The Lived Experience of Older Women with Learning Disabilities

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ABSTRACT

Background: In recent decades, improvements in medical treatment, public health, technology and education have resulted in people living much longer. This includes people with learning disabilities, the fastest growing sector being the over-70s, and those who are women. There have been a limited number of studies exploring ageing in the population of people with learning disabilities, and very few of these have studied ageing from the perspectives of women.

Aim: To develop a contemporary perspective of the lived experiences of older women with learning disabilities.

Objectives

- To identify how women with learning disabilities construct the experience of ageing, through the lens of an asset theoretical framework
- To examine how older women with learning disabilities experience the wider cultural and socio-political influences, and how these impact on their lives
- To utilise a narrative approach that integrates stories and photo elicitation to facilitate a more in-depth understanding of their experiences
- To indicate how a refined model could be developed to improve policy and practice in the provision of services for older women with learning disabilities

An inclusive methodology is central to this thesis, with an expert reference group of four women with learning disabilities working in partnership with the researcher. The expert reference group ensure that this work is grounded in everyday experience, providing both support and challenge. Ten women over 55 with mild or moderate learning disabilities were purposively invited to take part. Narrative methods integrated with photograph elicitation captured their lived experiences, facilitating a more in-depth

understanding of their experiences of ageing. In methodological terms this offered a number of strengths in helping the women to engage with the research process and provided a visual reference that promoted a more inclusive and flexible approach to capturing the lived experiences of older women with learning disabilities.

Findings

The findings identify how a group of older women construct their experiences of ageing. The equanimity and positive outlook on life is interpreted and understood through developing and understanding their protective health assets. A central theme is the importance of friendships and relationships, providing a buffer during adverse times and helping the women to feel supported and valued by their local community.

Conclusion

In its contribution to service development and knowledge, this thesis provides a contemporary perspective of the lived experience of women with learning disabilities as they age. Furthermore, mapping the narrated assets of these women introduces a new and alternative model for representing individual experiences that challenge the mainstream perspective that has been central to UK policy and practice during the 21st century. This thesis has begun to address a gap between policy and the reality of the lived experience, and presents an alternative asset-based relationship framework (Fig 30 p. 248) that has the potential to guide and shape future learning disability practices. Finally, this appears to be the first study to apply an asset theoretical framework to underpin research with women who have learning disabilities, offering an alternative perspective that challenges social care policy and professionally-defined integration and social inclusion indicators.

ACKNOWLEDGEMENTS

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Chapter 1: INTRODUCTION

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1.1 Personal Reflection

I qualified as a registered nurse for people with learning disabilities in the spring of 1981, and started my nursing career at a long-stay hospital in a remote location in Hertfordshire. At that time, nearly one thousand children and adults with learning disabilities lived in the hospital. The hospital grounds were extensive and a central drive functioned as, what I would later learn to be, a demarcation for the male and female wards. On the perimeter of the grounds there were a couple of children's wards, and a school. Although my experiences of the hospital were as a paid member of staff, at that time the staff also resided on the site, spending many hours within the hospital's boundaries. With limited public transport services operating, and very few people owning a car, the hospital became both home and work for many staff. During the early part of my career, life for people with learning disabilities living in these hospital settings was very restrictive: they had very little opportunity to make decisions or express preferences, and were seldom seen outside of the hospital grounds. There was very limited access to the community for those who lived at the hospital, unless they had family who still visited them. In the early days of my career no one – myself included – questioned the segregated lives that the hospitals provided, as we had no reference-point for any alternative model of care, and so did not know what it could look like. The dominant cultural and professional discourse stated that the 'best option' for people with learning disabilities was a life outside mainstream society.

However, I have always questioned a highly medicalised model of care that I feel deny people autonomy and control over their lives, and have long-held the belief that people

with learning disabilities are entitled to a life that is equal to wider society. Consequently, I have advocated for their right to be included in the community of their choice. My beliefs and values have been reinforced by my two adult nieces with have learning disabilities; as I have observed and experienced the rich contributions, challenges and love that they have brought to our family and communities.

In 1984 I was successfully appointed to my first ward sister role at another long-stay hospital also situated in Hertfordshire. This post was based in a ward that cared for thirty elderly women with learning disabilities. I had always enjoyed working with older people, but taking on this management role was where my passion to make positive change began, as I was now in a position to make improvements in the model of care that was delivered. The changes that I instigated provided the women with more choice in their day-to-day life, however these changes were often difficult to implement, as many of the staff had worked on the ward for many years, and they disagreed at times with my approach. Some of the women who resided on the ward as patients also found it difficult to adapt to some of these changes. Many of the women living on the ward had experienced multiple losses, of parents, siblings, children, friendships, and community, and the women were living what could be described as very restricted and segregated lives. Despite the multiple losses they had experienced, a large number of the women appeared to have 'survived'. Having experienced such extreme loss and years of institutional treatment with regimented routines, many of the women still had a fiery spirit. I was inspired by their strength of character, and how the institutional system had not beaten them. The women seemed to have an inner strength that at times protected them from the institutional environment.

During the late 1980s and 1990s the hospital populations started to reduce in size in response to political and societal change, which led to alternative residential services

being provided in the community. At this time, life in the hospitals changed too: institutional practices and attitudes were slowly being replaced by new ideologies, such as the principles of normalisation, which had originated in Europe and had been promoted in the UK and the USA (Wolfensberger, 1972). This change of ideology and practice had a major impact on my career, and tested both my values and my beliefs about what 'normal' actually meant. In the early-twentieth-century, many families had been told that long-stay hospitals were the best place for their relatives with learning disabilities. These families were now being told that this was not the case, and their relatives should be moved to a range of community settings, with the discourse stating that they would have a 'better life' in the mainstream community. Nurses who had trained in the field of caring for those with learning disabilities were being told that, as hospitals were closing and the philosophy of care was changing, they were no longer required. Therefore, like the people who had lived in the hospital, I too stepped out of the hospital setting, in order to work as a nurse in one of the newly-established community health teams.

It was during my time as a community nurse that I began to fully appreciate how care had evolved and how many individuals lived successfully in the community. Working with individuals and their families helped me to appreciate how important their involvement was and how individual choice quite often required the support of family members. The hospital had paid little reference to individuality, whereas community care was beginning to pay close attention to providing choice, respect, privacy and dignity to the receivers of care. I was now working in an environment that largely recognised the values of those with a learning disability. I can remember that the transition to community living was confusing for some of individuals; an older gentleman who had lived in a hospital setting for many years once asked 'What ward is

that over there?' as he pointed towards a house belonging to his neighbour. However, the resettlement was generally successful, with over 120 people moved to the urban area of London where I worked as a community nurse. Later, at a more senior level, I worked with others to reduce the barriers that individuals faced when accessing mainstream services in the community.

A number of years later, when undertaking postgraduate studies, I was privileged to watch a presentation on inclusive research: an oral history study which had captured the narratives of individuals living in long-stay hospitals. This approach to research was exciting and echoed my belief that people had a story to tell that was valuable and worthy of being shared. I went home from this presentation very excited and began reading about other research that had been undertaken in an inclusive way. Hearing the voices of individuals with a learning disability in the context of the research resonated with my values and thoughts as both a woman and nurse. The stories of their experiences were a part of history that we needed to hear. I can remember thinking at the time that, when and if I undertook a research study, I would ensure that I drew on the values of inclusive methodology.

Some years later I embarked on a professional doctorate as I wanted to expand my knowledge and to support my ambition to be able to undertake research that could inform professional practice. During the professional doctoral programme, a guest speaker presented an oral history study of women who had experienced life in English workhouses. This rekindled my interest and passion for inclusive research, and confirmed how this approach to research could capture a different history: the history of people who have been voiceless.

The personal and professional experiences and passions outlined above combined with my wish to understand more about inclusive research, and led me to related

academic literature. I wanted to understand how women with learning disabilities talked about their experience of growing older. A literature review was undertaken and I found that there was a dearth of literature, and what had been published was predominantly taken the perspectives of professionals or family members. There appeared to be a gap in the academic literature in terms of capturing the individual experiences of ageing from a female perspective, particularly in the United Kingdom, and I was intrigued to explore this more.

As a nurse in a community team I was aware that the population of older people with learning disabilities was growing, and it was becoming increasingly important to understand their experiences and to respond to them appropriately. The literature confirmed that older women with mild learning disabilities were the fastest growing cohort amongst the learning disability population (McDonald, 2002; Emerson and Hatton, 2008). Given the dearth of literature in terms of ageing and women with learning disabilities; my quest was to explore the experiences of a contemporary cohort of older women with learning disabilities. Thus I undertook this research.

Using an inclusive frame for this study was not always an easy option, and there arose some practical challenges. Building trust with participants, and encouraging a reciprocal relationship was not problem-free, and there were occasions where the boundaries that had been carefully cultivated between the participants and myself were brought into question. The benefits and challenges of inclusive research will be discussed in greater detail later in the thesis (Ch.3.4, pp.84-90; Ch.3.18, 134-136). However, despite the challenges that inclusive research can pose working in partnership with women with learning disabilities, the overall experience of working with an expert group of women helped me to value their uniqueness, and provided me with support as a novice researcher.

1.2 Introduction to the Thesis

This is a qualitative research study that embraces an inclusive design by working in partnership with an expert group of four older women with learning disabilities and utilises a definition of inclusive research that has five components (see: Table 4, p.77). This study would not have been possible without the expert and invaluable contributions made by four women: Nalini, Pat, Christine, and Wanda. This group worked alongside me and helped to shape the design of this study. The women requested that their real names were used within this thesis in recognition of the important contributions that they had made to this study. A partnership approach with experts by experience ensures that their personal experiences are considered and inform the research design, in advance of the in-depth interviews with individual women participants, and as such this kept the research grounded in real-life experiences.

This study used an underpinning theoretical model of assets, whilst drawing on both narrative and visual research methods. Ten women with learning disabilities agreed to take part in the individual in-depth interviews and I met with each of these women on at least two occasions. The narratives captured during these interviews were enhanced through the visual integration of photographs taken by the women themselves. The photographs they took were of people, places and possessions that were important in their lives as older women.

As mentioned earlier, there is a lack of literature on the experiences of ageing from the perspective of women who have a learning disability. In England, women with learning disabilities have seldom been asked about their individual experiences of ageing, and what we do know has often been influenced by the views of professionals, policy

administrators, paid staff and family members. In addition, ageing of this population has generally been reported as a genderless issue. The literature review outlines some of the key markers across the historical journey of learning disability policy and practice (Chapter 2.6, pp.49-55), and how these have had a major impact on influencing public attitudes, and so, the life of individuals with a learning disability. This study has used an underpinning theoretical model of health assets to frame the areas of positive support that each of the women described.

This thesis is presented across six chapters and a summary of these is provided below.

1.3 Summary of Chapters

Chapter 1

This chapter provides a reflective account and a brief overview of the background of this study, including the social and political context of this research. The justification for this research is presented, and the aims and objectives of the study are introduced.

Chapter 2

This chapter provides a critical overview of the relevant literature on ageing and individuals with learning disabilities. A historical and political background is plotted to understand the influences that this has had on the lives of women with learning disabilities. This chapter also includes a critical review of the asset framework, its suitability and its fit within this study. Additionally, this chapter presents key concepts that informed this study: social capital and social inclusion. These are discussed and provide further justification for this study.

Chapter 3

This chapter provides an overview of the various research methods and approaches that are used in this qualitative study. The chapter also gives an account of the process that was undertaken to recruit both the expert reference group and individual women who participated in this study. The ethical issues that arose, and my personal reflections and position in respect of inclusivity, are also included in this chapter.

Chapter 4

This chapter of the thesis presents the findings that emerged from a thematic analysis of the narrative data, and how the expert reference group were involved in the process. The chapter introduces the asset mapping process that provided a theoretical underpinning to the analysis of the data (interviews and photography), and how the asset framework provided a new and positive lens through which to view the participants' everyday experiences as older women.

Chapter 5

This chapter provides a focused discussion of the findings of this study in terms of the academic literature, and the underpinning theoretical model of health assets.

Chapter 6

The final chapter of this thesis considers the contribution that this study has made to the existing body of knowledge. The limitations and strengths of this study are also included, together with the impact and implications for learning disability practice and future research. A relationship model which has the potential to support learning disability practice is also presented (Figure 30 p.248). This chapter includes a plan for

the dissemination of the findings of this study and concludes with some final thoughts and comments.

Chapter 2: LITERATURE REVIEW

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2.1 Introduction

This chapter provides an overview of the historical perspectives of the lives of people with learning disabilities, and examines how political influence and historical perspectives have had a major impact on the life experiences of this population. Through this, the importance of documenting the perspectives of women and their adaption and experiences of life in England today. This chapter also includes the overall search strategies that were employed for this study, together with a comprehensive review and critique of the literature. The literature review includes the experience of ageing, women with learning disabilities and the concepts of feminism, and normalisation. Finally, this chapter examines the asset-based model that was used in this study and considers how far it provides a valuable, underpinning framework to interpret and understand the narratives of the women participants.

This study is important because it develops a contemporary perspective of the lived experience of older women with learning disabilities as they age. It builds on academic literature that values listening to the voices of people with learning disabilities telling us about their experiences from their own perspective. Women with learning disabilities are among the least studied members of both the general and the disabled population. It is possible that learning from this group of older women will help the wider disability population with their experiences of ageing, and provide messages for younger women with learning disabilities that may assist with their preparation for old age, and influence future policy and practice.

The design of this study contributes to discussions on inclusive research and provides a view on alternative research methods by critiquing the visual methods used in this study to enhance the traditional language-based interviews. More importantly, this study has addressed some of the imbalances in research by focusing on the views of women with learning disabilities, rather than hearing from the dominant discourse of those who hold powerful positions in policy or service development. This study has provided a platform for sharing individual experiences and has positioned itself within the cultural and socio-political context of England.

2.2   Search Question, Method and Strategy

The search question used for this literature review is: 'What are the lived experiences of older women with learning disabilities'. The initial search involved accessing the Summon facility; this provided a broad search across both electronic and printed literature held or accessible by the University of Hertfordshire. This delivered a very broad overview of the topic and produced a range of publications that were, in the main, related to health changes in old age or population studies (Janicki et al., 1999; Holland, 2000; Blackman, 2007; Kerr, 2004; Lifshitz et al., 2008; Kumar et al., 2009; Hirst et al., 2013), or ageing as perceived through the lens of paid staff or relatives (Buys et al., 2012; Walker and Ward, 2013).

Following this initial scope of the literature, the search question was broken down into the following: 'key concepts', 'lived experience', 'women', 'old', and 'learning disabilities'. Once the key concepts were identified, it was important to include all related words to enable access to the full range of publications (Table 1 – Key Search Terms).   The key search terms in Concept 4 relate to different global historical and social contexts.

Table 1 Key Search Terms

Concept 1	Concept 2	Concept 3	Concept 4
"Lived Experience"	Women	Old	Learning Disabilities
Life Story Narrative Life History Voices Quality of Life Well-being	Woman Female	Older Age Later life	Mental Retardation Developmental Disabilities Intellectual Disabilities Learning Difficulty

Inclusion Criteria

All primary studies that addressed ageing from the experience of women with learning disabilities were included. As there was a paucity of literature, a wider range of papers were included in the review, including life stories where the sample of women with learning disabilities had included participants over the age of fifty-five years. Additionally, studies where the experiences of ageing had been captured from multiple views were included, and the views of older women with learning disabilities were extrapolated.

Exclusion Criteria

All studies centred on the experiences of males with learning disabilities, or the perspectives of families, carers, and professionals, and did not address or include the perspective or experiences of older women with learning disabilities were excluded from this research. The studies that captured the views of ageing but did not include women over the age of fifty-five, were also excluded. Papers that predominantly

focused on health or population issues, with no reference to the narratives or experiences of older women with learning disabilities were also excluded.

The literature (Gash, 2000; Greenhalgh and Peacock, 2005) advocates the use of a computerised database search. This enables one to locate a number of studies in a timely way, and provides access to multiple sources. The databases that were accessed included the Nursing and Allied Health Literature Social Science Index (CINAHL), CINAHL plus, Medline, Psych Info, Pub Med, Department of Health, and Google Scholar. The original search began in 2009 and was last updated in the early part of 2015. The key concepts were used to search the literature and truncation was utilised to widen the literature search (Table 1). The Boolean operator NOT, AND, OR were also used to link the key concepts to search for peer reviewed publications with the most relevance.

In addition to the computerised database search, a manual search was undertaken, based on the references cited in published papers: this has been described as a 'snowballing' technique and can be very useful when pursuing references, identifying high quality sources in obscure locations (Greenhalgh and Peacock, 2005). The grey literature was also searched through the retrieval of material from a variety of dedicated learning disability websites, such as the Learning Disability Foundation and the British Institute for Learning Disabilities, both of which are predominantly managed by third sector non-statutory organisations. These sources provided an additional dimension to that of policy makers, practitioners, and researchers; however, as the academic status of such work can be questioned as this material was not reviewed in the same way as peer-reviewed scientific publications.

Quality Criteria and Span of the Literature

There was no date range applied to the literature review undertaken for this study, and the literature review was last updated in the early part of 2015. Only published papers that had undergone peer review were included in the final literature review for this study. The total number of full papers retrieved was in the region of 92, although only 25 of these met the inclusion criteria, and these have been critiqued in the literature review for this study [Ch. 2, pp 36-49].

2.3   Aims and Objectives of this study

Aim: To develop a contemporary perspective of the lived experiences of older women with learning disabilities.

Objectives:

- To identify how women with learning disabilities construct the experience of ageing, through the lens of an asset theoretical framework

- To examine how older women with learning disabilities experience wider cultural and socio-political influences, and how these impact on their lives

- To utilise a narrative approach that integrates stories and photo-elicitation to facilitate a more in-depth understanding of their experiences from the women's perspective

- To indicate how a refined model could be developed to improve policy and practices in the provision of services for older women with learning disabilities

2.4 Background Literature

The lives of people with learning disabilities residing in the UK have been greatly determined and influenced by government policy (DHSS, 1971; Barton, 2001; Department of Health 2001a, 2009). The main thrust of British health and social care policy over the last thirty years has been to end institutional care provision for this population through the closure of hospitals and similar establishments, and to promote an ethos of community care (Department of Health and Social Services, 1971). In addition to national policy, the principle of normalisation has been another major influential factor. The concept of normalisation had its roots in Denmark in 1959, where it was included as part of the Danish Mental Retardation Act. This concept was initially used to define an existence for the mentally retarded that would be close to normal living conditions (Bank-Mikkelsen, 1980). This initial definition focused on the need for normal housing, education and leisure, and was based on humanistic values that placed equality and human rights as the primary concern, and normalisation as the secondary. In the early 1970s, an American author, Wolf Wolfensberger (1972), criticised the Danish model, describing it as ineffective: he argued that the concern with equality and human rights could not succeed, and he proposed a revised model. Central to Wolfensberger's model of normalisation was the need for social contact and the abandonment of segregated services. Wolfensberger described how the public perception of handicapped individuals as deviant often prescribed them with socially deviant roles such as sub-human organisms, menaces, objects of pity, and eternal children. The Wolfensberger model of normalisation had a set of underpinning principles: it proposed that people with a learning disability should live in ordinary places and do ordinary things with ordinary people, essentially experiencing the 'normal' patterns of everyday life. Although it could be argued that normalisation

brought about significant opportunities for those with a learning disability, critics have suggested that the normalisation model neglected to take into account gender, class, race, sex or age, as it took a blanket approach to a diverse population (Williams and Nind, 1999).

The American model of normalisation had a huge influence on the British political agenda, and stimulated public campaigns that reinforced the need to close segregated services. This led to one of the biggest life-changes for people with learning disabilities in the UK: the closure of institutional-based care and the birth of community care. The closure programme was commonly referred to as the 'hospital resettlement programme'. As it progressed, people with learning disabilities were moved from hospital settings, usually situated in isolated areas, to new homes in the community. It should be acknowledged that, although many historical accounts have concentrated on the state provision of care, the majority of people with learning disabilities were living with their families. Families have continued to be at the centre of community care philosophy and provision in England today (Wright and Digby, 1996; Foundation for People with Learning Disabilities, 2002; Emerson and Hatton, 2008).

Over forty years ago, Better Services for the Mentally Handicapped (Department of Health and Social Services, 1971) laid the foundations for community care, and many of the values it contained were detailed in the white paper 'Valuing People: A strategy for people with learning disabilities for the 21st Century some thirty years later' (Department of Health, 2001a). This paper endorsed the four key principles of independence, choice, rights and inclusion for this population, and promoted a human rights model that paved the way for people with learning disabilities to live as equal citizens, supporting them to make choices and decisions about varying aspects of their

lives (Department of Health 2001a, 2009). Person-centred planning was central to 'Valuing People' and the delivery of the four principles. Person-Centred Planning aims to consider the aspirations and capacities expressed by individuals, and to include and mobilise the individuals' family and wider social network, thereby providing the support required to achieve individual goals (Cambridge and Carnaby, 2005, p.20) Person-Centred Planning is based on a different way of seeing and working with people with learning disabilities, which is fundamentally about sharing power and community inclusion (Sanderson, 2000). However, Hall (2010) argues that the social inclusion messages that were central to 'Valuing People' placed too much emphasis on the importance of paid employment as the only route to social inclusion for people with learning disabilities. Although there has been critical debate on the successes and failures of the white paper 'Valuing People', it did promote further hospital closures, and escalated the provision of services in the community, where they have much greater visibility (Holland, 2000). However, it should be acknowledged that this population is still more likely to be absent from mainstream social spaces, and a number of individuals have reported incidents of abuse and experienced a low quality of life in their community (Hall, 2005).

Despite the changes that have occurred in services and society, there has been very little empirical research exploring the perspectives of women with learning disabilities, and even less is known about the experiences of these women as they age. During the twentieth century, the dominant paradigm of research in learning disabilities was positivist and rooted in the medical model of learning disabilities (Walmsley and Johnson, 2003). Over the last fifty years, research in the UK has progressed and there has been a growth in inclusive research methodologies (Atkinson, 1988, 1989; Atkinson and Williams, 1990; Richardson, 1997; Atkinson et al., 1997, 2000; Walmsley

2001; Walmsley and Rolph, 2001; Dew et al., 2006; Hamilton and Atkinson, 2009; Bigby and Frawley, 2010; Bigby and Atkinson, 2010; Tuffrey, Wijne and Butler, 2010; Woelders et al., 2015); however, even with this surge of change, there is still very little known about the individual experiences of ageing from an insider viewpoint, with the perspectives of older women with learning disabilities being virtually unexplored.

The escalating numbers of older people with learning disabilities are thought to be a result of improvements in standards of living and access to medical treatments which have resulted in increased life expectancy; this is especially relevant for those that have a mild learning disability (Hatzidmitraiadou and Milne, 2005; Haveman, 2004). This, coupled with the longer life expectancy of women compared to men in the UK, means that the ageing population of people with learning disabilities is predominantly female (McDonald, 2002). The cohort of people over the age of seventy has become one of the fastest growing sectors of the learning disability community (Emerson and Hatton, 2008). As this growth in the older population has been well documented, policy makers not only need to plan how best to develop services to meet this mounting need, but recognise that women with learning disabilities have a lot of personal experiences that can inform these plans.

There is no definitive point where one begins the journey of old age, particularly if one has a learning disability; however, there has been a general consensus across the literature that old age starts somewhat earlier in those who have a learning disability, and fifty years of age has been used as a general marker in the United Kingdom (Department of Health, 2001a; Ward, 2012). In comparison to the general population, the age of fifty could be seen as premature; however, this numerical marker is thought to take into account a number of contributory factors, such as greater health and social

difficulties (Cooper, 1998; Jenkins, 2005), unhealthy lifestyles (World Health Organisation, 2000), and the difficulties experienced in accessing health and social care services (Emerson and Baines, 2010). The majority of older people with learning disabilities have tended to be more able than previous generations, and the largest increase has been seen in the numbers of women with mild learning disabilities living into old age (McDonald, 2002; Moss et al., 1998). This is possibly the first generation of women with learning disabilities to survive into old age in significant numbers in the UK (Walker and Ward, 2013), and as they are a sizeable segment of the population, they merit the close attention of researchers. Ferri and Gregg (1998) argue that the absence of voices of women with disabilities in the world of research has created an ableist view of society. It could be argued that women with learning disabilities as members of the disability population are even less likely to be heard. This is due, in part, to their separation from society and the evidence that ordinary women's issues have not always been acknowledged as relevant for this population (Brown, 1996). However, there has been some positive progress in the research world where the voices of women have been heard through a variety of oral history projects (Atkinson et al., 1997; Atkinson and Walmsley, 1999; Atkinson et al., 2000; Hamilton and Atkinson, 2009). Asch and Fine (1992) claim that women have the potential to provide a new perspective that broadens and expands our images of life; this has even more relevance when one considers the historical context and the marginalisation that women with learning disabilities have experienced.

Relative to women, men have generally occupied a privileged position within British society (Connell, 2002) and one could argue that this has been replicated in the population of those living with a learning disability. There are only a handful of examples where women with learning disabilities have been acknowledged to have

different experiences to men, and these have largely been reported in studies of sexual abuse (Brown and Turk, 1992; McCarthy and Thompson, 1996) and in the documentation of life history research (Atkinson et al., 1997; Cooper, 1997a; Atkinson et al., 2000).

International public health data acknowledges that the number of people who are living to a much greater age in the developed world is significantly increasing (WHO, 2000). Furthermore, the Office for National Statistics (2016) states that the UK's ageing population has continued to grow, with over 11.6 million people aged 65 plus in 2015, and it has been recognised that, within this growth trajectory, the subdivision of the older population with learning disabilities has doubled (Emerson and Hatton, 2008). Given the projected growth in the older population, the needs and experiences of people with learning disabilities need to be accounted for when generic policy and services are reviewed. The National Service Framework (NSF) for older people sets standards for health provisions across this population and there is very little reference to the specific needs of those who have a learning disability (Department of Health, 2001b). Additionally, the founding principles within the NSF are far less aspirational when compared to the key values of choice, independence, rights and inclusion that are at the core of the 'Valuing People' strategy (Department of Health, 2001a). It seems probable that these contrasting principles will leave services struggling to support individuals with a learning disability as they grow older. The Quality and Choice for Older People Strategy (Department of Health, 2006a) does not appear to make any reference to how older people with a lifelong disability are to be included in their plans; this lack of reference to those who have a learning disability has been repeated in the Older Persons' Policy (Department of Health, 2004, 2006b). An inclusive argument has often been put forward in defence of this situation (Department

of Health, 2001a). Macintyre (2008) suggested that access to health services and education in the mainstream have been good measures in terms of social inclusion. However, regardless of policy and good intentions, when these are translated to everyday practice, those with a learning disability have often been forgotten or excluded, and as a result, gaps start to appear in the implementation phase of policy with tragic outcomes. This was demonstrated vividly in a confidential inquiry that was carried out in response to the concerns over the premature deaths of those with a learning disability: the findings revealed that 22% of the deaths that were investigated were considered to be preventable (Heslop et al., 2013). This confidential inquiry was commissioned following concerns about the incidence of preventable death of those with learning disabilities within health settings (Mencap, 2007). A government-commissioned independent inquiry found convincing evidence of sub-standard services that had devastating consequences for those with a learning disability (Michael, 2008). It is worth recognising that the gaps in the translation of policy to practice may also be replicated in the world of research, where the voices of women with learning disabilities have seldom been heard (Forbat, 2006). There has been a lot of discussion on a macro level about societal structures and how these inform policy and change life at an individual level; however, this study is interested in taking a bottom-up approach, focusing on the expression of the micro, the self, and day-to-day social interactions, and how these individual experiences can influence the macro level of social structures in England.

It has been suggested that successful ageing for a general population occurs when an individual retains their capacity to function as independently as possible, maintaining autonomy and continuing to engage in productive endeavours of their choice, outside of institutional services (Janicki, 1994). However, for many women with learning

disabilities, retaining independence and living outside of institutional services has been something that they have strived for since childhood; therefore, women with learning disabilities may have a different perspective on successful ageing. Rowe and Khan (1997, 1998) suggests that there are three key features to successful ageing: being free of disability, maintaining functional skills, and being engaged with life. Once again, being free of disability may be a difficult concept to understand when individuals have been born into, and lived their lives with, the diagnosis and label of a learning disability. Rowe and Kahn (1987), in an earlier publication, acknowledge that psychological and other extrinsic factors could influence successful ageing. Gerontology theory proposes that later life is a time when the needs of an individual increase and the activities they partake in decrease (Fennell et al., 1988; Posner, 1995). There has been criticism of the successful ageing theory, and Baltes and Baltes (1990) propose a different model where older people have a positive impact on society. Thompson et al. (1990) found that a number of older people who were not physically ill or emotionally depressed generally did not 'feel' old, and these individuals were often resilient and had continued to adapt to life changes, and seized or created chances for fulfilment. However, gerontology has been relatively silent on the impact of lifelong disability in terms of ageing. Furthermore, the views of those with a learning disability have often been ignored by academics working in the field of disability, and it has been assumed by some that the label of disability includes those that have a learning disability, with the presumption that they face the same issues as the wider disabled population (McCarthy, 1999; Goodley, 2001).

However, it could be argued that if we have not asked the people themselves, we cannot be sure that the issues are the same, and the need to continue to close this gap in research world is vital. Learning Disability has not just been neglected by the

disability movement; gerontology has paid little attention to lifelong disability and gender (Arber and Ginn, 1995). Russell (2007) argues that the masculine bias within gerontology should be challenged.

> "*Successful agers continue to grow and learn as they use past experience to cope with the present and set goals for future development". (Fisher, 1995:240 cited in Fisher and Specht, 1999: 458)*

Russell (2007) also suggests that despite the rhetoric, there has been repeated failure by researchers to assign value to individuals' perceptions and experiences of ageing, and studies on ageing and learning disabilities have generally taken a population approach (Holland, 2000; Thompson, 2002b; Jenkins et al., 1994; Jenkins, 2005). It has been suggested that the dominant storyline has continued to construct people as objects rather than as subjects or citizens (Russell and Kendig, 1999).

One of the most compelling reasons for carrying out this research study is the dearth of literature on learning disability, gender and ageing. Feminist researchers and theorists have been criticised for ignoring women with learning disabilities (Traustadóttir and Johnson, 2000), and disability researchers and theorists have been criticised for ignoring gender (McCarthy, 1999).

> "*Intersection of feminist and disability studies is one of the least explored because of the dominance of disability at the primary category of analysis and the avoidance of feminist studies to include disability in their categories of difference. The process whereby women with disabilities have fallen through the gaps of definition, theory and consciousness has manufactured a silence around them and their experiences". Chenoweth, 1996. p 394.*

McCarthy (1999) argue that it has fallen to those working in the field of learning disability who are feminists to raise the experiences of women with learning disabilities. The inclusive research paradigm has tried to redress some of these imbalances (Atkinson, 1989, 1990; Atkinson et al., 1997; Walmsley, 2001; Walmsley and Johnson, 2003; Bigby and Frawley, 2010; Hamilton and Atkinson, 2009; Strnadova and Evans, 2012); however, there is still very little known about the lived experiences of women with learning disabilities as they age. With the passage of time there will be fewer women living who are able to give an account of a lived experience that spans the context of both hospital and community systems of care and these stories need to be heard as a historical account of this transitional period. There is a need to capture their individual narratives as older women in order to inform and complement the dominant views recorded by professionals, including medics, nurses and social workers. During the twenty-first century, historians worked in partnership with individuals with a learning disability who had lived in long-stay institutions, and documented their accounts of life in these hospitals (Atkinson, 1989, 1990; Atkinson et al. 1997, 2000; Hamilton and Atkinson, 2009), and this has provided a person-centred perspective on their experiences (oral history) that has added a new perspective to the history of institutional care. Oral history has set a strong foundation for participatory research and has demonstrated how valuable individual experiences are.

This progress to more participatory research has had a positive impact on people with learning disabilities and their involvement in research (inclusive research) both as participants and as co-researchers. This has been especially evident in research studies that have utilised life or oral histories or narrative inquiry methods (Atkinson et al., 1997; Brigham et al., 2000).

Participatory research has led to the voices of certain groups of people being heard, possibly for the first time, and has provided confirmation not only that their views are important, but that they enact a valuable social role through their participation in research (Atkinson and Williams, 1990; Atkinson et al., 1997, 2000; Hamilton and Atkinson, 2009). If leaders are serious about their wish to shape services around the needs of this population, they need to ensure that their perspective is heard: this means creating research opportunities to hear those that have been relatively silent (Booth and Booth, 1996; Walmsley and Johnson, 2003). Some of the advancements that have been made through inclusive research could be reflective of the changes that have occurred across professional practice, and the social and policy context in comparison to thirty years ago, where a more inclusive position in terms of human rights and equality had been reported (Department of Health, 2001a, 2009). However, it could be argued that these are not the only drivers of change, as pressure groups such as Mencap have also instigated change. Both academic literature on oral histories and inclusive research with people with learning disabilities have informed the design of this research, and this study has embraced an inclusive approach to understanding the individual lived experiences of a small group of older women living in an urban area of England, in the twenty-first century. Although this study has taken an inclusive approach, it should be acknowledged that only excluded and marginalised groups require this emphasis on inclusivity (Walmsley, 2004).

It cannot be assumed that the needs and experiences of older people with learning disabilities parallel those of the general population as they age. As noted earlier, people with learning disabilities have often appeared to lack distinctive visibility in both policy and service provision for older people. One could argue that this has presented a number of challenges for those who are leading any change in services, as arguably,

if a section of the population has not been acknowledged in policy, they are likely to be forgotten when the translation to practice is made.

Canuunscio and Kawachi (2003) suggest that older people who do not have a learning disability are at greater risk of losing critical parts of their social network as they enter older age. Whilst we do not know if this is the same for women with learning disabilities as they age, we do know that people with learning disabilities are often heavily reliant on face-to-face contact in terms of maintaining their social network. In addition, their reduced abilities in terms of written language and use of email, limited access to personal telephones, and their reliance on paid workers as social facilitators may also impact on sustaining their social network. Research studies have recognised that the maintenance of relationships has often been neglected by agencies during important life-cycle transitions, and as a result, people with learning disabilities have often lost contact with close friends and relatives (Ward, 2012). Thompson (2002a) found that people with learning disabilities place a great deal of value on maintaining relationships with their relatives, although this is not always valued or acknowledged by the providers of care. People with learning disabilities have been described as having small circles or networks of friends and relatives and as a result they often define paid staff as friends. In a qualitative study of friendships and residential care, 30% of people with a learning disability identified a staff member as their best friend (Dudley, 2005). However, a lack of friendships is not just associated with residential care services, as Krauss et al. (1992) found that 50% of adults with learning disabilities living with their family have no friendships outside of their family circle. In a study of adults with learning disabilities living in residential care, there is some evidence to suggest that women have smaller networks as they aged (Robertson et al., 2001). Given the projected increase in the population of older women with mild learning disabilities

(McDonald, 2002), this study seeks to understand their experiences of wider cultural and socio-political influences, and how these have impacted on their social networks.

The next section of this chapter presents a review and critical analysis of research studies that have explored ageing in the population of adults with learning disabilities. As this is an under-researched area, the scope of the literature search and critique was extended to include studies that were undertaken outside of the UK, and those that captured the narratives of institutional life of both middle-aged and older people with a learning disability. Although the literature review for this study focuses on literature that has an individual perspective on ageing, studies that include the views of parents and paid carers in the sampling are also discussed.

2.5 Studies on Ageing from the perspective of individuals with a learning disability.

2.5 (i) Narratives of institutional lives

Studies of communities with learning disabilities have a long history in social science research. From the late 1960s onwards, Edgerton (1967), Atkinson and Williams (1990), Walmsley (1995), Cooper (1997a) Atkinson et al. (1997), Rolph (1999), Atkinson et al. (2000), Walmsley and Rolph (2006), and Hamilton and Atkinson (2009), considered the lives of people who had moved from institutional settings to community based services, both in Europe and North America. These were primarily small-scale qualitative studies, and predominantly employed individual narrative interviews alongside document review methods (Atkinson et al. 1997; Rolph, 1999; Atkinson et al., 2000; Hamilton and Atkinson, 2009), and photographs and poetry (Atkinson and Williams, 1990). The narratives of people with learning disabilities made

an important contribution to field, including an insider's perspective that could be viewed alongside that of professionals.

A pivotal longitudinal study, Edgerton (1967) tracked the move of 48 people from the long-stay institutions in California to life in the community. Edgerton focused on institutional life as experienced by people with learning disabilities; this was an important perspective as, up until this point, their narratives of institutional life were absent from all of the historical accounts. The participants in Edgerton's study were most often middle-aged adults, but during the latter stages of the study some older participants were interviewed. However, all of the older participants in this study shared a lived experience that was based on institutional living, and consequently, the voices of those older individuals' who lived with their families were not included in this study.

Across the life-story literature, there were limited reporting on gender issues; however, Atkinson and Williams (1990) identified that the stories were told with a gendered difference. The men in this study were far more comfortable with the chronological life-story approach, whereas the stories told by the women were more about relationships and people. Atkinson et al. (1997) studied the historical accounts of women and a key finding to emerge from this research was the importance of relationships with family and friends, and how these connections helped the women participants to define themselves and to support them in establishing where they belong (Atkinson et al., 1997). Later, when compiling a gendered account of both good and bad times experienced by women with learning disabilities, Atkinson et al. (2000) identified four common themes of unfairness, fighting back, identity and relationships. Another common theme to emerge from the historical narratives was the harrowing abusive experiences that women endured during their years of segregation, and their resilience to such situations (Atkinson et al., 1997; Atkinson et al., 2000; Hamilton and Atkinson,

2009). Hamilton and Atkinson (2009) found that the narratives of abuse were generally reflective and were told with a sense of acceptance, and it was this latter feeling that enabled the participants to move on with their lives.

The narratives within these life-history studies (Atkinson and Williams, 1990; Atkinson et al. 1997; Rolph, 1999; Atkinson et al., 2000; Hamilton and Atkinson, 2009) introduced the importance of including this population in research, and provided some narratives from older people's perspective (Atkinson and Williams, 1990; Atkinson et al., 1997) that added to the historical accounts of life in institutional settings provided by professionals. Their stories have provided a valuable insight into the lived experiences of a particular learning disability community that had previously been silent. However, the gendered narratives of the participants, and their individual experiences of ageing remain relatively unexplored. The life stories in the research mentioned generally focus on individual accounts of segregated living in an institution, and the subsequent transition to community living, whilst acknowledging that some of these women are now older, and their stories are told from that position.

2.5 (ii) Mixed gender studies on ageing

Other qualitative and quantitative studies in the USA, Canada, Australia and Europe have interviewed older learning disabled participants as part of their sample to understand the experience of ageing or certain aspects of ageing (Erikson et al., 1989; Salvatori et al. 2003; Thompson, 2002a, 2002b; Buys et al., 2008; Judge et al., 2010; Burke et al., 2014; Kahlin, 2015).

