). They may also be part of other disadvantaged groups depending on their gender, ethnicity and socioeconomic status. There are alternative viewpoints to the multiple jeopardy hypothesis. The idea of age-as-leveller (Ferraro & Farmer, 1996) suggests that ageism overrides other forms of discrimination and all older adults are treated according to the same stereotypes. This idea would mean that older people with learning disabilities would be no more disadvantaged by discrimination than any other older people. Another view is the inoculation hypothesis (Whitbourne, 2008), suggesting that women and people from minority groups have become accustomed to discrimination and stereotyping over their lifetime, and as a result they are immune to the effects of ageism. Jenkins (2010) made a similar suggestion for people with learning disabilities, that the negative effect of being labelled as "old" may be lessened as they have already experienced lifelong negativity from having the label of "learning disability". The findings of this study did not fully support this idea. It was clear that some participants had experienced longstanding anxiety over their ability to satisfy others, and to some extent getting old provided a more socially acceptable reason for finding things difficult, however for many participants getting old represented a threat to valued abilities and independence so it seems likely that the label of "old" may have a negative effect on their self-esteem in addition to existing stigma from the learning disability label.

For some participants there seemed to be a contrast between their current image of themselves as an older person slowing down and becoming more vulnerable, and their image of their younger self as more active and independent. Most participants had chosen to maintain some type of useful role whether in formal employment or within their home, as feeling useful and purposeful seemed to be an important part of their identity which had not

changed with age. Most participants had maintained a coherent sense of self and felt that they are the same person they have always been, as reported Troll and Skaff (1997) with older adults in the general population.

Strengths and limitations

This section will begin by discussing the strengths and limitations of each stage of this study. Guidelines developed by Elliot, Fischer and Rennie (1999) for the publication of qualitative research were used to aid consideration of the strengths and weaknesses.

Study design. A major strength of this study was that it looked at the experiences of people with learning disabilities by interviewing the people themselves, which is important as it acknowledges that people with learning disabilities have views and experiences that are worth hearing and understanding (Nind, 2008). The selection of IPA as a method enabled an in-depth examination of individual experiences of ageing.

Sample and recruitment. A total of nine interviews were completed with seven participants, which is a suitable sample size for an IPA study (Smith, Flowers & Larkin, 2009). The small sample enabled the study to achieve an in-depth account of individual experience, but it must be emphasised that this study is a description of the experience of a small group of people, and it should not be assumed that other older people with learning disabilities will share the same experience. A strength of the research was that all participants were over 60 with a mean age of 69.43, whereas some previous studies on ageing in people with learning disabilities have included people as young as 40 (Bigby, 2004). The higher age limit in this study provides a more accurate picture of the experiences of older adults with learning disabilities. Recruitment was carried out through services for people with learning disabilities, with most participants being recruited through Community Learning Disability Teams. This resulted in a limitation, as it is likely that the majority of people accessing a Community Learning Disability Team would have some form of physical or mental health difficulty, which is problematic as this study aimed to look at experiences of normal, healthy ageing. The individual analyses acknowledge that the meaning of ageing for some participants may have been affected by their experiences of pain or low mood. Recruitment through third parties was necessary but it represented a limitation as recruitment was affected by staff opinions on who would be most suited to the study. This may have introduced some bias, so for example staff may have

selected people who seemed aware of ageing on the assumption that they would be more interested in the study. A limitation was that the study only included people with relatively mild learning disabilities. This was due to the nature of the study, as participants needed to have sufficient verbal ability to take part in an in-depth interview, although the questions were simplified as much as possible. A strength was that recruitment material was well designed and accessible, enabling people to understand the study and make informed decisions about whether to participate.

Data collection. Data was collected through semi-structured interviews, which tend to be the preferred way of gathering data in IPA studies (Reid, Flowers & Larkin, 2005). Questions and prompts were designed around topics likely to be of interest on the basis of a literature review. On reflection, it would have been useful to have included attitudes towards death as an additional topic as this came up in a few accounts. Questions were designed to be accessible for people with learning disabilities, and on the whole participants were able to understand and respond to questions. However there were a number of occasions where participants struggled to understand questions, or to articulate their responses. On some occasions I was able to use skills from my work with people with learning disabilities to reword questions, enabling people to respond. On some occasions this was not possible and at some points I chose not to follow up on a topic if a participant was struggling and I felt it may cause them distress to continue. I was able to use my clinical judgement as a Psychologist in Clinical Training to make these decisions. As a result of the difficulties outlined, the interviews varied in depth with some participants being very eloquent and providing detailed accounts of their experience whereas other interviews were thinner, which was a limitation of the study.

Data analysis. Some participants did not have the vocabulary to communicate the complexity of their experience of ageing. In some cases more interpretation was necessary to read between the lines and understand the participants experience when they had not been able to articulate it fully. I had to find a balance between applying enough interpretation to bring out the meaning in participants' accounts, while ensuring that my interpretation remained grounded in their accounts. I did this by repeatedly going back to the interview recordings, and applying quality checks. A colleague carrying out a study using IPA was asked to review a sample of anonymised coded transcript, and her comments on the analysis were taken into account. At each stage of the analysis, extracts were shared with a supervisor experienced in the use of IPA to check the credibility of the themes. It was difficult to determine how much of

the participants' experience was specifically related to ageing, and how much was related to the experience of living with a learning disability. It is likely that some of the experiences and meanings reported in this study would also be relevant to younger people with a learning disability. A strength was that the study captured participant's unique perspectives and showed the range of experiences amongst the group. This could also be considered a limitation, given that this small group of participants varied so much in their experience it is likely that there is an even wider range of experiences among older people with learning disabilities, which this study was unable to capture given its small sample size.

Clinical Implications

It was clear that a number of participants experienced feelings of powerlessness and restricted autonomy due to relying on staff or family members to facilitate activities. Service change had increased levels of autonomy for many participants, but some were still experiencing disappointment and frustration at their activities and contact with loved ones being restricted by the availability of staff. It will be important for service to bear in mind the importance of maximising autonomy and enabling older people with learning disabilities to take control over their lives as far as possible.

The findings of this study highlighted the importance of friendship and companionship for older people with learning disabilities, and in particular the importance of close, affectionate relationships. It is vitally important for services to recognise the importance of any longstanding close friendships that a person may have, and to support the person to maintain these friendships. This will be particularly relevant when people move house, or when they stop or change their day-service or other activities, perhaps due to retirement. Consideration could also be given to ensuring that existing friendships are not restricted by practical difficulties such as unavailability of staff meaning that visits are cancelled. As people with learning disabilities age, it becomes more likely that they will experience bereavements among their social network. Given the central importance of close relationships in people's lives it is important for services to recognise the likelihood of distress when someone loses a loved one, and to provide appropriate support to enable the person to understand and come to terms with their loss.

Work was highly valued by participants as a source of valued roles, meaningful activity and social networks. Those who did not work found the same benefits through attending day-services or by helping out at home or in their community. Many participants were keen to maintain their work or day-service role despite realising that they could retire if they wanted to. Day-services and employment providers will need to accommodate this by considering how employee needs may change as they get older, and how their work can be adjusted to accommodate changing needs while still providing job satisfaction. Services will need to consider how to support people with learning disabilities in planning for their retirement. It will be important to find alternative ways of meeting the person's need for a sense of purpose and meaning, and ensuring that they still have roles where they feel valued and useful. Consideration also needs to be given to how retirement will affect the person's social network, and how they can be supported to maintain any friendships they have built up at work or day-service.