In a number of these studies, individuals with a learning disability were not the only sample group participating in the research, with groups taken from both family members and paid carers (Salvatori et al., 2003; Thompson 2002a 2002b; Bigby and

Knox, 2009). The interview and survey methods applied in these studies identified that the perception of ageing was different across each of the participant groups (Salvatori et al., 2003; Thompson, 2002a, 2002b; Bigby and Knox, 2009). The themes that emerged from the views of paid staff and relatives were more focused on their concern about the individual's future in terms of ageing (Salvatori et al. 2003; Thompson 2002a, 2002b) and at times, the needs of a service took precedence over the wishes and aspirations of individuals (Bigby and Knox, 2009). Individuals with a learning disability were more concerned about relationships (Salvatori et al., 2003; Thompson, 2002 a, 2002b; Bigby and Knox, 2009) and other key themes were the value they placed on day-to-day experiences, autonomy and life satisfaction (Salvatori et al., 2003); having a pet, TV and running a home (Thompson 2002 a, 2002b); and keeping active (Bigby and Knox, 2009). Bigby and Knox (2009) and Thompson (2002a, 2002b) found that, although the survey methods adopted in these studies were able to reach out to a larger sample size, the numbers of questionnaires returned by those that had a learning disability were low, and those returned appeared to have been influenced by paid staff or relatives (Thompson, 2002a, 2002b). These studies (Thompson 2002a; Salvatori et al. 2003; Bigby and Knox, 2009) identified the different perceptions of ageing across the sample groups, and highlighted the value of listening to the views of those with a learning disability. However, the data was not analysed or presented as a gendered issue, and any gendered differences or similarities in their findings were not discussed; thus, these remain relatively unexplored.

There has also been other qualitative international research that have studied certain aspects of ageing for example active ageing and retirement, interviewing communities of older people with learning disabilities in a range of institutional and community services (Erikson, 1989; Buys et al., 2008; Judge et al., 2010; Kahlin et al., 2015) and

an additional quantitative longitudinal study was carried out in Ireland (Burke et al., 2014). The key themes that emerged in an Australian study on active ageing were empowerment; active involvement; maintenance of skills and learning; feeling and being safe; congenial living arrangements; and satisfactory supports and relationships (Buys et al., 2008). On the other hand, a qualitative study on retirement that took place in Scotland (Judge et al., 2010) identified four key themes related to independence: continuity, being active, the importance of the day centre, and continuing to connect with the learning disability community.

In a recent longitudinal study, the self-report section on ageing perception found that good things about getting older were identified by 77% of the respondents with a learning disability (Burke et al., 2014). These were increased activities, increased independence, having wisdom, being able to wind down, and being able to retire. However, ageing concerns were responded to by 25% of the participants, and these related health changes, loss of independence, and death/bereavement. Later, Kahlin et al. (2015), in a phenomenological study about the lived experiences of older individuals with learning disabilities in Sweden, found two major themes. These were ageing as a process of change (bodily functions and health, activity and participation, the supporting environment) and existential aspects of ageing (being old, becoming like others, and death/dying). Kahlin et al. (2015) also found that the transition to old age was not such a major transition for the participants, with the lived experience narrated as a multifaceted experience. Transition has also been discussed by McCarthy (2002), who suggested that the life-cycle changes of mid-life and old age might not be meaningful to this population, as they often do not experience similar transitional points. Many of these studies explored ageing or aspects of ageing from an individual perspective and this provides some valuable insight into the experiences of

ageing as perceived by the older person themselves. These are different to the perception of significant others (Thompson, 2002a, 2002b). Although both men and women participated in these studies, the research did not explore possible gender similarities or differences in their perceptions of ageing, but took a learning disability population view (Erikson et al., 1989; Thompson 2002a, 2002b; Salvatori et al., 2003; Buys et al., 2008; Judge et al., 2010; Kahlin et al., 2015)

2.5 (iii) Ageing and Women with Learning Disabilities

In a qualitative study McCarthy (2002) studied the experiences of the menopause in a small group of women with learning disabilities, some of whom were over the age of 60. Although the main focus of McCarthy's research was the women's experiences of the menopause, a set of generalised questions about ageing was also included in the interview schedule. Emerging from their narratives of ageing were themes of health deterioration, and death and dying. As previously discussed in the critiques of life story research (Ch. 2.5, pp 36-38), the women in McCarthy's work also shared disturbing narratives of their experiences of past sexual and physical abuse. However, there were some positive narratives as well, with some women sharing their experiences of greater opportunities as they aged, and some of the participants not perceiving themselves to be old.

Recent international work has seen the publication of research that has begun to explore women's experiences of ageing (LeRoy et al. 2004; Walsh and LeRoy, 2004; Dew et al., 2006; Strnadova and Evans, 2012). One of the first of these studies, LeRoy et al. (2004), carried out a pilot qualitative study that explored ageing with two groups of older women with learning disabilities. The larger sample resided in the USA (twenty) and the other, smaller, sample of participants (nine) lived in Ireland. The

survey was carried out using a qualitative interview schedule of 103 semi-structured questions that were later utilised in a worldwide study with older women (Walsh and LeRoy, 2004). The interview schedule covered five areas, namely health, wellbeing, economy, personal safety, and social roles. The themes that emerged from the findings of this study suggested that the things that the women valued most were their family, having a pet, being healthy, going to church, and having their own place to live. The resilience of older women with learning disabilities emerged as a central concept in this study, reporting that this was the happiest time of their life. Possible limitations of the Walsh and LeRoy study include the interview schedule, which contained 103 questions, and the prolonged face-to-face interviews, which lasted two to three hours, although the research discussed neither in any detail. Some questions within the schedule required quite a high level of comprehension, and these are discussed later in this chapter when critiquing the interview schedule (p.43). However, the Le Roy et al. (2004) pilot study did contribute to the body of research on ageing, especially with its focus on a gendered female perspective, and helped to shape a larger study critiqued in the next paragraph.

One of the largest studies to explore the individual perspectives of women growing older with learning disabilities was a collaborative effort undertaken across eighteen countries and carried out by separate research teams (Walsh and LeRoy, 2004). A total of 167 women worldwide were interviewed face-to-face using the interview questionnaire that had been piloted in an earlier study, discussed earlier in this chapter (Le Roy et al., 2004). The questionnaire was divided into five categories of questions: wellbeing, health, economic, personal safety, and social roles. The UK based research team interviewed ten women with learning disabilities, and each of these face-to-face interviews lasted between two and three hours. The researchers described this global

view of ageing as a collection of stories that had been sewn together like a patchwork quilt, and emphasised that it should not be regarded as empirical research. However, there were some consistent themes that emerged from this study, such as the women's experiences of being removed from their birthplace, and feeling as if they were outsiders in their current residency. The concept of resilience was put forward as a means of understanding how they had overcome difficulties against the odds, and had developed skills of hope, courage and forgiveness that enabled them to have insight into their life and approach older age with dignity.

There were some limitations with the interview schedule, as the language and structure of some of the questions was often very complex, and the face-to-face interviews were prolonged. Booth and Booth (1996) argue that traditional research methods are not always effective when interviewing people with learning disabilities and their involvement requires flexibility and the use of more direct questioning by the researcher. An example of an ambiguous question that was used in the Walsh and Le Roy study is:

"Look down the road in five years, tell me what you see"

Another question used in the interview could also have been difficult for people to comprehend and may have received a variety of responses:

"Are you interested or excited about something?"

The analysis of the interviews with participants' from across different countries suggested that there were some cultural variables in their responses, and these often related to their perception and experience of ageing. However, the themes of resilience

and feeling like an outsider ran through all of the narratives of these women, regardless of their cultural reference (Walsh and LeRoy, 2004).

Later Dew et al. (2006) carried out an exploratory study with a group of thirteen older Australian women with learning disabilities. This focused on the women's perceptions about their experiences of ageing. Interviews were based on the same questionnaire that was used in the global study of older women with disabilities by Walsh and Le Roy, 2004). However, Dew et al. adopted a narrative methodology, and the data was analysed using a comparative analysis technique, which brought an in-depth understanding of the women's individual experiences of ageing. Nevertheless, there were some limitations to this study, as eight of the participants resided in the same home and this may have influenced the findings. Additionally, although the responses were grounded in their individual experiences of life as older women, Dew et al. had used the interview framework developed by Walsh and LeRoy discussed earlier in this chapter (p. 42-43). The results of the Dew study may have been influenced by cultural differences, as life in Australia might be quite different to life in England; however, it demonstrated how important it was to understand ageing from an individual perspective rather than understanding people's lives through the voices and opinions of others. The women in this Australian study described themselves as ageing well, and their stories recalled a life that had improved when compared to their past experiences. The women were familiar with the ups and downs of life, and many of them acknowledged that their earlier lives had not been easy; however, the women all had a high degree of connectivity in their local community, and were leading meaningful lives as older women. Dew et al. (2006) found that the women had a largely positive view on their own experiences of ageing. The concept of resilience is suggested as a means to understand the optimism of these women, recognising that

their families and friends acted as a cushion when life was troubled. The findings produced a number of key messages for policy and service development, namely the importance of community networks, staying healthy, and having the opportunity to access a range of services. Dew et al. demonstrated through their research, the importance of listening to the perspectives of older women with learning disabilities and developing services and support systems based on their needs and aspirations. However, there were some limitations to the study, as some of the shared connections that were expressed may have arisen as a result of the participants' shared residential experience. Regardless, Dew et al. (2006) provide a valuable an insight into the gendered experience of ageing across different cultures.

There have also been a number of Australian studies carried out by Christine Bigby that have explored a wide range of ageing issues such as, policy, retirement and service provision from a learning disability population perspective (Bigby and Knox, 2009; Bigby, 1997a). In one of these studies, Bigby (1997a) interviewed 62 women with learning disabilities over the age of 55 who had left their family home after the age of 40, and were living in a range of community settings. A mixed quantitative and qualitative method of data analysis was applied within this research, focusing on the transition from living with family to living in a community. Bigby found that most of the women had strong informal networks and had a key person in their lives. Many of the women talked about the importance of being treated as adults once they had left the family home. However, the women participants were vulnerable to decreased mobility with the passing of years, and reduced access to specific learning disability services and house moves as they grew older were associated with a loss of friendships. Those in poor health (n.14) were found to be less likely to have friends or acquaintances within their social network. However, 92% of the women still named at least one family

member who was still part of their social network. Although the main aim was to understand their transition from family life to a greater level of independence, Bigby's work contributes to the body of literature that has explored the experiences of older women.

Strnadova and Evans (2012) studied the subjective quality of life in two groups of women with intellectual disabilities living in Australia and the Czech Republic, and this study aimed to gain a greater understanding of their level of self-determination and potential barriers to self-determination. In-depth semi-structured interviews were carried out using an interview protocol based on the Walsh and Le Roy (2004) framework, with a reduced set of questions, and a grounded theory approach was used to analyse the data. The women (n55) were between the age of 40 and 78 in Sydney, and between the age of 40 and 65 in Prague. The dominant theme that emerged from their research data was the perceived lack of control that the women had over their own lives. One of the strategies that the women used to gain control over their lives was through friendship with those that were close to them and that the shared history that they had in common. The perceived lack of self-determination reported by the women contrasts sharply with the increased autonomy that was reported in previous studies of older women with intellectual disabilities living in Australia (Bigby, 1997a; Dew et al., 2006). The differences in experience of autonomy that emerged in these studies could be related to the variance in their living situations; a number of the women in the Strnadova and Evans research were living with their family, and this can sometimes promote a level of dependency (Bigby, 2000). In contrast to this, participants in other studies had all moved from the parental home and were living in more independent living arrangements (Bigby, 1997a; Dew et al., 2006).

2.5 (iv) Key Messages from the Literature

Despite decades of research on learning disabilities, both from narrative accounts of institutional settings and from studies that actively sought participation of people with learning disabilities as part of the research process (Edgerton, 1967; Atkinson and Williams 1990; Atkinson et al., 1997; Rolph, 1999; Atkinson et al., 2000; Hamilton and Atkinson, 2009), there remains a limited amount of literature that is specifically focused on the experience of ageing from the perspective of women with learning disabilities (Walsh and LeRoy, 2004; Dew et al., 2006; Strnadova and Evans, 2012) .

This review of the literature has included published life history research, as the narratives of older women contained in this have key messages for the ageing literature, in terms of the importance of relationships and connections in the lives of women with learning disabilities (Edgerton, 1967; Atkinson et al., 1997; Atkinson, 1990).

The central theme across the body of literature is the importance of relationships in the lives of older women with learning disabilities; relationships with family, friends, partners and paid staff (Atkinson et al., 1997; Salvatori et al., 2003; Thompson, 2002a, 2003b; Walsh and Le Roy, 2004; Dew et al., 2006; Buys et al., 2008; Bigby and Knox, 2009; Strnadova and Evans, 2012). These relationships appear to be central to the women in most studies and the participants often define themselves through their relationships with others.

Another key message evident in these empirical studies is that the women have the ability to overcome adversity, and this is often defined using the concept of resilience (Walsh and Le Roy, 2004; Dew et al., 2006). The women's narratives across these studies describe a shared experience of abuse and institutionalised practices that are

harrowing (Atkinson et al., 1997; McCarthy, 2002; Hamilton and Atkinson, 2009; Walsh and LeRoy, 2004), but despite these traumatic experiences, the women are able to use techniques such as reflection to face life with a level of matter-of-fact acceptance (McCarthy, 2002; Walsh and Le Roy, 2004; Hamilton and Atkinson, 2009).

The importance of independence is another key theme to emerge across the literature with greater independence as a component of ageing arising from a number of the recent studies (Dew, 2006; Judge et al., 2010; Burke et al., 2014). However, this was not consistent; Strnadova and Evans (2012) and Bigby and Knox (2009) highlighted a lack of control and autonomy, with decisions being made by paid staff and family members without the interviewees' involvement. This review of the body of literature demonstrates that there are variable narrated experiences in terms of independence and autonomy, some of which appear to be related to the resources that are located in the family or community.

Over the last fifteen years, published literature has made an important contribution to the body of knowledge and our understanding of ageing from the perspective of those with learning disabilities (Atkinson et al., 1997; Salvatori, et al., 2003; Thompson, 2002a 2002b; Bigby, 1997a; McCarthy, 2002; Bigby and Knox, 2009). However, few have considered women's experiences, how long term institutions are gendered in their organisation, the structuring of participant's experiences, or even reported on the gender of their participants – albeit with some notable exceptions, such as Atkinson (1990), Atkinson et al. (1997), and later Walsh and Le Roy (2004), Dew et al. (2006) and Strnadova and Evans (2012). Across the literature, there is also a significant gap in terms of the experiences of older women with learning disabilities from a UK perspective (Walsh and Le Roy, 2004; Thompson, 2002a, 2002b). Strnadova and

Evans (2012) suggests that cultural differences were not a major feature in their research with older women with learning disabilities. On the other hand, Walsh and Le Roy, (2004) propose that there were some cultural differences in the responses to their study of older women.

This thesis builds on the academic knowledge discussed in this chapter, and aims to understand the lived experiences of older women with learning disabilities living in a range of community settings across the UK. This research aims to address a gap in the literature, whilst also exploring the use of a range of research methods that can be used to enhance the more traditional narrative of interviews with women.

2.6 Historical Context

Intertwined with the twenty-first century concept of inclusion is the lived journey of the population of people with learning disabilities; therefore, an historical overview of society and learning disabilities follows, in order to provide a deeper understanding of socio-political influences.

It is worth noting that in the nineteenth century the very early asylums were created and provided accommodation for both people with learning disabilities and those with mental health problems. Later moves from asylums to the colonies were based on the belief that people with learning disabilities could develop to a point where a return to their community of origin was possible. This view prevailed up until the twentieth century, when the ethos became more about containment than rehabilitation (Gates and Atherton, 2007, p.53). The historical journey of care for people with learning disabilities in the twentieth century was shrouded in negativity and segregation, a far cry from the earlier nineteenth century establishments, which were more closely concerned with support and rehabilitation.

In 1907, the Eugenics Education Society was founded. This was informed by the work of the British scientist Francis Galton, who used the term 'eugenics' to refer to healthy breeding in a population. Like the early institutions, eugenic theories began with positive intentions. However, these were later garnered negative interpretations and resulted in thirty American states passing sterilisation laws, in a bid to eradicate dysgenic traits of feeblemindedness and promiscuity. The American sterilisation proposals had some support in the UK, and although sterilisation was never part of British law, Winston Churchill's controversial 1910 proposals included the forced sterilisation of 100,000 moral degenerates, rather than the proposed segregation programme (Gilbert, 2011). This was thought to be based on the notion that people with learning disabilities were a threat to the human race (Stainton, 1992). The term 'moral degenerates' or 'defectives' was defined within the Mental Deficiency Act of 1913, describing persons who, from an early age displayed some permanent mental defect together with vicious or criminal tendencies, on which punishment had little or no effect. It should be noted that under the Mental Deficiency Act 1913, it was not possible to be committed to an asylum on the grounds of mental degeneration alone, and there was a requirement to meet one of the other social criteria within the grouping of degenerative characteristics, such as promiscuity.

Under the 1913 Mental Deficiency Act, asylums were built; although during this period they were not described as hospitals but as colonies, and were designed to separate perceived 'defectives' from the wider gene pool of the nation, having been influenced by eugenic ideology. The 1913 Mental Deficiency Act particularly targeted women and girls with learning disabilities, categorising them as a sexual menace, and once they were institutionalised, they remained so for life (Thomson, 1992). As a result, supervision and monitoring procedures in the community were established, and during

this time, these women were viewed as a cause of potential social, economic and moral decline (Williams, 1992, p.153). As such, control of their behaviour was seen as the solution to the growing problem of moral decline in the UK, and gave birth to the term 'moral degenerate'.

Over the next twenty years, the eugenic ideology began to take a stronger hold across Europe, and it was adopted as a core concept by the Nazi political party, which came to power in Germany in 1933, under the leadership of Adolf Hitler (Friedlander, 1995 p.23). The Nazi party manifesto expressed a commitment to the development of a racially-pure Aryan society. Under the auspice of the Nazi's 'final solution' thousands of Jewish people and those with mental health problems and learning disabilities were murdered in a bid to create a pure German race (Mitchell and Snyder, 2003). Following the Second World War, and the discovery of the extensive atrocities, Great Britain, and other societies across Europe rejected the eugenic movement due to its association with the Nazi party (Friedlander, 1993, p.9).

After the Second World War and up to the present date, there has been a steady stream of policy directives, some of which have been enshrined in law [Table 2]. These influenced major changes in the provision of services for people with learning disabilities in the UK. One of the key drivers of change in the UK during the twentieth century was the NHS Act of 1946, and the rise of the NHS as the lead agency for those who had a learning disability. This facilitated a move to a medical model of care, leading to thousands of people with learning disabilities being assessed as having a medical diagnosis that required hospital treatment (Atherton and Crickemore, 2011, p.53). Hospitals for those with learning disabilities were often built in isolated areas, and were therefore detached from "normal" living.   It was not until the late 1960s that

people began to question whether the medical model of care was appropriate. Public enquiries at Ely Hospital, Cardiff and later at Normansfield Hospital, Teddington (Atherton and Crickemore, 2011, pp.183-198) reported appalling cruelty and inhumane conditions triggering large-scale media interest and resulting in a series of political and public debates about the future care options for this population (Department of Health and Social Services, 1971). During the 1970s, hospitals were criticised for their institutional approach to care, and this was apparent through the socialisation process of staff working in these types of institutions and the reinforcement of a culture of control, later defined by Goffman (1961) as Total Institution theory. Key Historical Landmarks in Policy and Legislation are summarised in Table 2.

Table 2 – Key Historical landmarks in Policy and Law in England

Year	Title	Key Messages
1886	Idiot Act	Specialist care provision for idiots under this Act
1913	Mental Deficiency Act	Proposed an institutional separation, with those described as mentally deficient taken out of poor law institutions and sent to colonies. These had a rehabilitation and work ethos. People were certified according to one of four categories of deficiency, renewed at twelve months and then every five years.
1929	Wood Report	Self-sufficient colonies under the control of the local council. Often had a shop, laundry, school on site. Admission was on the request of the family, signed by two doctors.
1946	NHS Act	Colonies became mental sub-normality hospitals with the birth of the NHS. Control moved from the local councils to the Regional Hospital Boards.
1957	Percy Commission 1954-57: Report of the Royal Commission on the Law relating to Mental Illness and Mental Deficiency	Responded to the growing concern about the care of people with mental illness and mental deficiency. Mainly a review of mental health law but did include reference to the need for more community care.
1959	Mental Health Act	The first time that mental illness and mental handicap were differentiated by law. Ended compulsory certification. Strong emphasis on the treatment of mental handicap and the role of the Responsible Medical Officer.
1969	Report of the committee of enquiry into Ely Hospital (The Howe Report)	First report published citing extreme institutional abuse of people with learning disabilities at Ely Hospital in Cardiff.
1970	The Education Act	For the first time ALL children, regardless of disability, had the right to an education. This Act discontinued the classification of handicapped children as unsuitable for education at school.
1971	White Paper: Better Services for People with Mental Handicap	This government report advocated a 50% reduction in hospital places by 1991, and an increase in local authority provision in the community. First discussion of movement from health to local authorities
1979	Jay Committee Report on Mental Handicap and Care	Called for a change in services to respond to social need and to develop the LA role. People with learning disabilities had the right to valued life experiences in community settings. Closures of hospitals began to be debated.
1981	Green Paper: Care in the	Consultation document that mainly

	Community	dealt with the movement of finances to enable people to move to community settings
1983	Mental Health Act	Terminology changed from sub-normality to mental impairment and severe mental impairment and other legislative changes.
1989	White paper: Caring for People: Community Care in the Next Decade and Beyond	Possibly the most significant, as it proposed that all hospitals should close and the move from hospital to community care should be accelerated.
1990	NHS and Community Care Act	Legislation that supported the hospital closure programme and the move to care in the community, with a combination of humanitarian and financial drivers.
1995	Disability Discrimination Act	Placed an onus on providers of goods and services to make reasonable adjustments for disabled people.
1998	Human Rights Act	Sets out a number of fundamental rights and freedoms
2001	White Paper. Valuing People: A strategy for people with learning disabilities for the 21st century	First white paper for thirty years. Set out changes that cut across a range of services and a valued life. Key Principles of Rights, Choice, Independence and Inclusion.
2008	Mental Capacity Act 2005: Deprivation of liberty safeguards - Code of Practice to supplement the main Mental Capacity Act 2005 Code of Practice	Provides a framework for approving the deprivation of liberty for people who lack the capacity to consent to treatment or care in either a hospital or care home
2009	Valuing People Now: A three-year plan	Re-emphasised the commitment to Valuing People. Emphasis on inter-compartmental working to bring about change.
2010	Equality Act	Protects people from discrimination in the workplace and in the wider society

(Wright and Digby, 1996; Gates and Atherton, 2007)

The eugenic ideology and the stigma generated by these negative views sit firmly within the historical landscape; however, the ripple effects of these historical views have influenced some of the decisions that led to a segregated model of hospital care in the UK after the Second World War. In the USA, sterilisation laws were also used, and these influenced and legalised decisions through most of the twentieth century (McCarthy, 1999).

> *'It is better for the entire world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing*

their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes' (Buck v Bell, 1927: cited McCarthy, 1999, p54).

Negative views and changes to the law are not likely to have been isolated to the USA, and would have had an influence on the sterilisation of large numbers of young women with learning disabilities across Europe, often without their informed consent. In a Belgian study, young women with learning disabilities were found to be three times more likely to have been sterilised in comparison to the general female population (Servais et al., 2004). Early ideologies and practices identified in this chapter would have contributed and shaped the views held by society, and the shame and stigma that were experienced by people with learning disabilities (Edgerton, 1967).

2.7 Key Concepts

(i) Asset-based approach

An asset can be defined as any resource, skill or knowledge which enhances the ability of individuals, families and neighbourhoods to sustain health and wellbeing (Morgan et al., 2010). Assets can operate at an individual, community or population level and can act as protective or promoting factors to buffer against life stresses (Morgan and Ziglio, 2007). Health assets are concerned with identifying the protective factors that support health and wellbeing. Assets can enhance both the quality and longevity of life through focusing on the resources that promote the self-esteem and coping abilities of individuals and communities (Morgan et al., 2010). Morgan et al. (2010) explain how the asset model is not a stand-alone concept, but a framework that brings together a number of existing concepts and ideas in a systematic way. The three integrated concepts that come together within assets are social capital (Putnam, 2000), resilience (Rutter, 1987; Barnard, 1994; Windle, 1999), and salutogenesis (Antonovsky, 1979,

1987, 1993). Although, the majority of publications have demonstrated the application of an asset-based approach with children and young people, there are referenced publications in early psychiatric literature (Beiser, 1971). The asset framework moves the focus away from needs and problems to a far more positive view of an individual and/or community, as one that has both strengths and resources that can be drawn upon. The theoretical framework of assets has a good fit with this study as it reflects some of the historical journey seen across learning disabilities services and policy in the UK, moving from a medical model, which had predominantly placed the problems and cure with individuals, to a social model, which takes a much wider societal approach to improving life opportunities for this population that was based on strengths and resources. The theoretical framework of assets has the potential to stimulate a different perspective by mapping the resources of individuals with learning disabilities and their community. The next section of this chapter examines an overview of each of the three key concepts that form the asset framework, and a critique of how the framework of assets was applied to underpin the findings in this study.

2.7 (i) Social Capital

Putnam (2000) suggests that social capital refers to the social networks and norms of trust that enable everyone in a community to have full and fair access to activities, social roles and relationships. At a more practical level, it is about networks and norms that allow people to work together to resolve problems and achieve common goals (Stone and Hughes, 2000). Partington (2005), in a critical analysis of community integration, suggests that full integration for those with learning disabilities is often an unrealised ideal, and that having friends and family networks built on trust and reciprocity are the factors which make the difference at an individual level. It is worth

acknowledging that people with learning disabilities living in Australia and the UK have often been very socially isolated after their move into the community, whether they are living in urban or rural communities (Gething, 1997; Partington, 2005). Some critics of social capital have suggested that the concept does not always reach out to those that might be living on the margins of society, and additionally it has been criticised for its systematic oppression of women (Riddell et al., 2001). Bates and Davis (2004) suggest that social capital can provide a helpful perspective when reviewing or researching learning disability issues, and in the general population of older people, successful ageing has been associated with improvements in social capital (Cannuscio and Kawachi, 2003)

2.7 (ii) Resilience

There has been considerable variation in how resilience has been conceptualised and defined. A recent review of the concept of resilience defined it as the effective negotiation or adaption to, or management of, significant stress and trauma through individual internal or external resources that assist someone in recovering from adversity (Windle, 2011). Resilience has been described as a dynamic process wherein individuals display positive adaptation, despite their experiences of significant adversity or trauma (Luther et al., 2000). The concept of resilience has developed and expanded to include the strengths that both people and systems use to rise above adversity at an individual, family and community level (Van Breda, 2009). However, critics of the theoretical model of resilience have suggested that too much focus has been placed on the individual overcoming adversity, and not enough attention has been paid to the wider social systems when examining resilience (Howard et al., 1999).

2.7(iii) Salutogenesis

Salutogenesis is a public health model that links health, stress and coping, with a focus on what keeps people healthy (Antonovsky, 1979, 1987, 1993). Eriksson and Lindström (2006) discuss how Antonovsky's research with female holocaust survivors found that some of the women had been able to maintain good health and lead a good life despite the unimaginable trauma they had gone through in their younger years. Their conclusion was that chaos and stress are part of life, and the a far more interesting factor was how people survived adverse conditions against all odds. This moved the public health model from a position of disease causation (pathogenesis) to what creates health and keeps people healthy (salutogenesis). Central to the salutogenic concept are the Generalised Resistance Resources (GRR) and a Sense of Coherence (SOC).

GRR includes the biological, material and psycho-social factors that made it easier for people to understand and structure their lives, for example: money, social support, knowledge etc. It suggests that people who have these kinds of resources available to them are better able to deal with life challenges (Lindström and Eriksson, 2005). The SOC is also a positive way of looking at life alongside the ability to successfully manage the many stresses that occur throughout life. Antonovsky describes three types of SOC: comprehensibility, manageability, and meaningfulness. A fourth concept– emotional closeness – was added, and this relates to emotional bonds that individuals have with others that enable them to feel part of a community (Sagy and Antonovsky, 2000).

2.8 The Theoretical Framework of Assets

A theory consists of a number of concepts that are designed to explain an entire situation or behaviour; these can provide a model or map that explains the situation or behaviour (Strauss, 1995), which can help researchers to make sense of what is going on in the social setting in the study (Flinders and Mills, 1993). The important place that the application of theory and/or a theoretical framework has within qualitative research has been acknowledged (Creswell and Miller, 2000).

Health Assets has predominantly been applied as a theoretical framework for public health research with children, young people, and to some degree with adults who have mental health issues (Search Institute, 2006; Morgan and Ziglio, 2007), and within the social sciences (Kolm, 2002) and psychology (Peterson and Seligman, 2004). Health assets are concerned with identifying the protective factors that support the health and wellbeing of individuals or communities and maximising opportunities for health and wellbeing (Morgan and Ziglio, 2007; Morgan et al., 2010). The health asset model has been used by different disciplines including psychology and nursing (Rotegard et al., 2010), and this theory has been recognised as central to the World Health Organisation policy framework (WHO, 2012). Although, the research literature does not appear to have reported the use of an asset framework with individuals with learning disabilities, the health asset literature suggests that the asset framework has the potential to offer a unique and person centred perspective.

This chapter has discussed the historical context of the lives of people with learning disabilities. Although there has been a shift to community care, the mainstream disability political movement has not fully recognised individual issues or identities, and they remain one of the most marginalised groups in Western society (Hall, 2005). The

marginalisation of this population has often been accompanied by negative perceptions and deficit models of care that have, at times, clouded and severely restricted the potential contributions that this population can make to society (Foundation of People with Learning Disabilities, 2001). Therefore, it is important that by starting from a participatory approach, this study moves away from a deficit perspective and towards a theoretical framework that allows for the possibility of a positive interpretation concerning the lives of women with learning disabilities, by examining strengths and capabilities. Kretzmann and McKnight (1993) suggest that deficit models are useful when identifying population needs or prioritising services, but these should be complemented by other approaches. A deficit approach leads to a negative perspective dominating services provision, one that overlooks the strengths and capabilities that people with learning disabilities possess, thereby limiting potential gains. This is particularly problematic for a population who has been severely marginalised, as it reinforces that process of marginalisation, and can lead to further loss of independence and an over-reliance on health and social care services. In contrast, an asset approach offers an alternative that commences with the identification of the strengths and capabilities of individuals, whilst recognising that external support needs to be in place (Morgan and Ziglio, 2007). Health assets are present in every person (Rotegard, 2010), and recognising and valuing these strengths was an important factor in the selection of this theoretical model.

Across the learning disability literature, a number of theoretical models have been applied for research with this population. One of the most commonly used has been the Quality of Life (QOL) framework (Parmenter, 1992; Rapley, 2003; Schalock et al., 2002; Schalock et al., 2004). The strengths of the QOL in learning disability research have been well documented (Rapley, 2003; Verdigo and Sabeh, 2002; Strnadova and

Evans, 2012); however, there are also limitations to the QOL framework, in particular the recognition of individual satisfaction (Goode, 1994; Felce and Perry, 1996; Cummins, 1997; Rapley, 2003). The QOL application has typically been used for the evaluations of learning disability services, but these have often neglected to include the experiences of individuals (Verdugo et al., 2005).

Although the QOL was considered as a theoretical model for this study, the asset framework was able to add something distinctive in terms of my research, and shifted the focus to the capabilities and strengths of the individual, and their solutions. It enabled an exploration of the resources within and around the women that enabled them to navigate older age. Focusing on the protective factors that existed within individuals and their communities can help to identify what supports are naturally available to buffer or protect against life stresses (Morgan et al., 2010). Exploring how these can be nurtured to act as a form of protection during difficult times (Perez-Wilson et al., 2013), and unlocking some of the barriers to the inequalities that they experience (Morgan and Hernán, 2013). This framework looks beyond the usual mainstream outcome measures that have been used for determining learning disability policy (Cummins, 1997; DOH, 2001, 2009), offering a new and individually-rooted perspective. The asset framework works horizontally, seeking solutions that can have a positive impact on life, and this has the potential of developing their status as passive recipients of learning disability services to that of independent people with choices (Morgan and Hernán, 2013).

In this study, health assets provide an underpinning framework that identifies the strengths that are located in the individual and across their social network, and in Chapter 5 [pp 210 - 236] these resources and capabilities (assets) are presented in terms of strengthening and protecting women during old age.

One of the key concepts employed within an asset framework is the Sense of Coherence (SOC). This is grounded in the work of Antonovsky, whose research focuses on the sociological aspects of the determinants of health and the salutogenic model of health (Antonovsky's, 1996; Lindström and Erikkson, 2006). The Sense of Coherence is a theoretical formulation of the health/disease continuum, and details how maintaining a position that moves individuals towards the healthy end of this range. A stronger SOC enables individuals to respond flexibility to the stress and demands of life. To measure SOC, Antonovsky (1987) developed the Sense of Coherence Scale - a self-reported questionnaire - which has a focus on the three components of SOC i.e. comprehensibility, manageability, and meaningfulness.

There are two versions of the questionnaires - a 29 and 13 item version – and the results provide an individual health status (SOC-29; SOC-13; Antonovsky's, 1987, 1993), although in recent years, adaptions to the measurement of SOC have been applied (Eriksson and Lindström, 2005). The SOC-29 and SOC-13 are 7 point Likert Scales, and a high score equates to a higher SOC, thus demonstrating the individuals' ability to find solutions to specific situations and to resolve these through adaptability (Read et al., 2005). A strong SOC increases the chances that a person will mobilise available resources and actively seek out new means to handle stressors. Measuring SOC within research studies has been with used with children, adults and cross culturally (Eriksson and Lindström, 2006). The measurement of SOC has been used less frequently with populations that have disabilities (Jahnsen et al., 2002), and there do not appear to be any current empirical studies that have employed this measure with a learning-disabled population.

A recent review of studies using Likert-type scales with learning-disabled population groups was undertaken, and this demonstrated that 5 point scales are not responded to effectively, due to the complex task of distinguishing subtle differences in attitude or behaviours (Hartley and Maclean, 2006). Williams and Swanson (2001) found that people with lower literacy had difficulties responding to a five-point scale, and Fang et al. (2011) concluded that a 5-point scale was not suitable when evaluating the quality of life in those with learning disabilities, and that reliability was improved when 3 point scales were used. Therefore, although the measurement of SOC in this study might have proved to be useful, this would have required the development and validation of a scale appropriate for women with learning disabilities. Other research has demonstrated that it is possible to use a health asset framework when studying populations and communities, without the self-reported measurement of a sense of coherence (Kretzmann and McKnight, 1996; Kerka, 2003; Morgan and Ziglio, 2007, 2010; Rotegard et al. 2010; Brooks et al. 2012) As a consequence, a decision was reached to underpin the findings of this study with the theoretical framework of assets, without the self-reported measurement of the SOC (Morgan and Ziglio, 2007). However, the measurement of SOC within this population should be considered as a future development in research [Ch. 6, p. 246].

Other key concepts within the asset framework that have been a central focus in the learning disability literature are resilience and social capital, particularly referenced in studies with children who have learning disabilities (Morrison and Cosden, 1997; Meltzer, 2004; Margalit, 2004; Emerson and Hatton, 2007). Bates and Davis (2004) suggest that social capital is a useful concept for reviewing or researching learning disability services as it provides an additional perspective to social inclusion. However, social capital places emphasis on the relationship between citizens and their

community, but this can result in individuals 'slotting in' rather than creating transformational societal change. The Social Action Research Institute use six components to define social capital: participation in the local community; reciprocity; feelings of trust and safety; social connections; citizen power; and community perception (Health Development Agency, 1999).

Kretzmann and McKnight (1993) discuss a process that they describe as asset mapping, which has been largely used to identify strengths of communities and social capital. There has been a growth in the literature on asset mapping as a public health resource: it has been used as a tool to map out the assets of a community and inform policy development (Benson, 1996; McKnight and Kretzmann, 1997; Beaulieu, 2002; Benson, 2003; Mathie and Cunningham, 2003; Jones, 2013). In recent years, health policy has been increasingly drawing on asset-based approaches to help rebuild communities and tackle inequalities (Scottish Government, 2011; Public Health Wales, 2012). Mapping the assets of communities has enabled the positive attributes of people, organisations, environments and structures to be acknowledged, and has enabled a collaborative approach that improved communities by using their resources. Rotegard et al. (2010) conducted a concept analysis of health assets, and this critique includes a definition of health assets that are situated within the individual, described as internal and external strengths. These can be built, strengthened and maximised by individuals through the integration of new life experiences such as relationships.

Rotegard et al. (2010) defines assets as a

> '[r]epertoire of potentials, internal and external strengths qualities in the
> Individual's possession, both innate and acquitted that mobilise positive
> Health behaviours and optimal health/wellness outcomes'

The definition above has a key focus on the individual, and does not refer to the wider community. However, this study has used an approach that combines elements from the asset mapping process (Kretzmann and McKnight, 1993) with the individual health assets model (Rotegard et al., 2010). Critics of asset-based approaches to health have argued that it is an ill-defined concept that is too individualistic. As a result, they have argued that the asset-based approach does not tackle the structural inequalities that trap communities or address the need for a redistribution of power and wealth across the wider society (Friedli, 2012a; 2012b). However, Friedli's critique focuses on the inequalities of the asset approach, but does not specifically discuss the strengths and weaknesses of the approach for populations that have a disability.

The literature review undertaken for this study does not reveal any publications where an asset model had been applied as a theoretical frame for either individual or population-based studies with people with learning disabilities [Ch. 2.5, pp 36-49]. However, the theoretical framework of health assets was used to discuss the findings of a study that sought the views of professionals in regard to health promotion and people with learning disabilities (Wahlstrom et al., 2014).

Over the past fifteen years, social inclusion has been a central concept in English policy and this has guided much of learning disability practice. However, there has been some critique suggesting that it requires individuals to fit in rather than societal reform (Partington, 2005), while others have critiqued its lack of clarity as a concept (Bates, 2002). Walker and Avant (2013, p.59) recommended that a sound definition of a concept is critical to research development, as if a concept is not clear, each person defines it within the context of their own experience. This can then lead to variable interpretations, making it difficult to measure outcomes or success. It was concluded that the use of the concept of social inclusion for this study may have placed the

findings in a framework that has driven learning disability policy, and one could argue that this has not always helped us to understand or place the findings in the everyday experiences of older women with learning disabilities. However, these concepts, in tandem with the principles of normalisation, have been largely responsible for steering some of the improvements in learning disability practice and services over the past thirty years (Walter-Brice et al., 2012).

The asset framework helps to ensure that this study utilises the value system of the women rather than that of others (Popay et al., 2006), whilst recognising the importance of connections across the wider community. This is achieved through the mapping of their narrated and visually-captured experiences of ageing in terms of an assets framework, and presenting these experiences in terms of the individual's internal and external strengths.

This study uses an asset mapping process that was developed with the women from their narratives, and resulted in the creation of a model, *'Having a Good Life' [Fig. 1 p. 68]*. This study contributes to the paradigm shift that has been described as being more empowering and nurturing research (Richardson, 2002). Storytelling has been at the heart of narrative methodology, and has also been identified as one of three main approaches that are used to map assets across a community (Fuller et al., 2002, p.9). The asset-based approach is aligned with the participatory methodology of this study, and as such it is an effective framework for underpinning the findings of this study, and has the potential to be used in future research. Equally, the asset framework is strengthened by the ethos of ability rather than disability, focusing on what a person can do rather than on what they are unable to do. The positivity of this model has similarities with the process known as person-centred planning, which is commonly

used across UK services for those with a learning disability (Department of Health, 2001a).

2.8 (i) Limitations of an asset-based approach

Taking an asset-based approach has limitations for this group, as although it offers a positive contribution to underpin their lived experiences, it is a relatively under-developed approach to structural inequalities, and it is important not to overlook these and the barriers they can create (Friedli, 2012b). Adopting an asset approach does not replace or exclude services and support that are still likely to be needed by this group. Equally, the assets that have been captured in this study are a moment in time, and these could change at any time due to external factors such as service funding or staffing variabilities.

Figure: 1 'Having a Good Life': Mapping the assets

Family

My support

Friends

Internal Assets

Equanimity

Being valued

My life

Getting out and seeing people

Dolls and Soft toys: my babies
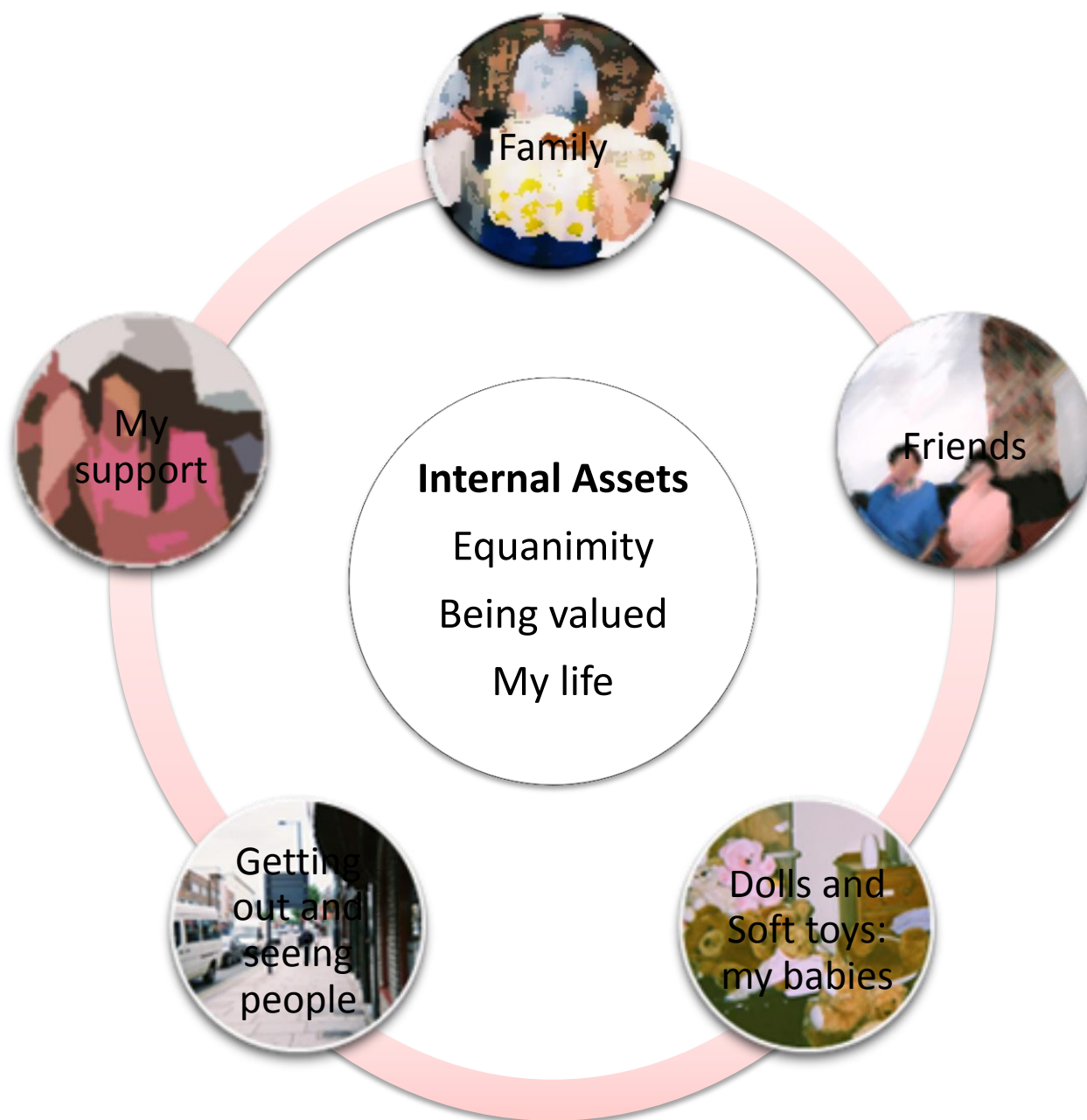
The asset framework held resonance with the emerging narratives of the older women with learning disabilities in this study, as despite some very difficult and traumatic life experiences, they had approached old age positively. Dew et al. (2006) also found in a small narrative Australian study that resilience is fundamental and is born from the women's self-acceptance, family, friendships, being part of a community and having enough money to live meaningful lives. The Australian research applied the theoretical framework of resilience; an examination of the literature suggests that exploring a framework that goes beyond a single conceptual approach could be helpful. Adapting the theoretical framework of assets to underpin the lived experiences of older women is new in the field of learning disability research. It has thus added to the academic body of work that exists on health assets (Rotegard et al., 2010) and asset mapping (Benson, 1996, 2003; Mathie and Cunningham, 2003; Jones, 2013). The asset framework provides a lens that combines the concepts of resilience, social capital and salutogenesis, and this offers a broader framework for understanding the women participants' experiences. However, it is worth noting that there is a gap in the literature on the application of an asset theoretical frame in relation to the population of people with learning disabilities, and as such their lives have not been critiqued in this way. It is possible that one could claim that the language that has been used across learning disability services and policy – for example, social inclusion and person centred planning – could be compared to the meaning and intentions of the theoretical framework of assets. These are discussed in this chapter.

2.9 Social Inclusion

There are some parallels to be observed within the concepts of social capital and social inclusion, and some key principles have been identified (Bates and Davis, 2004;

Chenoweth and Stehlik, 2004; Hall, 2010). Both of these concepts recognise the value of citizenship and the contributions that each individual can make to their community and with care, the concept of social capital can add a different perspective that is helpful. Bates and Davis (2004) suggest that these concepts are too vague at times, and to assist with this challenge, the key similarities and differences across these two concepts have been extrapolated and reproduced in a comparative table (Table 3, p.72). Learning Disability policy and service provision in the UK has made less reference to social capital and more to the concept of social inclusion (DoH, 2001, 2009). For example, 'Valuing People' (DoH, 2001) promoted social inclusion as one of the four key principles of the Learning Disability Strategy. This was likely to have been influenced by the launch of a new wave of British socialism, described as New Labour, and its overarching commitment to social inclusion as a means of addressing inequalities (Lister, 1998). At the core of the concept of social inclusion are the rights that everyone has to lead an 'ordinary life', having a home, job and leisure opportunities within mainstream society, rather than within segregated settings (Bates and Davis, 2004). Although social inclusion has been criticized as being a fluid term, Bates (2002) suggests that it has helped services to ensure that people with learning disabilities have full and equal access to activities, social roles and relationships directly alongside non-disabled citizens. However, critics of the concept of social inclusion have suggested that it has a tendency to ignore some concerning issues, such as bullying, oppression and discrimination, which are a sizeable problem for those with learning disabilities, and have often acted as a deterrent to the use of public spaces (Williams, 1995; Mencap, 1999; Williams and Evans, 2000). Social inclusion has, at times, assumed that inclusive relationships were easy to achieve; however, in practice, this may not be reality. Robertson et al. (2001) found that only a third of

people with learning disabilities had one non-disabled friend, suggesting that fitting in was perhaps not as easy as believed. Abbott and McConkey (2006) carried out a series of focus groups with people with learning disabilities to understand their perspectives on social inclusion, and from these discussions it is evident that being socially included is a reality for some but not for all.

Table 3: Social Capital and Social Inclusion (Comparative Table)

Social Capital	Social Inclusion
Citizenship and service user participation	Citizenship and service user participation
Achieving status of employee by building social capital through networking with others or relationship building	Promotes positive roles such as employee or student
Two different relationships are defined: bonding and bridging relationships Bonding (relationships where there is a common bond that unites); Bridging (relationship that brings together diversity)	Does not define relationships in the same way as social capital. Greater emphasis on relationships that span all the structural divisions in society. Breaking down barriers between non-disabled and those with a disability, thus creating an inclusive society.
Weak ties or relationships are viewed as a valuable source of information and contact e.g.to get a job	No mention of weak ties
Slotting into society rather than societal change	Slotting into society rather than societal change
Participation in various networks through family and friends, neighbours and work. Social capital is generated through these networks and relationships.	Getting an ordinary life - Connections, relationships, valued roles, contributing and social networking through accessing mainstream services.
Social capital unrealised for some vulnerable people who are different e.g. oppression of women	Social inclusion has tended to ignore the existence of bullying, oppression and discrimination within mainstream community.
Value of voluntary to build community, trust and reciprocity	Value of paid employment

Source: Bates and Davis (2004); Chenoweth and Stehlik (2004); Hall (2010).

It has been well documented that people with learning disabilities are a disadvantaged group with greater health needs and higher mortality rates when compared to the general population (Hollins et al., 1998; Holland, 2000; Heslop et al., 2013). However, despite a range of policy and service initiatives (Department of Health and Social Security, 1971; Department of Health, 2001a, 2009), significant health inequalities experienced by people with learning disabilities continue to prevail. Some of these may be attributed to group differences in socio-economic position and social capital (Emerson and Hatton, 2008). However, Exworthy et al. (2003) argue that inequalities go beyond these differences, and they suggest that transformational policy changes are needed to ensure that there is long-term change. Thus, it is likely to be necessary to look beyond the usual models of health and wellbeing to address these long-standing inequalities. It was concluded that the assets framework could provide an alternative lens through which to understand women with learning disabilities and their experiences of growing older.

2.10   Conclusion of Chapter 2

This chapter has outlined a number of studies which have explored ageing across the population of people with learning disabilities; however, there is a dearth of research in respect to women's' perspectives on ageing in the UK. This chapter has also discussed how feminist and disability theorists have largely failed to address the intersection between being a woman and disabled, and it has been argued that it is the role of those working in the field of learning disabilities to make mainstream research aware of the experiences of women with learning disabilities (McCarthy, 1999).

This chapter has revealed that older women with learning disabilities have very seldom been heard, and that their perspective on life today in the UK is extremely important,

as they are one of the first cohorts of women to grow older in their local community. Some of the women participating in this study have experienced periods of their past life in an institutional setting, and so, these women represent a unique cohort that are able to provide a living account of an institutional past and its influence on their experience of growing older as women today in an urban community.

This chapter that this study is important, because it reports a contemporary perspective of the lived experience of older women with learning disabilities as they age. This study builds on a body of literature that values the voices of people with learning disabilities telling us about their own experiences. Speaking out and being listened to can equate to power and privilege, and this has often been denied to women with learning disabilities. This study aims to provide these women with a platform to share their narratives, and visual images. Although women with learning disabilities are living much longer than they did in the past, they continue to be one of the least studied and least understood members of the disability population (LeRoy et al., 2004). Therefore, the findings of this study should provide valuable information that can inform policy, local service delivery and future planning, and add to our understanding of the experience of growing older in the UK. Capturing the narratives of women with learning disabilities and their experiences can help other able-bodied women to learn how to cope with problems that arise in their daily lives, especially if they are coming to terms with living with a long-term disability. It is possible that learning from this group of older women may inform younger women with learning disabilities, by assisting with their preparation for womanhood and ageing, whilst contributing to the future development of learning disability services for older women.

Equally, the design of this study contributes to the discussion on inclusive research and provides a view on alternative research methods. Some of these methods demonstrate visual approaches to conducting research with those who have some limitation in their verbal communication.

Most importantly, this study has begun to address some of the imbalances within research, providing women with learning disabilities with a platform to share their individual experiences. This chapter has discussed the theoretical framework of assets and its potential to contribute to the understanding of the lived experiences of women with learning disabilities, whilst acknowledging its limitations.

The next chapter provides an overview of the various research methods and approaches that were used in this qualitative study. This includes an account of the recruitment process that was undertaken to involve the expert reference group and to invite individual women to participate in this study. Reference is also made to the ethical issues that were presented when researching collaboratively with women with learning disabilities, and some personal reflections and positions are discussed.

Chapter 3 – METHODOLOGY

3.1 Introduction

This chapter presents two broadly distinctive parts of the research study: the methodological framework, and the research methods applied. The chapter starts with the epistemological position of inclusive research and explains how an expert advisory group of four women with learning disabilities supported the development of the research design. The chapter then progresses to defend and justify the application of the narrative and visual methodologies used within the individual interviews with the ten women participants. This is followed by an introduction to the research methods that have been selected for this study, which provides the rationale for selecting these particular research methods and describes how they have been applied and emphasizes the importance of building trust and ensuring that ethical considerations are integral to each stage of the research process. Finally, the chapter closes with a personal reflective account, and a summary and conclusion on the choice of methodology and methods.

3.2 Inclusive Research

This thesis represents an under-researched area on the experience of ageing as a woman with learning disabilities living in England. Life for women with learning disabilities has changed significantly over the past fifty years, and it is important that their individual accounts are heard. Early research in this area, as demonstrated in Chapter 2, does not always consider the lived experience of people with learning

disabilities, and tends to concentrate on the beliefs, perceptions and attitudes of carers, parents and professionals (Whittemore et al., 1986 p.5).

Over the past fifty years, there have been a number of studies in the UK that have provided an insight into certain aspects of ageing, service provisions for older people, experiences of health care, life history research, and the life experiences of older people living across the globe (Chapter 2.5, p.36-49). However, in the UK, ageing from the lived experience of women with learning disabilities has been largely an underdeveloped area of research, despite it being acknowledged that women are living much longer and this population has seen and experienced many changes in their lifetime. Thus, it is vital that we hear their narratives and learn from their experiences.

To hear women's stories, it is important that an inclusive framework is used. 'Inclusive research' is a broad term that draws on participatory and emancipatory research methodologies (Creswell, 2007), and embraces core inclusive values. Walmsley and Johnson (2003) propose that inclusive research has a number of key components; these are outlined in Table 4, below.

Table 4   Key components of Inclusive Research

1. Research problem should be owned by disabled people but can be initiated by nondisabled researchers

2. The research should further the interests of people with learning disabilities

3. People with learning disabilities should be involved in the research process

4. People with learning disabilities should have some control over the process and outcomes

5. The research questions, the research process and the reports should be accessible to people with learning disabilities

Source: Walmsley and Johnson, 2003, p.64.

Over the past fifty years, the movement towards inclusive models of research with this population has reflected a change in attitude, which has transformed the way that research is carried out with populations that had previously been excluded, such as those who have a learning disability (Atkinson et al. 1997, 2000; Chappell, 2000; Hamilton and Atkinson, 2009; Blunt et al. 2012). Early references to inclusive research with people with learning disabilities was often referred to as participatory research and historically was championed by Robert Edgerton in the USA (Edgerton, 1967). In the UK, participatory methodologies have underpinned life story research revealing hidden history (Atkinson et al., 1997, 2000; Rolph, 1999). Since these earlier publications, participatory research has evolved, and there are variances in its application. These can be seen across the methodology of participatory, emancipatory and inclusive models; however, they all have a golden thread that reflects common core principles of justice and equality.

Early research with people with learning disabilities often took a positivist or medical approach, measuring what people could or could not do, and these studies sought to improve or cure the condition or the person (Rioux and Bach, 1994). One could argue that this reflected the general views and attitudes that were commonly held by a large section of British society during the twentieth century, attitudes which supported care in hospital settings, miles away from the family home. These restricted conditions were highlighted in the report by a committee enquiry of hospital care (Jay, 1979). Over the last fifty years, there has been a general move away from segregated living. This was influenced by the 'normalisation' of Health and Social Services, and the need for people to have an 'ordinary life' (Kings Fund, 1980). Pressure groups and professional networks have also advocated a move from hospital to community services (Holt et al.,

2000) and the call for closure of the long-stay hospitals was signposted in early UK policy (DHSS, 1971).

There has been a continued commitment to the move to community settings for people with learning disabilities and these principles were the cornerstone of 'Care in the Community', and the later, the Valuing People Strategy for England provided a vision of inclusion for the twenty-first century (Department of Health, 1981, 2001a, 2009). Walmsley and Johnson (2003) noted that the changes in life opportunities for people with learning disabilities were reflected in the development of participatory and emancipatory methodologies within the research world.

Another key influence in the world of inclusive research has been the feminist movement, which has an epistemological positioning that underpins the belief that knowledge is embedded in social relationships (Denzin and Lincoln, 2005). Oliver (1992) suggests that disability research has a lot to learn from the feminist research paradigms that are sensitive to diversity and empowerment of individuals and provide rich accounts of personal experience. However, it has been argued that feminist research itself has not always been inclusive in terms of women who have a disability (Morris, 1991; Traustadóttir and Johnson, 2000); therefore, the researcher needs to be both flexible and inclusive to ensure that studies are accessible to those who have a disability.

One could argue that inclusive research is not so much about research methods and techniques, but more about the degree of engagement and positioning (Pain and Francis, 2003). Some authors have suggested that it is not possible to have truly inclusive research partnerships with people who have learning disabilities when they do not control the research process (Barnes, 2004). This school of thought argues that

inclusive research can only truly be achieved through emancipatory methodologies, where people with learning disabilities are in the driving seat, leading research and utilising the researcher as they choose (Boxall et al, 2004). This has chiefly been the methodological position endorsed by the disability movement, which promotes a social model of disability (Oliver, 1992). Walmsley and Johnson (2003) acknowledge the differences in the epistemological positions of these inclusive methodologies, but have suggested that there are complexities associated with the application of emancipatory research which has halted a full-scale migration within the world of research. Equally, there have been some interesting epistemological debates in connection with emancipatory and participatory research and their range of inclusivity (Tregaskis, 2002). Walmsley and Johnson (2003) recognise that the epistemological position of the researcher is important in all types of inclusive research, and describes this as 'standing with', as it is about breaking down barriers and power imbalances between the researcher and the participants. Angen (2000) suggests that stepping into the mythical, all-knowing and neutral standpoint as a researcher is not always possible. Individual values and beliefs can emerge whether these are stopped and thought about or not, as we are already morally implicated. The epistemological position between researcher and participant is one that has its roots in philosophy. In principle, it is the philosophical approach that a researcher takes to engage with the research participants, with epistemology guiding methodological choice (Carter and Little, 2007).

Over the past fifteen years, there has been an increase in the application of participatory research methodologies (Gilbert, 2004). This is demonstrated by the number of published studies where people with learning disabilities are reported to be active participants or co-researchers and it is reflective of an increased application of inclusive methodologies (March et al., 1997; Walmsley, 2001; Walmsley and Rolph,

2001; Hamilton and Atkinson, 2009; Haigh et al., 2013). Key messages have emerged from the inclusive methodologies of these studies, with reciprocal relationships based on mutual respect between participants and researcher and the empowerment of vulnerable groups within the research world.

3.3 Inclusivity

The epistemological position of this study is grounded in participation and collaboration, and as such it lends itself to the research paradigm referred to as inclusive research. Inclusive research provides a platform for capturing the experiences of an oppressed group, and challenges the dichotomy of researcher and researched (Williamson and Smyth, 2004); thus, it has the potential for promoting justice and equality (Walmsley and Johnson, 2003).

It was therefore appropriate to design a study that was inclusive from the onset, and this was achieved through working closely with a small expert reference group of four older women who had learning disabilities. Their experience of ageing from an insider perspective is extremely valuable, and their views and questions informed my understanding and shaped the choice of research methods.

Inclusive methods were also informed by my review of the literature; research methodologies carried out from a professional perspective carried fundamental difficulties and did not always value the voices of individuals (Klotz, 2004). Some of the earlier studies of people with learning disabilities have been criticized for their positivist stance and their inability to bring about immediate change in policy or practice. However, Kiernan (1999) argues that it is naïve to suggest that early research studies are without value, and that in fact, they provide an example of instances where the views of people with learning disabilities were first largely ignored and had no

immediate impact, but later were considered alongside journalist reports and provided strong leverage for policy reform in the late 1960s.

Equally, inclusive research has not been without its own ethical dilemmas. Bigby and Frawley (2010) have suggested that researchers taking an inclusive approach to research need to be honest when reporting the degree of ownership, control, and involvement. These are all noted as essential factors which necessitate a reflective position that critically examines these areas. The need to stand within is presented as a vital component of inclusive methodology, but when confronted by difference, this has proven to be challenging for researchers. Alan, a co-researcher with mild learning disabilities, describes how 'standing within' is difficult when he is conducting research with people who had severe or profound disabilities (Bigby and Frawley, 2010). However, there are many benefits to using inclusive research methods and the ethical dilemmas can be overcome (Grant and Ramcharan, 2001).

Darlington and Scott (2002) suggest that there are three basic requirements to undertaking research with people with learning disabilities, namely valuing the experiences of those who are not as articulate or verbal as some; accepting that their experiences are valid; and taking responsibility for finding ways to elicit their experience. Therefore, it is crucial that research studies with this population use methods that are flexible and encourages participation. Studies with other vulnerable populations have demonstrated how the combination of visual and narrative methods has yielded important and novel ways of understanding the experiences of women (Harper, 2002; Pink, 2001). This is especially important when working with groups that have been excluded from the general population, and have lived on the boundaries of society (Booth and Booth, 1996; Darlington and Scott, 2002). Andrews (2002) suggests that the narratives of members of groups which sit on the margins of society

are sometimes referred to as 'out-groups': once again, this signals the benefits of using flexible and inclusive research methodologies for this study of women's experience of ageing. In this study, the combination of qualitative methods of storytelling and photo-elicitation provided an inclusive space to capture the women's lived experiences through an exciting blend of visual images and text. This enabled the inclusion of women participants with a wider range of communication differences, and captured the unique experiences of women with learning disabilities as they grew older, through an inclusive lens.

The evidence from the literature suggests that an inclusive methodology has been fundamental in capturing the lived experiences of people with learning disabilities (Atkinson et al., 1997, 2000; Walmsley and Rolph, 2001; Dew et al., 2006; Hamilton and Atkinson, 2009; Strnadova and Evans, 2012). This methodology was selected because it has the potential to address some of the afore-mentioned power imbalances by valuing the women as equal partners in the research and fostering meaningful involvement. McClimens (2008) argues that the pitfalls of inclusive research have sometimes been glossed over; leaving others to think that inclusive research is easy. In recognition of this - and to ensure that women with learning disabilities were at the heart of this study - a small expert reference group helped to shape the design of the research study. An overview of the partnership approaches to working with experts is presented in the next section of this chapter (3.4), and a discussion of some of the challenges that I faced as a researcher are presented in a reflective account (Ch. 3.15, pp.115-122).

3.4 The Expert Reference Group

The expert reference group helped to shape the design of this study, ensuring that the interview schedule reflected the issues that were of key importance to them. The partnership approach to this study meant that interview questions were debated in terms of their relevance and comprehensibility, and photographs were tested as a tool for visually capturing the lived experiences. The partnership approach taken in this study builds on previous inclusive research, and the next section of this thesis provides a narrative on some of the issues that were encountered.

3.4 (i) Recruitment to the Expert Reference Group – Practical Issues

Before embarking on the study, the engagement of an expert reference group (ERG) was a fundamental means of including women with learning disabilities as partners in the design of this study. Other researchers have demonstrated the success of including people with learning disabilities in research designs (Atkinson, 1988, 1989; Atkinson and Williams, 1990; Atkinson et al., 1997, 2000; Walmsley 2001; Walmsley and Rolph, 2001; Dew et al., 2006; Hamilton and Atkinson, 2009; Bigby and Frawley, 2010; Bigby and Atkinson, 2010; Tuffrey-Wijne and Butler, 2010; Woelders et al., 2015).

First contact was by telephone conversation with the manager of a local day centre, where the study and the role of the expert group were explained. To supplement this, an easy-to-read informational leaflet about the purpose of the expert group was also provided (Appendix 4). Third party recruitment to the expert reference group via the centre manager enabled the women to make a decision about being part of the group without the influence of the researcher, and without the fear that they were letting anyone down if they said no.

The manager invited a group of older women who attended the centre to a meeting where she discussed the study and the role of the expert reference group. After some consideration four of the women who attended the day opportunity project expressed an interest in being members of the expert reference group, and agreed to participate as co-researchers. The four women Nalini, Wendy, Pauline and Carol were all above the age of 55 and had a mild or moderate learning disability. An initial meeting was held with the four women to answer any questions that they had about the research.

The four women agreed to take part in the study and wanted to share their experiences, and they expressed that they were excited about talking about their lives, and helping to shape the research. There were a series of discussions to ensure that all of the women understood what being part of an expert group meant in terms of their role and their contributions to the study. The practicalities such as meetings, sharing experiences, and taking photographs were a key part of these early discussions.

Having small numbers in the expert group allowed sufficient time and space for the women to discuss and share their perspectives, and any worries that they may have had (MacTavish, 2000). The meetings with the expert group were initially held once a week; however, this weekly commitment was reduced to a fortnightly meeting, and then a monthly meeting, as the research design progressed and the field work began. The meetings with the four women provided a forum to listen to their perceptions and feelings about ageing, and to test out a variety of research methods that were being considered for use in the main study.

3.4 (ii) Getting started – Working as Partners

The expert group provided the researcher with a forum to listen to the women as experts on their own lives, and to learn about their perceptions and feelings related to their ageing experiences. At the same time, the group provided an opportunity for the

researcher to test out a variety of visual prompts and questions that could be used in the individual interviews with women. The initial topic areas for the group meetings were informed by the academic literature, in particular the interview schedule from the global study of women with disabilities ageing well (Walsh and Le Roy, 2004). The themes of relationships, social roles, health and wellbeing from the global study afforded the group with a structure for talking about ageing as a woman; however, these were only used as a rough guide with the intention that it would be revised as the meetings progressed.

During the initial meetings with the group, there was a discussion regarding the aims of the study, what being an expert by experience meant, and the importance of their role. After a couple of meetings, there were also agreed some group rules; these were discussed at the beginning of each of the sessions, and were kept on display on the wall of the room at the centre. (Figure 2: Ground Rules)

✓ To come to the all the meetings
✓ To come on time
✓ To listen to others
✓ To talk about my ideas and experiences
✘ I will not interrupt anyone
✘ I will not shout or laugh at anyone

3.4 (iii) Sharing Experiences

After a number of weeks, we began to talk about what it was like to be an older woman. These were interesting sessions as three of the women had never talked about getting older before. Initially, the women discussed their friends and relatives who were older and needed help with daily chores, rather than reflecting personally on their own experiences of ageing. However, once I shared my experiences of getting older, this seemed to help the women to start thinking about their own lives, and how

they had changed over time. The changes that they initially discussed were centrally about health and mobility, and how they had seen the health of relatives worsen as they had aged. We discussed the importance of good health and mobility in older age and the physical changes that occur as part of ageing. These discussions with the women were supplemented with a number of resources, and an accessible booklet by the Scottish Downs Syndrome Association (http://www.dsscotland.org.uk/publications/learning-disability/talk-about-getting-older.pdf) proved very helpful. The visual representation of ageing within this resource aided recall, and at times the pictures helped to transform a challenging meeting into a successful one (Owens, 2007). The resources helped the women to talk about their own experiences, both in terms of new opportunities and difficulties as they became older. The following week a range of magazines with photographs and pictures of women who were older stimulated a lot of discussion, and also a lot of amusement about how old age is portrayed. Everyone agreed that having friends and family were very important when you were older. Ageing and health was something that the women had not had the opportunity to talk about before, and they agreed that it was something that all women with learning disabilities would benefit from.

The women also discussed the importance of friendships and family relationships through their childhood and adulthood, and their significance during later life. To understand the importance of each of these relationships a diagrammatical model was used, adapting a model often used in person-centred planning, called a circle of support. Members of their family and friends were added to the circular diagram in a position that demonstrated closeness or distance from the individual placed at the centre (Foundation for People with Learning Disabilities, 2006, p.48-49). The diagrammatical model worked very well, and on reflection was a fun session with pens

flip chart and lots of laughter. It was during one of these sessions that Nalini shared

with the group how her family had not thought that she could ever live independently.

'I showed them that I could when I moved out to a flat of my own' (Nalini)

Nalini shared with the group how important her family were to her, but she was happier

having her own place.   The women discussed how relatives were often a source of

great support and were often the people that the women contacted when they needed

help.

Pat had taken a number of photographs from inside a moving vehicle.   Pat explained

how this was her car and she told the women in the group how the car had given her

the opportunity to see things that she had only dreamt of before.

> 'I went to see Buckingham Palace where the Queen lives and have been to Big
> Ben and the Tower too, before I had the car I was never able to go into London
> as I was too scared of the trains – it was like a dream' (Pat)

3.4 (iv) Using Photographs – Visual Methods

Empirical research and the value of photographic methods with vulnerable groups has

been presented in this thesis (Ch. 3, 97-104) and the use of photographic methods

was found to emphasise the capacity of those that were vulnerable, rather than focus

on their incapacity (Booth and Booth, 2003; Aldridge, 2007). Health and social care

services have also demonstrated that the use of pictures and symbols can improve

reading comprehension (Karreman et al., 2007; Pothier et al., 2008) and that pictures

have been found to improve the understanding in those that have poor literacy, but do

not have learning disabilities (Katz et al., 2006).   Providers and charities that support

individuals with learning disabilities (for example Mencap, British Institute for Learning

Disabilities, the Department of Health, and St Georges Medical School) have published a range of resources such as easy read literature, and picture books for the past twenty to thirty years. However, the limitations of easy-read have been acknowledged; it cannot be a one size fits all approach, and needs to be part of a wider overall approach to communicating effectively with people that have learning disabilities (Walmsley, 2013). Hurtado et al. (2014) found that participants benefited most when information was read out to them regardless of whatever the format, although they acknowledged that drawings, photographs and pictures were thought to be the most effective way of improving understanding.

The women talked about using the cameras, and although they thought that this would be fun they were nervous about using this equipment as they worried that they would not have the skills required, so we agreed that it would be a good idea to practice taking photographs when we met in the following weeks. As the relationships across the group grew, two of the sessions were dedicated to practicing the use of the disposable cameras. As a number of the women had not used a camera before we used the safety of the group to develop these skills and to build their confidence in photography, by taking snaps of each other and of the day centre. At the end of these group sessions the women were all given a 24 shot cameras and guidance (appendix 2a), to support them and their support staff with taking photographs of what was important in their life, such as people, places and things in their life over a period of four weeks.

The disposable cameras were collected at the end of the four-week period and we agreed that the photographs would be developed as 5 x 7 inch photographs; these would be shared with the group. We agreed that the photographs belonged to the women and would be theirs to keep. The women all took an average of 18

photographs and these were presented at a later meeting. The women shared their experiences of photography, and relayed how they had enjoyed this experience. The photographs that the women had taken were mainly of friends, family, their home, activities they enjoyed, and important objects in their life such as dolls, soft toys, ornaments and TV's. The photographs helped to steer the group discussions over the next few weeks. Packard (2008) suggests that visual methods can be disempowering, especially when the participants describe their pictures as not very good or of little value and this was evident when some of the photographs that the women had taken were judged as not very good; they expressed their disappointment when an area of the photograph was too dark or you could not see the object that they had taken. However, this was in part overcome by explaining that not all photographs come out the way that we expect them to it, as sometimes the flash does not go off or sometimes the weather effects the quality of the photograph. The group discussed all the photographs with equal importance regardless of their quality, and through the mode of photography, their life narratives emerged; the importance of relationships, special places, soft toys and dolls, what their life was like now and what they would like to do in the future.

3.5 Justifying the use of the Interview and Photo-Elicitation Methods

The main study was grounded in the experiences four older women with learning disabilities, and we tested the benefits and pitfalls of using photography as one of the research methods, alongside some other visual aids and interview questions. However, one of the strengths of using photographs was how the camera had the ability to position those with a learning disability as a creator**.**

Exploring the lived experiences with people as a way of understanding is seen as an essential element of the collaborative journey (Knox et al., 2000). The partnership

work with the four co-researchers resulted in the development of an interview framework that was based on a number of themes: Our Health and Keeping Active, Keep Doing Things, Relationships, Getting Out and About, and Goals for the Future. These had emerged as key themes during the narratives and photographs that the women had taken to reflect their lived experiences. This was enhanced by the photographs they had taken using a disposable camera. The views of the expert women supported the inclusion of visual methods within the main study.

There have been some difficulties engaging and including people with learning disabilities in early research, and acquiesce, compliance, consent are three areas that have been documented as problematic (Sigleman et al., 1980, 1981; Stalker, 1998; Booth and Booth, 1996, 2003; Aldridge, 2007; Climens and Allmark, 2011). The use of photo-elicitation within the expert reference group demonstrates that photographs had the potential to add rather than detract from the usual word based interview research methods. Booth and Booth (2003) suggest that photographic research methods are well suited for individuals who are sighted and have a learning disability, and suggest that, as a method, it corresponds more closely to the thinking of people with learning disabilities than other more abstract models. The photographs that the women had taken often helped to shape the topic of the interview, and the women were able to define what was significant about the photograph that they had taken. All of the women in the group had taken photographs of televisions, and these photographs helped them to talk about the various television programmes they enjoyed watching and the importance of having a room of their own. The photographs of the dolls and soft toys that they took also helped the women to share their experience of owning things that were important to them, and reflect on childhood and early adulthood when this was not always possible.

Hurworth (2003) suggests that documenting lives through photography can help vulnerable populations use reflective techniques to provide an insight into their lives which supports their narratives, providing a multi-dimensional lens to understand their day-to-day experiences of ageing. Equally, in research with mothers with a learning disability (Booth and Booth, 2003) and at a day centre project (Aldridge, 2007) confirmed that photographic methods supported the principles of inclusion and had the ability to include those who lacked verbal fluency as active participants in research.

3.6 Narrative Research

A qualitative research design was used in this study in an attempt to capture a rich and deep understanding of the experiences of women with learning disabilities. It has been argued that the traditional qualitative methodologies have excluded a large number of people who are inarticulate, such as those with learning disabilities or with dementia (Owens, 2007). As a consequence, many people with learning disabilities have been subject to having research carried out on them, and at its worse have been exploited in the name of research (Balandin, 2003). This is a complete contrast to the ethos of inclusive research, which has a partnership approach between the researcher and the participants based on mutual respect at its heart (Walmsley and Rolph, 2006). It was important that the women participating in this study were viewed as being the authority on the topic, and were enabled to tell their stories; this meant giving them both time and space to make meaning of their social world (Hesse-Biber, 2010). Furthermore, this was not only dependent on hearing their stories but also seeing the important aspects of their lives through the visual representation of the photographs that they had taken, and integrating photographs with the narrative. This is referred to as 'photo-elicitation', and these methods produced a richer and more rounded view for "telling stories", thereby enabling marginalised groups of women to be heard (Hendry, 2007).

Narrative methodology is inextricably linked to phenomenology and social constructionism (Owens, 2007), having its roots in the more traditional phenomenology and hermeneutics methods. It draws on the philosophical thoughts of John Dewey, and considers individual experience as being the central lens to understanding a person. It has been more widely employed over the last twenty-five years (Ollerenshaw and Creswell, 2002). Webster and Mertova (2007) argue that the fundamental difference is that narrative captures the whole story whereas phenomenology only tends to communicate the understanding of a phenomenon at certain points of time. Narrative is a way of thinking about experience, and some believe that this was the best way to understand the lived experience (Clandinin and Connelly, 2000; Clandinin, 2006). Narrative methodology can capture the multiple realities through the stories people tell:

> *'In every culture, people give meaning to their stories (what happened to me as a child that affects me now, how I met my husband, why I got sick and why I got well'. (*Wylie, 1994, p.43).

The conventional paradigm of narrative research was based on stories told in an interview, and inspired by the work of Labov and Waletzky (1967). This work paved the way for others, meaning that there is no single narrative methodology, and it is possibly better to think of narrative research as an umbrella term with no single method or methodology (Phoenix et al., 2010) or as a family of methods (Riessman, 2008). The use of narrative within qualitative research has been firmly established in the research world since the 1990s (Häggström et al., 1994; Riessman, 1993; Gilbert, 2002).

Wengraf (2001) describes a biographic narrative method which uses a single question to stimulate the telling of the story and is only followed up with probes. Although this has a place with participants who are highly articulate, it would require some flexibility when working with individuals who have communication difficulties. Owens (2007)

suggests that a repertoire of interpersonal skills and an active partnership approach is required when conducting research with those who have a learning disability. Booth and Booth (1994) acknowledge that research with this population poses additional challenges due to the range of communication barriers. In particular, they note how some people with learning disabilities have problems with inarticulateness and unresponsiveness, an inability to generalise from experience and think in abstract terms, and difficulties in understanding the concept of time. Although it is important to acknowledge any communication problems, these should not be seen as an impossible barrier, and the use of inclusive styles of interviewing can help to support the process (Norah Fry Research Centre, 2004). It is clear that these problems can be rectified with a flexible application of methods, style and positioning of the researcher, rather than the participants' language variance.

Communication and flexibility influenced and informed my decision to explore the use of visual methods alongside the narratives, as this approach had the potential to overcome or reduce some of the barriers posed by a traditional interview-based research methodology, and would be better-suited to responding to the individual needs of each of the participant. In the past, it has been argued that research with people with learning disabilities is not reliable. This thinking arose due to issues regarding response validity when certain types of questions were used (Sigleman et al., 1981). However, this can no longer be used as an argument to support their exclusion; not including certain groups as participants of research in itself is unethical and results in their views not being heard. This may leave individuals or certain groups feeling disempowered and less likely to provide an opinion or view that could help inform others.

'Nobody ever asks my opinions; I'm not used to that'. (Scoir, 2003, p. 782)

When people have little effect on their life outcomes, they stop trying to solve problems and overcoming hurdles (Roets and Van Hove, 2003). Others have demonstrated how narrative methods can facilitate our understanding of the lives and worlds of populations that would ordinarily be kept silent, and these methods have been applied successfully in research with people with learning disabilities (Booth and Booth, 1996; Dew et al., 2006). The successful inclusion of this population in research is well documented in life history research, in cases where people with learning disabilities have shared their experiences of living in an institution and how these have shaped their lives (Atkinson et al., 1997, 2000). This is an example of a silent population talking about their unique experiences of life in an institution, a valuable personal contribution that needs to be part of the documented history of these institutions, providing a counter-reality to the officially documented view provided by previous employees or written accounts (Delgado, 1995, p. 64).

Walmsley and Rolph (2006) describe this type of insight into a different world experience as a view of 'more history', as it has the potential to add new history by capturing life from another and very important perspective. The difference in views can be stark: an example of this is taken from oral history, where the historical documents describe the work carried out by people with learning disabilities as therapeutic, but the narrative of those that experienced this work describe long hours of gruelling labour that is not in any way therapeutic. Their individual stories bring a different and very important perspective on institutional life, one that would remain unknown if people with learning disabilities had not been able to share their experiences.