This study has shown that older people with learning disabilities are capable of engaging in a process of life review, and that they can struggle with this process just as any other older adult can. At present, life review work is not commonly used in services for people with learning disabilities, and this is something that needs to be addressed. Life story work is used fairly often with people with learning disabilities, but most commonly with the aim of producing a biography to help staff get to know the person and to provide a written history for people who might struggle to remember or communicate their own life story. Life story books could usefully be employed more often as a way of structuring and facilitating reminiscence to enable older people with learning disabilities to reflect on the life they have lived and make sense of how they have reached their current point in life. It is important to be aware that reminiscence in itself may not be sufficient. Some older people with learning disabilities may want or need to engage in a more in-depth process of life review to enable them to integrate past experiences and reach acceptance of their past and the approaching end of their life. It will be necessary to consider which service would be best placed to offer this type of therapeutic work when it is needed. Services for older adults are most likely to have expertise in facilitating life review, but may not feel confident adapting this work to suit the needs of people with learning disabilities. There may need to be collaboration between older adults' services and services for people with learning disabilities, for example an older adults' psychologist providing consultation on life review work to staff in a Community Learning Disability Team.

Understanding of the ageing process varied between participants, and there is likely to be a huge variation in understanding among the population of older adults with learning disabilities. Several of the participants were aware of changes happening to them and attributed these changes to getting older, but their understanding of what getting older means was largely a negative, stereotypical view of ageing. Some participants were worried about getting older, and I would suggest that this fear was partly due to not fully understanding what was happening to them and what would happen in future. There is a lack of information on the ageing process for people with learning disabilities. It seems common for people to go through the ageing process without being given any preparation or explanation, and as a result people with learning disabilities are left to form a tentative understanding of ageing based on the most visible signs of ageing in those around them, and images or comments about old people which are largely negative due to ageist stereotypes in society. This seems unacceptable, and I recommend that services for people with learning disabilities develop a package of psychoeducation around the normal ageing process. This could help people with learning disabilities to develop a fuller understanding of what getting older means in order to prepare for and make sense of their own ageing process. Services will need to give careful consideration to what information should be included, and accessible ways to deliver the information in group and individual formats. It may also be useful to provide training for staff working with people with learning disabilities to increase their awareness of stereotypes that may cause them to inadvertently work differently with older people.

Future Research

This study found that some participants were aware of their own mortality and able to articulate their attitude towards death. Death was not included as a topic for investigation when the study was designed and as a result participants' feelings towards and conceptualisation of death were not followed up in great depth, and this topic was not discussed with participants unless they brought it up. Further research to explore how people with learning disabilities conceptualise death would be a useful addition to the literature. This study identified that participants were engaged in a process of life review. Further research could look into whether younger people with learning disabilities engage in a similar process, or whether it is specific to old age. Further information on the process of life review for people with learning disabilities would be of interest, and in particular how this process affects people's level of acceptance of past events and their own mortality.

It is recommended that services develop psychoeducation around the ageing process for people with learning disabilities. When the intervention has been designed there will need to be a rigorous process of evaluation to ensure that the package is meeting its aim of increasing understanding of the ageing process. Further research will then be needed to investigate the effect of increased understanding of ageing, for example looking at whether or not people with more understanding of the ageing process feel more accepting and less fearful of age-related changes.

Conclusions

On a personal level I was struck by the diversity in participants' accounts. Some participants surprised me with their philosophical attitude towards ageing, some had clearly thought a lot about getting older while others had little awareness of ageing. Some participants were struggling with bodily changes with only a limited understanding of their wider process of ageing, and I was aware that I would find it very frightening to experience changes without having a framework to make sense of them. I gained a much richer understanding of how people with learning disabilities make sense of the ageing process which will be valuable for my future clinical work.

This study has provided an insight into how a group of older people with learning disabilities experience the ageing process and old age, and what meanings it holds for them. The findings of the study have added to the existing literature by providing evidence that older people with learning disabilities are capable of engaging in a process of life review. The findings have also provided new information about the degree to which people with learning disabilities are aware of their own age-related changes and how they make sense of these changes as part of the wider process of getting older. The study has raised the issue that some older people with learning disabilities have a negative, stereotypical view of ageing as a process of deterioration and as a result, find it difficult to make sense of the ageing process outside this stereotype and fear deterioration in the future as they get older. I hope that these findings will make it possible for services to take action to improve understanding of the ageing process and facilitate a process of life review for people with learning disabilities. This will hopefully result in a smoother transition to old age and improved quality of life for older people with learning disabilities.

REFERENCES

- Abraham, J., Cooper, M. & Ferris, G. (2010). Spending time and money: memories of life in St. Lawrences. *British Journal of Learning Disabilities*, 38, 95-96.
- Amado A. (ed.). (1993). *Friendships and Community Connections between People with and without Developmental Disability*. Baltimore: Brookes.
- Andrews, J. & Rolph, S. (2000). Scrub, scrub, scrub...bad times and good times, some of the jobs I've had in my life. In: Atkinson, D., McCarthy, M., Walmsley, J., Cooper, M., Rolph, S., Aspis, S., Barrette, P., Coventry, M. & Ferris, G. (Eds.). *Good Times, Bad Times: Women with Learning Difficulties Telling their Stories*. Kidderminster: BILD Publications.
- 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.
- Askham, J., Ferring, D. & Lamura, G. (2007). Personal relationships in later life. In: Bond, J., Peace, S. Dittman-Kohli, F. & Westerhof, G. (Eds.) *Ageing in Society: European Perspectives on Gerontology*, third edition. London: SAGE Publications Ltd.
- Atkinson, D. (2005). Research as social work: participatory research in learning disability. *British Journal of Social Work*, 35, 425-434.
- Barron, D. (2000). From community to institution – and back again. In: Brigham, L., Atkinson, D., Jackson, M., Rolph, S. & Walmsley, J. (Eds.). *Crossing Boundaries. Change and Continuity in the History of Learning Disability*. Kidderminster: BILD Publications.
- Beart, S. (2005). 'I won't think of meself as a learning disability. But I have': social identity and self-advocacy. *British Journal of Learning Disabilities*, 33, 128-131.
- Beart, S., Hardy, G. & Buchan, L. (2005). How people with intellectual disabilities view their social identity: a review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18, 47-56.
- Benz, M.R. & Kennann, K.E. (1988). Educational Experiences, Needs and Interests of Older Adults with Mental Retardation. *Educational Gerontology*, 14 (6), 509-523.
- Bigby, C. (1997). Later life for adults with intellectual disability: A time of opportunity and vulnerability. *Journal of Intellectual & Developmental Disability*, 22, 97-108.
- Bigby, C. (2004). *Ageing with a Lifelong Disability: A Guide to Practice, Program and Policy Issues for Human Services Professionals*. London: Jessica Kingsley Publishers.
- Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual & Developmental Disability*, 33 (2), 148-157.