Narrative research has been used for harnessing the detailed stories or experiences from an individual or small group perspective (Riessman 1993), and is well suited to

addressing humans' experience, capturing the whole story from their point of view (Webster and Mertova, 2007). It is a multi-faceted method, and its data have been analysed using either a thematic, structural, interactional, content, holistic and categorical, discourse, or performative analysis (Riessman, 1993; Holloway and Freshwater, 2007). Narrative research has been described as a study of the ways humans experience the world (Connelly and Clandinin, 1990), and has been viewed as being both the phenomenon and the method of analysis, the phenomenon being the story told by the participant and the method being the process of analysis of the narratives. Clandinin and Connelly (2000) present the narrative inquiry as a three-dimensional process: the personal (inward) and social (outward), temporal (past, present and future), and spatial (place). (See Figure 3)

Figure 3 – Three-dimensional process (Clandinin and Connelly, 2000)
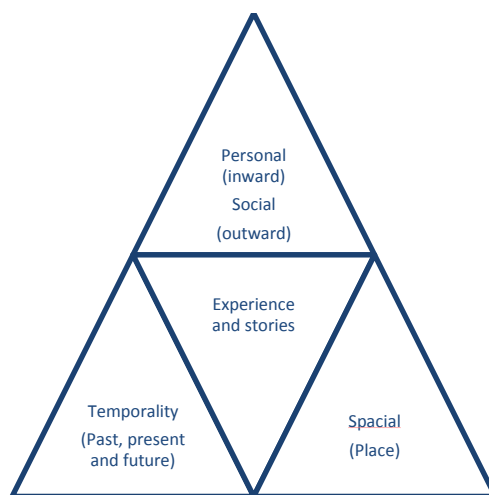
Narrative inquiry is concerned with understanding experiences as lived and told stories. This necessitates a collaborative relationship between the participant and the researcher, one that is integral to an inclusive methodology. Active listening and sufficient time to build a trusting relationship also facilitates and encourages

storytelling, and both of these are key principles of inclusive research (Walmsley and Johnson, 2003). Stories and narratives have been used to describe human experience and to provide a context for understanding and constructing meaning (Polkinghorne, 1995). Narrative research makes sense of the experience of life as lived, and requires relationships to be negotiated throughout the process (Clandinin and Connelly, 2000). There has been some published research that has demonstrated the positive use of narrative methodology with people with mild learning disabilities (Smith et al., 2008). However, the literature also acknowledges the limitations of an over-reliance on narratives with this population, and suggests that the use of visual material such as photographs produce a richer understanding (Aldridge, 2007). The use of photographs within research with those who have a learning disability is a surprisingly an underdeveloped area, although the use of visual methods appears to hold many potential benefits. In the next section of this chapter, the integration of photographs and visual methodologies are explored in terms of the literature and the contributions to this study.

3.7 Visual Research Methods

Over the past few years there has been a revival of interest in the use of visual methodologies. This is especially evident in health and illness research, and includes a range of media, such as video, documents and photographs. The early use of the camera by anthropologists was mainly to support fieldwork, and produce a documentary-style text. However, the classical work of Bateson and Mead (1942) uses visual imagery to capture the Balinese character, and this was built upon by Harper (1986), who used photography as a collaborative method with participants. Harper (1998) argues that even though most sociology depends upon observation, sociology has not been derived from, nor has it reflected, a visual record of the world. This

absence of images as a research method is also evident in mainstream methodology textbooks, and Prosser (1998) notes that the practice of visual research methods in the UK has been somewhat fragmented. Meanwhile, in everyday life in the western world, there have been major advances in technology, particularly demonstrated in the growth of visual media. Therefore, it is surprising that these advances are not more commonly utilised within research., particularly as our understanding of the western world has been dominated by visual technology and this has resulted in a decrease in our reliance on other sensory systems (Sturken and Cartwright, 2001). Grady (2004) argues that there are at least five reasons why visual images have much to offer the study of society. These are summarised as being able to convey mass communications in contemporary society through its unique form of data; the ability to make the story more vivid and lucid; the fact that visual imagery aids documentary production; and that it is ideal for teaching social and cultural processes in the classroom.

Over the past five years, the use of images in social research has grown in popularity (Mason, 2005). This is particularly evident in research studies that have used photographs to explore illness or disability (Radley et al., 2005; Pink, 2007; Frith et al., 2007). Photographs used as part of everyday communication have the ability to transcend different cultures and show us what is significant to them in everyday life (Böck, 2004). Visual images have been used as the key topic of investigation or as a resource within a study (Harrison, 2002), and can bridge the gap when words are not enough (Collier, 1957). People with limited verbal communication are often excluded from research and this can skew samples (Cambridge and Forrester-Jones, 2003), and the use of visual methods may help to reduce some of the challenges posed by traditional language-based research.

This study used photographic images that were taken by the women participants as an integrated resource to enhance the narrative interviews. This technique has been referred to as 'photo-elicitation': quite simply, this means inserting photographs into the interview to understand the world as defined by the participant (Harper, 2002). Hurworth (2003) describes four approaches to photo-elicitation: auto-driving, reflexive photography, photo novella, and photo voice. This study draws on the reflexive and photo novella approaches; it required each of the participants to reflect on the visual images that they had created. This has been a common feature of social science research and helps individuals to tell their story (Belin, 2005; Darbyshire et al., 2005; Morrow, 2001; Harworth, 2003). As previously stated, photo-elicitation is not a method that has been commonly used in research with participants with a learning disability; however, it has been used extensively with children as a means of enhancing qualitative interviews (Hubbard, 1994; Cavin, 1994; Clark, 1999; Orellana, 1999; Rich and Chalfen, 1999; Kaplan and Howes, 2004; Pahl, 2006; Whiting, 2009).

Although not a common feature within learning disability research, visual resources are used frequently by health and social care services when supporting individuals with a learning disability. Photographs, videos, books and pictures are utilised to enrich the verbal communication with people with learning disabilities, especially in the context of health promotion and during certain transitional points in life. However, although the benefits of visual resources are known, there is still very little use of visual methods within research with this population. There were restrictions set by the linearity of narratives and it was important to explore the use of photographs, and to investigate how visual methods could provide a deeper understanding of the lives of this excluded group. Although not wishing to compare adults with learning disabilities to children, it is noteworthy that both these population groups have similar challenges in terms of

verbal communication when it comes to conventional research methods. It is clear from the literature that visual methods assist in unlocking the voice of the child, and that this had led to children having a more participative role within research. Therefore, a parallel could be drawn for women with learning disabilities in terms of greater participation and empowerment.

Communication goes beyond conversation and involves the interpretation of these articulations by other people (Kress and Van Leeuwen, 2001), and the ability to transmit and receive messages via a medium of shared symbolic code. The richness of our social and cultural lives depends on the ability to influence and be influenced by others, through the use of language, spoken or written (Van der Gaag, 1988). The difficulties that people with learning disabilities can experience in respect to communication often arise from the fact that the mechanisms of normal communication having failed to develop (Emerson et al., 1998). In UK-based studies, between 50 to 90% of people with learning disabilities were found to have some degree of communication difficulties (Hallas et al., 1982; Enderby and Davies, 1989; Noble, 1990). People whose communication is underdeveloped can feel excluded unless others are prepared to be flexible, and this often requires an individually tailored approach using different communication methods: pictures, photographs, gestures, symbols, objects of reference and sign language can support and promote two-way communications (Thurman, 2009). Participant-generated images provide an additional resource for a traditionally silent population to document their lives (Hubbard, 1994; Levitt, 2002). This reduces the power imbalance that can exist between the researcher and the participants. A number of researchers have used photographs to enhance the narratives of other excluded adult groups. In a study of people who were homeless, photographs alongside the narrative enabled the researcher to understand with greater

depth the interviewees' experiences of living on the streets of London (Radley et al., 2005). Boċk (2006) argues that visual methods such as photographs can also promote inclusivity in terms of research participation and bridge the digital divide that exists between different population groups. Photographs that people have taken themselves are shaped and interpreted by their values, beliefs, assumptions and experiences: this can then create a window into their world (Cavin, 1994: Hubbard, 1994). Some critics of visual methods are sceptical about the analysis of pictorial representations and suggest that it is hugely problematic. Instead, they imply that written text is the gold standard in research (Oliffe and Bottorff, 2007). However, Cicourel (1964) reminds us that we cannot assume that verbal language-based methods are problem-free, and there are similar difficulties with these forms of data, and other methods of research (Knowles and Sweetman, 2004). One could argue that every form of social science data has some problems, and it is more about acknowledging these (Becker, 1998, p.91).

In practice, using visual formats to enhance communication with people who have learning disabilities is not a new technique: body maps and photographs have been used within health promotion for some time, such as helping to measure and understand the self-perception of pain (Bromley et al., 1998). Additionally, people with learning disabilities have taken and shared photographs that captured their view of the world; this can be seen in the wonderful examples submitted for the annual Mencap competition (http://www.mencap.org.uk/snap/snap_2011/photo_index.asp).

However, although the use of photography and pictures in practice has expanded, these have seldom been used within the world of research with people with learning disabilities. Nonetheless, there are some examples where photography has been used in research with this population, including a horticultural project (photo-elicitation) and

motherhood (photo-voice). The conclusions from these studies suggest that photographs have the ability to bridge some of the communication challenges posed by traditional talk-based interviews (Booth and Booth, 2003; Aldridge, 2007). Aldridge (2007) demonstrates how participative photography and the use of photo-elicitation methods enable people with learning disabilities to be more fully involved in the research process. Photo-elicitation is a method in which photographs are integrated within an oral interview, providing stimulus and provoking responses (Pink, 2007). The use of photographs is not always as straightforward as it seems, as they provide a multi-vocalisation that can create a complex entanglement of photographs and social relations (Banks, 2001). However, Frith et al. (2007) argues that photographs also provide a reference point during conversation, and more importantly, this is the participants' reference. Visual methods have been shown to shift the power balance, as traditional research has more frequently sought the perspectives of the dominant members of society, but this has meant that the voices of women and those who have a disability have often been silent (Riley and Manias, 2004). Boxall and Ralph (2009) propose that, although it is right to celebrate the power shift that visual methods can bring, it is also worth considering the ethical considerations of gaining informed consent, copyright and internet publication.

In the present study, greater attention was paid to ensuring that the information about participating in the study was accessible and understood as people could only consent to participate in research if this was informed consent. This meant that when consent was sought, this was not regarded as a one-off task with the researcher explaining and the participant signing a form, but an integral process that was revisited at each stage of the study to ensure that the women continued to understand and consented to participate in the study, in the knowledge that they had the right to step out at any point

(Cameron and Murphy, 2007). Copyright in relation to the photographs was also discussed with the participants. Legally the photographs are owned by the person who took them, the photographer (Rose, 2007), but there is also moral ownership to be considered, advocating that copies of the photographs are returned to the people in the photograph (Banks, 2001).

In this study, the women had exclusive rights to their photographs, and all publications were subject to their permission. The women participants also ensured that copies of photographs were offered to relatives, friends, and staff who had been photographed as part of this study. Each time photographs were used outside of the study – for example, in conference presentations – the women and others captured on film were asked for their consent. With the growth in the World Wide Web and social media sites such as Facebook and Twitter, people are sharing information that was previously regarded as private, and this has caused some concern regarding the anonymity of research participants, as visual methods have the potential to identify individuals. However, this ability to share experiences through the global network can be positive, as demonstrated in a photo album compiled by mothers celebrating the lives of their children who happen to have Down's syndrome, providing positive insight into the lives of children. One of the key purposes of sharing these photographs is to promote the positive rather than the negative frame that disability can evoke. However, Wang (1998) argues that the publication of photographs that depict disability can incite a prolonged gaze and as such can contribute to further stigma. These ethical considerations return us to the importance of the individual, who has to be at the centre of these decisions. To take an informed decision, participants require the right information and sufficient time to enable them to ask questions, seek clarity, weigh up the pros and cons, and make their own choices about participating in research.

Although visual methods posed some ethical considerations, this is far outweighed by the advantages of using photography within a narrative study. Visual methods have been shown to support a collaborative partnership between the researcher and participant and to enhance communication during the interviews (Aldridge, 2007).

3.8 Ethical Considerations

Lack of research with this population has been well recognised due to the methodological limitations and ethical issues such as capacity and informed consent (Andre-Barron et al., 2008). However, Smith (2007) argues that when researchers take a reflexive stance and a facilitative position, it is possible to hear the voices of silent worlds. The foundation for research involving people with learning disabilities and other vulnerable groups needs to be built with a greater level of integrity on the part of the researcher. The ethical issues posed by this type of research need to be considered throughout the study, and these are not tackled as a hurdle to be overcome once, but as a part of the total research experience. Later in this chapter, I reflect on some of the significant ethical and moral dilemmas that this research with women with learning disabilities presented, and how ethically sensitive approaches are essential and part of the researcher's moral obligation as detailed in the quote by Hallowell (2005).

> "*As researchers (and human beings) we act as 'morally responsible selves' we need to be flexible and reactive but above all accountable for our actions*" (Hallowell et al, 2005, p.149)

3.9 Research Ethical Approval

Ethical approval for this study was received from the Camden and Islington Primary Care Trust Research Ethical Committee, and annual progress reports have been submitted to the committee. There were some initial questions posed by the ethical

committee, which centred on the participatory work with the expert reference group. It is not unusual for ethical committees to ask a high volume of questions when being asked to approve research proposals that involve an expert reference group. Boote et al. (2002) found that NHS ethics committees tend to take a protective position when reviewing research proposals that involve individuals with learning disabilities, and suggests that they needed to draw away from protectionism and move towards a position of empowerment. The questions were, by and large, about whether the expert reference group were co-researchers or participants in this study. However, there is an abundance of evidence that suggests that people with learning disabilities as co-researchers can add depth to research (Tuffrey-Wijne and Butler, 2010). The work of INVOLVE, established in 1996, also supports the involvement of the public in NHS, public health and social care research, and demonstrates the importance and value of carrying out research with rather than about people (http://www.invo.org.uk/about-involve/ Accessed 23/4/2012). Tee and Lathlean (2004) suggest that attending the research ethical approval committee to present a study proposal does help to allay some of the panel's fears and helps them to understand the benefits. Attending the research ethics committee enabled a dialogue to take place that addressed the panel's concerns about the involvement of an expert reference group in the present study. After some debate, there was an acknowledgement that the expert group were in fact co-researchers and not research participants. Research ethical approval committees have changed, and are beginning to recognise how important it is to include research partnerships, and this has led to a rise in inclusive projects (Hannigan and Allen, 2003), and ensures that women with learning disabilities were kept at the heart of the process.

The Research Ethics Committee made some recommendations on how to improve the participants' information leaflet, and these were incorporated into the accessible documentation that gained this study full ethical approval (Appendix 5). The Research Governance approval for this study was received from the Medical Director and research governance lead at Barnet Primary Care Trust (Appendix 6). Research ethical and governance approval provided the formal assurance and protection for carrying out the study in the Borough of Barnet.

However, when in the field, consent was a frequent dialogue with all of the participants, and there were times when I needed to reflect on my communication skills, and ask myself how I would do this better next time. There were occasions when I reflected on conversations that I had with the women about taking part in this study, where their full understanding of the research created a degree of disconnection. This encounter occurred at the end of the first interview with Eve, who paused when leaving, and asked:

"Will I get a certificate when I have finished these interviews?"

I remember feeling very disappointed in myself at the time, as I thought that I had taken an inclusive approach, and had checked Eve's understanding of the study. However, her question demonstrated how, as a novice researcher, I had underestimated the differences in our life experiences and cultural backgrounds (Oakley, 1981), and how her understanding of what research meant was perhaps different to mine. I should not have felt disappointed or surprised when Eve asked this question, as it has been found that people with learning disabilities often repeat college classes, collecting certificates, but never graduating (Kinsella, 1993). It was evident that Eve had compared taking part in this study with her past experience of college

education. However, one could also argue that if an inclusive approach had not been taken, then this question might not have been raised, and the misconception might have persisted.

3.10 Recruitment Sample

There is debate in the literature concerning the commencement of old age, and whether those who have a learning disability age earlier when compared to the general population (Bigby, 2004). The Department of Health (2001) suggests that the ageing process of this population should be considered, to commence earlier than that of the general population, starting at approximately fifty years of age. Research studies have used different reference points to signal the beginning of old age: some have used forty as the marker (Thompson, 2002a), whereas others have used the age of fifty (Dew et al., 2006; Buys et al., 2008; Brown and Gill, 2009). To align with the majority of learning disability research on old age, fifty was used for this study, and only women with learning disabilities that were over the age of fifty were invited to participate. This study excluded women under the age of fifty, women with learning or educational difficulties, women who were considered to be in poor health, and those who were unable to give informed consent to participate in the research.

A purposive sample of thirty older women was taken from the Learning Disability Service register held by social services, and these women were all invited to take part in this study. This study initially recruited ten women with learning disabilities over the age of fifty (Table 5), however one of the women was only interviewed once, and therefore the second interview with Carolyn did not take place. Pseudonyms have been used to preserve and respect the confidentiality of the participants. Participation in this study involved a minimum of two face-to-face interviews and a commitment to

take photographs of places, objects and people that the women considered to be important in their lives.

Table 5 – Women participants who were interviewed for this study

Numbers	Name (Pseudonyms)	Age	Home	Marital status
1	Jenny	60	Group Home for 4 people	Single
2	Eve	55	One-bedroom flat	Single
3	Carol	59	One-bedroom maisonette	Married
4	Marie	61	Group home for 4 people	Single
5	Deborah	62	Group home for 4 people	Single
6	Linda	78	Older person, religious home 30+	Single
7	Belinda	74	One-bedroom flat	Single
8	Susan	61	One-bedroom flat	Single
9	May	72	Residential home for 6 people	Single
10	Carolyn +	64	One-bedroom flat	Single

+ Interviewed once only

3.11 Definitions

What is a learning disability?

The definition of learning disability used for recruitment in this study was based on the classification outlined in the national strategy 'Valuing People' (Department of Health, 2001a). This definition characterises learning disabilities by using the following components:

> *A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, and has a lasting effect on development.*

This study approached women with a moderate to mild learning disabilities, with intelligence quotient (IQ) scores of between 35 and 70. IQ measurement needed to be considered alongside other factors, such as social skills and abilities because levels of

learning disability are only points on a spectrum, and there are no clear dividing lines between people with mild learning disabilities and the general population. Holland (2011) suggests that a descriptive statement that is linked to everyday life might be more helpful.

> '*Most people with a mild and moderate learning disability communicate using some verbally spoken language; have reasonable daily living skills and if they have been given opportunities can manage to live fairly independently with appropriate support*'
> *http://www.bild.org.uk/information/faqs (Accessed 27/06/2016)*

3.12 Participants

Thirty women who were known to social services met the sampling criteria, and were potentially suitable to participate in this study. These women were initially approached by staff employed within the voluntary sector or social services, and these staff had been briefed about the study and had been provided with easy-to-read information. Using third party recruitment enabled the women to ask questions about the study without worrying or thinking that they may be letting anyone down by choosing not to participate. This enabled the women to gain a greater understanding of the details of the study without being influenced by the researcher's enthusiasm. The third party recruiters provided the names and contact details of those who had expressed an initial interest in participating in the study, and a meeting with was arranged at a place of their choice. At this meeting the research was described using accessible information (Appendix 2b) and any questions the women had about this study were answered. The women were very enthusiastic, and as a result, as soon as the study had been explained, a number of them started to talk about their lives straight away, although these conversations were not recorded as part of the study. At each of these initial meetings, the women who agreed to participate were provided with a 24-picture

disposable camera, and were asked to take photographs of people, places and objects that were important in their lives. An information sheet and consent form was available for those being photographed (Appendix 2a). The women often asked if they could start using their cameras straight away, and some of them began by taking a photograph of me or a friend nearby. There were a couple of women who had not taken photographs before and additional time was set aside to learn this new skill. A week or two after the initial meeting, the women were contacted by telephone to establish whether they still wanted to participate in the study, eleven women agreed to do so.

Although these eleven women expressed an interest in taking part in the study, only nine participated in both of the face-to-face interviews. One of the women who had been very keen to participate eventually chose not to take part following a conversation with her son. She explained that her son thought that it was not a good idea to participate, as others might hear about their family life. Family members can have an impact on the decisions taken by adults with learning disabilities, and although it was very disappointing news for this study, the wishes of this woman and her family have been respected. Mander (1992) describes how family carers can take on a gatekeeping role to protect the wellbeing of those who are considered vulnerable, and in this role they have ensured that their relative was not exposed to any perceived external demands. However, this can mean that for some people with learning disabilities, participating in research is not a decision that they are encouraged to make independently. Another woman initially consented to participate in this study and took part in the first face-to-face interview at her home, but at a later date she decided that she no longer wanted to take part in the study. However, she did agree to her first interview being included as part of the analysis. All of the women who participated

signed an accessible consent form, although these alone did not provide assurance of their consent (Appendix 3); it was far more important that their consent to take part was discussed as an ongoing dialogue that took place at every meeting between the researcher and the participant. Each of the remaining nine women was visited between two and three weeks later, at which point some of them had already started using their cameras. Some of the women had finished taking all of the pictures, and handed the cameras over so that they could be sent for developing, whilst others had not taken any photographs. After the initial introductory meeting, nine women who had agreed to participate in the study were interviewed on at least two separate occasions, with the tenth participant being interviewed once. The research process can be broken down into four distinct phases: the contact by a person external to the research and the workplace; the initial meeting where the study was explained in more detail; the first face-to-face interview; and second interview that used both the narrative and photo-elicitation. Additional follow-up meetings were also arranged with those who had requested them. However, this four-phased process in practice was not as straightforward or linear as expected, and researcher flexibility and responsiveness to each of the participants' needs was required.

3.13 (i) Materials

Each participant was provided with a disposable camera that had 24 exposures. The women were asked to take photographs of people, places, and objects that were important in their lives. On completion, each of the participants received a set of printed photographs, a copy of their photographs on CD-ROM and a photograph album.

3.13 (ii) Interviews

The narrative interviews that took place in this study were face-to-face, and nine of the ten women were interviewed on at least two occasions. The interviews took place at a venue chosen by the women, and nine of the ten women choose to be interviewed in their own homes. One of the women chose to come to the office where I had a work base: Eve explained that this was because she did not want residents of her neighbourhood to know her business.

An interview framework was used for the first interview. This was based on the views of the expert reference group, supplemented by information gathered from the literature review. The second interview was an extension of the first interview, with the additional benefits of the women's photographs, which were integrated into their stories; the photographs enhanced the narratives of each of the participants. I had originally planned for each interview to last for approximately two hours, based on the literature review of studies that had used face-to-face interviews (Walsh and Le Roy, 2004; Dew et al., 2006). However, in practice, two hours was often too long, and a number of the women looked tired one hour into the interview. The option to rest or stop the interview was always discussed, and some of the women curtailed their interviews early. As a result, the time frame for the interviews was reduced to between one and one-and-a-half hours.

3.14 Reflexivity

Reflexivity was a key component of this inclusive study, and required critical examination and a disclosure of my personal beliefs and values. This section of the chapter reflects on how my personal beliefs and values have shaped or influenced this research. During this research, a reflective diary was kept to ensure that reflection was

a key component throughout this research, and time was set aside to sit quietly and reflect on the stories that had been told (Goodley, 1996; Clarke, 2009). Reflecting on the interpretation of these stories helped to ensure that the study remained grounded, and was representative, of the lives of those it was touching (Warr, 2004). Critical self-reflection enabled time to acknowledge the presence of power differences between the participants and myself (Northway, 1998).

When I started meeting the women who wanted to take part in this study, I found that a number of them had surrounded themselves with dolls and soft toys, and had built up extensive collections. This challenged my views on what was regarded as 'normal', as it was clear that the dolls and soft toys were important to these women, and for some, they forged a link with motherhood.

> 'I can't have kids… So they are my kids, my three kids over there: one is Carol has the same name as me, one is Rose, she is the smallest, and the bear over there is Patrick. But these are my special ones I want to play with them all. I dress them in babies' clothes, you see. I can't get any teddy clothes so I dress them in baby's clothes. Rosie is the youngest, and the one next door to Rose, his name is Patrick. These are all mine'. (Carol, pp.63-65)

> 'Course I wanted babies. I wanted two girls or a girl and a boy, I am not sure if I could bear the pain of pregnancy, I would have loved to have had children'. (sitting and thinking) (May, pp.54-56)

These women spoke with sadness about their lost opportunity of motherhood, and how mostly well-meaning people/staff had often removed these dolls from them; this could now be perceived as an act that went against their wishes. During one of my earlier interviews, one of the research participants asked if I had any dolls at home that my children did not want, and I found myself going through an old toy box and taking a number of soft toys with me to my next meeting with her.

Using an inclusive frame for this study was not always an easy option, and there were some practical challenges. Building trust and the promotion of a reciprocal relationship was not problem-free, and there were occasions when the boundaries that had been carefully cultivated between the participants and I were brought into question.

> Jane: "How many others are you interviewing?
> A: "There are ten women in all"
> Jane: "Oh that is nice, am I going to meet the other women?
> A: "Would you like to meet the other women?"
> Jane: "Yes that would be lovely, we can have a chat"

I had not expected to be asked this question, and had made an assumption that the women would not want to continue to meet up after the interviews with either myself or any of the other participants. Northway (2000) argues that there is limited reference on how best to draw inclusive research to an end, and she suggests that some participants may want to continue to meet for some time after the research is concluded. I had to pause and think, but after a short delay, I explained that I had not discussed meeting up with any of the other women, but agreed to do this and see if anyone else wanted to meet socially. I was surprised to find that, when I did ask the women about meeting for Christmas meal with those who had participated in the study, they each expressed great excitement. Although we struggled to find a day that was good for everyone, six of us met up and enjoyed each other's company. I continue to have contact with two of the women who participated in this study and meet with them socially.

I commenced this research with a very idealistic view of inclusive research; however, in practice, it is not always as straightforward as the models in the literature suggest. There were times when I wondered if there should be more or less of a boundary between myself and the participants. I also questioned my style of research: should I

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be talking more or less, and was I being too friendly, resulting in a reliance that continued after completion of the research? During the early interviews, my lack of interviewing skills was especially noticeable when playing back the recorded interviews: I frequently failed to probe at interesting points, and at times asked too many questions, or asked a closed question that had a blocking effect, rather than encouraging women to share their life experience. This is particularly evident when interviewing Linda, as she shares a wonderful piece of poetry about her life.

> A: Did you write this?
> Linda: 'No, I did it on the computer at college, but I don't go to college anymore
> A: Why don't you go to college anymore?

When I played the interview tape back, I wondered why I had not asked her more about her wonderful piece of expressive poetry. The result of this was that Linda became distracted, and then went to look for an invitation to an exhibition of her art work that she wanted to show me. However, in the follow-up interview with Linda, I was able to talk about this and I listened to her poetry (Fig.22, p.155).

3.15 (i) Critical Reflection on Inclusivity

Inclusive research with individuals with a learning disability is underpinned by a long established body of supporting research (Atkinson, 1988, 1989, 1990; Atkinson et al., 1997; Walmsley, 2001; Walmsley and Rolph, 2001; Walmsely and Johnson, 2003; Williams and Simons, 2005; Tuffrey-Wijne and Butler, 2010; Blunt et al., 2012; Strnadova and Evans, 2012). The strengths of inclusive research methods are discussed in this thesis in order to offer a new generation of ideas, testing research themes, designing questions, and providing an insider expert perspective. However, in practice, during the fieldwork 'inclusivity' was at times like chasing an elusive butterfly,

requiring me to constantly step back, and critically reflect on whether I was truly being 'inclusive' and 'standing with' as described in the literature (Walmsley and Johnson, 2003, p.39), rather than standing above.

Living up to the expectations of inclusive research has been acknowledged as being a challenge (Woelders et al., 2015), and as a research methodology, Nind and Vinha (2012) have proposed that we are still learning how to embed the principles within the reality of research and fieldwork. Certainly, at times, I struggled to ensure that the five principles outlined by Walmsley and Johnson (2003) were adhered to throughout the partnership with the expert reference group. The five principles are:

1. The research proposal must be one that is owned by disabled people,

2. It should further the interest of disabled people, and non-disabled researchers should be on the side of people with learning disabilities,

3. It should be collaborative, and disabled people should be involved in the process of doing the research,

4. People with learning disabilities should be able to exert some control over process and outcomes,

5. The research question, process and reports must be accessible.

Having these principles provided a framework for working with the four women experts in an inclusive group. However, I very soon realised that being a research facilitator was a delicate role in which wrong turns would be taken, and that I would needed to constantly reflect on my position and change my stance when I had ventured away from these five inclusive principles. What follows are some reflections on the principles of inclusivity, and some of the challenges I faced when working with a group of four older women over a period of fourteen months.

3.15 (ii) Ownership

The women had not been involved from the beginning of the study, as the initial research proposal and authorisation of the study had been approved by senior positions within academic and governance establishments. Because of this, the research aims and objectives were not owned by the women in the group. Ensuring that the women understood the aims of the research and their role was discussed at some of our earlier meetings as some of the research terms are very complex and academia has its own set of jargon. One of the key roles was to discuss this in easy to understand terms; this helped to provide the women with a means to feel that the project was accessible and comprehensible (Appendix 2a, 2b, 3, 4). However, empowering the women to share their experiences presents some challenge, as it requires the capacity for personal reflection (Grant and Ramcharan, 2001). By working with the same group of women over a period of approximately fourteen months, relationships and trust across the group developed along with some sense of ownership. Resources, photographs, and checking out their understanding were central to the facilitation of these meetings. This enabled their expert experiences to be shared, and in the process, I began to understand with greater clarity a range of issues and insights from the perspective of a facilitator, which influenced the design of the study.

3.15 (iii) Control

Despite my commitment to the principles of inclusive research I had not envisaged some of the challenges that working in collaboration would pose. Firstly, I did not have access to any research funding or resources to pay for their time, and therefore I was reliant on the goodwill, commitment and enthusiasm of the women who participated in

the expert group. Equally, I needed the cooperation of the staff employed at the day service where the meetings were being held. This meant that some of the women were not always punctual in their attendance, and others decided that they would prefer to do something else that day rather than participate in the expert reference group. These choices required careful facilitation to ensure that the group were not meeting under duress, but at the same time, for the research group to be valued by everyone, the group required some agreed commitment. One particular meeting day I walked into the centre to find that Pat had chosen to go to the local shops with a member of staff, and this had made the other three experts very cross. We overcame some of these problems of attendance and contributions to the group through writing up a set of agreements (Ground Rules) for the meetings, and these were on a flip chart that we kept in the room where our meetings were held (Figure 2 page 86). These ground rules proved to be helpful as they were written with and agreed by the group, although it must be said that they were not infallible as there were still times when the women wanted to be elsewhere, and the group tried to be flexible in response to their choices.

During the earlier sessions the women sometimes took the opportunity to discuss different issues, and at times this was in conflict with the planned theme of the meeting.   As a facilitator I needed to be aware of the need to listen to each of the women, whilst still keeping the plan of the meeting prominent, and reminding the participants of the importance of their research roles. This balance was often difficult to achieve, so I tried to draw some flexible boundaries by having the first 15 minutes of each meeting as a 'chance to talk' slot. When I reflected on this, I questioned whether my experiences of chairing meetings had influenced my need for taking control and replicating an agenda-type format for our group meetings. As a result of my reflection, I

talked with the group, and we decided together that it was still worth continuing with this approach.

3.15 (iv) Collaboration and Involvement

Facilitating the group on some occasions also proved to be a challenge; there were times when women talked over each other, or told one of the members to be quiet or even to stop talking. I found that enabling everyone to have a chance to be heard was at times almost impossible. This was especially noticeable with regard to one of the group members who had no verbal communication, and used an electronic voice box to convey her thoughts, ideas and experiences. There was a time-lag in terms of entering the communication request into the box and this being projected to the group as a vocalised contribution and this often created a sense of frustration for the other women. One of the women in the group would start to complain about the delay, and how A should not be in the group, as she was not able to participate in the discussion in the same way. This required delicate facilitation and discussions about how everyone had a valuable role in the group, and how hearing different views were important for me to understand the diverse experiences that the group members had. The life and educational opportunities of the women were very different from mine, and their views on equality was not always be the same as mine, and this incident is an example of the power disparity which was evident between the researcher and the experts by experience, and between the members of the group. Some of the women experts had lived in different forms of institutional care as children and young adults, whilst others in the group had been raised with their families. Some of the women found it difficult to understand how children could grow up outside of the family, and this also required some sensitive facilitation and explanation.

At a later meeting, one of the women talked about her harrowing experiences of abuse as a child, when living in an institution. It was important that she was able to share this experience butt the end of the session I asked her if she wanted to discuss this in more detail with a member of the local clinical team where I worked. On reflection, I question whether I would have done this if I had not been a nurse. Nursing had been my career since the early 80s and I was aware that some of the women in the group might see me in this health care role and expect me to behave in a certain way. There were times when my clinical role influenced the direction of the narratives at the group meetings, especially when the narratives centred on health and old age. The boundaries between being a nurse and a researcher can become blurred during inclusive research, and this was something I needed to constantly be aware of during our meetings. Facilitating a balanced conversation across the group meant hearing their views, whilst at the same time not getting stuck on what for me were comfortable health related topics, because of my nursing background, and this was not always an easy task.

3.15 (v) Further their interest

None of the women experts had been involved in research, and the first important aspect as a research facilitator was to explain what being an expert by experience for a research study meant, what the study aims and objectives were, and the role of the expert group. One of the key starting points was to convey to the women that the group would not be participants in this study, but that they had the important role of being experts by experience, and as such they were research partners and would help to shape the design of the interview schedule.

In the same way that social inclusion can be a challenge for service providers, the art of inclusivity within research is equally challenging. Regardless of how committed one is as a researcher, to the importance of collaborative research and the promotion of

social inclusion, the difference in life experiences between the research facilitator and other group members can make this difficult to achieve. The differences can affect communication and interaction within the research group, placing the researcher in a position of 'knowing best' and suggesting that others 'know less'. Facilitating inclusive research could pave the way for greater social inclusion in everyday life. However, staying true to the principles of inclusive research, as with the promotion of social inclusion in practice, requires a level of self-checking, group discussion, and critical reflection.

3.15 (vi) Accessibility

Initially, the women were unclear about the research process. The group members were amused that their views and experiences about ageing were being sought, as they did not seem themselves as old. Talking about relatives or other individuals they knew who were older helped, as did the use of props such as photographs and pictures provided the women with a visual frame. These visual models gave them a better understanding of the purpose of the research together with a translation of research terms into easy-to-understand words. Kiernan (1999, p.46) emphasises how the research process relies heavily on intellectual skills, and this can be more difficult for people with learning disabilities than a group of disabled people who do not experience intellectual impairment.

Some inclusive researchers have reflected on the challenges and strengths of carrying out inclusive research (Walmsley, 2004; Bigby and Frawley, 2010; Woelders et al., 2015). Working with experts as research partners in this study confirmed these challenges, and the need for constant reflection on both my position and values. Overall, the experience of working together has helped me to value the differences that the experts' views and experiences add to the research process. The principles of

inclusive research, as with those of social inclusion, are not about everyone being the same or having the same roles, but valuing their uniqueness and adjusting the research approaches accordingly, and adapting my position too.

3.16 Data Analysis

Qualitative analysis is not for the faint-hearted. It does not have any hard and fast rules and can be daunting, but it can equally be very exciting (Barbour, 2008, p.9). Qualitative data provide rich, deep and holistic information, but there is recognition that this can be messy and at times a nuisance (Miles, 1979, p.590). Unlike other forms of qualitative analysis, there are no set methods for conducting the analysis (Riessman, 1993, 2002). The qualitative data in a narrative study needs to be analysed for the story or stories to be told, and this usually involves some degree of chronology, turning points or epiphanies (Creswell, 2007, p.155). A narrative analysis method was chosen for this study because it is able to respond to the aims and objectives of the research by using the stories told to understand the lived experience of a group of older women with learning disabilities. Consideration was given to other forms of qualitative analysis, such as Interpretative Phenomenological Analysis, which has also been used to analyse data that explore the lived experience. However, it was important for the women's stories to be heard within the social and policy context, and so, a narrative analysis seemed more appropriate for this study.

3.16 (i) Credibility

Narrative analysis does not profess to definitive truths, but rather, is a shifting interpretation that is not assumed to be replicable (Creswell, 2007). Consequently, it is

important that there is absolute transparency throughout the analysis process, as this strengthens integrity and credibility (Yardley, 2008).

In this study, to enhance credibility, I explored the data and presented disconfirming instances within the findings. An example of this is in (Chapter 4, p.168) when Marie explains how, unlike the other women in the group of participants, she does not enjoy participating in some of the activities that are provided through the learning disability services.

'I can't stand swimming, no I don't do that, or bowling'. (Marie, pp.882-3)

Similarly, eight of the ten women enjoyed going out walking in their local community, but Deborah did not value this leisure activity.

'I hate walking; sometimes I go out walking, only sometimes'. (Deborah, p. 157)

3.16 (ii) Transcription

The first step in data analysis is the completion of an accurate transcription (Dickson-Swift et al., 2007), so, as soon as possible after each interview, a verbatim transcript was produced from the audio recordings of the interviews. This has been suggested as the first stage of the interpretation (Riessman, 2002). The transcripts were uploaded onto a Microsoft Word document to facilitate analysis. The written transcripts included conversational details such as expressive sounds, pauses and body language. I transcribed the majority of the verbatim transcriptions personally; although this was time-consuming, the task of transcribing did enhance my familiarisation with the content. However, due to other commitments, I engaged the services of a professional transcriber to complete the last two interviews; this was done with the agreement of the women concerned. Once professionally transcribed, these too required vigilant review,

checking these written accounts for accuracy against the audio recordings. This process provided me with an opportunity to become fully acquainted with the data.

3.17 Thematic Analysis and Narrative Analysis: A blended approach

Thematic analysis can be used within narrative research, and is initially concerned with identifying themes within the written and (if available) visual information (Riessman, 2002; Hunter, 2010). A 'theme' is a pattern in the data that, at a foundational level, describes and organises possible observations and can extend to interpreting aspects of a given phenomenon (Boyatzis, 1998). To analyse the data, I used the guidance of a number of narrative researchers: Minister (1991), Lieblich (1998), Riessman (2002, 2003), and Holloway and Jefferson (2000). I also utilised an adaptation of a six-stage thematic analysis process (Table 6 p.125), which helped to frame the evaluation of the data (Braun and Clarke, 2006).

Table 6: Adaption of the six-stage process (Braun and Clarke, 2006)

Phase 1 Become familiar with the data	Transcription of the interviews (multiple readings) Listening to the audio-tapes a number of times
Phase 2 Generate initial codes	Interesting patterns of the text are coded systematically across the data set
Phase 3 Search for themes	Codes are collated into potential themes, and all the data relevant to a theme are gathered
Phase 4 Reviewing the themes	Themes are checked in relation to the coded extracts and then across the entire data set
Phase 5 Define and Name the Theme	Analysis continues until the specifics of each theme are refined and story of analysis told
Phase 6 Produce the report	Analysis finalised

Although the framework (Table 6 p.125) was helpful in providing structure in the early stages of the analysis, I did not follow a clear linear pathway from Phase 1 to Phase 6. There were times during the analysis where I moved back and forth between the phases, to check that my interpretations were fair and accurate. In addition, I supplemented the analysis with guidance from the narrative literature, paying attention to both structure and performance (Riessman, 2002, 2003). Thematic analysis was also selected as it would facilitate the mapping of individual assets.

3.17 (i) Phase 1 Becoming familiar with the data

I listened to the tape recordings three or four times, taking note of the tone of voice during the interactions between myself and each of the participants; this stage of the process was carried out by hand. The tape recordings were transcribed verbatim using Microsoft Word, and these were read and re-read to identify initial thoughts and coding; at the same time notes within my reflective diary were reviewed.   The photographs

that the women had taken were also viewed in the context of the women's narratives. During this stage, certain quotes were highlighted and some initial coding was carried out. This was completed by hand rather than by the use of a computer software programme.