- Bigby, C. & Knox, M. (2009). "I Want to See the Queen": Experiences of Service Use by Ageing People with an Intellectual Disability. *Australian Social Work*, 62 (2), 216-231.
- Bigby, C., Wilson, N.J., Balandin, S. & Stancliffe, R.J. (2011). Disconnected expectations: Staff, family, and supported employee perspectives about retirement. *Journal of Intellectual & Developmental Disability*, 36 (3), 167-174.
- Biggs, S. (2005). Beyond Appearances: Perspectives on Identity in Later Life and Some Implications for Method. *Journal of Gerontology*, 60(3), S118-S128.
- Blythway, B. (1995). *Ageism*. Buckingham: Open University Press.
- Bond, J. & Cabrero, G.R. (2007). Health and dependency in later life. In: Bond, J., Peace, S., Dittman-Kohli, F. & Westerhof, G. (Eds.) *Ageing in Society: European Perspectives on Gerontology*, third edition. London: SAGE Publications Ltd.
- Bowling, A. (2005). *Ageing Well: Quality of Life in Old Age*. Maidenhead: Open University Press.
- Brown, R. (1993). Quality of life issues in ageing and intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 219-227.
- Brown, J., Dodd, K. & Vetere, A. (2009). 'I am a normal man': a narrative analysis of older people with Down's syndrome who lived in institutionalised settings. *British Journal of Learning Disabilities*, early view, published online 15 December 2009, 1-8.
- Bullington, J. (2006). Body and self: a phenomenological study on the ageing body and identity. *Medical Humanities*, 32, 25-31.
- Butler, R. (1974). Successful aging and the role of life review. *Journal of the American Geriatrics Society*, 22, 529-535.
- Buys, L., Boulton-Lewis, G., Tedman-Jones, J., Edwards, H. & Knox, M. (2008). Issues of active aging: Perceptions of older people with lifelong intellectual disability. *Australasian Journal on Ageing*, 27, 67-71.
- Cadbury, H. & Whitmore, M. (2010). Spending time in Normansfield: changes in the day to day life of Patricia Collen. *British Journal of Learning Disabilities*, 38, 120-126.
- Caine, A., Hatton, C. & Emerson, C. (1998). Service Provision. In: Emerson, E., Hatton, C., Bromley, J. & Caine, A. (Eds.) *Clinical Psychology and People with Intellectual Disabilities*. Chichester: Wiley & Sons, Ltd.
- Cameron, L. & Murphy, J. (2006). Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 35, 113-120.
- Cameron, P., Stewart, L. & Biber, H. (1973). Consciousness of death across the life-span. *Journal of Gerontology*, 28, 92-95.

- Cavanaugh, J.C. & Blanchard-Fields, F. (2006). *Adult Development and Aging*. Fifth Edition. Belmont: Thomson Learning Inc.
- Coleman, P. (1990). Adjustment in later life. In: Bond, J. & Coleman, P. (Eds.) *Ageing in Society: An Introduction to Social Gerontology*. London: SAGE Publications Ltd.
- Collins, A.L. & Smyer, M.A. (2005). The Resilience of Self-Esteem in Late Adulthood. *Journal of Aging and Health*, 17, 471-489.
- Cooper, M. (1997). Mabel Cooper's Life Story. In: Atkinson, D., Jackson, M. & Walmsley, J. (Eds.). *Forgotten lives: Exploring the History of Learning Disability*. Kidderminster: BILD Publications.
- Cooper, M., Ferris, G., Coventry, M. & Atkinson, D. (2000). Croydon lives. In: Atkinson, D., McCarthy, M., Walmsley, J., Cooper, M., Rolph, S., Aspis, S., Barrette, P., Coventry, M. & Ferris, G. (Eds.). *Good Times, Bad Times: Women with Learning Difficulties Telling their Stories*. Kidderminster: BILD Publications.
- Cooper, S. A. (1997). Epidemiology of Psychiatric Disorders in Elderly Compared with Younger Adults with learning Disabilities. *British Journal of Psychiatry*, 170, 375-380.
- Crabtree, J. & Rutland, A. (2001). Self-evaluation and Social Comparison Amongst Adolescents with Learning Difficulties. *Journal of Community & Applied Social Psychology*, 11, 347-359.
- Dagnan, D. & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research*, 43(5), 372-379.
- Department for Constitutional Affairs. (2007). *Mental Capacity Act 2005: Code of Practice*. London: Author.
- Department of Health. (2001a). *National Service Framework for Older People*. London: Author.
- Department of Health. (2001b). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Author.
- Department of Health. (2001c). *Seeking consent: working with people with learning disabilities*. London: Author.
- Department of Health. (2009). *Valuing People Now: A new three-year strategy for learning disabilities*. London: author.
- De Vries, B. (1996). The understanding of friendship: An adult life course perspective. In Magai, C. & McFadden, S.H. (Eds.), *Handbook of emotion, adult development, and aging*. San Diego: Academic Press.
- Dodd, K. (2008). Transition to old age – what can we do to aid the process? *Advances in Mental Health and Learning Disabilities*, 2 (3), 7-12.

- Dupuis-Blanchard, S., Neufeld, A. & Strang, V. (2009). The Significance of Social Engagement in Relocated Older Adults. *Qualitative Health Research*, 19 (9), 1186-1195.
- Dye, L., Hendy, S., Hare, D. & Burton, M. (2004). Capacity to consent to participate in research – a recontextualisation. *British Journal of Learning Disabilities*, 32 (3), 144-150.
- Efrainsson, E., Rasmussen, B.H., Gilje, F. & Sandman, P. (2003). Expressions of power and powerlessness in discharge planning: a case study of an older woman on her way home. *Journal of Clinical Nursing*, 12, 707-716.
- Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Emerson, E. & Hatton, C. (2008a). *People with Learning Disabilities in England*. Centre for Disability Research, Lancaster University.
- Emerson, E. & Hatton, C. (2008b). *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*. Centre for Disability Research, Lancaster University.
- Emerson, E. & Hatton, C. (2011). *Estimating Future Need for Social Care among Adults with Learning Disabilities in England: An Update*. Improving Health and Lives: Learning Disabilities Observatory.
- Erickson, M., Krauss, M.W. & Seltzer, M.M. (1989). Perceptions of Old Age Among a Sample of Aging Mentally Retarded Persons. *Journal of Applied Gerontology*, 8(2), 251-260.
- Erikson, E. (1973). *Childhood and Society*. New York: Norton.
- Erikson, E. (1982). *The life cycle completed: Review*. New York: Norton.
- Evenhuis, H., Henderson, C.M., Beange, H. Lennox, N. & Chicoine, B. (2001). Healthy Ageing – Adults with Intellectual Disabilities: Physical Health Issues. *Journal of Applied Research in Intellectual Disabilities*, 14, 175-194.
- Featherstone, M. & Hepworth, M. (1991). The mask of ageing and the postmodern life course. In: Featherstone, M., Hepworth, M. & Turner, B (Eds.), *The body, social processes and cultural theory*. London: Sage.
- Ferraro, K.F. & Farmer, M.M. (1996). Double Jeopardy, Aging as Leveler, or Persistent health Inequality? A Longitudinal Analysis of White and Black Americans. *Journal of Gerontology: Social Sciences*, 51B, (6), S319-S328.
- Festinger, L. (1954). A Theory of Social Comparison Processes. *Human Relations*, 7, 117-140.