The next step involved a decision to use a computer software package MAXqda10, allowing for the transcriptions, recordings and photographs to be stored in one place. MAXqda10 provided a system that made it relatively easy to navigate across the files. Computer software programmes have been increasingly used for the analysis of qualitative data and these can help to organise, develop linkage and theory (McLafferty and Farley, 2006). However, it has been argued that computer software programmes can create distance between the researchers and the data (Cresswell, 2007, p.165). Therefore, although a computer programme was used as the main tool to analyse the data, it was supplemented with handwritten charts, and notes that were used during each stage of the analysis. These handwritten records enabled me to remain close to the data, and to share early thoughts and emerging findings with the expert reference group.

3.17 (ii) Phase 2 Generation of initial codes

Once the data (transcriptions and photographs) were imported into the MAXqda10 programme, I was able to review the data and identify some initial codes. The codes were taken directly form the text data in a process that was inductive (Asieh and Shannon, 2006). At this stage of the data analysis, 74 codes were identified, and these were then reviewed and checked against the transcribed interviews and photographs to ensure nothing had been missed. The 74 initial codes were entered onto a set of

hand-written charts and these facilitated discussions with the expert reference group, and later helped with discussions about linkage across the coding.

3.17 (iii) Phase 3 Searching and Reviewing Potential Themes

During this next phase of the analysis, linkage and connections were made across the 74 codes and these were refined by moving them into potential categories where there was some natural linkage. At this stage of the analysis there were 54 categories. Although the expert reference group had not been trained to undertake analysis of research data, they were involved in discussions about the early coding process and the potential themes. Their lived experiences as older women were valuable, and supported my analysis by ensuring that the emerging findings held some resonance for them. There were times when a longer debate took place with the expert reference group; an example of this was the potential theme of dolls and toys that had emerged from the early analysis of the data. One of the experts in the group did not think that dolls or toys were a good thing for older women to have, whereas the other three women disagreed. Having the photographs that the women had taken of the soft toys and dolls supported the dialogue, and it became clear that there were different views held by the women experts, and these had been influenced by their individual life journeys. However, the group decided that although they had different views, dolls were a feature of the narrative and visual data, and they were categorised as an emerging theme together with the other 53 categories.

3.17 (iv) Phase 4   Reviewing Themes and Categories

Having agreed the potential categories with the expert reference group, I then reviewed each of the coded sections of the data to ensure that these were aligned to each of the 53 categories. The next step involved reviewing the categories and

identifying broader themes across the whole data set looking closely for linkage. During this stage of the analysis categories were integrated; for example, concepts of 'equanimity' and 'resilience' were combined under the theme of 'equanimity', as the narratives and photographs were more closely aligned to a balanced outlook on life.

3.17 (v) Phase 5 Defining and Naming the Theme

The next phase of the analysis involved analysing the data for common themes that told the story of their lived experiences. Nineteen themes had been initially defined, and the asset framework was then applied to map these themes to external or internal assets (Table 7 and 8, pp.130-131). During this process, special attention was also made to identify any deficits that emerged from the data.

Despite acknowledging that I would not be involving the expert reference group in the analysis, inclusivity in terms of sharing and consulting with the group could have been improved. The photographs that the women had taken supported the discussions within the expert group, and support their inclusion. Equanimity proved to be a complicated concept to explain, and Pat queried how good and bad times (equanimity) was an asset. Assets were explained as things that help us in our life, and that some things involve other people (external) and other things such as equanimity are within ourselves (internal). To support this, we talked about the things that we have that have helped us to pull through during difficult times e.g. strength, happiness, courage, love. The term equanimity was a very complex concept and was explained by using the words of two of the participants 'Life is not a bowl of cherries but you just get on with it' and by looking at some of the photographs the women had taken.

This final stage of the process of data analysis resulted in identifying three internal assets and five external assets and one deficit, all of which represented the capacity and capabilities of the women's narratives (Tables 7 and 8, pp. 130-131).

Table 7 – Data Analysis Internal Assets

Potential Categories	Themes	Related Core Internal Asset
Old age Young adult Childhood Health Wishes Hopes	Self-perception of old age Future	'I am not old yet'. This asset represented the women's self-perception of old age. 'My life and hopes for the future'
Value Independence Voluntary work Friends Staff	Value Independence	'Being Valued'. This reflected the women's view of a place in the community and also a sense of accomplishment.
Strength Determination Resourceful Balance Hope Perseverance Courage Independence Abuse	Equanimity	'You just get on with it'. This asset reflects the women's balanced approach to their life (equanimity).
Fear Worry Sad Scared Lonely Abuse	Womanhood and Vulnerability Abuse	

Table 8   Data Analysis - External Assets

Categories	Themes	Related Core External Assets
Shopping Eating out Walking Employment Voluntary employment College Clubs Church Community Gym Classes Cinema Holidays TV, Radio Hobbies Independence Choice	Leisure and Recreation Employment Clubs and Connections Independence Hobbies	'Getting out and meeting people'. These reflected the importance of keeping busy, and seeing people. 'Keeping Busy at home'.
Dolls Soft toys Babies Children Family	Holidays Motherhood Family	'My Babies'. This asset reflected the important role that dolls and soft toys, such as teddy bears, had in the women's lives.
Family Partners Best Friend Friends Staff Neighbours Choice	Relationships - family Marriage Choice Friends Staff	'My Family'. This represented the important role that family had for the women. 'My Friends'. This asset represented the important role that friends had for the women; a further division between best and other friends was also made. 'My support staff'. This represented the importance of good support with reference to facilitation of connections rather than direct care support.

The data analysis revealed a shared story that the group named 'having a good' (Fig 1. p.68). This diagrammatic representation of the key findings, using the asset framework to underpin it, was developed with the expert reference. This diagrammatic model facilitated the group discussions and held resonance with the expert group, and it was hoped that this would support the dissemination of this research across the learning disability community.

During the data analysis stage of this research, I worked with the expert reference group. The health asset framework became instrumental in interrogating the data, and it was fundamental to understanding the lived experiences of the ten women participants in this study (pp.125 - 134). The health asset framework helped us discuss how the initial protective factors and strengths of the women participants had been identified during the data analysis. Working with the expert group, we discussed how critical these were for the individual. Morgan and Hernán (2013) argue that protective assets often lie within the social context of people's lives, and identifying these is the first stage in the mapping of health assets. By mapping the internal and external assets with the expert reference group, we could see how these resources could be strengthened through family and friends. The health asset framework has an alliance with the QOL theory, whilst offering a distinctive position by prioritising the narratives of the participants in terms of the resources and support systems that were important to them in their everyday life as older women. For example, the prominence of relationships that were based within the learning disability community was an external support that the women trusted, and this could be mobilised.

Thematic analysis was applied to this study as it provides both an accessible method that could analyse experiences from an individual perspective (inductive), and is more

accessible in terms of working with an expert group of women with learning disabilities. The flexibility of taking a thematic approach to the analysis enabled the analytical claims to be underpinned by the health asset framework, and to identify the internal and external resources of the women participants.

The health asset framework enabled the identification of capabilities, strengths and resources of the women participants in a concrete way, and provided a more tangible pathway into how these strengths and resources needed to be valued and organised. This was an important lens through which to view the data, as the internal resources of individuals have often been underestimated. Martensson et al. (2008), and Rotegard et al. (2012) demonstrate how you can maximise benefit by using personal strengths. Other studies have also indicated that health assets maybe essential for living a good life (Cochrane, 2006, Rotegard et al, 2012).

3.18 Challenges of data analysis and the involvement of the ERG

The analysis of the data raised a number of ethical dilemmas in terms of how involved the expert participants should be in the analysis, and the challenges that a non-disabled researcher has when analysing the narratives of women with learning disabilities. In Chapter 2 of this thesis, as part of the literature review, I critically analysed the literature on inclusive research. This led me to question whether the involvement of the women should extend to the analysis of the data, and if so, how, and to what degree.

Recent studies have shown that individuals with a learning disability participating in research can bring their thoughts and interpretation to the analysis of the data (Bunning and Steel, 2007; Stevenson, 2010; Tuffrey-Wijne, 2010), although this is not always a problem-free journey in practice (Minkes et al., 1994; Stalker, 1998). Over

the past fifteen years there has been a rise in the number of inclusive research studies, and this has expanded our knowledge and changed the way that people with learning disabilities are viewed and included (Walmsley, 2004; Abell et al., 2007; Manning, 2009; Brookes et al., 2009). However, there remains a challenge in terms of the analysis of research data that still needs to be addressed; although there are some examples where inclusivity has been achieved, it is largely the non-disabled researchers who continue to lead the analysis of the data (Walmsley, 1995) and in some cases, the involvement has been described as tokenistic (Tuffrey-Wijne, 2010).

Often, the decision not to include participants in the analysis of the data has been partially based on academic requirements, set by institutions that are responsible for postgraduate research. Coleman et al. (2005) challenges the scientific and education communities, reminding them that rigid application of such requirements can have an impact on some population groups, and that these can be unethical. Williams (2005) suggests that involving those with a learning disability in the analysis of research is possible, and frequent periods of concentrated time helps to assist with their memory problems.

The expert reference group had not received training in analysing research data, and the initial information did not include attending any such sessions. . Therefore, the women experts were not requested to analyse the data, and their involvement in the analysis is be better described as consultative. The expert group were involved in discussions about the emerging codes that arose from the interviews and photographs, the development of themes and the model of having a good life (Figure 1, p.68). I tried to reconcile my decision to conduct the analysis with consultation by using some of the words, phrases, and photographs that the women participants had used to represent their experiences.

On completion of this study, an easy-read version of the findings will be shared with the women participants and the expert reference group. Guidance is available from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215923/dh_121927.pdf [last accessed 17/07/2016]. Easy-read is written information that often supported by images, for example, pictures, symbols and photographs (Oldreive and Waight, 2013). An easy-read version of the key findings of this study will also be disseminated to the wider population of people with learning disabilities, and shared with those who provide or commission services for this population. As easy-read written information on its own is not always the best way of presenting information (Hurtado et al., 2014), , the contributions and the advice of the expert reference group will be included in future publications and presentations.

3.19 Conclusion of Chapter 3

This chapter began by discussing the epistemological position of inclusive research, and why this was selected as the partnership approach for understanding the experiences of ageing from the perspective of women with learning disabilities. The chapter then progressed to defend and justify the application of a mixed qualitative methodology that combines narrative and visual methods. This includes a discussion on how these two methods were integrated as a means of enhancing the one-to-one interviews with women with learning disabilities, and the involvement of the ERG. Some of the ethical challenges and dilemmas of carrying out research with women with learning disabilities experts were presented, both in terms of the literature and through personal experience. Within the chapter, there was an explanation on how ethics became an integral component that was considered throughout the research journey. The chapter also discussed how the population was defined, and how recruiting participants often required the engagement of families and professionals.

In the next chapter, the qualitative analysis of the data that emerged from the individual interviews with each of the ten women is presented, alongside the photographs the nine women had taken. Each of the emergent themes is analysed using an asset-based theoretical framework to underpin the experiences of women and ageing.

Chapter 4   FINDINGS

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4.1 Introduction

In Chapter 3, I outlined the methods that were used in this inclusive research study, and the narrative and visual approaches that were taken when working with the women participants and their individual accounts of their lived experience. In this chapter the findings that emerged from a thematic analysis of their narratives are presented. The thematic analysis of the findings essentially identify three internal, and five external, assets that sustained and supported the women in their lives; these assets are presented in this chapter as an alternative model to encapsulate and understand their lived experience of ageing.

The design of the asset model was   based on the qualitative data and has been described in language that resonated with the women: 'Having a Good Life' (Fig. 1, p. 68). This model was developed with women who had shared their lived experiences of ageing through the expert reference group meetings. Direct quotations have been included to support the discussion, and these have been enriched by the inclusion of a selection of photographs taken by the women, included to add a visual context and provide further understanding of their lives.   A specialist software programme has been used to blur the photographic images contained in this chapter, resulting in a low quality of photography. This has been carried out to protect individuals and respect their anonymity.

 Building on innovative research undertaken with younger people (Scales and Leffert, 1999; Murphy et al., 2004, 2010; Whiting, 2012) in which health assets were mapped

out at an individual and a community level, a thematic technique was used to facilitate the mapping of the internal and external assets that underpinned the women's lived experience of ageing.

4.2 External Assets

'Having a Good Life' (Figure 1, p.68) was developed with the expert reference group and from the key themes of the narratives of ten women participants, and diagrammatically presents the external and internal assets that emerged during the thematic analysis.

The framework provides a visual representation of the lived experience of the ten women participants, portraying their experiences in terms of internal and external assets that underpinned their lives as women in twenty-first century England. A number of asset models used in other studies were reviewed (Search Institute, 1997, 2006; Morgan and Ziglio, 2007; Morgan et al., 2010). However, these were predominantly developed for use with children or adolescents, and as such were not felt to be appropriate for the findings from the women participants in this study.

4.3 Social networks

Over the past twenty years, there has been some critique of the importance of social networks with the emergence of community care. However, for women with learning disabilities, ageing and social networks have often been presented as a genderless issue. The literature on social networks and ageing is fairly limited, and what is available refers to mixed-age gender populations of adults with learning disabilities (Dagnan and Ruddick, 1999; Robertson et al, 2001; Cambridge et al. 2002; Emerson and McVilly, 2004; Forrester-Jones et al., 2006; McVilly et al. 2006; Bigby, 2008)). The literature does not try to understand what differences the issue of gender may

introduce in terms of growing older, or how it may impact on social networks. In the general population there has been some gender-specific research, and it is recognised that women often maintain their social networks better in old age when compared to men, and their networks are usually larger (Arber et al., 2003; Grundy, 2006).

There have been a number of definitions of the concept of a social network, but I have largely used the women's descriptions of what they see as the composition of their social networks. They described people with whom they had some form of social bond, or had regular contact with, and those who provided them with support and companionship. All ten of the women commonly talked of friendships that fell into one of two categories: a best friend and other friends. In addition to friendships, all ten of the women also talked about special relationships that they had with partners and relatives.

4.3 (i) My Best Friend

In later life, friends are often sought for companionship, sharing an interest or activity, enabling people to participate in activities together for company, enjoyment, amusement (Barber and Hupp, 1993; Chappell 1994; Knox and Hickson 2001; Read, 2002; Uchino, 2004; Brackenridge and McKenzie 2005; McVilly et al., 2006; Lunsky 2008), and help and advice (Frith and Rapley, 1990). Friendships can be a source of emotional support, especially during stressful circumstances, and can have a positive impact on a person's well-being (Chappell, 1994; Brackenridge and McKensie, 2005; Lunskey, 2008). In a small study, long-lasting friendships have been shown to be particularly valuable to older women with learning disabilities, helping to preserve their self-identity, and acting as a conduit for sharing common experiences across time (Knox and Hickson, 2001).

Friendships were at the heart of the participants' experiences of growing older, and this was demonstrated throughout their narratives and evident in the photographs that they took. Eight of the ten women spoke about having a fairly small circle of friends; in keeping with literature which suggests that adults with learning disabilities often have small networks (Robertson et al., 2001, Cambridge et al., 2002). This can also be complicated by the difficulties people with learning disabilities have in maintaining and making new friendships (Moore and Carey, 2005). Bigby (2008) found that friendship circles were at risk of becoming smaller as individuals with learning disabilities aged. However, Cambridge et al. (2002) suggests that those over the age of fifty have closer relationships in comparison to those under the age of fifty. Five of the ten women in this study described long-standing friends that they were very close to as their 'best friend'.

Best friends often help each other through difficult times, and in this study they were often friends who had been made during their early school life. There has been some suggestion that women with learning disabilities do not sustain long-lasting friendships because of various transitional or geographical circumstances (Amado,1993, p.305) and that these often were not sustained due to the need for staff support to keep these friendships active (Bigby, 2004, p.127). However, five of the ten women had friends that they had grown up with and had known since childhood, and although they had taken different life journeys, their friendships had remained strong with the passing of years. There remained a common thread across their narratives that spoke of the value they placed on having and keeping a best friend.

> 'My best friend is Ann: actually she is my only friend. We became friends at school, you know. I was friends with another girl who came in to help me and then she introduced me to Ann and that's how we got talking. So she invited me over to hers and then I went to hers and she came to me. It is, she's my best

mate, we're the best of friends, you know, we care for each other best, you know'. (Marie, pp.271-75)

'I have known Madeline since school, a special friend. We have a chat, and she likes to watch TV or we listen to the radio together'. (Belinda, pp.271-74)

A number of these special friendships had endured the test of time, and the challenge of geographical distance. For example, Marie had been admitted to a long-stay hospital miles away from her place of birth and childhood as a young adult. Her parents had died prior to the hospital admission and she had lost contact with all of her remaining relatives, but her 'best friend' had always been there, providing support and companionship. Visiting people in long-stay hospitals could be very difficult during this period of time, as they were often situated in isolated areas, with limited or no bus routes. However, her best friend had visited her at the hospital regularly for over ten years, and was the sole constant between Marie and her early childhood community. When Marie was resettled back in to the community, their friendship continued to thrive, and her best friend remained the one constant link across the passing years. With the passing of time, the visiting aspects of this friendship have reversed, and Marie visits her 'best friend', who is now housebound; their mutual support was evident throughout the narrative of their friendship. School friends can provide mutual support in old age, although this has been found to be more likely to be the case for women in comparison to men. This type of mutual support has been shown to help people cope with the battles of life and difficult times (Atkinson and Williams, 1990; Atkinson et al., 1997; Knox and Hickson, 2001; Buys et al, 2008).

Three of the women talked about having to make a high level of personal investment to sustain friendships. Belinda explained how she visited her best friend as often as she could, even though it meant taking a number of bus journeys across London to get

there. Belinda's friend was no longer able to get around independently and this meant that keeping in contact had become more difficult, as she was now more reliant on others.

> 'Well she hasn't been for a long time, not so good on her feet now, no somebody has got to bring her and see her home, or somebody that's coming and staying and take her home after'. (Belinda, pp.199-205)

Across social policy agendas in England, there has been an emphasis on the concepts of social integration and social inclusion for those with a learning disability (DHSS, 1971; DOH, 2001, 2009). These concepts have often placed greater value on the development of friendships with those who are non-disabled, almost dismissing the value of friendships with those that have a disability. As a result, a number of research studies have focused on friendships with non-disabled people (Richardson and Ritchie, 1989; Lutfiyya, 1991; Van Dam and Cameron-McGill, 1995) and the findings suggest that friendships with the non-disabled community are very few or non-existent. However, in this study, the 'best friends' that the women described were usually women with similar learning disabilities to themselves. When the women did describe friendships with those who did not have a learning disability, these were often in reference to either paid staff or relatives, and were firmly placed in a different bracket to those of the 'best friend'. These relationships will be discussed later in this chapter.

4.3 (ii) Friends

The geographical convenience of living in the community is expected to yield new friendships, bringing those with a learning disability and the non-disabled community together, and widening the range of friendships through social inclusive opportunities (Department of Health, 2001, p. 77). However, the Department of Health (2009)

recognises that there are challenges in developing and sustaining friendships and relationships, and this is one of the key regional priorities across England.

Whether through personal choice, shared interests, or other opportunities, all ten of the women in this study described a social network that was predominantly made up of friends who had a similar learning disability to themselves, with no friendships with those who did not have a disability. Some of these friendships had formed as a result of the transition from living with their parents to living in a residential service, or through their participation in community leisure or daytime opportunities organised through a variety of learning disability organisations. When individuals have moved to residential care, it is common to observe schemes that are based on functional groupings, e.g. autism or challenging behaviour, rather than social connections or personal choice (Emerson and Hatton, 2008). Friendships that had developed through activities or groups were often described differently by the women in this study: these friends were not usually seen as their confidantes, and were more often associated with shared interests and activities or in some, instances companionship. High connectivity in the local community was found to be important to older women with learning disabilities in Australia (Dew et al., 2006), and shared activities usually within the learning disability services have been shown to nurture friendships (Bigby and Knox, 2009; Judge et al., 2010).

Four of the women participants talked about a community art group for the over 50s that they went to every week, and about how they had met new friends there and looked forward to seeing them each week.

Figure 4: 'This is a photograph of us in the art group; we were doing cabbages and things. Drawing bits of fruit and vegetables like. We are friends; we don't live near to each other though'. (Susan, 70-83).

It is not unusual for women with learning disabilities to choose friends who are similar to themselves in terms of gender, age and social position; therefore, it should not be a revelation to discover that the women participants valued friendships with others of a similar age, disability, and those who enjoyed similar interests (Chappell, 1994; McConkey, 2005). One could argue that some of these friendship connections have been maintained in older age through their attendance at segregated learning disability services (Judge et al., 2010; Bigby and Knox, 2009).

Friends are known to improve women's quality of life and wellbeing as they grow older, and it is known that women with learning disabilities (in comparison to men) place greater importance on relationship and friendships (Atkinson, and Williams, 1990; Atkinson et al., 1997; Dew et al., 2006). Although social inclusion is the unifying

principle of health and social care policy in the UK, it is often difficult for individuals to achieve this, as it requires a wider system change: therefore, it may be an unrealistic goal for many women with learning disabilities (Cummins and Lau, 2003). Most of the friendships the women participants talked about were linked to services for people with learning disabilities, and their narratives suggested that they bonded more readily with others from their own community.

Figure 5: This is me having a BBQ with my friends, eating with friends. [May 14-16]

The friendships that the women shared with me during their interviews were predominantly friendships with those of the same gender, but this was not always the case. Jenny talked about her close friendship with one of the other male tenants, and she made it clear during the interview that he was a friend, not a boyfriend.

> 'I cook for Phillip and me, we are going to the Isle of Mann together on holiday, we go on lots of holidays together, we went to Cannes together, he is like a friend you know'. [Jenny: 102-06]

Friendships with men were not a common experience for the women in this study. This could be a result of the segregated living that was common in long-stay hospitals, due to family or staff protection, or simply a matter of individual choice. Friends, whether they are the same or opposite gender, are known to provide companionship and reduce loneliness, especially during older age (Kirkevold et al., 2012), and older women with learning disabilities place great importance on both relationships and friendships (Atkinson et al., 1997; Dew et al., 2006; Buys et al. 2008; Strnadova and Evans, 2012). Friendships described by the women participants in this study were usually seen to provide a level of companionship, support, and affection that was nurtured through their shared history.

4.3 (iii) Intimate Relationships

Two of the ten women in this study talked about the intimate relationship and support that they received through their close relationships with men. Carol had been married for twenty years, and Eve had been with her boyfriend for five years. It is worth acknowledging that historically, women with learning disabilities were often discouraged from developing relationships with men, and in long-stay hospitals this division was extended to structural separation of the male and female wards.

Even in today's society, intimate relationships for individuals with a learning disability are not always encouraged, and opportunities to develop relationships are often not available due to the constant supervision of support staff or relatives (Eastgate, 2008; McConkey and Leavey, 2013). Women with learning disabilities have not always been given the privacy or support to develop intimate relationships, and this has often been due to the attitude and beliefs of residential services, and/or the public views and opinions that have often discouraged relationships between men and women who have disabilities (Robbins, 1990; Eastgate, 2008; McConkey and Leavey, 2013).

Historically, women with learning disabilities were often denied the opportunity to develop meaningful relationships with men, marry, or have children (McCarthy, 2002). Living as a couple was often seen to be conditional on independence, skills and financial autonomy, all of which have rarely been attainable for women with learning disabilities. The English learning disability policy agenda is silent on the topic of intimate relationships and marriage (Department of Health, 2001a, 2009), and pays little attention to the importance of intimacy. Health and Social Care policy does contain some broad statements, such as the fact that everyone should have equal opportunities within society; however, there is no guidance on how this might be achieved. The women in this study talked about the support that an intimate relationship brought, in terms of having a confidant, and, having emotional and practical support with the additional closeness and comfort that intimacy brings.

Although the benefits of having a best friend and an intimate relationship were similar, the women in this study made a distinction between the relationship with their best friend and that with their boyfriend or husband. This dissimilarity between best friend and boyfriend was also found in a small scale study on friendship amongst people with learning disabilities (Knox and Hickson, 2001). Eve had many friends but shared a special relationship with her boyfriend Chris, who lived in a different part of the same housing scheme.

> 'Me and Chris, we really get on well and I have known him for 6 years, not 5, its 6 in May. He is very umm, he helps me, takes me to different places; he takes me to Wembley and to London and all that sort of thing. He is good on the trains and buses'. [Eve: 150-52].

Figure 6: 'My boyfriend' (Eve)

Carol had been married for 25 years, and described her husband as her best friend.

Figure 7: 'Yes, it was love at first sight; I got Michael to take me home from the club. [Carol 50-51]

Summary

It was clear from the narratives that the relationships that the women had with their spouse or partner were intimate, and that they provided them with close companionship and emotional support. These relationships also provided the women with practical support, helping them with the daily tasks of life such as using public transport, shopping, paying bills, and visiting relatives and friends.

The women's social networks provided both support and companionship to the women in this study, and spending time with their friends was very important to them. Five of the women had a best friend who had a pivotal role in their lives, stemming from their shared experiences and a shared history that spanned many years. Their best friend was described as a person whom they could rely on and who was often their confidant.

All ten of the women in this study had small social networks; however, the friendships were more likely to be with people of the same gender, similar interests, age and disability.

The women participants did not find it particularly easy to make new friends, especially with members of the non-disabled community; however, certain activities through learning disability services, although segregated, did provide a foundation for making new friendships. Some of the women acknowledged that keeping in contact with friends had become more difficult as they had aged, especially when their friends relied on the support of staff for reciprocal invitations.

4.3(iv) My Family

Family and relatives emerged as an external asset from the narratives and photographs that the women had taken, and it was evident that these were valued relationships that were part of their social networks. Despite many people with learning disabilities being sent to live in long-stay hospitals or hostels, the majority of individuals with learning disabilities living in the UK have continued to live with their parents.

Even though eight of the ten women in this study no longer had living parents, they talked about them and how much they missed them, and stressed to me that they wished they were still present. However, it needs to be acknowledged that with the passing of time, family support does change and non-disabled siblings often assume additional parental caring responsibilities (Bigby, 1997b; Seltzer et al., 2005; Hodapp and Urbano, 2007).

Linda had lived most of her life with her parents and had moved with her mother into her current home, a religious establishment for the care of the elderly, when her

mother had become frail and needed full-time nursing care. This joint move of mother and daughter enabled them to remain together, although at the time Linda was in good health and was a number of years younger than the other residents. Linda had not and did not require this type of care home, but it was the result of their express request to stay together. Emerging from the narratives of a number of the women participants was a strong sense of loss following the death of their mother and father.

> 'We were very close, I moved here when my mother got very old, so I could stay with her'. (Linda 89)

> 'My mum was kind, I loved her very much, and she was very kind'. (Marie, pp.192-193)

> 'Yes I miss my mum and my dad too. My dad died in 1998 and my mum on 21 April 2001, I still miss them, yes I do'. (Jenny, pp.299-306)

Carol's mother was still a large part of her life, and this was shared when we met for the first interview. Sadly, her mother died in the period between the first and second interview; therefore, the final interview was postponed for some time to allow Carol time to grieve. I had wondered how Carol was going to cope, as she had described a very close relationship between her and her mother, with daily phone contact and regular visits. During the second interview, Carol described how she missed her mum, and how her passing had left a void in her life.

> 'I will miss my mum, I would talk to my mum and tell her how I was feeling, she would ring me and say good morning and then I would wake up'. -(Carol, pp.157-60)

Carol's father had stepped in to continue the daily telephone calls to help Carol adjust, and this had possibly helped him too. Carol's husband was also very supportive, as was her link support worker. Carol did not see her father as much as she wanted and

was keen for me to understand that he lived quite a distance away and it was difficult for him now that he was older.

Most of the women had experienced a close relationship with their parents when they had been younger, and had been especially close with their mothers. However, Eve had never had any connections with her family, and had been raised in a children's home from a very early age.

> 'No (looking downwards), I got used to it. We tried to find out, but we couldn't do it. They say that she is still alive but she, um, it was very hard when I was young. I didn't find out until I was about seven, and I was very upset. I did not want to do anything, just went and stayed in my room. I did not want to eat or drink anything and then in the end I got dressed and I, um, what they told me had been very hard to take. Julie helped me most and some of the other staff, they were upset as they did not know what to do see, but eventually I pulled through (pause) I pulled through. (Eve, pp.201-220).

Although Eve talked of pulling through the loss of not knowing who her parents were, it was apparent during the interviews that finding her parents was still important to her. Susan was the only women in this study whose mother was still alive. Susan lived very near to her mother and visited her every two weeks; however, Susan recognised that there would come a time when she would not have her mother present. Susan described how her role had changed with the passing of time; she was now part of her mother's 'carer' network. There has been some acknowledgement of the interdependency that can occurs as parent's age, with their adult children with learning disabilities stepping into aspects of the carer role (Williams and Robinson, 2001; Taggart et al., 2012).

> 'I see her every two weeks: I go to her; it is easier for me to go to her. My mum is in good health, sort of, she knows when she has had enough and she sits down and we tell her not to go tripping over pavements again. We are getting her one of those things that you hang around her neck. She has help: someone comes in and does a couple of jobs for her. My mum, always my mum, if she wasn't around then I speak to my link worker or contact the office and speak to someone there. My family is getting smaller and smaller'. [Susan: 14-19]

There was a sense of loss and bereavement following the death of the women's parents, and recognition that their families had become smaller. With growing age, there was also an acceptance amongst the women that their role and contact with their family had changed. Changing relationships are often an expected pattern of old age; however, the role of siblings in the support of relatives with a learning disability has often been overlooked across the literature (Rawson, 2010). Women with learning disabilities are less likely to have children of their own, and as a result, their siblings quite often assume supportive or caring responsibility in later life (Seltzer et al., 2005; Hodapp and Urbano, 2007).

As women with learning disabilities age, their siblings often found to be residing in other parts of the UK, and geographical proximity and their own ageing experience can be significant predictors of types of support and frequency of contact (Heller and Arnold, 2010). Four of the ten women in this study used the term 'family gatherings' to refer to the times when they met with their siblings, explaining that these were often the only times when they would meet up. Usually these gatherings centred around special occasions such as birthdays. Christmas and summer holidays were also frequently part of the narratives of spending time with their family. Although the family visits were not as regular as they had been in the past, the closeness of these relationships was demonstrated in their narratives and in the visual context of the photographs that they took.

> 'Oh yes, we would do then – supposed to be coming over from Australia. I might get to see them; they are going on a tour somewhere. They will be at my sister's in a week or two'. [Belinda: 18-20]

Figure 8: 'We had a family gathering of relatives from Australia' [Belinda: 31-32]

Some of the other women also talked about family gatherings as a time for sharing: these were very important occasions for all of the women.

> 'Hmm (nodding) and we all go to theirs for Christmas, yeah, Christmas: that's the best time because we all play cards because dad's card table and we have some great games, laughing'. [Carolyn: 136-138]

> 'They come and collect me at Christmas time in the car as I have lots of presents'. [Jenny: 103-4]

Summary

In this study, the views of siblings were valued by the women and were commonly placed at the top of their support hierarchy. Six of the ten women sought the opinion of siblings once their parents had passed away; this was especially noticeable when the

women were faced with choices or everyday dilemmas. The women described how they often contacted their sibling when they wanted help with a decision or if they wanted an opinion.

'They (support staff) wanted to help me get rid of this (points at old bills and paperwork), what do you call it, is it a shredder? [A: yes] and they were going to get me a shredder, but I called Ann (sister) she was not keen on that idea in case I cut my hands. So I did not get one'. [Belinda: 28-30]

'No, the reason was, you see, my family wants somebody to check to see that I'm all right at night time. I can get myself to bed and into bed sort of thing, but he just wants somebody to come in to make sure that I'm okay, to say are you okay? If I'm watching the television, you know I might be ready for bed and they come in and just have a quick chat and see if I'm okay. Of course I never want to have a hot drink at night anyway. But they might just pop in for five minutes to see if I'm ok. It's only really because I've had two falls in this flat'. [Carolyn: 397-409]

Parents and siblings were very important to nine of the ten women in this study. Although the relationships that the women had with their families were diverse, there was a general recognition that roles and contact had changed as they had grown older and that they were juggling other commitments (Orsmond and Seltzer, 2007). Many of the women talked about the loss of their parents and described how siblings had moved into a 'parental' type role.

The women recognised that their siblings had families of their own and were busy, and they appreciated that visits to and from the family now took place less frequently, when compared to the past. The women did not complain about the reduced contact with their families and had a very measured understanding of the family pressures their siblings had, and there was a general acceptance that this was another part of life changes as you grew older and parents had passed on. However, the women in this study had a shared narrative in respect of celebrations such as birthdays and

Christmas, and saw these as times when their families would get together and share stories and have fun.   Although contact with their families had reduced, when important decisions were required, the women were more likely to ask for the views of their families, rather than a member of their paid support staff.

For those who still had contact with their families, there was an acceptance that contact had reduced over time; however, the influence and the value of family relationships was still very central in these women's lives.

4.4 Support staff: Help with getting on with my life

Eight of the ten women in this study were living or had lived at some time, in support services provided by the public or private sector specifically for people with learning disabilities. Living in this type of residential service can bring a different dimension to a person's social network, as there is an important role that paid staff have in terms of maintaining their social networks and community participation, and this has been acknowledged when providing services (Hunter and Perry, 2006). Five of the ten women in this study lived in supported housing arrangements; usually this was rented housing with paid staff (link workers) providing varying hours of support each week. Link workers frequently supported the women in this study with their household bills, shopping and leisure. The other five women participants, resided in residential care and received twenty-four-hour support from paid staff. This usually included a varying level of personal care and support, with daily living activities in the home, community and healthcare access. The difference that paid staff support brought to their local connectivity is significant, as having an enthusiastic support staff team tends to influence the shape and access to community activities for these older women. It has been acknowledged in the literature that personal relationships require the attention of

staff if people with learning disabilities are to have a better quality of life (McVilly and Rawlinson, 1998; Reinders, 2002).

Eight of the ten women all talked about the value of 'good' staff and how staff had helped them with a number of practical yet essential tasks. As the women had aged and family visits had reduced, the reliance on members of paid staff had become more apparent; however, there was still an expressed preference to speak to family first when the women faced problems. Their narratives described the help that they had from support workers to complete housework, pay bills and participate in activities outside of the home.

> 'They help me with bills, cooking, all sorts of things. I get about four hours a week'. [Susan: 253-54]

> 'They book my holidays with me. I like Grace: she is someone that I can trust'. [Jenny: 454-56]

The diversity of support described by the women was noticeable, and this had an impact on what the women were able to do during the day. Those who lived in residential settings with twenty-four-hour support were often reliant on adequate staffing being available before they were permitted to go out. The support staff were often seen to be in the position of decision-makers, and the women were expected to understand that when there were staff shortages, there was less access to activities and support. Equally, they were aware of – and frustrated by – the constant turnover in the staff team.

> 'No, the staff don't, cause two of them are off on Saturday so we can't go out. They are all busy doing things. The manager said "you can go in September, you can do the jewellery, you can do it from 1:30pm." This is alright for me'. [Linda: 203-05]

> 'Different people come and go, don't they?' [Belinda: 17-18]

'Oh they don't always come, not every day. If they don't come I stay in, I stay in and watch telly, but they don't come all the time, but when they do I go out and then I get back'. [Marie: 488-491].

Although there was a general acceptance that staff were not always available, Belinda and Carolyn shared their frustration about the unreliability of support staff and their frustrations when they did not arrive as planned or when changes to their day occurred that were outside of their control.

'My carer was supposed to come yesterday but they rang me up Tuesday because the person we have who's been covering and they're on leave and I was just going out on Tuesday and the person that organised it phoned me up and they said "I don't think we've got anybody", so I hope I get somebody next week'. [Belinda: 289-294]

'Why don't they ring me and tell me what's going on? But they never do. I mean, xx leaving, right? But they never really tell me what's going on and I've had falls when I've been living here and that really gets my back up, and if I go and say I get told off if I go and have a go at somebody. So it really annoys me, especially if they don't call'. [Carolyn: 206-211].

Having regular and reliable support was very important to all of the women, and this had an impact on their daily lives. They all talked about how their link workers had helped them to become more independent in their lives, and helped them to make choices.

'My link worker goes on the net for me. I sit down next to her and she writes it all down. We find holidays on there: we found more than last year. We took all the details and wrote the numbers down or sent a message through the computer to ask for them to send stuff, which they did. What was good we kept a file of all the holidays so I could choose'. [Susan: 42-43]

Some of the women saw their support or link worker as someone who could help them when they were worried, or needed to speak to someone.

'No there isn't, there isn't: both my brothers are at work, and there is only my mother if she is home. So I get hold of the office and I phone the office. I have a list of link workers'. [Susan: 275-281]

After many years of receiving varying degrees of support from paid staff, the women were keen to share their experiences of good and bad support. The women described the qualities they would want to see in their support staff, and what aspects were essential to being a good support worker.

> 'The right person, understanding people, understanding people's problems and something like that: someone who can understand our medical problems and our learning difficulties and something like that, yes - kind'. [Eve: 143-45]

> 'She is someone I can trust, yes I trust her'. [Jenny: 454-55]

Figure 9: This is Michaela - she works here. [May 2, 17]

Three of the ten women had experienced some very difficult times during their lives, and recalled the times when they had been living in care settings where some of the staff had been 'nasty'. Providers of care in all types of settings have, on occasion, employed a workforce that is poor quality or abusive, and public enquiries and reports by the regulators confirm that abuse of those that are vulnerable have continued to

occur in both institutional and community services (Plomin, 2013; Flynn and Hollins, 2013).

> 'No, I didn't like it there. I didn't like the people, I didn't like the staff, I didn't like the others there. They were nasty to me and only my friend that used to come and see me, I enjoyed that'. [Marie: 290-293]

Eve recalled a time when she did not have the independence that she enjoys now, and how life in a residential setting was far more planned around routine rather than what each individual wanted or could do.

> 'I am more independent now, yes I like that but back then we couldn't go out on our own: we had to go out with a member of staff, if we needed shoes or clothes we had to go with a member of the staff'. [Eve: 47-49]

There is variability across the literature in terms of the definition of social networks: some have included paid staff whilst others have excluded them (Dagnan and Ruddick, 1997; Robertson et al., 2001; Forrester-Jones et al., 2006). However, for the women in this study, the support workers were included, as it was clear from the narratives that the women viewed these relationships as a positive resource that helped them to carry out everyday activities and tasks, visit friends, and enjoy their leisure time.

Summary of Support Staff

The women in this study had variable levels of staff support, ranging from six hours once a week, to twenty-four-hour-support, seven days a week. Most of the women valued the contact that they had with staff, and associated 'good' staff support with positive aspects of their lives: cooking nice food, visiting places, organising holidays, and getting on with their lives. Good staff support also appeared to increase the women's opportunities to take part in various interests and activities within the local community. Having 'good' support staff has been shown to be important, especially before or during a crisis. Support staff provide comfort, companionship, and emotional

support, and people with learning disabilities reported close relationships with paid staff (Forrester-Jones et al., 2006).

During the interviews, the narratives of the women highlighted the importance of asking others for help, and most of the women contacted their support staff if they could not get hold of any of their family. For those without relatives, the support worker was often their first port of call.

There was a general expression of frustration and anger about the unreliability of some support staff. Staff not turning up at the required time, or the agency sending a replacement or reducing their support time, caused great dissatisfaction amongst the women. These situations placed the women in a vulnerable position, although most of them did not want to complain about their support staff, and very seldom did.

Eight of the ten women were able to articulate the qualities that good support staff possess, and their expectations were possibly very similar to those of any member of the general population. Given their life experiences of being in receipt of care, the women described negative traits that they did not like to see in any of their care staff. Three of the women had been involved in selecting their own support staff and this was viewed as valuable.

Emerging from the narratives was a general message that the women wanted paid staff to support their continued independence and to facilitate their opportunities for taking part in a wide variety of activities. Support staff were not viewed by the women participants as being there to carry out traditional caring tasks or to encourage dependency.

4.5 My babies: dolls, soft toys

Five of the ten women in this study used their cameras to take photographs of their soft toys and dolls and their stories included them, describing them as valuable items in their lives. There have been different views on whether adult women with learning disabilities should be supported to have toys and dolls, and during a period of 'normalisation' dolls were not thought to be age-appropriate possessions, and were actively discouraged. It is interesting that these women, who had greater levels of independence, increased choice, a room or flat of their own, still chose to have dolls and soft toys. The dolls and soft toys had a very strong presence, and were very much a part of their narrative of external support, and seemed to bring comfort to the women. In the past, many women with learning disabilities were denied the opportunity to have children of their own, and accompanying this were high rates of reported sterilisation of young women with learning disabilities in the UK and across Europe (Dyer, 1987; Thomson, 1992; McCarthy, 1999; Servais et al., 2004). Two of the women talked about how the dolls had become a replacement for the children they could not have.

> 'I can't have kids, so they are my kids, my three kids over there, my three kids over there. One is Christina - has the same name as me. One is Rose, she is the smallest and the youngest, and the one next door to Rose, his name is Patrick. These are all mine (points to a collection of soft toys) but these are my special ones. I want to play with them all. I dress them in babies' clothes, you see - I can't get any teddy clothes so I dress them in babies' clothes'. [Carol: 65-68]

<u>Figure 10</u>: 'Christina, Rose and Patrick - they are very good babies'. [Carol, 72]

The public's view dolls and toys is that they are possessions that are usually associated with childhood, and the sight of an older adult with a doll can reinforce the negative stereotype of 'eternal child' (Walmsley, 2001; McCarthy, 1999). However, some pilot studies, dolls have been given to older women who had a diagnosis of dementia: touching and holding these dolls is observed to have a positive reaction (James et al., 2006; Mackenzie et al., 2006; Alander et al., 2013). Although in these studies many of the staff and relatives were initially uncomfortable with the infantilisation created by the dolls, this was resolved when they were able to see that there was an overall positive impact on the women's well-being.

> 'Well, Michael bought me Christina in one of the shops where they sell cards and all other things, and when I go out I take her and look in the shop. People do look at me and they do laugh, I just don't take any notice. [Carol: 72-74]

Two of the women in this study associated the dolls with memories of their early childhood and it might be that this brings some comfort and security. It has been demonstrated in preliminary studies that dolls can have a therapeutic role in care

homes for the elderly, as early indication is that they do appear to promote comfort and alleviate distress (James et al., 2006; Mackenzie et al., 2006; Alander et al., 2013). Further studies are required to gain a better understanding of the therapeutic role of dolls and their possible links to memories of childhood or mothering. Four of the women in this study have experienced life journeys that have been traumatic, and having dolls or soft toys appeared to bring comfort to them. During the interview one of the women was eager to share the numerous photographs she had taken of her dolls: they were a large presence in her life and her life story.

> 'I love them, I do. I could collect them. This is Marina and this is Christopher. My mother gave me my first black dolly'. [May: 149-156]

The association of dolls with childhood memories is one that has been found to bring comfort and security to elderly women who have dementia, especially during the night. In pilot studies, dolls have been found to have a calming effect and improved older women's lives (McKenzie et al, 2006). However, there are ethical and practical problems that can arise when women take dolls into community places, as this can reinforce a societal image of older age as a second childhood, and strengthen the negative images of a woman with learning disabilities as both asexual and innocent, an 'eternal child' (McCarthy, 1999; Walmsley, 2001).

Figure 11: 'My most important thing now: my black dolly'. [May: 127-28]

Marie also had a huge collection of soft toys in her bedroom; she was very proud of them and, like May, had given each of them names. The dolls and soft toys took up a large amount of her bedroom space, and May described clear associations between her early childhood spent with her family and the presence of dolls and soft toys in her current life.

Figure 12: 'Look at all my teddies, I love them'. [Marie: 6]

Figure 13: 'This is nice picture with my teddy bear and nice of me too'. [Marie: 28]

Figure 14: 'My lovely babies', [Carolyn: 196]

In the past staff, who were employed to provide support to adults with learning disabilities often encouraged people to give their dolls and soft toys away, as a result of the normalisation principle and 'age appropriateness' (Wolfensberger, 1972). Age-appropriateness sets out to encourage individuals with learning disabilities to act according to their chronological age so as to increase community acceptance. Dolls were seen as symbolic of childhood and deemed to be age inappropriate, and as a result, these have often been discouraged or removed (Heenan, 2013). This blanket approach to age appropriateness, although often well intentioned has been questioned in the literature as, instead of promoting a good life the principles can contribute to practices that can compromise wellbeing and human rights (Forster, 2010; Heenan, 2013).

The women who participated in this study had an increased level of independence and had made a number of choices in their lives, and one of these was to have dolls and soft toys of their own. The photographs and interviews with five of the ten women demonstrated that their dolls and soft toys were very important to them; for example, when the women talked about the dolls a number of their responses began with the word 'my': for example, 'my babies' or 'my dolls'.

The central place that dolls and soft toys had in the lives of a number of the women in this study inspired me to reflect and question my own attitudes towards dolls and the views that had a linkage with normalisation, age-appropriateness, and the negative concept of the 'eternal child' (Wolfensberger, 1972). However, the dolls and soft toys that they possessed held a special place in the lives of these women. For two of the women, dolls were associated with strong memories from their childhood, and for others they had become substitute babies and children, and a means of fulfilling the role of mother.

4.6 Getting out and Meeting People

Women with learning disabilities are known to be one of the most excluded groups in society, and often remain largely invisible in their local communities (Hall and Kearns, 2001). This is despite the promotion of social inclusion through a central policy drive across England which was intended to ensure that excluded groups were included (Department of Health, 2001, 2007). This meant that women with learning disabilities would be seen and included within normal spaces and activities in the community that they lived. After the closure of the long-stay hospitals, a new life in a community was intended to offer everyone the same opportunities, and the success of this policy was closely linked to increased employment, integrated leisure and home ownership or tenancies. However, the lived experiences of people with learning disabilities have

suggested that the reality of social inclusion is far more complex, that taking part in 'normal' community life still holds barriers and separation for women with learning disabilities, and paid employment for many remains nothing but a pipe dream or 'romanticism' (Burton and Kegan, 2006). The latest Health and Social Care stats confirm that only 6.8% of adults with a learning disability known to the Council are in paid employment as of 2013/14 (Department for Work and Pensions, 2014).

The narratives of the ten women in this study suggest that they are more likely to select friends and activities that were associated with those that had a learning disability, rather than engage with the more inclusive leisure or work options within the wider community.

The photographs and interviews demonstrate that the women thought it was important for them to keep busy and to meet up with people. They enjoyed doing voluntary work, taking part in leisure activities that took place in the local community or at home. I have presented these as two separate themes

- Work and Leisure: getting out and meeting people
- Keeping busy.

4.6 (i) Work and Leisure: Getting out and meeting people

A key component and challenge of the English policy 'Valuing People' (Department of Health, 2001a) was getting people with learning disabilities into some form of paid employment. This was seen as a key marker of success and a prime indicator of social inclusion and acceptance as a valued citizen. At the time of this study, Eve was the only woman who was in some form of paid employment, working part time hours at a local supermarket. Eve was 55 at the time, and the youngest woman in this study; she had worked every Saturday in the staff dining room at the store for twenty years.

> 'I do the washing up, keep everything clean, but I don't do the cooking now: it was difficult for me as their oven is very big. It is this big. The way that they cook the frying egg, the fat goes on my arm and I am a bit frightened. I have been there for a long time, longest in the dining room' [Eve: 172-75]

Although Eve had been working there for some time, outside of her working hours she did not meet up with any of the staff who worked there, and this did not seem to be something that she wanted or thought about. What she did value about being employed was receiving a salary, and the staff discounts that came with the job. Although none of the other women in this study were in paid employment, three of the women participated in voluntary work, often at one of the local charity shops, and this seemed to help them to structure their day, keep them busy and add positive values to their lives.

> 'I work in Oxfam in Barnet. I do a half day - I do sorting, pricing, working on the till: gives you something to do. I wouldn't want to sit at home all day like. Some of them do but I say no, I wouldn't do it'. [Susan: 86-88]

Figure 15: 'Sorting, ironing and serving on the till, I work Monday, Thursday and Friday and have been there for 2 years' [Eve: 45-57]

Generally, as people approach old age, retirement from employment is often seen as a 'normal' transition point, and there is a correlation between volunteering and improvements in health in later life. It has also been connected with making a valued contribution to the local community (Putnam, 2000).

Taking part in voluntary work has been viewed as an opportunity for improving the social capital of those who have a learning disability. Putnam (2000) defines social capital in terms of social networks and the norms of trust that enable everyone in a community to have full and fair access to activities, social roles and relationships (Chapter 2, p.56). The 'Valuing People' strategy (Department of Health, 2001a, 2009) did not actively promote the importance of volunteering, and in fact was relatively silent on the benefits of voluntary work, focusing in the main on increasing opportunities for paid employment. The valuable contributions that individuals can make through volunteering may be a missed opportunity for many women with learning disabilities, especially as they grow older. In this study, the women who were volunteering in local

charity shops talked with great pride about how they helped others, and this appeared to contribute to their sense of value and provided some structure and purpose to their daily life.

Some of the older women in this study associated paid or voluntary employment with their younger adult life.

> 'I don't work anymore, too old now you see. Yes, I worked when I left school, I worked in a place called xxx, packing, you know, no not packing, adding up something, you know, different things and putting them in a bag like you know like, but it made me sort of ill. It made me ill so many times, you know, she'd come home and find me white, so I left there and told mum, and she got me out of there'. [Marie: 352-57]

Being employed was one of the key goals of community integration, and a core component of the social inclusion and central to English Policy (Department of Health, 2001, 2009). English policy has suggested that if people with learning disabilities are employed in paid jobs, then this brings with it a sense of belonging and citizenship, and provides individuals with a sense of value, however it has been argued that this can be a very narrow perspective and does not take into account the changes to structures or attitudes within these spaces that are required (Hall, 2005). For two of the women in this study who had been in paid work, employment had not been a good experience. The sense of belonging and camaraderie that can be a key element of paid work had often not been realised, and in this study there was a contrary story that emphasised difference.

> 'I worked with them for a couple of weeks, but I was too slow, they told me I was too slow, after that I went to help my mum and dad'. [Jennifer: 262-67]

Eight of the women participants in this study were past the usual age of retirement, and one could argue that they have now become part of the retired population; the generic population the age of sixty often marks the beginnings of a life without work and one

where leisure time is enhanced. However, for many individuals with a learning disability, paid work and retirement are often not part of their life experiences. Although many people with learning disabilities have expressed a desire to work during adulthood, only about 9% of the population of people with learning disabilities in the England have experienced paid employment (Department of Health, 2001a). Many individuals continue to attend day centres or their equivalent well past the normal retirement age (Foundation for People with Learning Disabilities, 2002), although in some areas day services cease at the age of retirement, even though individuals voice their wish not to retire (Jingree et al., 2005).

One of the dominant narratives that emerged from this study was the importance of being part of an organised group that shared a common interest or hobby; this was a key part of the women participants' busy day, and a time for friendships to be nurtured. Living on a low income can have an impact on how older women with learning disabilities are able to occupy their leisure time, and a lack of financial security can be a barrier to certain activities (Walsh and LeRoy, 2004). Early research on retirement for those with a learning disability paints a gloomy picture, with fewer choices and restricted opportunities for many as they reach retirement (Walker and Walker, 1998). However, all ten of the women in this study had some form of regular help from paid support staff, and when this worked well, staff encouraged and either provided direct support, or facilitated their participation, in a range of leisure activities. The findings of this study suggest that support received from paid staff, family and friends is an external asset, and enabled the participants to take part in interesting activities and clubs in their local community.

When the long-stay hospitals first closed, community activities were often housed in large day centres for people with learning disabilities. However, with the passing of

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time, these have largely been replaced with smaller and more individually-tailored services that are either building-based or based with virtual teams that provide support that enables access to a range of leisure activities.

All ten of the women in this study were regular attendees at a number of small group community events, and these focused on interests such as exercise, drama, art, cookery or music. All ten of the women in this study also shared their love of restaurants and the theatre. There was a consensus across the narratives that told a story of increased leisure opportunities in old age.

> 'It was the Five Bells, you know the Five Bells, let me see - I think six or seven of us went for the meal. It is a lunch club for the over 50s'. [Belinda: 1249-52]

> 'I go out more now, they say I do more things now - I do the steering group when they have it, I do the walking group and the tenants' meetings'. [Susan: 49-51]
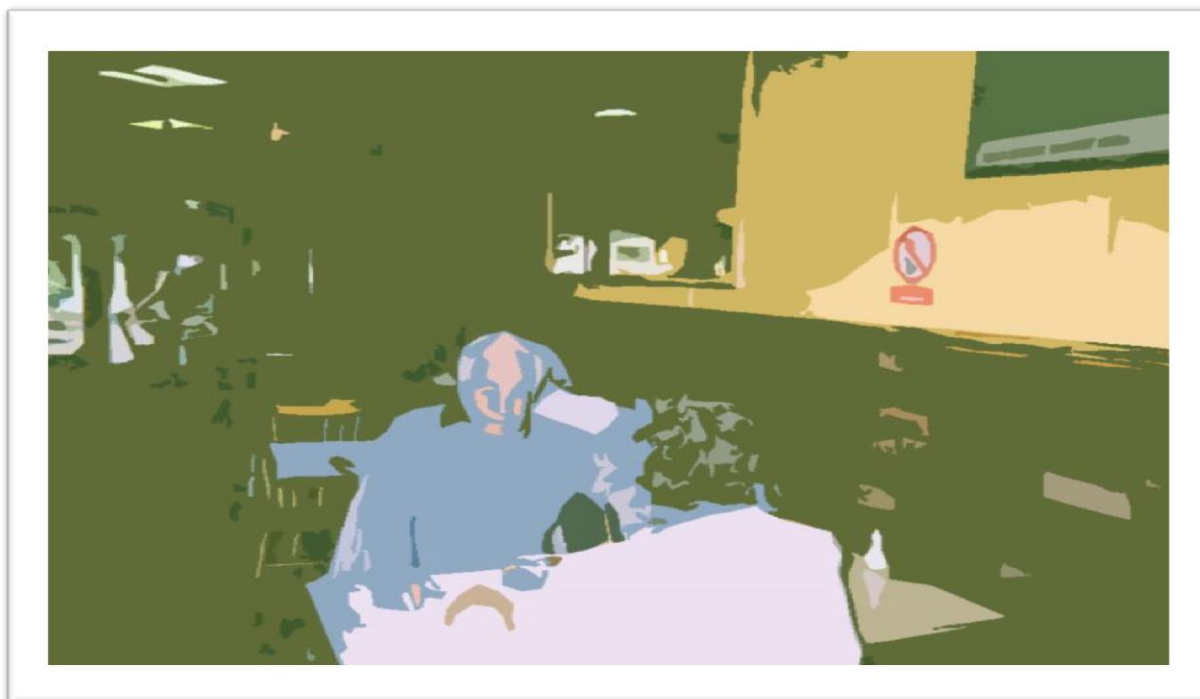

Figure 16: At the lunch club (Belinda)

All ten of the women in this study were fairly active and enjoyed having a variety of things to do during the day. The organised groups that women participants attended were more likely to be arranged through learning disability organisations, and these would often be segregated events.

It should be acknowledged that not all of the activities provided through learning disability services received a positive response from the participants. Marie was very vocal about the activities she did not like, and preferred to stay in, rather than join in with some of the events that had been arranged. Marie lived in a residential setting and the activities seemed to be organised group events rather than individually-tailored, which was likely to make a difference and influence participation. However, choosing to participate or remain at home was an option for Marie, and one that she frequently took.

'I can't stand swimming, no I don't do that, or bowling'. [Marie: 882-3]

One of the community activities that had the potential for promoting inclusion was going out to the local shops; this emerged as a regular event from the narratives of all ten of the women in this study. Seven of the ten women were able to travel independently across the local area, usually to purchase household items or personal clothing.

'Sometimes I go to the big shops in Brent Cross by myself'. [Jane: 358-9]

'I go round the shops on my own if I want something at the shop, like maybe the TV Times, you know, with the programme list'. [Marie: 239-40]

'I go shopping on my own, yes - I will go to Sava Centre or Enfield. I go to the Sava Centre: I go on the 84 and use my bus pass. I like the big Marks; I don't buy things unless I need it'. [Susan: 20-22]
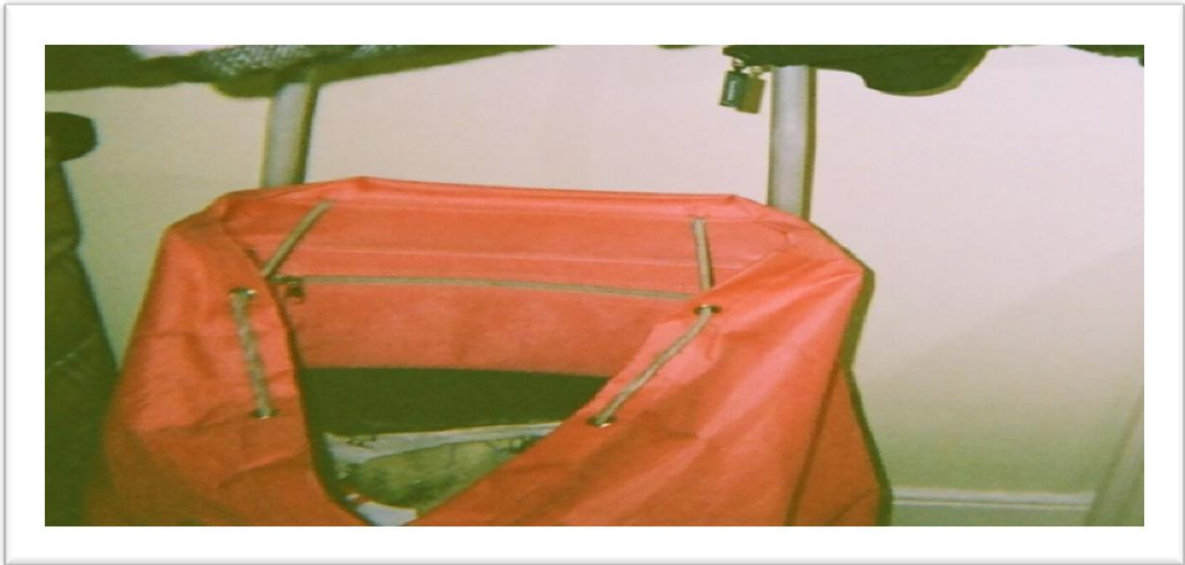
Figure 17: 'That is my shopping trolley - I put all my shopping in there'. [Jane: 43-45]

Shopping was an activity enjoyed by all ten of the women, and it was seen as a leisure activity as well as a practical necessity; however, this often required them to travel independently using public transport. Three of the women were unable to travel independently and required support from members of the staff team for shopping activities.

> 'I had some nice bacon sandwiches, and bought some new trousers'.
> [Debbie: 134-5]

For three of the participants, paid staff were viewed as people who could facilitate shopping trips, and these activities were valued by the women participants.

Walking was another leisure pursuit that was central to the women's narratives. Eight of the ten women in this study associated walking with getting out and about, and the women saw this as a source of enjoyment and a means of keeping healthy. However, a number of studies have found that people with learning disabilities are leading sedentary lives too (Hove, 2004, Emerson, 2005). In this study, walking as a leisure or health-promoting pursuit seemed to be influenced by the attitude of paid support staff

and their perceptions on walking and staff availability. Another contributing factor to the uptake of walking seemed to relate to the availability of outdoor pursuits, dependent on the variability of local opportunities.

Many women with learning disabilities have never experienced paid work, and as a consequence leisure activities have become a part of a continuum of activity and leisure that follow through from adulthood and into older age. This meant that the usual transition of work and retirement was not a major change that they experienced.

Walking appeared to be a community pursuit that enabled eight of the older women with learning disabilities to access a variety of leisure opportunities well past the usual retirement age of sixty. This opportunity to continue to take part in leisure activities could be advantageous to older women with a learning disability (Judge et al., 2010).

> 'I am a good walker, sometimes my link worker gets me walking, and it's good for me'. [Susan: 154-56]

> 'I walk there - it is good exercise you see'. [Jenny: 321-322]

Figure 18: 'The link workers and tenants, we go there for a walk there'[Susan: 4-6]

Eight of the ten women walked for pleasure, and six of them also associated walking with keeping healthy, keeping fit or being good for you. However, not all the women viewed walking as pleasurable, and Deborah much preferred going to visit places by car.

'I hate walking; sometimes I go out walking, only sometimes'. [Deborah: 157]

A number of English health and social care policies and public health initiatives have aimed to increase the frequency of walking amongst the older population. This has had varied success and has not always been fully inclusive (C3 Collaborating for Health, 2012).

Besides the daily and weekly leisure activities, the women shared their enjoyment of going on holiday. The women participants who lived in supported housing associated their holidays with an increased levels of independence and choice, and described going on 'unsupported holidays' i.e. holidays without any staff presence.

Eight of the ten women in this study shared narratives and photographs that demonstrated that holidays were very important to them, and these often symbolised their newfound independence. The women had received varying degrees of help to plan their holidays, either from the paid staff or through a travel agent, and a number of the women had gone away on adventurous holidays both in England and abroad, on their own or with friends. Eve's narrative was about going on holiday with her friend Jeanette.

'Jeanette and I went to lots of places; look, I have a key ring (takes one from her bag). That was on pleasure beach [displaying a photograph of the two of them]. We had weather that was off and on. No we went on our own - it wasn't a supported holiday; we just went away on our own. I don't really like supported holidays 'cause I went to Cornwall one year and we went to stay in this house and ur the staff and we couldn't go out on our own, we had to be with the staff 24 hours. I did not really enjoy it

and I thought "I am not doing that again". We then decided to go away on our own. I have been to Blackpool, Butlin's and Haven; I have been away three times on my own'. [Eve: 98-113]

Going on independent holidays was very important to the women in this study; it was clear that they enjoyed the freedom that these holidays brought, and it appeared to have increased their self-esteem.

'It was an unsupported holiday you see, that we had to look after ourselves, and we were alright anyway, I think when we buy you know the holiday itself, you know I had always wanted to go, you know, to the South of France and visit St Tropez, and now I have'. [Jenny: 134-140]
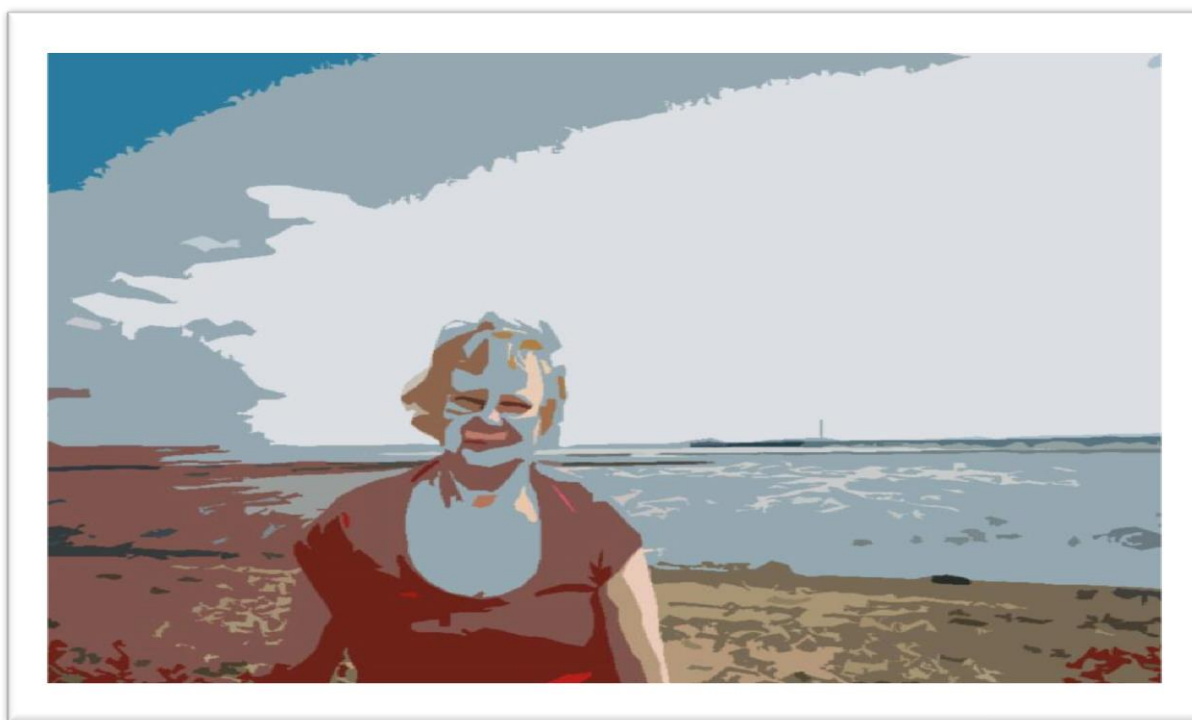

Figure 19 'In Minehead on holiday. We are going again next year. We love it'. (Carol: 111-112]

The women who enjoyed unsupported holidays were very proud of the independence and freedom that these holidays gave them, and valued the opportunity to choose where they went and with whom. However, independent holidays were not available to all of the women. Deborah, May and Marie lived in twenty-four-hour staffed residential care, and their stories were about a different type of holiday. The opportunities for them

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to go on holidays unsupported did not appear to be available, but central to all of their narratives of staffed holidays, were mentions of enjoyment and fun.

> 'When we go on holidays we go where everybody else wants to go or whatever. The newer holidays I have started I never know what is going to happen. I have tried new ones'. [Susan:118-120]

Linda had very limited opportunities to go on holidays in comparison to the other women participants in this study. This is perhaps a reflection on Linda's residential arrangements; she lived in a very large religious home for the elderly. This meant that the staff support she received was not always responsive to her individual needs and aspirations. However, Linda expressed an air of acceptance when talking about her reduced opportunities for going out and having limited holidays in the UK that were usually associated with religion.

> 'No, not really. We went to Walsingham, that is, it was a lovely day that day, a couple of days, but we had a nice time'. [Linda: 164-65]

Summary

In this study, it was notable that, in comparison to those in supported housing, women who lived in residential services were more reliant on the availability and commitment of staff in terms of taking holidays and pursuing leisure interests. However, keeping busy and meeting with people was very important to all ten of the women in this study.

Eight of the women regularly took part in a number of organised groups, and also enjoyed going shopping and walking for pleasure. Taking an annual holiday was also something that they valued, and those who were now enjoying unsupported holidays were very proud of their newfound independence. Most of their leisure time was organised through various learning disability services, and the pursuits that were part

of community life, such as walking, shopping and holidays, were either undertaken independently or facilitated by paid support.

4.6 (ii)   Keeping busy at Home

Not all of the activities took place out of the home, and a number of the women's narratives and photographs demonstrated their enjoyment of lone activities at home, such as watching the television or listening to the radio. Most of the women had a television in their bedrooms and preferred the privacy that this offered, rather than joining others in the communal lounge. All ten of the women in this study appeared to enjoy having a quiet place to watch television, and three of the women sited their favourite television programmes as the British and Australian soap operas.

'At the moment my favourite programme is Home and Away, it's just not on at the moment otherwise I just stay here and watch telly'. [Marie: 490-93]

'I like to watch the television, it was on um, Coronation Street last night, do you see Coronation Street?' [Deborah: 566-68]

Figure 20: 'This is my television - it is in my bedroom'

However, soap operas were not always the most favoured television programmes: two women shared their interest in other types of programme and one of the women participants enjoyed listening to women's hour on the radio.

'I like Gardeners' World or I watch a film or documentary, I don't watch the television in the morning like some people. I have the radio on. I listen to radio 2 in the afternoon and sometimes listen to Women's Hour'. (Susan, pp.200-205)
'When he goes to work I watch the children's programmes, it is not on now but I like Blue Peter'. [Carol: 211-213]

Four of the ten women had taken photographs that included their televisions, and the sets often had a central position in their personal space. The women who lived in group settings could choose to watch the television in a central lounge, but they did not appear to want to sit with the other individuals to watch television, often preferring the peace and quiet that their own room offered.

Figure 21: 'I just wanted a picture of my flat, so I took one of my flat'. [Susan: 37-38]

Summary

Getting out and about and seeing people was an external asset that was demonstrated through the narratives and the photographs that the women had taken. Some of the women in supported housing were busier than others living in residential care in terms of planned activities, and this related to a number of factors such as staff support and availability, their individual ability to travel independently, opportunities in the local community and their own preferences for keeping active.

For some of the women in this study, being a member of a club or church was also a key part of life in the local community. However, although four of the women went to the local church, only one of them, Belinda, took part in what would be considered the extended social life of the church. This once again confirms earlier research findings that suggest that, despite countless policies and good practice guidance that has social inclusion or integration at its heart, in practice this is often an elusive vision or aspiration that is not translated to the lived experiences of people (Hall, 2005). Most of the clubs and meetings that were enjoyed by the women in this study were co-ordinated by learning disability organisations. These leisure activities were a source of external support to the women, and were places where they met friends, and staff who knew them well.

Taking a vacation was important to all of the women, regardless of the type of holiday available to them. Although some of the women had a choice in respect of their holiday destinations, this was very much dependent or steered by the selection that was presented by paid support staff. Those who were living independently valued holidays with friends and without the presence of paid staff, and valued the opportunity to take holidays that did not highlight difference. The five women living in homes where they received twenty-four-hour care from paid staff recalled a different type of holiday: one

that was selected, planned and supported by staff. Generally, the holidays being taken by the women living in twenty-four-hour care were more group-focused and tended to be booked at tried-and-tested places, such as holiday camps; however, most of the women appeared to enjoy these holidays and looked forward to time away.

The women who had participated in unsupported holidays had had assistance in choosing them. Many of these holidays were overseas, and the women had visited new places which they had never been to before. These women talked with pride about their ability to select and go on these adventurous holidays unsupported, and valued the freedom of choice that this brought. Regardless of the type of holiday the women chose, none of them appeared to be at segregated holidays for those with a disability.

The theme of staying at home emerged in the narratives and photographs of most of the women. This was valued as a place where they could relax and watch television or listen to the radio. Most of the women expressed a distinct preference for spending time alone, and enjoyed the privacy of their own space when they were indoors. However, none of the women in this study appeared to be spending excessive periods watching television.

4.7 Internal Assets

This section of the chapter examines the internal assets that emerged from the thematic analysis of the data. Internal assets are those that nurture internal growth and provide the women with a positive identity.

Three internal assets emerged from the thematic analysis of the women's narratives; these were:

- Being valued,
- Equanimity: good and bad times

- Getting older: I am not old.

4.7 (i)   Being Valued

Being valued contributes to a person's self-esteem and their state of well-being; however, it is often a concept that is unfamiliar to many individuals with a learning disability. The social inclusion steer within 'Valuing People' (Department of Health, 2001a) was intended to create a rebalance across society through the key principles of choice, independence, inclusion and rights; however, the policy did not give many, if any, specific directions as to how this might be achieved.

Seven of the women in this study expressed some sense of value that had been derived through their participation in activities where they were able to express their creativity. Four of the women in this study were members of an over-60s art group, which had been organised by a local voluntary organisation for people with learning disabilities, and took place every week. This group activity provided the women with an opportunity to meet others and to express themselves using a range of creative materials.

'We went, oh actually, two of us in the class we got in and we'd won a prize, there was a competition, I think, and exhibition in Chichester and I was on the phone to Angela and she said I had won a prize or something'. [Belinda: 857-860]

'This is snakes on a black background, and this is another one that I did, they are up in the office, in our meeting room. Do you like it?'
   A: Yes, it is very good
   'Yes, it is, everyone says that'. [Susan:25-27]

Figure 22: 'Snakes, Snakes on a black background' by Susan.

The sense of accomplishment derived from painting, pottery and drama for older women has been linked to positive outcomes, particularly in relation to building self-esteem (Reynolds, 2002). This sense of accomplishment emerged from the narratives of the women participants.

> 'They picked me out as I done the pink flower, and I am going to be in the art exhibition. I am very happy and pleased as punch'. [Linda: 143-44]

Creative art had instilled a sense of pride in Linda, and when she had her work accepted at a national exhibition and thus, a visible record of her achievement, this built her self-esteem. Having the opportunity to create pieces of art at a weekly group encouraged them to value their creativity, and this was evident in the art that they created at home.
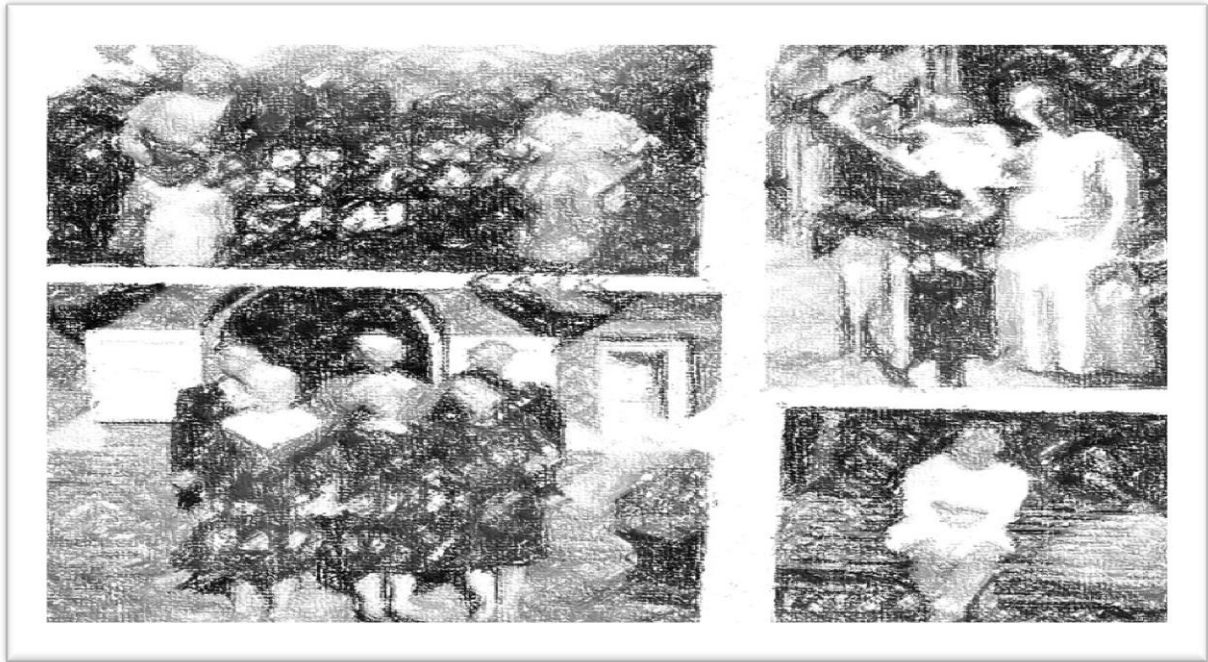
Figure 23: My Family Collage by Linda

Linda described herself as always being an artist, and talked about her enjoyment of painting and writing poetry when she had lived at home with her family. Her self-perception as an artist sat alongside negative labels that might have existed for her, and was reinforced by the positive reactions she received from her social network.

Figure 24: My life by Linda

On the 13th January in 1934 was when I got born in the town of Aldershot.
My Grandfather farmed with many a pig, sent my Dad out to dig,
My Mum helped the sick when they felt worse
Yes, you guessed she was a District Nurse
Then she became a very good cook,
Second helpings I always took,
My school days are in a very dim past
For twenty-one years I was at Edgware
A happy life with my dear Mum there
Now where I live I am very helpful
On open days I am welcoming and cheerful
You will often find me in my room in a huddle
Making up a jigsaw puzzle
As all my friends know I love to have a puzzle on the go
For exercise I like to swim, always the first one in
That is all for now
I am still around having lots of fun. [Linda: 101-124]

The expression of creative talent does not have to be restricted to art and poetry, and some of the women participants took great pride in pursuits such as knitting.

Figure 25: 'That is me knitting; I do a lot of knitting' May

Three of the women participants also enjoyed teaching or helping others. These were central to their narratives, and were demonstrated by each of the women, through the giving of their time either to teach a new skill or to make something for another person.

> 'I can teach you to dance: have you got time to listen to the music?' [May: 271-272]
>
> 'I am very good at necklaces and bracelets to match, I give them to people for their birthdays and Christmas presents I am making a mat (sewing). You never know - this might be for you. If I made you a necklace or a bracelet, would you wear it?' [Carol: 104-10]

Five of the ten women in this study wanted to share certificates of their achievements with me, and an achievement that they were proud of.

> 'Oh, I have a certificate for cookery, it's up there. We can have a look at it in a minute'. [Belinda: 749-752]

> 'I did like an exam, got a certificate, so eventually you can get somewhere; I did it later in life'. [Susan: 81-83]

> 'I won a prize for dancing'. [May: 94]

The receipt of written confirmation of accomplishment at times provided confirmation of their value.

> 'Hold on a minute - I have a big envelope that I had from Chichester (gets up wanting to look for it), Oh where did I put it, where did I put it? Don't say I lost it, I can't find the envelope. Ah ha, yes, this is the one (pulls out the envelope from inside a writing book on the table). Yes, this is the one. I thought that it was under there. They want me to…' (Gave the letter to me to read). Yes, they picked me out as I done the picture with the pink flower'. [Linda: 140 – 143]

Figure 26: Pink Flower by Linda

Creative hobbies, in addition to providing a sense of achievement, can support older women to remain active, providing both internal and external assets (Judge et al.,

2010). Marie enjoyed collecting pictures of her favourite stars, Cliff Richard and members of the Royal family, and was very proud of her collection.