- Fido, R. & Potts, M. (1997). Using Oral Histories. In: Atkinson, D., Jackson, M. & Walmsley, J. (Eds.). *Forgotten lives: Exploring the History of Learning Disability*. Kidderminster: BILD Publications.
- Finlay, W.M.L. & Lyons, E. (2000). Social categorizations, social comparisons, and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, 39, 129-146.
- Finlay, W.M.L. & Lyons, E. (2001). Methodological Issues in Interviewing and Using Self-Report Questionnaires With People With Mental Retardation. *Psychological Assessment*, 13(3), 319-335.
- Finlay, W.M.L. & Lyons, E. (2005). Rejecting the Label: A Social Constructionist Analysis. *Mental Retardation*, 43 (2), 120-134.
- Goble, C. (1999). "Like the Secret Service Isn't It". People with Learning Difficulties' Perceptions of Staff and Services: mystification and disempowerment. *Disability & Society*, 14 (4), 449-461.
- Grant, G. (1993). Support networks and transitions over two years among adults with mental handicap. *Mental handicap Research*, 6, 36-55.
- Haigh, A., Lee, D., Shaw, C., Hawthorne, M., Chamberlain, S., Newman, D.W., Clarke, Z. & Beail, N. (2013). What Things Make People with a Learning Disability Happy and Satisfied with Their Lives: An Inclusive Research Project. *Journal of Applied research in Intellectual Disabilities*, 26, 26-33.
- Halliday, S. & Robbins, L. (2006). Lifespan family therapy services. In: Baum, S. & Lynggaard, H. (Eds.) *Intellectual Disabilities: A Systemic Approach*. London: H. Karnac (Books) Ltd.
- Hamilton, C. & Atkinson, D. (2009). 'A Story to Tell': learning from the life-stories of older people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, 37, 316-322.
- Heller, T. & Factor, A. (1994). Facilitating Future Planning and Transitions Out of the Home. In: Seltzer, M.M., Krauss, M.W. & Janicki, M.P. (Eds.), *Life Course Perspectives on Adulthood and Old Age*. Washington DC: American Association on Mental Retardation.
- Hendry, L.B. & Kloep, M. (2002). *Lifespan development: Resources, challenges and risks*. London: Thomson Learning.
- Holland, A.J. (2000). Ageing and learning disability. *British Journal of Psychiatry*, 176, 26-31.
- Janicki, M.P., Dalton, A.J., Henderson, C.M. & Davidson, P.W. (1999). Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability and Rehabilitation*, 21 (5), 284-294.

- Jenkins, R. (2010). How older people with learning disabilities perceive ageing. *Nursing Older People*, 22 (6), 33-37.
- Jerrome, D. (1990). Intimate relationships. In: Bond, J. & Coleman, P. (Eds.) *Ageing in Society: An Introduction to Social Gerontology*. London: SAGE Publications Ltd.
- Johnson, C.L. & Troll, L.E. (1994). Constraints and Facilitators to Friendships in Late Late Life. *The Gerontologist*, 34 (1), 79-87.
- Kalish, R.A. & Reynolds, D.K. (1976). *Death and Ethnicity: a Psychocultural Study*. Los Angeles: University of Southern California Press.
- Kastenbaum, R. (1999). Dying and bereavement. In Cavanaugh, J.C. & Whitbourne, S.K. (Eds.) *Gerontology: An interdisciplinary perspective*. New York: Oxford University Press.
- Keller, J.W., Sherry, D. & Piotrowski, C. (1984). Perspectives on death: A developmental study. *Journal of Psychology*, 116, 137-142.
- Kimmel, D.C. (1990). *Adulthood and Aging: an interdisciplinary, developmental view*, third edition. New York: John Wiley & Sons.
- Kleinspehn-Ammerlahn, A., Kotter-Grühn, D. & Smith, J. (2008). Self-Perceptions of Aging: Do Subjective Age and Satisfaction with Aging Change During Old Age? *Journal of Gerontology*, 63B(6), 377-385.
- Knox, M. & Hickson, F. (2001). The Meanings of Close Friendship: the Views of Four People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14, 276-291.
- Krauss, M.W., Seltzer, M.M. & Goodman, S.J. (1992). Social support networks of adults with intellectual disabilities who live at home. *American Journal of Mental Retardation*, 96, 432-441.
- Kunemund, H. & Kolland, F. (2007). Work and retirement. In: Bond, J., Peace, S. Dittman-Kohli, F. & Westerhof, G. (Eds.) *Ageing in Society: European Perspectives on Gerontology*, third edition. London: SAGE Publications Ltd.
- Lang, F.R. & Carstensen, L.L. (1994). Close emotional relationships in late life: Further support for proactive aging in the social domain. *Psychology and Aging*, 9 (2), 315-324.
- Lee, D.T.F, Woo, J. & Mackenzie, A.E. (2002). A review of older people's experiences with residential care placement. *Journal of Advanced Nursing*, 37 (1), 19-27.
- Lifshitz, H. (2002). Attitudes toward aging in adult and elderly people with intellectual disability. *Educational Gerontology*, 28, 745-759.
- Lloyd, V., Kalsy, S. & Gatherer A. (2007). The subjective experience of individuals with Down syndrome living with dementia. *Dementia*, 6, 63-88.

- MacDonald, M. & Tyson, P. (1988). Decajopardy – the aging and aged developmentally disabled. In: Matson, J. & Marchetti, A. (Eds.). *Developmental Disabilities: A Lifespan Perspective*. San Diego: Grune and Stratton.
- Manners, P.J., Russ, M. & Carruthers, E. (2006). Working reflexively in learning disabilities: what Emma taught us. *British Journal of Learning Disabilities*, 34 (4), 211-214.
- Marcoen, A., Coleman, P.G. & O'Hanlon, A. (2007). Psychological ageing. In: Bond, J., Peace, S., Dittman-Kohli, F. & Westerhof, G. *Ageing in Society: European Perspectives on Gerontology*, third edition. London: SAGE Publications Ltd.
- Marshak, L.E., Seligman, M. & Prezant, F. (1999). *Disability and the family life cycle*. New York: Basic Books.
- McAdams, D.P. (2001). The Psychology of Life Stories. *Review of General Psychology*, 5(2), 100-122.
- McCarthy, M. & Millard, L. (2003). Discussing the menopause with women with learning disabilities. *British Journal of Learning Disabilities*, 31, 9-17.
- McDermott, S. & Edwards, R. (2012). Enabling Self-determination for Older Workers with Intellectual Disabilities in Supported Employment in Australia. *Journal of Applied Research in Intellectual Disabilities*, 25, 423-432.
- McKeown, J., Clarke, A. & Repper, J. (2006). Life story work in health and social care: systematic literature review. *Journal of Advanced Nursing*, 55 (2), 237-247.
- Meininger, H.P. (2005). Narrative ethics in nursing for persons with intellectual disabilities. *Nursing Philosophy*, 6, 106-118.
- Mencap. (2004). *Treat me right! Better healthcare for people with a learning disability*. London: author.
- Mencap. (2012). *Death by indifference: 74 deaths and counting. A progress report 5 years on*. London: author.
- Mental Health Foundation / Foundation for People with Learning Disabilities. (2002). *Today and Tomorrow: The Report of the Growing Older with Learning Disabilities Programme*. London: The Mental Health Foundation.
- Mitchell, D. (2000). Ambiguous boundaries: retrieving the history of learning disability nursing. In: Brigham, L., Atkinson, D., Jackson, M. Rolph, S. & Walmsley, J. (Eds.). *Crossing Boundaries: Change and Continuity in the History of Learning Disability*. Kidderminster: BILD Publications.
- Moya, H. (2009). Identities on paper: Constructing lives for people with intellectual disabilities in life story books. *Narrative Inquiry*, 19 (1), 135-153.

- Murphy, K., Cooney, A., Shea, E.O. & Casey, D. (2009). Determinants of quality of life for older people living with a disability in the community. *Journal of Advanced Nursing*, 65 (3), 606-615.
- Murray, M. (2003). Narrative psychology. In: Smith, J.A. *Qualitative Psychology: A Practical Guide to Research Methods*. London: SAGE Publications Ltd.
- Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. National Centre for Research Methods.
- Nunokoosing, K. & John, M. (1997). Friendships, relationships and the management of rejection and loneliness by people with learning disabilities. *Journal of Learning Disabilities for Nursing, Health and Social Care*, 1, 10-18.
- Owen, A.L. & Wilson, R.R. (2006). Unlocking the riddle of time in learning disability. *Journal of Intellectual Disabilities*, 10 (1), 9-17.
- Papalia, D.E., Sterns, H.L., Feldman, R.D. & Camp, C.J. (2007). *Adult Development and Aging*. Third Edition. New York: The McGraw-Hill Companies, Inc.
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research*, 44 (5), 591-599.
- Rabbitt, P., Diggle, P, Holland, F. & McInnes, L. (2004). Practice and drop-out effects during a 17-year longitudinal study of cognitive ageing. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59, 84-97.
- Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18, 20-23.
- Rickabaugh, C.A. & Tomlinson-Keasey, C. (1997). Social and Temporal Comparisons in Adjustment to Aging. *Basic and Applied Social Psychology*, 19(3), 307-328.
- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A. & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39, 201-214.
- Seltzer, G. (1985). Selected psychological processes and aging among older developmentally disabled persons. In: Janicki, M. & Wisniewski, H. (Eds.). *Aging and Developmental Disabilities. Issues and Approaches*. Baltimore: Brookes.
- Seltzer, G. (1993). Psychological adjustment in midlife for persons with mental retardation. In: Sutton, E., Factor, A., Hawkins, B., Heller, T. & Seltzer, G. (Eds.). *Older Adults with Developmental Disabilities: Optimising Choice and Change*. Baltimore: Brookes.

- Shaw, R.L. (2010). Embedding reflexivity within experiential qualitative psychology. *Qualitative Research in Psychology*, 7 (3), 233-243.
- Sherrard, C. (1998). Strategies for well-being in later life : A qualitative analysis. *British Journal of Medical Psychology*, 71 (3), 253-263.
- Singer, J.A. (2004). Narrative Identity and Meaning Making Across the Adult Lifespan: An Introduction. *Journal of Personality*, 72(3), 437-460.
- Singer, T., Verhaeghen, P., Ghisletta, P., Lindenberger, U. & Baltes, P.B. (2003). The fate of cognition in very old age: Six-year longitudinal findings in the Berlin Ageing Study (BASE). *Psychology and Ageing*, 18, 318-331.
- Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage Publications Ltd.
- Smith, J.A. & Osborn, M. (2008). Interpretative phenomenological analysis. In: Smith, J.A. (Ed.). *Qualitative Psychology: A Practical Guide to Research Methods*. Second Edition. London: Sage Publications Ltd.
- Sneed, J.R. & Whitbourne, S.K. (2003). Identity Processing and Self-Consciousness in Middle and Later Adulthood. *Journal of Gerontology*, 58B(6), 313-319.
- Stevens, A. (1997). Recording the History of an Institution: The Royal Eastern Counties Institution at Colchester. In: Atkinson, D., Jackson, M. & Walmsley, J. (Eds.). *Forgotten lives: Exploring the History of Learning Disability*. Kidderminster: BILD Publications.
- Strnadova, I. & Evans, D. (2012). Subjective Quality of Life of Women with Intellectual Disabilities: The Role of Perceived Control over their Own Life in Self-determined Behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25, 71-79.
- Strydom, A., Hassiotis, A., King, M. & Livingston, G. (2008). The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID. *Psychological Medicine*, 39, 13-21.
- Stuart-Hamilton, I. (2000). *The Psychology of Ageing: An Introduction*, third edition. London: Jessica Kingsley Publishers.
- Tajfel, H. (1978). *Differentiation between social groups*. London: Academic Press.
- Thompson, D. (2002). "Well, We've All Got to Get Old Haven't We?" Reflections of Older People with Intellectual Disabilities on Aging and Change. *Journal of Gerontological Social Work*, 37, 7-23.
- Thompson, D. & Wright, S. (2001). *Misplaced and Forgotten: People with Learning Disabilities in residential services for older people*. London: The Mental Health Foundation.

- Thompson, P. (1993). 'I don't feel old': The significance of the search for meaning in later life. *International Journal of Geriatric Psychiatry*, 8, 685-692.
- Thorpe, L., Davidson, P. & Janicki, M. (2001). Healthy Ageing – Adults with Intellectual Disabilities: Biobehavioural Issues. *Journal of Applied Research in Intellectual Disabilities*, 14, 218-228.
- Troll, L.E. & Skaff, M.M. (1997). Perceived Continuity of Self in Very Old Age. *Psychology and Aging*, 12(1), 162-169.
- Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J.A. & Walsh, S. (1997). Standards for research projects and theses involving qualitative methods. Suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 108, 3-7.
- Van Puyenbroeck, J. & Maes, B. (2009). The Effect of Reminiscence Group Work on Life Satisfaction, Self-Esteem and Mood of Ageing People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, 23-33.
- Walker, A. & Walker, C. (1998a). Normalisation and 'Normal' Ageing: the social construction of dependency among older people with learning difficulties. *Disability & Society*, 13, 125-142.
- Walker, A. & Walker, C. (1998b). Age or disability? Age-based disparities in service provision for older people with intellectual disabilities in Great Britain. *Journal of Intellectual & Developmental Disability*, 23, 25-39.
- Walmsley, J. (1997). *Uncovering Community Care: Evidence in a County Record Office*. In: Atkinson, D., Jackson, M. & Walmsley, J. (Eds.). *Forgotten lives: Exploring the History of Learning Disability*. Kidderminster: BILD Publications.
- Walmsley, J. (2006). *Organisations, Structures and Community Care, 1971-2001: From Care to Citizenship*. In: Welshman, J. & Walmsley, J. (Eds.). *Community Care in Perspective: Care, Control and Citizenship*. Basingstoke: Palgrave Macmillan.
- Welshman, J. (2006). *Ideology, Ideas and Care in the Community, 1948-71*. In: Welshman, J. & Walmsley, J. (Eds.). *Community Care in Perspective: Care, Control and Citizenship*. Basingstoke: Palgrave Macmillan.
- Westerhof, G.J. & Tulle, E. (2007). Meanings of ageing and old age: Discursive contexts, social attitudes and personal identities. In: Bond, J., Peace, S., Dittman-Kohli, F. & Westerhof, G. (Eds.) *Ageing in Society: European Perspectives on Gerontology*, third edition. London: SAGE Publications Ltd.
- Whitbourne, S. K. (2008). *Adult Development & Aging: Biopsychosocial Perspectives*. Third Edition. Hoboken: John Wiley & Sons, Inc.