> 'This is a picture of my scrap book with bits of graffiti, there that is nice. I went out and bought it at the shop Smiths in the High Road, I am sticking in pictures of Lady Diana and Cliff Richard'. [Marie: 9-12]
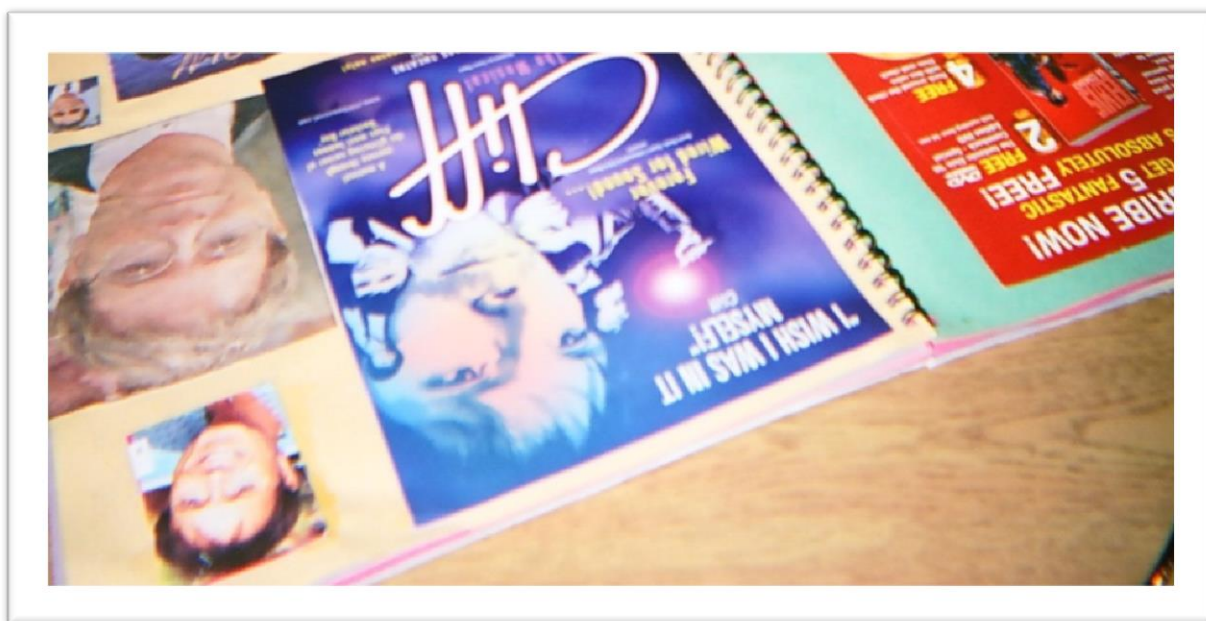

Figure 27: 'My scrapbook', [Marie: 7]

The photographs and narratives of the women in this study demonstrated that the women were all very proud of their artistic and creative talents, and that these provided the women with a sense of self-worth. Four of the ten women talked with pride about their contributions at the local art group, sharing stories of how their art work had been chosen and displayed at both local and national art exhibitions and in the local charity offices. Creative art provided the women in this study with an avenue for demonstrating their skills and the positive responses from others provided affirmation of their value.

A literature review of creative art in hospital and in community settings during periods of ill health found creative art promoted wellness and healing (Stuckey and Nobel, 2010). The learning disability literature also demonstrates that art can be beneficial in

terms of building self-esteem, enjoyment and achievement (Atkinson and Williams, 1990; Gilroy and Lee, 1995; Reynolds, 2002).

Generally, the contributions of women with learning disabilities have not always been acknowledged or valued by the wider society narratives suggest that creative art has provided four of the ten women in this study with a visual reference of their achievements and value. Achievements through creative art can act as a contradiction to some of the negative stereotypical labels that have been attached to older women with learning disabilities as a population with little or no productivity or value (Lifshitz, 2002).

4.7 (ii) Equanimity – 'Life is not a bowl of cherries'

Equanimity is a term that has been developed from the concept of resilience and has been described as an individual's ability to see their life in a balanced way (Wagnild, 1990, 1993). This term is used in this study as it underlines a strong theme of acceptance and the balanced life view which emerged from the analysis of the interview data of ten older women with learning disabilities, and the visual images that nine of the women had taken. The concept of equanimity appears to have a better fit with the data, as the narratives of the women demonstrated how each of them had developed a balanced acceptance of life. Equanimity has been described as a key aspect of the concept of resilience; it is defined as an individual thriving or bouncing back following difficult or traumatic experiences, and developing a balanced perspective on life (Wagnild and Young, 1990, 1993). This suggests that the person has the capacity to overcome hardship or has made significant achievements in the face of major life difficulties. This strength of human spirit in women with learning disabilities is in sharp contrast to the previously mentioned eugenic assumptions (pp.

50-51), and demonstrates how women with learning disabilities develop capacity throughout their life span, adapting to changing circumstances (Grant et al., 2007 p.80) The adjustments that older women with learning disabilities have to make during their life are often achieved through their management and survival of what can be best described as traumatic events, such as social exclusion, institutionalisation and a range of abuse (Brown and Turk, 1992; Booth and Booth, 1996; McCarthy and Thompson, 1996; Brown, 1996; Atkinson et al., 1997; Darlington and Scott, 2002; Grant et al., 2007). By the time women with learning disabilities reach old age, it is estimated that 31% of the learning disability population are living with their families or friends, whilst the remainder reside in a range of residential services or have supported housing tenancies (Emerson and Hatton, 2008). Family and friends can provide potential resources to strengthen resilience (Walsh, 2012). Having a balanced account of life as an older woman is indicative of women who are resilient and, as a result, are able to view life through the lens of equanimity (Wagnild and Young, 1990, 1993).

The concept of equanimity has been used in this thesis, but it could be argued that the concept of resilience that has been referenced in other learning disability literature could also have been applied, as it recognises the adversity that many people with learning disabilities may have endured (Margalit, 2003). Resilience has also been identified as a key concept in a number of studies with older women with learning disabilities (Walsh and LeRoy, 2004; Dew et al., 2006). Resilience is optimistic, resists oppression, and challenges the under-estimation that is often placed on individuals who have been given the label of learning disability (Goodley, 2005). However, resilience places much of its emphasis on the individual and their ability to overcome adversity, whilst traditionally, little attention has been given to the wider system and its protective factors (Morrison and Cosden, 1997; Howard et al., 1999; Grant et al.,

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2007). Kinsel (2005) describes equanimity in terms of connectivity and Wiles et al. (2012) argue that there is a significant risk in using the concept of resilience as a measure of ageing well, as it tends to focus exclusively on individual characteristics and behaviours, and this can lead to individuals being blamed when resilience is not achieved in later life. In a review of the concept of resilience, Windle et al. (2011) found that most of the studies that had used the concept of resilience were with children or adolescents, and that far less is known about its role in adulthood.

In the literature review of the lived experiences of older women with learning disabilities (Chapter 2.5, pp.36-49) there was reference, in a number of studies, to the use of self-reflection to help them face their life with a level of acceptance, despite suffering adversity in their life (McCarthy, 2002; Hamilton and Atkinson, 2009; Walsh and Le Roy, 2004). This acceptance, balanced perspective, and overcoming of adversity is recognised in the literature and defined as 'equanimity', and has been described as a key concept that underpins resilience and courage in older women (Wagnild and Young, 1990, 1993; Nolan, 2010; Finfgeld-Connett, 2014). Alex (2010) describes how equanimity can be interpreted as feeling connected, and for older women this was through relationships with friends and family. Hoogland (2015) found that older women were often influenced by their lived experiences, and that this was frequently expressed as an acceptance of others and their own life situation, 'equanimity' (p. 36).

Having a balanced approach to life is a theme that emerged from the data with seven of the women participants expressing an acceptance of their life situation. This behaviour was in sharp contrast to what might have been expected after many years of social exclusion, institutionalisation and stressful experiences as sited in other, older population studies (Carr et al., 2010; Grodin, 2011). Instead, the women in this study had evolved, and possessed maturity. Whilst living in a different environment they had

grown into older adults with grace in their own inimitable way, as demonstrated in their narratives.

Seven of the women in this study were able to accept that things were not always easy, and that their life's journey had been a mixture of good and bad times. This balanced perspective on their life demonstrated both inner strength and resilience.

> 'You just get on with your life and all that, and be happy' [Eve:158]

> 'Life is not a bowl of cherries, yeah, we would, I mean, wouldn't it be lovely, I mean…I think to myself if I could change something it would be lovely, but there again, I can't really moan. I've a lovely…I've got a caring family, so I must be one of the lucky few who can say that'. [Carolyn: 774-78]

Nine of the woman in this study had experienced traumatic times during their lives, and some of their narratives related to their life's journey as women with a learning disability. Their experiences of life as younger women were often tainted with painful memories of difference, moving from a life with their family, and/or being sent to live in segregated settings, often managed by the public services and miles from their family and friends. During this time in British history, many children and young adults with learning disabilities living in the UK were admitted to long-stay hospitals, or sent to live in hostels or children's homes (as discussed in chapter 2.6, p 49-55). Moving from the safety of their families was a common occurrence for women with learning disabilities, with increased incidence following the death of their parents. The double loss of the death of parents, and moving from the home and neighbourhood that was familiar is more than most of us ever have to endure (Atkinson, 1989; Atkinson and Williams, 1990; Gates and Atherton, 2003), and has most likely contributed to their strength in older age.

> 'Because my mum died, that's why, I went in there because my aunties and uncles ... she got me in there, I mean … no she didn't get me in there, my

mum's sister Dolly got me there, you know took me there and went off, you know working, you know. Harperbury: yeah that's right. Oh, terrible, you know, I didn't like it. First my mum died and then they were all horrible, I didn't like the look of none of them. But when I lived there for so long I got used to them, oh dear I did not like none of them there. I didn't get on, I just wanted to leave and come here like, you know'. [Marie: 326-338]

Deborah had spent most of her adult life in a long-stay hospital, having been sent there after the death of her mother. At the time of this study, Deborah had moved from the hospital to a residential home, where she had been living for ten years, and unlike the other women I interviewed, she just wanted to forget about her past life and experiences of living in a hospital; it all seemed to be far too painful for her

'I didn't like the place much. I don't want to talk about Harperbury; I didn't want to live at Harperbury…no, I don't want to go back to Harperbury, I hated it, I couldn't go back to Harperbury. Talk about the weather, don't talk about that place. I'm good'. [Deborah: 338-39; 384-386]

Deborah's memories seemed to be so painful that she would rather talk about better times, and this was respected. Four of the women in this study had memories of abuse, and Marie was able to recall a very painful narrative: an account of sexual and physical abuse that she asked me to include in the research so that others could read about her experiences. She also wanted other women not to be frightened to talk about bad things.

'But gosh, and that's when that happened, you know. Because I was in some room and then when I got back, oh dear, all memories come back, like I can't explain and in the end, you know, I had to leave that home for something and then I had to go to another one and that's when that happened, you know, when I left there, because I was wotsisname. Because I saw some man at the other end who was screaming and carrying on and I didn't like the look of him and that's when I ended up at the police station, and what I told you. Some stranger he was, I tell you, he was dangerous, a dangerous man, but he lives in ... I don't know, there was another man that was there as well when he did it. The man got hold of me, the actual man that got hold of me was there sitting on the seat, he was there as well. I was a bit worrisome about them both, you know, but the man that did it to me, dangerous. He got hold of me, that's why my back's like this because you

know, they hurt me in that way, beat me, and they beat my head'. [Marie: 369-375]

Marie's personal story of sexual and physical abuse was tragic, but sadly not uncommon across services for people with learning disabilities in the 1960 and 1970s (Sinason, 1988; Turk and Brown, 1993). The vulnerability of women living in services that are segregated from society continues today, and this has been seen documented in organisations established to care for those who have a learning disability, as seen on the BBC television coverage of Winterbourne View on the Panorama programme (Department of Health, 2012). What was perhaps different during this period of time was that these types of abusive narratives were often accepted as a consequence of the institution by those working in the system, and therefore were often ignored or hidden. In a review of the literature, Horner-Johnson and Drum (2006) found that women with learning disabilities were more likely to have been both physically and sexually abused when compared to individuals with other disabilities. The traumatic events of the women's past may have contributed to their resilience in later life, as resilience following extreme trauma has also been seen in other populations who have suffered discrimination and abuse, such as the Jewish and disabled populations that survived the holocaust in World War Two (Greene, 2002; Kahana et al., 2005).

Figure 28: 'A very happy life' [Eve]

The concept of equanimity in older women has also been associated with those who have valuable connections with friends and family, and it has been suggested that resilient factors such as relationships and social networks can act as a buffer and protect women during turbulent and traumatic times (Department of Health, 2002). Self-determination and positive responses to stress and adversity have been known to enable women to recover and continue with their lives (Windle 2011). However, it is recognised that there is an integration of each of the key concepts of vulnerability, protective factors and resilience that work in unison to achieve equanimity (Wagnild and Young, 1990, 1993).

The narratives and photographs taken by the women demonstrated their ability to bounce back following adversity, and to reach a state of equanimity in older age; this emerged as an internal asset that had developed from a lifetime journey that consisted of both good and bad times, and a range of external supports that provided the women with strength that had been borne from a sense of acceptance and balanced

composure. Their inner strength was a testament to the women, and the narratives suggested that this group of women had an inner strength and balanced outlook on life.

> 'Life is not a bowl of cherries, yeah, we would, I mean, wouldn't it be lovely, I mean…I think to myself if I could change something it would be lovely, but there again, I can't really moan. I've a lovely…I've got a caring family, so I must be one of the lucky few who can say that'. [Carolyn: 774-78]

> 'That is just life, isn't it - you just get on with it'. [Belinda: 1213-14]

> 'When I had my flat at first, life was difficult but I got used to it and did it'. [Sheila: 177-180]

> 'I will see them after I have had my holiday' (talking about her siblings).
> Do you wish you were living nearer to them? 'I like going there but I like it here too, and they have their own family now and I have friends here'. [Jane: 265-269]

Equanimity is a relatively new and an emerging concept in learning disability and research into old age, hence the narratives of survivors of abuse, social exclusion and/or institutionalisation living in the twenty-first century are still unfolding. During the early years of my nursing career I had been astounded by the inner strength that older women with learning disabilities possessed, many of the women that I met had endured many years of institutionalised care. However, the older women in this study had an inner strength and maturity that went beyond my original perceptions, and their balanced acceptance of life's ups and downs was an internal asset that enhanced their later years in the community.

4.7 (iii)   Ageing: I am not old yet

The constant narrative across the learning disability literature has suggested that the lived experiences of ageing for women and men have different perspectives (Atkinson and Williams, 1990; Atkinson et al., 1997; Walsh and LeRoy, 2004; Dew et al., 2006; Stnadova and Evans, 2012). In the UK, planning and service provision for older people

with learning disabilities have been largely reliant on population needs analysis (Emerson and Hatton, 2008; Emerson et al., 2013). Although this knowledge is useful for planning purposes, it is only one view and this can be enriched by understanding the depth of individual experiences at a micro level and integrating this with the macro level of needs analysis.

A myth or negative attitude held by some of the public can lead to misconceptions about people with learning disabilities (Scoir, 2003), and the layperson's understanding of learning disability has been found to be limited (Mencap, 2007). At an early presentation of this study, a number of misconceptions were revealed when two postgraduate students asked how I would address the challenges of recruitment. When I asked them to expand on this question, it was evident that it was rooted in their belief that those with a learning disability did not survive into old age, and that finding participants would be difficult. The presentation of this study provided an opportunity to rectify some of this mistaken belief.

Growing old is a theme that emerged from the narratives of each of the women in this study, and the women participants generally held a very positive outlook on their own lives. Eight of the ten women that I interviewed did not see themselves as old, and their narratives were of 'old age' as another stage in their life that they would embrace when the time came. However, old age was generally something that they recognised in others, but not in themselves.

Being older in chronological years has often been defined by a decline in physical health and independence (Lifshitz, 2002). In this study there were two themes that emerged in the narratives of the women's self-conception of ageing: both of these were positive, and reflected a life that had got better and hopes for the future.

Within the gerontology literature, positive experiences of ageing were often accompanied by good health and an absence of illness or disability (Rowe and Kahn, 1987). This was difficult to position in terms of women with learning disabilities, as the presence of a disability was often something that they had lived with, usually since birth, and they had made certain adaptations during their life course. The same could be said of the barriers and attitudes that older woman face within their local community, as these would not have been new to older women with a learning disability who had faced such barriers and negative attitudes throughout their life journey.

Nine of the women in this study reflected on their individual life experiences and talked about their earlier life located in segregated settings in long-stay hospitals, hostels, or living with their families. In the past, life for many individuals with learning disabilities was more segregated in comparison to life in the twenty-first century. The reduced opportunities to make choices and take control when they were younger women seemed to apply, whether they had lived with their families or in public services.

> 'I did not really like it (hostel) when I got older, you could not do your own thing, you could not go shopping, or, um, we couldn't have our own money - all our money had to be handed in and we couldn't do our own cooking or anything like that'. [Eve: 41-45]

This was in sharp contrast to the narratives of the participants' lives and current experiences; these revealed a number of increased opportunities to make choices, have greater independence and spend time with family, friends and staff. Most of the women talked about a growth in confidence that had been the result of their increased independence, and they were able to recall stories of how their lives had changed for the better as they had become older.

'Yes, my life is much better now than when I was younger, I got a lot of friends'. [Jenny: 326-327]

'Well I was quite happy before when I was young but I am happier now, a lovely long life'. [May: 111-113]

'I enjoy my life. I go out I go out on a Wednesday swimming and what else I went out today and I just come back this afternoon, that is it, and no more now until September. I like being here and I can help the older people and the staff'. [Linda: 152-154]

These positive changes described by the women participants are at odds with some ageing policies and public attitudes, where old age emerges as a time of ill health and greater dependence, with pessimistic expectations, an inevitable loss of skill and capacity. However, these have been challenged by the global active ageing strategy (Walker, 2015, WHO, 2000). For older women with learning disabilities, this could have been a time where they experienced a double-edged stigma through the labels of old age and disability. The low value that society often places on older women with disabilities is, at times in conflict with the life experiences that the women shared with me, and how they perceived their life as being a 'good life'.

Being independent was one of the key principles outlined in the English policy 'Valuing People' (DH, 2001) and in this study the ten women participants, through the process of storytelling, shared how they had achieved greater independence which they wanted to preserve, as they were very proud of their self-sufficiency in later life. Although the women participants in this study made the general association between reduced mobility and health and the process of ageing, their narratives either placed these in relation to others' old age, or in a future context of self that would be tackled when they became old.

'I can manage the flat up until a certain time; when I cannot manage the stairs. That will be the time that I will think of moving to the ground floor. As long as I can still manage the flat, manage the stairs'. [Susan: 114-116]

Figure 29: My flat is on the second floor. [Susan: 14]

The women in this study associated ageing with reduced levels of mobility, and as a number of the women were living in flats located on a higher level, this was something that they were aware of; however, it was in their future reference rather than located in the present.

Eight of the ten women participants did not view themselves as old; one woman directly rejected the concept of old age. The narratives on ageing produced by two of the women described ageing as a negative phase of life that should be put off as long as possible.

I'm not going to get old, I don't want to get old … I'm not an old grandma; don't want to get a bloody walking stick. Oh don't worry about it, I'm not worried about that, I'm not going to get bloody old, I don't want to get old … not frightened - I'm 38 and 39, I'm a lady. Don't mention it; no don't talk about it … I'm a lady'. [Deborah: 586-597]

For two of the women participants, there was a degree of unspoken fear attached to ageing, and concern that the outcome could result in a flat or house move. With their past experiences of moving from a hospital to a home of their own, this was seen as a retrograde step, and two of the women in this study viewed old age more negatively than the label of learning disability. All ten of the women in this study accessed a range of community activities arranged through the learning disability services: these appeared to help them retain their independence, meet up with friends and keep active. Keeping busy was seen by five of the women participants as a means of rejecting older age.

'Well I don't know as you get older I think you need to be doing more things as this helps. Like I do, I do more things now - I do charity shop, tenants' meetings art steering group and things like that. I go shopping'. [Susan: 172-75]

The concept of 'old age' emerged during the interviews, and many of the women participants associated old age with life cycle changes associated with the appearance of grey hair, wrinkles, and walking sticks. However, although the women in this study had some understanding of old age, they generally did not feel or perceive themselves as old. One of the women reflected on a comment made by a paid member of support staff, and how this had not changed her view or self-perception.

'Oh, now 62 I'm getting on, Gertrude (support worker) says
I'm getting old, no, I don't feel it, I feel about 16'. [Marie: 797 -800]

The general view was that the self-perception of being old was often associated with a noticeable deterioration in health rather than triggered by a marker provided by a chronological number. Even when their health had deteriorated, two of the older women continued to strive to keep busy and treat health problems as a minor

inconvenience that they needed to overcome, rather than seeing them as a major problem that would restrict their lives.

> Yeah well, I'm keeping well, I mean we all get these aches and pains sometimes don't we? Life goes on, doesn't it, yes? Well as you get older the stairs and everything, I may have to move one day'. [Belinda: 1146-49]

For eight of the ten women in this study, the concept of growing older was positioned very much in the future, and their own experiences were contrary to the negative images of old age. It was admirable that, despite the rejection that the women may have experienced through the construct of learning disability and segregation, they continued to have a very positive outlook on what life had to offer them. Once again, their wishes about the future were associated with retaining their health, which may confirm some of what is in the literature.

> 'I would wish for good health, I mean that it effects everything else: you can't go out and you are not as able to and you are stuck in the flat. I would not want to be stuck in the flat'. [Susan: 120-23]

> 'I just hope to be happy. God keep us happy. I enjoyed working with you: can we meet up again?'. [Eve: 187-90]

> 'I am looking forward to the future; I do not know what it will be, but I am looking forward to it'. [Carol: 98-100]

Deborah found it very difficult to think about her future life, and after some prompting she decided that there would not be much in her life that she would want to change. This was perhaps her way of closing down this narrative.

> 'Not much, nothing much'. [Deborah: 80-81]

Nine of the ten women had an understanding of the concept of ageing; however, the photographs and interviews with the women demonstrated that they often associated

ageing as something that they observed in other people, rather than experienced on a personal level. The women in this study generally had a very positive and balanced outlook on life, and were very keen to keep busy and retain their friendships and family connections whilst actively pursuing their interests. Their wishes for the future reflected their personalities, and they were generous in terms of their compassion for others, and the importance of friendships and relationships were at the core of their narratives.

4.8 Vulnerability and Womanhood

Vulnerable has been defined as 'capable of being physically or mentally wounded or assailable and open to temptation or persuasion' (New Collins English Dictionary, 2014). There has been recognition in the literature that vulnerability has a strong association with women, and that this often stems from a fear of crime (Lorenc et al., 2013). The literature has shown that women are more likely to experience fear within their community if they are older or have a disability, and that this fear is far more prevalent at night (Pain, 1997; Lorenc et al., 2013). Emerging from the narratives of the ten women participants was a constant thread of vulnerability and fear; this was described as a deficit and did not fit the positive framework of other experiences in their lives.

> 'Well, by myself I might not feel safe around here, I go to the tenants' meetings but I don't like going out in the evening'. [Jenny: 426-29]

Although the women were leading fairly active and independent lives, and participated in a number of community-based activities, these generally took place during the daytime hours. Their vulnerability in the community became apparent when the women talked about going out in the evening, especially when it was dark. They expressed a general reluctance and fear about being out in the community once evening came and

it was dark, stating how they made sure that they returned home early to avoid being out at night time.

> 'I do not go out much in the evening, a little bit but I like to get home before it gets dark, because there are too many funny people around. No, I don't like to stay out late. I like to get home by 9 but I don't stay out till 10, 11 or 12, no - want to be home before the pubs close'.[Eve: 369-74]

Fear appears to become more acute when communities feel powerless or when they lack control (Lorenc et al., 2013). Older women with learning disabilities may be at risk of increased threats from others because of the association between disability and difference, with the result that they are afraid to leave the home (Mencap, 1999).

> 'No, I stay in. No, definitely no. I go to bed early and get up early the next day, and have a bath. Not on the top of the other one, you know, at the end of the week, and then get up, you know, and I get up and put the television on, you know. I won't go out in the dark, I can't stand the dark. Because I'm thinking I'm going to get murdered, you know, because you hear such strange things on television about people getting murdered'. [May: 925-934]

The reluctance expressed by the women in relation to going out in the evenings, and the haste to return home before it became dark, was a common vulnerability that emerged across their narratives. The explanations for their felt vulnerability were associated with their fear of strangers once daylight had ended. They worried about being approached by men who were strangers and being attacked, raped, or even murdered. One of the women participants connected her fear with the closing time at the public house and drunk men being out on the streets. Another of the women carried a personal alarm with her at all times, but this had not reduced her fear or given her confidence to remain out after dark.

Vulnerability has been closely associated with womanhood and being older, and having a disability has been connected with an inability to resist or defend an attack. Women with learning disabilities may fear an increased level of threat because of their

perceived vulnerability, and feeling unsafe when they leave their home (Fyson et al., 2007, p45).

4.9 Conclusion of Chapter 4

Within this chapter, the narratives of the women participants were thematically analysed, and the photographs that the women participants had taken were integrated into this process. The support of the expert reference group during analysis was also discussed. The research findings were mapped using the underpinning theoretical framework of health assets. The internal and external assets that emerged from the analysis of the data were linked to the women participants' individual experiences of ageing and their equanimity in older life. The value of connectivity and relationships were central to their narratives and the visual images of life as an older woman.

In the next chapter, the findings from the empirical work will be critically presented in the context of the literature.

Chapter 5: DISCUSSION

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5.1 Introduction

This participatory study explored the experience of ageing through the narratives of ten women and the photographs taken by nine women with learning disabilities. The previous chapter presented the findings that emerged from the analysis and considered to what extent these findings of this study are consistent with the current literature. The conclusions from this thesis will be compared with other published research in terms of similarities and differences. In this chapter these findings will be discussed through the lens of an asset theoretical framework, its value as an underpinning framework to interpret and understand the narratives of the women participants is demonstrated earlier in this thesis (Ch. 2, pp 59-69, Ch. 3.17, pp 125-134). The broad aim of this analytical discussion is to further unravel what the experience of ageing was for these women participants.

Finally, the implications of this study will be presented in terms of advancing thinking in terms of ageing as a woman with learning disabilities, future research, and the development of policy and professional practice. These are early days in the application of an asset framework to underpin research findings with populations that have a learning disability, and it is a new contribution to the asset literature. Through this study, a diagrammatic model was developed with the women (ERG). The model 'Having a Good Life' (Fig 1 p.68) and the underpinning framework of assets have the potential to inform other research studies, and provides some guidance to learning disability service development.

The public perception, and a proportion of the empirical literature, continues to portray a largely negative perception of both ageing and learning disability (Bigby, 2004 p.49); however, through an examination of women with learning disabilities' own accounts of their lives, this thesis provides a more positive account. All of the ten women participants in this study were largely enthusiastic about their lives and very proud of their achievements, despite often having endured challenging and traumatic experiences. There were some aspects of vulnerability that emerged from the women's stories, and these often related to their fear of being in the community once it was dark. This had implications for their inclusion in local community life.

5.2 Working with the women to develop the diagrammatic model

This research is inclusive in its approach and as such this study would not have been successful without the commitment and support of the four women who participated in the expert reference group, and equally the individual women who gave generous amounts of their time to take part in individual interviews and photography.

As presented in the methodology chapter, the expert reference group worked alongside me in selecting the interview themes and experimenting with photography that supported the data collection methods for this study (Chapter 3.4). This partnership approach gave this group of women with learning disabilities an opportunity to engage in research, and to share their unique lived experiences. Their individual experiences influenced my thinking and helped shape the design of this study.

In the past, the lives and experiences of women with learning disabilities were often silenced, and their views were often disregarded and absent from both research and the management of services (McCarthy, 1998; Nunkoosing, 2000, Walmsley, 2001). This study sought to contribute to the growing body of research that seeks to hear their

stories from their own frame of reference (Rioux and Bach, 1994; Booth and Booth, 1996; Atkinson et al., 2000; Walmsley, 2001; Richardson, 2002; Walmsley and Johnson, 2003; Walsh and Le Roy, 2004, Dew et al., 2006, Strnadova and Evans, 2012).

5.3 Internal and External Assets

A review and critique of the asset theoretical framework used to underpin this study was presented earlier in this thesis (Ch. 2.8, pp 59-69). Through the analysis of data, and through the use of an asset framework to map the findings (Ch. 3.16, pp122-134), a number of assets emerged (Figure 1, p.68); these are described as either internal or external assets. Internal assets are those that stem from within an individual and provide a strength that sustains, and external assets are those that are driven by factors external to the individual, and have a positive impact on their life and well-being.

(i)   *Internal Assets*

1. Being valued

2. Equanimity

3. My Life / Hopes for the future

(ii)   *External Assets*

1. Social Networks – Friends, Family and Intimate Relationships

2. Dolls and soft toys – My babies

3. Getting out and about

(iii)   *Deficits*

1. Womanhood and Vulnerability

5.4 External Assets

5.4 (i) - Social Networks

The importance of social networks for older women has been explored in previous learning disability literature, however the focus of these studies has more often been on the size and composition of their social network within the concept of social inclusion and community care (Robertson et al., 2001; Hall, 2005; McConkey, 2005; Forrester-Jones et al., 2006; Bigby, 2008). The value of friendships and relationships for older women in terms of offering mutual support and a sense of belonging to a community with a shared history (See Ch.4.3, pp 138-150) has been well documented. This research identified the key elements of the women's social networks were their friendships and the relationships that they had with a partner, family and staff.

5.4 (ii) Friendships, Relationships and Family

Social engagement and linked concepts such as social connectedness have been widely identified as being related to the development and maintenance of a positive sense of subjective well-being (Williams et al., 2006) The importance of social networks for older women has been explored in previous learning disability literature, as has the importance of support services in ensuring that these relationships with family and friends are maintained (Robertson et al., 2001; Hatzidimitriadou and Forrester-Jones, 2002; McVilly et al., 2006; Forrester-Jones et al., 2006). Social networks can be at risk when services or families ignore the importance of these relationships for women with learning disabilities. Social networks in this research were

found to offer older women support, companionship, and where the friendships were with other people with learning disability, an important shared experiential history (see Chapter 4.3, pp 138-150). Although these features have been documented elsewhere, this research identified key elements of the participant's social networks, such as mutual support, a sense of belonging, and strength to tackle their everyday life. I will elaborate on how the women's accounts provide both added weight to previous work and offer critical insights into the limitations of the existing literature.

One of the key findings of this current study was the support and strength that the women participants drew from the friendships they had with other women with a learning disability. The analysis revealed how companionship, support, and a shared past were vital components of these friendships. Their shared past provided the women participants with a special bond that had often developed following discriminatory experiences of institutional care and exclusionary practices within the mainstream community. The friendships were important to the women in this study as they helped them to feel connected to others who had similar lifestyles and enjoyed comparable interests in their local community.

The national policies for learning disabilities in England, and associated implications for practices, have often resulted in more value being placed on friendships with those who do not have a learning disability in the mainstream community, rather than on the maintenance of supportive relationships from within the learning disability community (Chappell, 1994; Department of Health, 2001a, 2009; Hall, 2005). Following the move to community services, friendships with those without disabilities were often thought to advance the integration of individuals with learning disabilities, and improve their social status within the community, although geographical location and its impact on social integration has been challenged (Cummins and Lau, 2003). In stark contrast to the

emphasis in policy and practice of friendships in the mainstream community in this study, all of the accounts of friendships that emerged from the ten narratives were of friendships with an individual who had a learning disability, and these friends were the main significant others in their lives. The women participants enjoyed spending time together, sharing stories, going on holiday, and participating in various leisure or social events in the community with their learning disabled friends. Five of the women in this study lived in supported housing arrangements and found this had fostered larger circles of friends when compared to those who remained living with family (Grant, 1993). This is in contrast to some other studies that found that continuing to reside with the family has nurtured larger circles of friendships and relationships (Bigby, 1997b; Forrester-Jones et al., 2006). The friendship circles in this study were not extensive, but most had between two and five friends, and the women participants maintained these relationships through attending learning disability events or through their regular visits to each other's places of residence.

Large-scale reviews of learning disability policy have used mainly social inclusion indicators as a measurement of success or failure, for example, percentage of people with learning disabilities in paid employment (Department of Health, 2009). The findings of this present study suggest that, although all of the women had between two and eight friends, none of them could be described as a friend without a disability, unless the person was a member of paid staff or family. This suggests that the English policy agenda of social inclusion did not have an impact on increasing friendships for these older women from within the general population (Hall, 2005), and most friendships that the women participants recounted during interviews for this study were maintained or established through learning disability services, for example social events for older person with learning disabilities. There has been some criticism of the

appropriateness of national service reviews, as it has been argued that exploring success should focus on what really matters to individuals, not professionals or other health and social care influences.

English learning disability strategy aims to increase the opportunity for paid employment; this was encouraged as a key indicator of social inclusion, and was seen as a means of creating 'citizenship' and developing 'mainstream' friendships (Department of Health, 2001). However, being in paid employment or working as volunteers alongside those who do not have a learning disability does not necessarily, on its own, guarantee new friendships (Petrovski and Gleeson, 1997). Although, only three of the women participants at the time of this study were in paid or voluntary employment, connections with others through these routes did not extend to leisure time or be of marked social value to the women. However, the women in this study did not identify this as a gap or a deficit in their social networks, and they did not appear to be actively pursuing friendships with their work colleagues. This has also been found previously: Bates (2004) found that having a job had not always created opportunities for friendships and socialising beyond the work environment. This was particularly evident when there was no concerted effort to demonstrate the skills of employees with a learning disability, and where equal opportunity employment policies did not promote the development of broader relationships, resulting in individuals feeling ostracized. Despite these findings policy and practice still appears to be responding to the 'Valuing People' strategy and its promotion of main stream relationships (Department of Health, 2001a, 2009).

The size of an individual's social networks in older age has been reported as variable, and findings of previous research indicate that many older people with learning disabilities have between two and six people in their network (Bigby, 2000; Robertson

et al., 2001; Thompson, 2002a; Dew et al., 2006; Buys et al., 2008). Dew et al. (2006) and Bigby (2000) also found that neighbours were a source of friendship and support. Whereas in this study, although the women were aware of their neighbours and could name a few, they did not describe them as friends, and did not name a neighbour who could provide a helping hand if they were experiencing difficulties, even in an emergency.

Findings are consistent with and supported by the existing learning disability literature which suggests that friendships continue to be important for women with learning disabilities as they enter old age (Walsh and LeRoy, 2004; Dew et al., 2006; Thompson, 2002a, 2002b; Strnadova and Evans, 2012).

Five of the women reported that they had a 'best friend', and three of the women had met their best friend during their formal schooling. Against considerable barriers, such as residential relocation and geographical distance, the women participants had managed to stay connected with their best friends. Long-lasting friendships had acted as a buffer against life stressors and illness, and contributed to the women feeling good about their life, and to their sense of equanimity. This was important as these friendships provided the women participants with a sense of belonging to a community, despite the lack of friendships across the mainstream community. Although there can be a loss of friendships during this later stage of life as people with learning disabilities age (Thompson, 2002a; Judge et al., 2010), the friendships and connectivity that the women participants had made through their use of residential and day services for people with learning disabilities were a valuable resource that they drew upon to provide stability and strength Marie (p.140), Jenny (p.145), and May [Figure 5, p. 145].

Friendships were a crucial asset in the lives of the ten women in this study, providing emotional and practical support, and a sense of belonging among a community with a

shared history and connectivity. The participants' friends were distinctly individuals who had a learning disability, were of similar age, usually of the same gender, and had a shared history. Friends were classified as either being a 'best friend' or 'friend', and these relationships were different. Best friends had usually been sustained for five decades or more and were reciprocal in nature, whereas friends in the context of this study were usually individuals who had similar interests and socialised with the women at clubs or other organised activities. These findings on the importance of friendship are in the main, congruent with those of other learning disability studies on the experience of ageing in women (Walsh and LeRoy, 2004; Dew et al., 2006; Strnadova, 2012), and the value of connections through learning disability day services has also been supported in a Scottish study (Judge et al., 2010). This study provides a greater understanding of the importance of friendships within the learning disability community, and the value of a shared history, by highlighting the central and exclusive importance of friends. It is important that these women have paid staff that value these friendships and actively support the mobilisation and nurturing of these.

This study demonstrates that individual life stories, together with the photographic images, reveal that relationships and friendships really do matter, particularly those that are established through their connections within learning disability services. Other studies that have included the views of older women with learning disabilities also support the findings of this study (Thompson, 2002a, 2002b; Dew et al., 2006; Bigby and Knox, 2009). The findings of this study add to what is known, and confirms that friendships are a very important asset in the lives of each of the ten women participants, providing the woman with a sense of belonging to a community that values them as individuals and provides them with support they can rely on during both good and bad times. The protective asset that friendships brought to the ten women

participants is supported by other learning disability research (Field, 2003; Walsh and LeRoy, 2004; Dew et al., 2006). The findings from this study have added something new to the existing empirical evidence. By eliciting the women's own accounts of their friendship, this study provides new evidence on the value of friendships from within the learning disability community. Their shared history, connectivity and mutual support were associated with a positive outlook on this stage of their life. Additionally, this study found that the women are actively engaged in maintaining these friendships despite their age.

5.4 (iii) Family

The societal perception of older women has often been presented alongside terms such as 'passive', 'dependent' and 'recipients of care', the latter of which was traditionally provided by families, neighbours and friends (Boneham et al., 2006). This is not dissimilar to the public image of those with a learning disability, who are often seen as dependent, non-contributing, and in need of care (Llewellyn et al., 2003; Bigby et al., 2004). A number of older women in the general population receive support from their families; this is mainly provided by their adult children or their spouse (Boneham et al., 2006). However, these two key providers of support are often absent in the lives of women with learning disabilities (Ashman et al., 1993; Bigby, 1997a) and for older women with learning disabilities, support is often undertaken by parents, and when they are no longer alive, siblings (Bigby, 1997b; Seltzer et al., 2005; Hodapp and Urbano, 2007). Women with learning disabilities have often been denied the opportunity of intimate relationships, marriage and children (Burns, 1993, 2000; Clements et al., 1995) and thus they rarely have either a spouse or offspring to take on this type of supportive role (Ashman et al., 1993; Bigby, 1997b). The relationships that

women in this study had with a spouse or intimate partner will be discussed in greater detail in the next section of this chapter (Ch. 5.4, pp 219- 221).

There appears to have been limited research within the learning disability literature that explores the social role and connections that families have as a female relative with learning disabilities gets older (Dew et al., 2004). The majority of the published British literature tends to focus on families in a caring role, and these have often been framed in the negative, with a focus on difficulties and the burden of having a child with a disability (Dyson, 1996; Heiman, 2002; Landsman, 2003). Other studies have taken a wider perspective, and explored the experiences of parenting; however, these studies have focused on mother-child relationships (Cohen et al., 2002; Lopez et al., 2005). There have also been a number of studies that have explored the role of siblings and these have acknowledged the profound effect that a child with a learning disability can have on the family as a whole (Burke and Cigno, 2000; Dodd, 2004). Naylor and Prescott (2004) acknowledge that siblings of children with a disability are an understudied and unsupported population (Naylor and Prescott, 2004). Heller and Arnold (2010) also suggest that siblings want to maintain long-lasting relationship with their sister or brother who has learning disabilities, and are prepared to take on a more supportive role, although the role that siblings take on is often based on the type of disability their sister or brother has (Seltzer et al., 1997; Orsmond and Seltzer, 2007). Even with the lack of research, we know that families have a pivotal role when raising a child with a learning disability, and the different dimensions of this role have been described as teacher, organiser of recreation, entrepreneur, supporter and advocate (Todd and Shearn, 1997). Although it has been acknowledged that some women with learning disabilities have reported a greater level of independence and improved life satisfaction in adulthood, following a move from the influence of their parents, they

equally have been found to help in overcoming the effects of lack of autonomy (Strnadova and Evans, 2012). Health and Social Care have, to some degree, recognised the important role that families play in the lives of children and adults with learning disabilities (Department of Health, 2001a, 2009). However, the academic literature appears to be relatively limited in terms of analysing the social relationships that women with learning disabilities have with their siblings or their extended family in later life (Seltzer et al., 1997; Flaton, 2006; Orsmond and Seltzer, 2007;), and sibling relationships in later life have been more closely associated with emotional and instrumental support, rather that hands-on support (Bigby, 2000, Dew et al., 2004). This thesis has shed further light on the social importance of family relationships in older age, especially in terms of support for the women participants. Where the women participants had contact with their siblings, they were the first port of call in terms of seeking advice, and they also provided continuity after the loss of a parent.