- Whitbourne, S.K. & Whitbourne, S.B. (2011). *Adult development & Aging: Biopsychosocial Perspectives*. Fourth Edition. Hoboken: John Wiley & Sons, Inc.
- Willig, C. (2008). *Introducing Qualitative Research in Psychology*. Second edition. Maidenhead: Open University Press.
- Wilson, D., Robbins, L. & Martin, C. (2012). People with learning disabilities and the construction of interpersonal relationships. *Context*, 124, 35-40.
- Wolfensberger, W. (1972). *The principle of Normalization in human services*. Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21(6), 234-239.
- Wong, P.T.P. & Watt, L.M. (1991). What Types of Reminiscence Are Associated With Successful Aging? *Psychology and Aging*, 6 (2), 272-279.
- Woods, R.T. (1999). Mental health Problems in Late Life. In: Woods, R.T. (Ed.). *Psychological Problems of Ageing: Assessment, Treatment and Care*. Chichester: John Wiley & Sons Ltd.
- World Health Organisation. (2000). *Ageing and Intellectual Disabilities - Improving Longevity and Promoting Healthy Ageing: Summative Report*. Geneva: Author.
- World Health Organisation. (2001). *Healthy Ageing – Adults with Intellectual Disabilities: Summative Report*. *Journal of Applied Research in Intellectual Disabilities*, 14, 256-275.
- Yu, D.S.F., Lee, D.T.F., Kwong, A.N.T., Thompson, D.R. & Woo, J. (2007). Living with chronic heart failure: a review of qualitative studies of older people. *Journal of Advanced Nursing*, 61 (5), 474-483.

APPENDIX A - Ethical approval**Letter of approval from Research Ethics Committee****National Research Ethics Service****Leeds (Central) Research Ethics Committee**

Yorkshire and Humber REC Office
 First Floor, Millside
 Mill Pond Lane
 Meanwood
 Leeds
 LS6 4RA

Telephone: 0113 3050108
 Facsimile:

30 July 2010

Mrs Gayle Newberry
 Psychologist in Clinical Training
 The Leeds Teaching Hospitals NHS Trust
 Leeds Institute of Health Sciences
 Charles Thackrah Building
 101 Clarendon Road, Leeds
 LS2 9LJ

Dear Mrs Newberry

Study Title: Experiences of ageing among people with a learning disability.
REC reference number: 10/H1313/65
Protocol number:

The Research Ethics Committee reviewed the above application at the meeting held on 16 July 2010. Thank you for attending to discuss the study.

Ethical opinion

Members agreed the potential distress of loss and change of identity was handled well and were satisfied that each interview would be ended on a neutral topic and that there would be a debrief and support from the clinical team if needed. The Committee agreed that the researcher had enough experience to recognise distress and that signs of distress during the interview would be looked out for. The Committee agreed that there had been good use of service users in the design of the research. Members were satisfied that the interview may be split into two if the participants would like to carry on for longer. Members commented that the payment should be made in the form of vouchers. The Committee noted that the information sheet and consent form were very clear.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of

the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

1. The consent form needs space for the researcher's signature

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers to the REC office by 30 August 2010.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV		01 June 2010
Protocol		
Supervisor CV		11 June 2010
REC application	3	18 June 2010
Covering Letter		10 June 2010
Interview Schedules/Topic Guides	1	25 May 2010
Participant Information Sheet: Project Flyer	1	01 June 2010
Participant Information Sheet: Information Flyer	1	01 June 2010
Participant Information Sheet: Information Letter	1	11 June 2010
Participant Consent Form	1	01 June 2010
Information Letter	1	11 June 2010
Research Panel constitution	1	01 June 2010
Evidence of Insurance		
Covering Letter to services	1	11 June 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating

Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1313/65

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Margaret L Faulk
Chair

Email: Rachel.bell@leedspft.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"

Copy to: Rachel de Souza, University of Leeds

Susan Moore, R&D Dept, St Mary's House, St Marys Road, Leeds, LS7 3JX

Letter of approval from Research & Development Department



West Yorkshire
Mental Health and Learning Disabilities Research Partnership

Our Ref: 2010/221/LS

Research & Development Department
North Wing, St Mary's House,
St Mary's Road
Leeds LS7 3JX

E-mail: john.hiley@leedspft.nhs.uk
Direct Line: 0113 295 2357
FAX: 0113 2954466

Mrs Gayle Newberry
Clinical Psychology
Leeds Institute of Health Sciences
Charles Thackrah Building
101 Clarendon Road
Leeds
LS2 9LJ

29th October 2010

Dear Mrs Newberry,

RE: Experiences of ageing among people with a learning disability

Following the recent review of the above project I am pleased to inform you that the above project complies with Research Governance standards, and has been approved by the relevant Partnership Trust management. We now have all the relevant documentation relating to the above project. As such your project may now begin within **Leeds Partnerships NHS Foundation Trust**.

The final list of documents reviewed and approved is as follows:

Document	Version	Date
Protocol		25 May 2010
Participant Consent Form	Version 2	20 August 2010
Participant Information sheet	Version 2	25 October 2010
Participant Information sheet – Project Flyer	Version 1	1 June 2010

This approval is granted subject to the following conditions:

- You must comply with the terms of your ethical approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform the relevant ethics committee and us immediately.
- You must comply with the Partnership's procedures on project monitoring and audit.

The Partnership members are:

- South West Yorkshire Partnerships NHS Foundation Trust
- Leeds Partnerships NHS Foundation Trust
- University of Leeds
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield

S:\R&D\Research Projects\PROPOSED\2010-221-SL Newberry\Approval Letter Non-Portfolio June 2010LPFT.doc

- You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care¹ (RGF). Failure to do this could lead to permission to carry out this research being withdrawn.
- You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines.
- If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.
- Research projects will be added to any formal Department of Health research register.

Details of participant recruitment to projects should be carefully maintained, and supplied to the R&D Department on request.

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for this Trust. Partnership R&D staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the research procedures and/or SUSARs (suspected unexpected serious adverse reactions) should be reported, in line with the protocol requirements, using **Trust incident reporting procedures in the first instance and to the chief investigator²**.

They should **also** be reported to:

- The Partnership R&D Department
- the Research Ethics Committee that gave approval for the study
- other related regulatory bodies as appropriate.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Changes to the agreed documents MUST be approved by both the Trust/s and Research Ethics Committee granting initial approval, before any changes in documents can be implemented. Details of changes and copies of revised documents, with appropriate version control, must be provided to the R&D Office. Advice on how to undertake this process can be obtained from R&D.

Projects sponsored by organisations other than the Partnership Trusts are reminded of those organisations obligations as defined in the Research Governance Framework, and the requirements to inform all organisations of any non-compliance with that framework or other relevant regulations discovered during the course of the research project.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

¹ Details from:

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=Wde1Tv

² SUSARs – this must be within 24 hours of the discovery of the SUSAR incident

The Partnership members are:

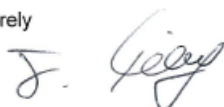
- | | |
|--|---------------------------------|
| • South West Yorkshire Partnerships NHS Foundation Trust | • Leeds Metropolitan University |
| • Leeds Partnerships NHS Foundation Trust | • University of Bradford |
| • University of Leeds | • University of Huddersfield |

S:\R&D\Research Projects\PROPOSED\2010-221-SL Newberry\Approval Letter Non-Portfolio June 2010LPFT.doc

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request.

If you have any queries during your research please contact us at any time. May I take this opportunity to wish you well with the project.

Yours sincerely



John Hiley
Research Management and Governance Manager

CC Carol Martin

APPENDIX B - Study information for recruiters

UNIVERSITY OF LEEDS
Doctor of Clinical Psychology Programme

Charles Thackrah Building
Leeds Institute of Health
Sciences
University of Leeds
101 Clarendon Road
Leeds
LS2 9LJ

16 March 2013

Dear

I am a psychologist in clinical training at the University of Leeds. I am writing to offer service users an opportunity to take part in a research project. It will give them the chance to have their experiences heard, and help increase understanding of what it is like for people with learning disabilities to get older. It would involve taking part in an interview at a time and location of their choice.

I have enclosed a leaflet with some brief information about my research. I would be grateful if you could share this information with any service users who:

- Have a learning disability
- Are over 60 years old
- Will be able, with support, to make an informed decision about whether they want to take part
- Will be able to take part in an interview

I will get in touch soon to find out whether anyone is interested in taking part. I will arrange to meet anyone who is interested to tell them more about the research, and answer any questions they might have. They can then take as much time as they need to choose whether or not they would like to take part.

If you need extra copies of the information, or if you have any questions, you can e-mail me at umgen@leeds.ac.uk, or phone me on 0113 3432732. Thank you for your assistance.

Yours sincerely,

Gayle Newberry
Psychologist in Clinical Training

Getting Older Project



UNIVERSITY OF LEEDS
Doctor of Clinical Psychology Programme

information



Information Sheet

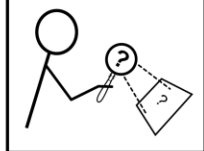


My name is Gayle Newberry.
I am training to be a Psychologist.



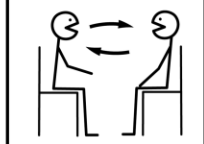
I want to find out about people with
learning disabilities getting older.
This is called the Getting Older Project.

finding out



I want to talk to people who are over 60
years old.
I want to find out what getting older is
like for you.
I want to help psychologists understand
older people better.

interview

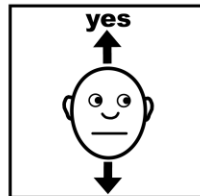


I will do this by asking you about what
your life is like.
I will ask about what it feels like for you
to get older.

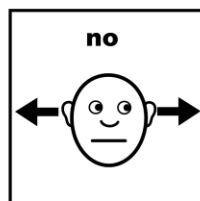


If you are interested in talking to me I will come and see you and tell you more.

Please tell me if you are interested in talking to me:



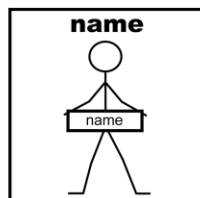
Yes I want to find out more



No I do not want to find out more

If you have said **yes** you are interested please tell me your name.

I will arrange to meet you and tell you more.





Gayle Newberry,
Clinical Psychology Training Programme,
Charles Thackrah Building,
University of Leeds,
101 Clarendon Road,
Leeds, LS2 9LJ
0113 3430815

APPENDIX C - Participant information sheet

Getting Older Project



UNIVERSITY OF LEEDS
Doctor of Clinical Psychology Programme

information



Information Sheet

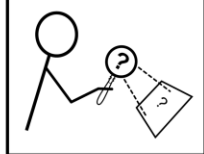


My name is Gayle Newberry.
I am training to be a Psychologist.



I want to find out about people with
learning disabilities getting older.
This is called the Getting Older Project.

finding out

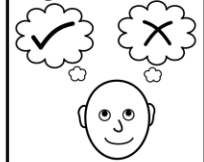


I want to talk to people who are over 60
years old.

I want to find out what getting older is
like for you.

I want to help psychologists understand
older people better.

yes or no



You can say **yes** or **no** to talking to me.
The **red** leaflet says more about this.

What will happen if we meet and talk together?



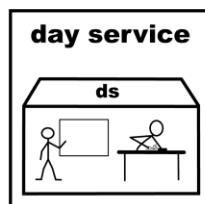
I will ask you about what your life is like.
I will ask about what it feels like for you to get older.

We might use some pictures to help us talk.

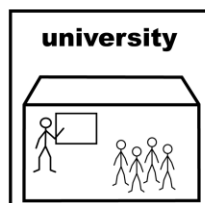
I can meet you where you want.



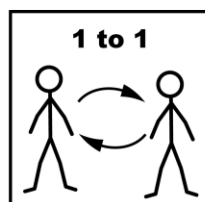
I can meet you at home.



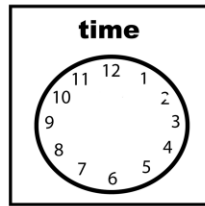
I can meet you at a day service.



I can meet you at the university where I work.



The interview will be **1 to 1**.
This means there will only be **you** and **me** in the room.
If someone comes with you they can wait outside.



The interview will take **1 to 2 hours**.

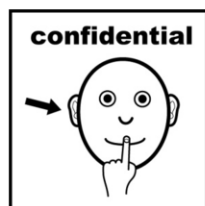
We can meet again if you want to tell me more.



I will record what we say on tape.
I will write down what we record afterwards.



I will keep the tape and what I write in a **safe place**.



What we talk about is **confidential**.
This means I will keep it private.

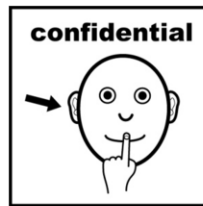
I will tell people **what** we talk about
but I will keep your **name** private.

If I am worried somebody might get hurt I will need to tell someone.
I will tell you if I have to do this.

What will happen to the information?



I will write a report saying what people have told me.



I might use some of your words in the report.
I will keep your name private when I do this.

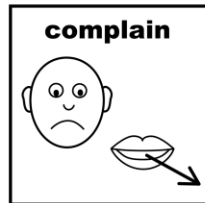


I will show the report to psychologists.
This will help them give a better service to older people.



I will make a report that is easy to read.
You can have a copy of this report.

If you want to complain



If you are unhappy with the way the interview is done you can complain.

You can tell me your complaint.



Or you can tell **Claire Skinner** who works at the university.

0113 343 4897



You can ask me if you have any questions about the Getting Older Project.

You can ask me if you have any questions about the interview.



My address and telephone number are:

Gayle Newberry
 Clinical Psychology Training Programme
 Charles Thackrah Building
 University of Leeds
 101 Clarendon Road
 Leeds
 LS2 9LJ

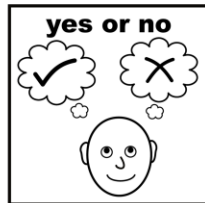
0113 343 0815

APPENDIX D - Consent form

Getting Older Project



UNIVERSITY OF LEEDS
Doctor of Clinical Psychology Programme



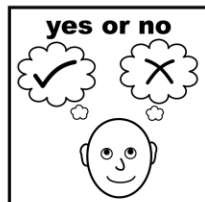
Consent form

This leaflet is about saying yes or no to talking to me.



My name is Gayle Newberry.
I am training to be a Psychologist.

I want to find out about what getting older is like for you.



You can choose to say **yes** or **no** to talking to me.

You can **change your mind** if you want to.

You can **leave** whenever you want.



If you want more information about the interview you can ask me.

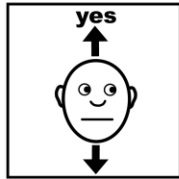
If you want more information about the Getting Older Project you can ask me.



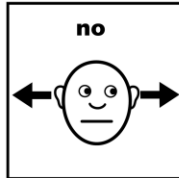
If you have any **questions** in the interview you can ask then as well.

Consent form version 2.0 20/8/10

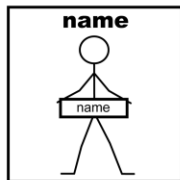
Please say **yes** or **no** to talking to me about getting older.



Yes I want to talk to you



No I do not want to talk to you







Researcher's signature: _____



Gayle Newberry,
Clinical Psychology Training Programme,
Charles Thackrah Building, University of Leeds,
101 Clarendon Road, Leeds, LS2 9LJ
0113 3430815

APPENDIX E - Interview schedule

- Check how much information about the project the participant has understood and remembered. Recap of any important areas missed. Revisit consent to ensure that the participant still wishes to take part.
- What interested you in taking part in this study?
 - When.....told you about the study, what did you think?
- The information about the study talks about “getting older”. What does “getting older” mean to you?
 - What happens when someone gets old?
 - Explore influences on conceptualisation of ageing
 - “where have you learnt about getting older?”
 - “how did you find that out?”
 - Explore the experience and meanings of their own ageing process.
 - what is it like to be/have... (relating to any changes mentioned)
- I’ve brought some pictures to help us think about getting older (picture of young, middle-aged and older men/women)
- Let’s put them in order, which one do you think is the youngest? And the oldest?
- How do you know that (s)he is the youngest/oldest? What differences can you see between them?
 - Follow up any age-related changes identified as appropriate
- Tell me a story about them? And their life?
- How old are you?
- Which of those pictures are you most like?
 - What is it about that picture that seems like you?
 - How are you different from these other pictures?
 - Explore any age-related features identified
 - Has that changed as you have got older?
 - What is it like to be/have....
- Could you tell me what your life is like?
 - Could you tell me about where you live/ how you spend your time/ the important people in your life?

(Aim to get participants to talk about how they experience life, using probes to get more depth of detail about their experiences, how their experience has changed over time, and what meanings experiences have for them)

If the person has brought their own photos in:

- Can you tell me about what is happening in this photo?
 - What was it like to....(live there/do that activity/be with those people)
 - Explore whether things have changed (or stayed the same) between photos and the present time, and meanings of these changes

If the person does not have their own photos (to give a similar opportunity to explore memories of past times):

- What are your strongest memories? Can you tell me about a time when...?
 - What was it like to....(live there/do that activity/be with those people)

- Explore whether things have changed (or stayed the same) between the memory and the present time, and meanings of these changes

Throughout the interview - look for opportunities to find out more about how the participants see themselves, and how they see themselves in relation to others in their life.

- What are your hopes for the future?
 - Friendship, interests, activities, family
- Is there anything else you want to tell me?
- What did it feel like doing the interview?
- Discuss what will happen following the interview
 - Do they want a summary of findings?
 - Arranging a second interview if necessary
- Give voucher
- Thanks very much for taking part

APPENDIX F - Transcriber confidentiality agreement

Confidentiality Statement for Transcribers

Ethics Committee, School of Psychology, Leeds University

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the Ethics Committee of the D.Clin.Psychol course requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

- 1) I understand that the material I am transcribing is confidential.
- 2) The material transcribed will be discussed with no-one.
- 3) The identity of research participants will not be divulged.

Transcription procedure

- 4) Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- 5) I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- 6) All materials relating to transcription will be returned to the researcher.

Signed.....Date.....

Print name.....

Researcher.....

Project title.....

APPENDIX G - Extract of transcript demonstrating data analysis process

Transcript showing steps 2 and 3 of data analysis

<p>Don't want to be alone + lose staff in crowd.</p> <p>Desire to stay with staff + not be left may be longstanding but is more difficult to achieve with age - hard to keep up (? more anxiety about losing staff with age?)</p> <p>Can't keep up because I'm getting older. - Attributing changes to ageing Physical decline</p> <p>Older - can't walk same as younger. Where have his ideas about ageing come from?</p>	<p>32 I I don't want to be on me own. If the staff walked ahead of me I might lose the staff in the crowd.</p> <p>33</p> <p>34 R Yeah, so holding onto the staff, is that something you've always done or has that changed as you got older?</p> <p>35</p> <p>36 I Because I'm getting older, I can't keep up with, with the staff and, and residents. I can't, I can't walk that quick.</p> <p>37</p> <p>38 When you get older you can't walk the same as when people is young.</p> <p>39</p> <p>40 R Right. Ok and how do you feel about slowing down as you've got older?</p> <p>41</p> <p>42 I My age worries me. I feel, I feel, I'm old, I feel, I felt that that I was 80 years old, 90 years old.</p> <p>43</p> <p>44 R Right and how old are you really?</p> <p>45 I 62 and I'm 63 next month.</p> <p>46 R Right so you feel quite a lot older than you are.</p>	<p>Anxiety about losing staff (linked to difficulty keeping up with them)</p> <p>Change (physical decline) attributed to ageing</p> <p>Ageing - physical decline</p> <p>Frustration - can't keep up.</p> <p>Worry about being old</p> <p>Feeling older than current age</p>
--	---	---

Transcript showing additional step: focusing on experience

<p>32 I I don't want to be on me own. If the staff walked ahead of me I might lose the staff in the crowd.</p> <p>33</p> <p>34 R Yeah, so holding onto the staff, is that something you've always done or has that changed as you got older?</p> <p>35</p> <p>36 I Because I'm getting older, I can't keep up with, with the staff and, and residents. I can't, I can't walk that quick.</p> <p>37</p> <p>38 When you get older you can't walk the same as when people is young.</p> <p>39</p> <p>40 R Right. Ok and how do you feel about slowing down as you've got older?</p> <p>41</p> <p>42 I My age worries me. I feel, I feel, I'm old, I feel, I felt that that I was 80 years old, 90 years old.</p> <p>43</p> <p>44 R Right and how old are you really?</p> <p>45 I 62 and I'm 63 next month.</p> <p>46 R Right so you feel quite a lot older than you are.</p>	<p>Anxiety</p> <p>Vulnerability</p> <p>Frustration at reduced mobility</p> <p>Slowing down is a normal part of ageing (making sense of changes).</p> <p>Worry about ageing</p> <p>Identity - self as 'old' (feeling old beyond his years).</p>
---	--