Family relationships were a crucial element of the women's social networks, and even though physical contact for some of the women had reduced, their ability to describe and recount stories of their families were central to their life stories. This corresponds with the findings of other studies of older women with learning disabilities (Thompson, 2002a; Walsh and LeRoy, 2004; Buys et al. 2008; Bigby and Knox, 2009) that suggest that connections with older parents and siblings, although reduced in terms of direct contact, continue to be vital to older women with learning disabilities (Walsh and LeRoy, 2004, p.97). Although there is a dearth of empirical research in terms of the relationships with siblings in later life, this study makes a contribution to this and cites this as an area for future research in the recommendations. (Ch. 6.4, p.245).

5.4 (iv) Intimate partnerships and sexuality

This study also highlighted the importance that intimate relationships had for older women, as evidenced by three of the women. Historically, heterosexual relationships between people with learning disabilities have been actively discouraged or explicitly forbidden, and although not discussed in detail, non-heterosexual relationships have had their sexual orientation denied or even punished (Cox, 1996; Jones and Magowan, 2010). The effects of the Eugenics movement meant that intimacy and sexuality was thought to cause many of society's problems, and intimacy was therefore a taboo (Ch. 2.6, pp. 50-51).

Care in the community has led to some positive life changes for women with learning disabilities; however, there are still some aspects of women's lives that have not progressed. This can be observed when one examines their right to a sexual life and motherhood; in fact, one of the criticisms of normalisation ideology was that it did not take account of differences such as gender, sexuality or age (Williams and Nind, 1999), and no explicit reference to gender difference is included in policy (Department of Health, 2001, 2009). Although the right to get married, have children, and have a sexual relationship is included in the United Nations Convention on Rights for people with disabilities (United Nations, 2006), adults with learning disabilities describe the inequalities they face in their everyday experiences (Healy et al., 2009).

There is very little evidence across the learning disability literature about the place of intimate or sexual relationships in the lives of older women (Chapter 2.5, pp.36-49). Walsh and LeRoy (2004) found that older women who had an intimate partner, had cited them as the most important person in their life. Research with older women with learning disabilities has not often included a discussion on intimate relationships during later life (Bigby, 1997a; Bigby and Knox, 2004; Strnadova and Evans, 2012; Burke et

al., 2014), although Salvatori (2003) makes reference to the lack of intimate relationships in the lives of older people with learning disabilities.

Findings from this research study add to the literature on intimate relationships by providing some insight into the value that older women participants placed on having a relationship that is intimate. The women participants that were in a heterosexual relationship had found that this had brought them companionship, emotional and practical support, and two of the women described their partner as their 'best friend'. Their partner was central to the women participant's narratives and they had been included in a number of the photographs that they had taken. Therefore, this study has provided some interesting findings that suggest that the affection and companionship that intimate relationships provides for the women participants are a valuable source of support on an emotional and practical level. Understanding the experiences of older woman with learning disabilities in terms of intimacy or intimate relationships is an area worthy of research, and this has been acknowledged in the concluding chapter of this thesis (p. 245). The dearth of literature, and this gap in our knowledge, is also reflected in the next section of this chapter, in which motherhood is examined.

5.5 Motherhood (Dolls and Soft Toys)

This is possibly the most contentious element of this thesis, as the findings revealed that dolls and soft toys had an important place in the lives of five of the ten women participants. The dolls and soft toys were described by three of the women participants as their 'babies' or 'children', and the women appeared to be substituting the absence of children with dolls and soft toys. Dolls and soft toys have often been discouraged by staff due to their association with the negative image of the eternal child or the childlike (Lennox et al., 2005): this was discussed in the reflective section of this thesis (Ch. 3.14, pp.112). The discouragement of dolls is particularly evident across learning

disability services during the era of 'normalisation' and 'social role valorisation' (Wolfensberger, 1983), with the possession of dolls and soft toys being hampered by variable translations of the concept of social integration (Lennox et al., 2005).

A systematic review of the literature was carried out and there is an absence of empirical research that discusses or acknowledges the presence of dolls in the lives of older women with a learning disability. The only reference found to dolls in the learning disability literature is within an educational context (McCarthy, 1999; Eastgate, 2008) or in the narratives of normalisation (Wolfensberger, 1972). However, as referred to earlier in this thesis (pp. 163-164), research with older persons with dementia has demonstrated a marked reduction in anxiety levels and improvements in the behaviour of older individuals as a result of the introduction of dolls that they can care for (James et al., 2006; Mackenzie et al., 2006; Alander et al., 2013).

Social care and health systems, alongside professional attitudes, have all contributed to a definition of women with learning disabilities which has often denied them the opportunity of motherhood (Kallianes and Rubenfield, 1997; Edmunds, 2000). The narratives of the women participants that emerged in this study suggested that at least three of the women could be compensating for this loss by caring for dolls and soft toys, whilst two of the women participants' associations were about their own childhood. Walmsley (2000, p.193) describes how caring for others has often been a women's route to a place in the public world, with many taking up employment in the careers of nursing, teaching and social work; however, these gendered opportunities have often been denied to women with learning disabilities.

Three of the women participants expressed a deep regret about not having children, but held the belief that this would have been too difficult for them; these self-perceptions have also been captured in previous research (Rodgers, 2001a).The

beliefs that are held by women with learning disabilities in regard to motherhood are often reflective of narratives told by their families, (Rodgers, 2001b) or wider society, and its largely negative views of women with learning disabilities and motherhood (Booth and Booth, 1994, 1995; Llewellyn and Brigden, 1995).

There has been some movement in the academic world to address some of the neglected gendered issues (Atkinson and Walmsley, 1995; Williams and Nind, 1999; Burns, 2000; Tilley et al., 2012); however, the translation of academic progress to the everyday experiences of women with learning disabilities has been slow. The literature on reproduction and sexuality has largely discounted the voices of women with learning disabilities, and the broader literature on motherhood has also been particularly silent on women who have a disability (Mayes and Sigursjondottir, 2010). Most of the empirical research on parenting in the learning disability literature was carried out in the 1990s by Booth and Booth (1994, 1995, 1996). One could argue that this issue needs to be revisited in the twenty-first century, as there still appear to be some barriers to discussing sexuality alongside disability (Scoir, 2003, Culham and Nind, 2003).

The findings of this study reveal that for five of the women, dolls and soft toys brought comfort, support and fulfilment, and one could suggest that carrying out mothering tasks with their dolls, the women were assuming an identity of motherhood, an identity that they have largely been denied by care systems and professionals (Mayes et al., 2008). The dolls and soft toys were used as a way of exploring motherhood.

The narratives of two of the women in this study demonstrated that when pregnancy has been prevented, it does not remove the longing to be a 'mother'. Due to the absence of research literature, it has not been possible to critique the role of dolls and older women with learning disabilities in any depth. However, the findings of this study

suggest that, for three of the older women with learning disabilities, dolls were filling a void created by the absence of their own offspring. Dolls and soft toys, and their role in the lives of women with learning disabilities, require further attention, with research studies that explore this and other possible explanations such as transitional objects (Winnicott, 1953) in more detail and discuss recommendations for practice (p. 244) as this is a new contribution to existing literature.

5.6 Keeping Busy - Getting out and meeting people

Keeping busy, particularly during the day, was very important to all ten of the women in this study, and the women participants all had a range of activities planned over their calendar week. These were often planned leisure pursuits or clubs that had been organised through learning disability services, where they gathered to meet friends with a learning disability. Nine of the ten women made reference to the need to keep busy, and this was accompanied with an excitement that they experienced when trying new activities or interests, and meeting up with friends. Having different and meaningful activities has been supported by the findings of other research (Mansell et al., 2003; Buys et al., 2008)

Llewellyn et al. (2004) suggests that the public image of older women with learning disabilities is one of dependency, vulnerability and as being non-contributory. However, the findings of this study suggest an image that is contrary to this negative image. Instead, it is suggested that the women participants had a full and active life both at home and in the community. The range of leisure and community activities often provided the women participants with a forum for meeting with friends from within the learning disability community, and sharing common interests, such as art, cookery, swimming, bowling and drama. Some of these activities were taken up as new

experiences in later life, and other were a continuation of clubs that they had been attending for many years, at a day centre for those with a learning disability.

Voluntary employment in local charity shops was a weekly commitment that two of the women participants had made, and both had done this for many years. Only one of the women participants was in paid part time employment at the time of this study. Paid and voluntary employment provided the three women participants with a sense of value and self-worth (pp. 170-171). The busy lives that the women participants led did not reflect any sense of slowing down or retirement due to their chronological age. In fact, retirement is not a transition that held any personal meaning for the women participants, and they all expressed a wish to remain active for as long as they could (Figures 15-19). Research in Australia and Scotland had similar conclusions with older individuals with learning disabilities rejecting quiet, sedentary lifestyles that are often associated with later life (Dew et al., 2006; Buys et al., 2008; Judge et al., 2010).

The activities that the women participants enjoyed helped to maintain old friendships and, for some, provided new friendships, and this had broadened their horizons. For example, the older person's art group had provided four of the women with new friendships and the experience of exhibiting their art. A number of other learning disability studies have also found that participation in social groups, and paid or voluntary employment, had a positive impact in older age (Dew et al., 2006; Bigby and Knox, 2009; Judge et al., 2010).

Some previous studies suggest a heavy reliance is placed on staff for transportation to and from events; as a result, the availability of staff and transport can often prevent or reduce participation in community leisure and social activities (LeRoy et al., 2004; McCausland et al., 2010). Access to transport was not expressed as problematic, as most of the women in this study were still able to travel independently on public

transport, and did not rely on staff in this way. Three of the women in this study either travelled by foot, or were accompanied by friends or paid staff. Therefore, the barriers of transportation highlighted in other learning disability research were not raised by the women participants in this study. As a result, nine of the women participants in this study were more in control of the choice and frequency of attendance and punctuality at events. However, one of the women participants who lived in a large residential provision for the elderly was very reliant on staff for transportation, and as a result, activities she attended were dependent on staff availability and other pressures within the home.

Very few studies have discussed the importance of vacations or holidays in the lives of older women with learning disabilities. The findings of this study show that all ten of the women participants had been on holiday during the last twelve months, and four of them had enjoyed more than one holiday. The type of holidays that the women had were often related to the type of residence that they lived in, with those who were in twenty-four-hour staffed housing being more likely to go on holidays accompanied by staff, when compared to those women participants who lived in supported housing, who all went on unaccompanied holidays. In addition to these holidays, most of the women also enjoyed holidays with their siblings once or twice a year. Holidays were an important feature of the women's narratives, and four of the women's stories of holidays included a narrative of increased opportunity in later life that enabled them to travel independently, without the support of paid staff.

The findings of this study suggest that most of the activities that the women participate in are segregated events that are organised through different learning disability services. However, the findings of this study also provided new insight into the value of holidays, especially those that did not rely on staff support. It was found that the

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women participants rarely visited public services such as the library, theatre or cinema as a regular pastime, with most of their time being spent with friends, at clubs and activities organised through learning disability services.

Other key findings in this study were that the women participants wanted to remain active and independent in later life, and did not view this as a time for slowing down. Independence was promoted largely through the women's new opportunities to take holidays and travel across the local geographical area independently. A large number of the activities that they participated in were segregated from mainstream community life; however, these provided the women participants with a forum for meeting up with friends and socialisation.

5.7   INTERNAL ASSETS

5.7 (i) Being Valued

Buys et al. (2008), in an Australian study of older people with intellectual disabilities, found that one of the eight categories to emerge was feeling valued. Other studies with women with learning disabilities have also demonstrated the importance of being valued (Walmsley, 2001; Strnadova and Evans, 2012). A positive perception of self-worth and value usually arises from being useful and feeling valued by others, and this has been found to be important to people with learning disabilities as they grew older in Australia (Dew et al.2006; Bigby and Knox, 2009). The women participants in this study achieved a sense of value through helping others, participating in voluntary work, producing creative art and remaining as independent as possible during later life.

5.7 (ii) My life is much better now: Equanimity

Equanimity is a term that has been developed from the concept of resilience and has been described as an individual's ability to see their life in a balanced way (Wagnild and Young, 1990, 1993). This term was used in this study as it emphasises a strong

theme of acceptance and a balanced view of life that emerged from the analysis of the interview and visual data of nine older women with learning disabilities. This strength of human spirit in women with learning disabilities is in sharp contrast to eugenic assumptions (pp. 50-51), and demonstrates how women with learning disabilities can develop throughout their life span, adapting to changing circumstances (Grant et al., 2005, p.80)

The women participants in this study all held a very positive view of their experiences of old age and shared narratives of a life that is better now when compared to their experiences as younger women. The asset of equanimity emerged from their stories; equanimity encapsulates both resilience and the balanced approach that the women took in terms of ageing. Equanimity has emerged as a predominant theme in gerontology studies of older women, and has been argued to be a reserve that reflects a lifetime of experiences (Felton, 2000). This positive and balanced outlook to ageing is in sharp contrast to some of the dominant myths and stereotypical images that have reported this as a time of reduced health, increased dependency and reduced activity (Cuddy et al., 2005). The learning disability literature on ageing has discussed how older individuals use self-reflection to help them face life with a general acceptance and despite suffering adversity (Walsh and LeRoy, 2004; Hamilton and Atkinson, 2009).

Another factor in this study that may have influenced the women participants' outlook on old age could be related to their self-perception. Eight of the ten women in this study did not view themselves as 'old', and they talked about ageing as something that was connected with their future life journey or a stage of life that they observed in others. The normal markers that society associates with old age have often been

related to life adjustments that come with a person's retirement from paid employment and loss of financial income, and are generally based on stereotypes or negative attitudes, and this was evident in a small scale study of adults with learning disabilities (Lifshitz, 2002). Hockey and James (2003, p.6) suggest that, for some older people, retirement may not mark a symbolic retreat into old age; instead, it can register the beginning of thirty years of a new and different life. Buys et al.(2008) found that many women with learning disabilities had not considered retirement from the workforce as significant in their transition to old age. The narratives of the women in this study did not include stories of retirement, but essentially focused on the importance of friends, family and staff whilst 'getting on with their life'. Bigby (2004) found that people with learning disabilities rarely talked about age-related indicators or roles, and this resonated with the women participants in this study. The women participants were generally in good health and this may have contributed to their positive view of their lives.

Linked to equanimity was the importance of external support, which was influenced by the involvement of good support staff (Mansell et al., 2003; Perry and Felce, 2005). The women with learning disabilities had varying degrees of support, ranging from staff who helped them with booking holidays to assist with weekly grocery shopping, household bills, and using public transport. It could be argued that this type of support enabled the older women in this study to continue to enjoy an active lifestyle well into their 70s and 80s, and this impacted on their self-concept of ageing and their balanced outlook on life. When they needed day-to-day emotional support, they mostly relied on siblings, a husband or partner, friends, or paid staff. Being self-sufficient and independent was important to the women participants and this can be seen in their narratives of holidays, shopping and visiting their relatives and friends.

The findings of this study suggest that the women took a balanced approach to their lives and were making the most of each day. They continued to have hopes and aspirations for the future, and had learnt to adapt following their exposure to trauma and losses, and they generally held a positive outlook on life. These findings resemble the recent body of learning disability literature that has emerged from Australia (Dew et al., 2006; Buys et al., 2008). However, Strnadova and Evans (2012) found that women with learning disabilities lacked control of their life and this had impacted on their self-determination. This lack of control was not evident in the findings of this study. As discussed in detail in Chapter 4.8 and the review of the literature, ageing and how it is experienced and perceived is another area that has received limited academic attention.

5.8   Womanhood and vulnerability - Deficit

Fear of the Dark/Community at Night

Alongside the assets that the women participants discussed a common deficit emerged during the data analysis. All ten of the women in this study expressed a fear of being out in the local community once it was dark. This fear was consistently expressed whether the women were living in residential care or had independent living arrangements. These findings are similar to those in gender-based studies that have explored women's safety in city streets during the hours of darkness (Pain, 1994; Gardner, 1994). A crime survey completed in Edinburgh found that 56% of the older women respondents did not venture out into the city after dark because of their vulnerability and fear (Pain, 1994). This fear associated with the dark has been expressed more frequently by older women (Koskela, 2003). However, across the learning disability literature, there appears to be very little acknowledgment of the

vulnerability of women in respect of targeted violence or abuse and the publications available have demonstrated some methodological weaknesses (Sin et al., 2010).

When the ten women in this study tried to explain their avoidance of community places after dark, most of their narratives related to a fear of being approached or attacked by men. These findings align with general research findings where women perceive sexual violence as a threat: a threat that is rarely felt or expressed by men (Valentine, 1992). In another study, it was found that women with disabilities expressed greater levels of vulnerability when out in their neighbourhood, and were more likely to take precautions when out on the street (Pain, 1997). It has been well documented that women with learning disabilities are more likely to have experienced traumatic or abusive events during their lives, often occurring from an early age (Mansell et al., 1998) and, in comparison to other women, they are more likely to have experienced gender-based violence (McCarthy, 1999; Martin et al.2006; Sullivan and Knutson, 2000). In the limited literature available, women with learning disabilities are reported to be more likely to be victims of violence and anti-social behaviour (Petersilia, 2001). Petersilia (2001) found that 70% of women with learning disabilities had been sexually abused; this was 50% higher than what had been reported by non-disabled women. Mencap (1999) reported that 90% of the people with learning disabilities that they surveyed had experienced harassment and bullying in their local community. Therefore, it was not unanticipated that the ten women participants would be frightened to be alone in their local community once it was dark.

Some studies have associated a loss of social networks and reduced services with feelings of isolation (Bigby, 1997a). Isolation has been cited as one of the factors that can place women with learning disabilities in a vulnerable position and this could contribute to the risks of violence and antisocial behaviours (Sin et al., 2010).

Womanhood and vulnerability has been given very little research attention and I would argue that this study supports the need for future studies to take a gendered view, rather than a population approach to research with ageing people with a learning disability. This is also recommended as an area that requires further attention (p.257).

5.9   My Life and Hopes for the Future

Most of the women in this study were positive about their future; they referred to things in their life getting better and reported increased opportunities to do things such as going abroad. This positivity could be associated with their self-perception of ageing, as none of the women referred to themselves as old. When the women participants were describing old age, it was defined through their observations of others. Most of the women did not express a fear of old age or of death, which is in keeping with gerontology studies which have found that older people are less fearful of death when compared to younger adults (Kalish and Reynolds, 1976; Kastenbaum, 1992). However, like many transitional points in the life experiences of women with learning disabilities, there appear to have been limited discussions by professionals that acknowledge or prepare women for changes that may occur in old age (Grant and Whittell, 2001).

Nine of the women in this study were able talk about their wishes for the future, and their aspirations were achievable. The women's narratives were about increased opportunities to take holidays, good health for their friends, family and self, better world news, happiness, and to continue to have interesting things to do. It should be acknowledged that although nine of the women in this study were able to share their wishes and aspirations, one of the participants was unable to articulate their hopes for the future.

The findings of this study in terms of the future aspirations or wishes of older women are consistent with the positive views of ageing found in other learning disability research studies (Dew et al., 2006; Buys et al., 2008; Burke et al., 2014; Kahlin et al., 2015). These studies found that older men and women with learning disabilities have similar aspirations to the rest of the ageing community, and most have clear plans in terms of their wishes for the future, reporting increased levels of participation in activities (Buys et al.2008; Judge et al., 2010; Kahlin et al., 2015). However, in an international research project, Walsh and LeRoy's (2004) findings differed, and the expression of aspirations of the women participants were not entirely consistent with these findings.

Through the use of a health asset framework to underpin the findings of this study a unique perspective on the lives of a small group of older women with learning disabilities has been analysed and discussed. The exploration of individual strengths and capabilities has demonstrated how the women participants are able to draw on internal and external resources that provide natural solutions to the challenges of everyday life. This study has demonstrated that women with learning disabilities have a range of capabilities that they can draw upon, and promotes the importance of maintaining and strengthening their connections with friends and family. The assets that were identified in this study have the potential to offer new solutions that are person centred rather than those constructed by health and social care policy. Further studies that test the application of the asset framework are required to understand if the findings of this study are unique to this group of women.

The key themes that emerged from this study were the importance of connections, friendships, and relationships – in particular, those that the women had through the learning disability community. Their connectivity with friends, partners and staff were

often sustained through their access to a range of learning disability day activities, and their desire to maintain bonds with friends that had a shared history.

5.10 Conclusion

This is very likely to have been the first study in the field of learning disability that has applied an asset theoretical framework to underpin the findings to support our understanding of the lived experiences of a group of older women as they age. It has thus added to the academic body of work that exists on individual health assets (Rotegard et al., 2010) and asset mapping (McKnight and Kretzmann, 1997; Benson, 1996, 2003; Mathie and Cunningham, 2003; Jones, 2013). These are early days in the application of an asset framework and its ability to underpin research findings with populations that have a learning disability. However, it is a new contribution to the asset literature. Through this study, a diagrammatic model was developed with the women (ERG). The model 'Having a Good Life' (Fig 1, p. 68) and the underpinning framework of assets have the potential to inform other research studies, and provides some guidance to learning disability service development.

This study demonstrates that working with an expert reference group from the onset grounded this research in the experiences of older women with learning disabilities, and therefore the study was not exclusively informed by empirical research or professional practice. The expert reference group helped to shape the design of this study, ensuring that the interview schedule reflected the issues that were of key importance to them. The partnership approach to this study meant that interview questions were debated in terms of their relevance and comprehensibility, and photographs were tested as a tool for visually capturing the lived experiences. The partnership approach taken in this study builds on the work of previous inclusive

research projects, and the methods used in this study demonstrate that an innovative approach can improve inclusivity.

This study also demonstrated how the experimentation of the use of disposable cameras with the ERG were found to be an appropriate research method that could be used alongside the more traditional talking methods, and this combined approach led to the discovery of a richer representation of the lived experiences of older women. During the analytical stage, the photographs and narratives aided the development of key themes (Ch. 3.17, pp 125-134) and provided the ERG with an opportunity to discuss patterns within the data. The photographs that the women participants had taken during the study helped to shape the discussions that took place with the ERG, and provided an insight into their inner world.

The photographs that the women participants took as part of this study provided their worldview through the lens of a camera, which enhanced the telling of their life stories. During the interviews, the photographs they had taken acted as a prompt, and other times the women used the photographs to emphasise a key life issue that was difficult to communicate through words alone. The photograph methods in this study provided an opportunity to uncover their priorities by getting under the surface of their references. Without the photographs, some of the themes identified in this study may not have emerged, for example the importance of dolls and soft toys that was central in a number of the photographic images.

This study has also demonstrated how taking photographs was also an opportunity for the women participants to demonstrate their skills, and this emphasised their capacity for learning new skills. The visual methods used in this study bridged some of the inequalities that can occur between the non-disabled researcher and experts with

learning disabilities, by using a mode of communication that was more accessible. The accessibility of visual images also has the potential of providing greater accessibility to the wider learning disabilities population, by sharing the visual findings. Although using solely photographic methods may have some limitations, this study has shown that an integrated approach can overcome some of the difficulties involved in representing lived experiences as interpreted narratives. There has been very limited research that has taken an integrated methods approach and this study has demonstrated its usefulness as a future research method with people with learning disabilities.

The experiences of women with learning disabilities of ageing in the UK are largely underrepresented in the literature, and this study has contributed to our understanding and can help to shape the plans for future service provision. This counter-narrative to dominant discourses challenges the prevailing view that older life as a woman with learning disabilities is likely to be isolated and lonely (McConkey, 2005).

In the next and concluding chapter, the key findings of this thesis will be presented in terms of their implications for future policy, practice and research. The strengths and limitations of this thesis are also discussed together with a plan for wider dissemination of the findings and potential service change. The chapter concludes with some closing remarks.

Chapter 6: CONCLUSION

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6.1   Introduction

This thesis seeks to present a contemporary perspective on the lived experiences of older women with learning disabilities. Narrative methods integrated with photo elicitation captured their lived experiences and this combining of visual methods with language-based interviews facilitated a more in-depth understanding of their experiences. This thesis also examined how these older women experience the wider cultural and socio-political context and its consequent impact on their lives as older women. The main findings (Chapter 4) identified how a group of older women with learning disabilities constructed their experiences of ageing. The women's equanimity and positive outlook on life was interpreted and understood through developing an understanding of their protective health assets.

The experiences and accounts from the women provided a critique of normalisation approaches to people with learning disabilities, by challenging social care policy and professional definitions of integration and social inclusion. The central theme is the importance of friendships and relationships, in particular those that the women had through the learning disability community. These are seen to provide a buffer during adverse times, and help the women participants to feel supported and valued by their local community, strengthening their capabilities and capacities to have a 'good life'. Their connectivity with friends, partners and staff were mainly sustained through their access to a range of learning disability day activities, and their desire to maintain bonds with friends that had a shared history. In response to these findings, some key points are put forward to support improvements in practice across community care

services for older women with learning disabilities: these are encapsulated in a Relationship Framework (Figure 1, p.68).

This chapter provides an overview of the contribution of this study to knowledge and the implications in terms of practice, policy and future research, and acknowledges both the strengths and limitations of this study. Finally, this chapter concludes with some key messages from the study.

6.2 Contribution of the study

Research in the UK on ageing from the perspective of individuals with a learning disability has been limited, and studies that have been undertaken have often taken a broad population approach, rather than exploring the personal views and perspectives of older people themselves. Moreover, ageing among the learning disabilities community as a gendered issue has been particularly unexplored in the UK. Consequently, this study was undertaken to further advance current understanding of the lived experience of older women with learning disabilities.

In terms of the women's own perspectives on ageing, the majority of the women did not perceive themselves as old, and some of them actively rejected the label of old age. The definitions and perceptions of old age that they held largely reflected the negative stereotypical images of ageing that have been commonplace in the UK, such as deterioration and dependency, which they felt did not apply to them as individuals. Their day-to-day experiences had little resonance with the stereotypical images of old age and they actively rejected this label through their narratives of meeting with friends, shopping, and leisure pursuits. Their own perspectives that emerged from across the narratives were of interesting, active, and independent lives, and of old age

as a period in their life that was much better when compared to their earlier lived experiences.

Another contemporary perspective that has emerged from the data is around the importance of relationships, friendships, partners, relatives and staff, who all provided companionship, comfort and support across their social network. These external assets were identified as being positive social connections that strengthened some of their internal assets, such as being valued and equanimity, and enabled the women to maintain a positive outlook on life. This group of older women had built their own communities through friendships, family and interests, which, in the main, were through learning disability connections and built on a shared history. This led women with learning disabilities to challenge this negative view on ageing by presenting an alternative lived experience.

This study also provides a challenge to mainstream learning disability policy through the rejection of some of the ideologies, such as social integration, which have been central to social inclusion and person-centred planning (Department of Health, 2001a, 2009). It has demonstrated how being fully integrated into the local community and having non-disabled friends was actually rare for the participants in this study; hence, the vision of policy in respect of mainstreaming and inclusion was not actualized in reality. However, this was not expressed as either a loss or a disappointment, as the women's sense of community had often existed within segregated spaces, and this harnessed their collective agency and sense of belonging. A number of the strengths and assets identified by the women in this study stemmed from relationships and services that would be regarded as segregated (Ch. 4, pp. 138-150, 168-180). There needs to be a greater acknowledgement of the strength of collective agency and how

this can be harnessed to improve feelings of self-worth and belonging, and thus have greater influence on wider system change.

The self-advocacy movement has had some impact on learning disability system changes, and this has in part been achieved through collective agency; however, self-advocacy has often been criticised as being male-dominated (Roets et al., 2007). The women in this study shared a range of changes across their lifespan, with the move from institutional to community care being possibly the largest of these, and their influence could help others to overcome hardship. There are still many improvements required across the learning disability system, and existing forums such as self-advocacy, participatory research, and other public involvement groups, would benefit from the contributions of older women, especially those who have overcome adversity.

The study has also opened a wider debate on the important place held by dolls and soft toys in the lives of older women with learning disabilities. While the debate in the literature has suggested that learning disability services perceived the presence of dolls as the promotion of childlike interests that fuelled the stereotypical image of the 'eternal child' (Wolfensberger, 1972; Craft and Craft, 1983; Lennox et al., 2005), this has emerged as an external asset that brings comfort to the lives of a number of the women participants. This study has some key messages that are worth exploring further to enable professionals and services to have a deeper understanding of the role that dolls have in the lives of women with learning disabilities.

In methodological terms, the integration of visual methods was found to offer a number of strengths; using photo-elicitation during the interviews helped the women to engage with the research process and provided a visual reference for understanding life from their viewpoint that enhanced the telling of their stories (Buckingham, 2009, pp.23-24). This study has demonstrated that there are benefits to using visual methods alongside

the more traditional language-based research methods; these add a different dimension, especially when interviews are carried out with those who have limited verbal communication. The photographs that the women had taken were used to support the narrative and this helped the participants to communicate their experiences when no words could be found, and added – rather than detracted – from the narratives. Exploring the visual and the verbal narratives assisted the researcher to have a greater understanding of what is important to the women participants, and supported the inclusive methods applied in this study.

This study has also contributed to the body of inclusive research literature through the collaborative design that was adopted throughout the study. The expert reference group established ahead of the individual interviews informed and shaped the research. Having the support of an expert reference group kept this study grounded in everyday experience, and has had immense personal value to me as a novice researcher, and challenged my thinking.

This was possibly one of the first qualitative studies in the UK to adapt the theoretical framework of assets to underpin the lived experiences of women with learning disabilities. It has thus added to the academic body of work that exists on health assets (Rotegard et al., 2010) and asset mapping (Benson, 1996, 2003; Mathie and Cunningham, 2003; Jones, 2013). The use of individual narratives as part of the research design employed in this study has provided learning disability research with an alternative framework to those commonly applied such as the Quality of Life. This study has demonstrated that the mapping of external and internal assets offers the potential to provide a framework for interpreting and understanding data that is based on individual strengths and resources, rather than created around the views of professionals or social policy indicators. There has been some criticism of this asset

framework in terms of its lack of attention to inequality issues; however, this study proposes that the positive lens of health assets has the potential to be used to frame the narratives of those who have experienced inequalities. The asset framework lends itself to the principles of inclusive and person-centred practice (as defined on p.26), and has a focus on strengths and abilities rather than disabilities and problems. However, more detailed application of an asset based framework as underpinning research findings with women who have learning disabilities needs to be undertaken, as it is still early days in the field.

In the search for a more inclusive society, policy, and practice have at times taken a generalist view of learning disability services and how they should be delivered in the twenty-first century. This has not often taken into account gender or age differences. Although person-centred planning has been promoted as the core principle within the learning disability strategy (Department of Health, 2001), I would suggest that person-centred principles in practice are variable, and they are still not always at the heart of service planning or delivery (Robertson et al., 2001; Rose, 2003; Mansell and Beadle-Brown, 2004; Mansell, 2005). This thesis proposes the use of a Relationship Framework (Figure 30, p. 248) that seeks to recognise and value the lived experiences by mapping the internal and external assets present in an older women's life, thus, gaining a better understanding of existing strengths and resources. The relationship model aims to promote the maintenance of important relationships and connections across their social network. The Relationship Framework and its implications for practice and policy are discussed later in this chapter (Chapter 6.5).

6.3 Limitations

Conducting qualitative research of this nature means that it is not possible to assume that the views of a small sample of women with learning disabilities will be representative of all women with learning disabilities. However, a number of the women participants did recall similar experiences that were shared through the telling of rich individual stories and the integration of photographs, and this may indicate some wider application.

The female participants all had a mild or moderate learning disability, and this may be perceived as a weakness in the research. The experiences shared in this study may be very different to those of women who are referred to as having a severe or profound learning disability, where a different research methodology may be required from the one used with women with mild and moderate learning disabilities. However, the findings of this study do provide a window into the lived experiences of women with learning disabilities, capturing their experiences of ageing, and this has made a contribution to the body of knowledge and challenged the mainstream perspectives that are dominant throughout learning disability practice and policy in England. Additionally, the benefits of using photo-elicitation have key messages for future research.

6.4 Implications for future research

In this study, older women were having a 'good life' despite some harrowing experiences in childhood and adulthood (Figure 1 p.68). The women in this study were found to be keeping busy and were approaching life with a positive 'can do' attitude. They were all active women with social networks made up of friends, staff, and relatives. Most of these women rejected the label of old age, and resisted this by continuing to remain active, independent and involved in their community network.

There are a number of different avenues that future research should explore. Due to the diversity of this population, research should respond to women who have severe or profound learning disabilities and women from different ethnic backgrounds (O'Hara, 2003). This study has also identified the need to understand ageing from a gendered perspective and so, the lived experiences of men should be a focus of future research to acknowledge both differences and similarities in the gendered experience.

Further research is also needed to expand our understanding of the supportive role that dolls and soft toys occupy in the lives of women with learning disabilities, and the relationship between these and issues of womanhood and motherhood (Ch. 5.5, pp 221-224). Winnicott (1953) introduced the concepts of transitional phenomena and transitional objects. Transitional objects usually develop at six months of age, and are commonly soft toys or blankets, and these objects can act as an anchor in periods of uncertainty or separation. Although there does not appear to be any published research on dolls and soft toys as transitional objects for women with learning disabilities, it seems an area worthy of future research given the separation that they have often experienced. In this study the external asset of dolls and soft toys was a key theme, although in this thesis the asset was discussed in terms of childlessness, it may also be associated with their life transition. It is worth exploring whether the asset of dolls identified in this study is unique to this group of women, or whether this is a consistent finding across the wider population of women with learning disabilities. Currently, increasing numbers of women with learning disabilities are reaching old age (Moss et al., 1998; McDonald, 2002; Walker and Ward, 2013), and many have experienced periods of their lives living in an institutional setting that separated them from their siblings and significant others. There is scope to compare care across the

range of agencies of health and social care whilst examining the assets that dolls do or do not provide to different cohorts of older women with learning disabilities.

Additional studies are required to understand the concept of womanhood and motherhood from the perspective of women with learning disabilities. Although some innovative studies have been carried out with women in relation to sexuality and parenting (Booth and Booth, 1992, 1994, 1995, 2003; Brown, 1994, 1996), the research world needs to reinvigorate this work to expand knowledge. Future research should be inclusive, to ensure that the views of women are heard; this would enable us to develop services that respect individual experience and gender difference. Women with learning disabilities in the twenty-first century should have the opportunity to understand and make informed choices about their right to experience womanhood, intimacy, and motherhood.

In this study, siblings were found to be a key person in the social networks of this group of older women, and sisters in particular often took on the role of confidante, especially after the death of a parent/s. Their views were often at the top of the hierarchy when this group of older women were seeking advice or help with a decision (Ch. 4.3, p.150-156). Further research would need to identify their current and future role in the lives of older women with learning disabilities in terms of emotional, psychological and practical support.

The theoretical framework of assets introduced in this thesis has demonstrated that it has the potential to provide a theoretical framework to underpin future studies with those with a learning disability. This framework can provide future research with a positive lens to map the strengths of individuals and their external supports that both nourish and strengthen resilience. This enables these to be framed as positive and protective resources that can improve life outcomes. This framework has the potential

to provide researchers with an alternative to medical models, which are largely focused on problems and fixing them, by capturing person-centred assets that are resources that can be strengthened and built upon. The asset model described in this thesis should not be viewed as a static model as there are a variety of factors that can influence individual external and internal resources. Additionally, there could be benefits in the development of a tool that measures the sense of coherence in this population.

6.5   Recommendations for Practice and Policy

The key messages from the women's narratives (Figure 1, p.68) have informed the development of a Relationship Framework (Figure 30, p. 248) that has the potential to act as a catalyst for service and policy change for older women with learning disabilities. The Relationship Framework that is proposed has some resonance with the principles of person-centred planning, which has been central to UK policy during the twenty-first Century (Department of Health, 2001, p.25).

Central to this Relationship Framework is that older women with learning disabilities have the ability to draw on individual and community strengths that have matured through their life experience, especially those that relate to the relationships that have developed and connectivity across the learning disability community (Chapter 4.3, pp.138-150).   Acknowledging the importance of life experience, relationships and connectivity across the learning disability community are the three key recommendations that this study has for both learning disability policy and practice.

6.5 (ii) Implementation and Evaluation

The relationship framework (Fig 30) would best be considered as another tool that could be used to assist with the initial steps in the person centred planning process. This has relevance to both commissioning, planning, and delivering individually tailored services for older women. Commissioning teams are responsible for the purchase of a range of health and social care services across England, with the majority of learning disability social care being commissioned by the Local Authority. The Care and Support Statutory Guidance issued under the Care Act 2014 includes person-centred planning standards (Department of Health, 2014, 2016). Therefore, positioning the relationship framework within a person-centred planning process has the advantage of being able to draw on what is already known in terms of good practice (Cambridge and Carnaby, 2005, p.165), whilst highlighting the value of mapping the connections and resources across the learning disability community. The relationship framework has the potential of bridging some of the gaps between the social integration model and the importance that women placed on social network connections across the learning disability community, whilst valuing their lived experience. The benefits of this added tool within the person-centred planning process is its ability to map a new perspective that highlights the strengths and capabilities of a community together with their own individual solutions.

Integrating this relationship framework as a tool within the person centred planning process would ensure that it was implemented and evaluated within the statutory requirements of the wider health and social care system; for example, care management and governance reviews.

Figure 30: Relationship Framework: A Service Model based on the women's narratives that can be used as part of person centred planning.

Individual

Lived experience

Values

Family, Relationships and Friendships

Internal

Equanimity

Value

Hopes

Aspirations

Facilitator

Negotiates barriers

Promotes community connectivity

Maintains friendships and relationships

Seeks out new activities

External

Relationships

Friends

Family

Staff

Dolls

Voluntary Work

Leisure

OUT COMES

Connectivity

Friends, Relationships and Family

Opportunities

Active

Community

Good life

This study found that a vital component of having a good life was the importance of promoting and sustaining relationships. The role of an enabler or facilitator would have the potential to promote and support the women's community connections and strengthen existing relationships. Paid social care staff would be well placed to take up this crucial role in building communities across the local area, and seeking out opportunities where older women can make and meet friends, and having a real presence in their local community would enhance the connectivity that women experience.

It is also important for Learning Disability organisations to acknowledge the vulnerability of women and provide them with opportunities to develop personal safety skills and to acquire equipment that enhances their safety at all stages of their lives. This might require the provision of advanced technology that promotes safety, a range of safety devices, training and individually tailored safety networks. These recommendations have additional workforce implications in terms of raising awareness through training and development.

6.6 Dissemination

Research can only influence changes in policy and practice when findings are disseminated widely (Barbour, 2008, p.50). In essence, the findings of this study have been integrated throughout the research process through the sharing of emerging findings with the expert reference group and through early discussions with individuals who have a learning disability. The design of this study has been shared at a number of local and national events in the gerontology and learning disability fields. The visual model that was developed with the women, 'Having a Good Life' (Figure 1, p. 68), and the integration of photographs with written language has supported the accessibility of this thesis.

During the next twelve to eighteen months, the findings of this study and their implications for research and practice will be disseminated through local and national events. Additionally, articles will be written and submitted for consideration to a range of professional peer-reviewed journals and those that encourage accessible publications.

To ensure that the population of those who have a learning disability have access to the findings of this study, an easy-read version of this report will be disseminated via local voluntary groups and published in a range of newsletters. The findings will also be presented at learning disability, gerontology and other partnership events.

6.7   Conclusion

Embarking on this thesis was a response to a lifelong interest in the lives of those who have a learning disability, and particularly how these women experience old age and womanhood. I was inspired by the narratives that emerged from earlier oral history work with men and women who had lived in institutional settings (Atkinson et al., 1997, 2000; Rolph, 1999), and motivated by a number of conference presentations led by inclusive researchers.

This thesis has demonstrated how the lives of women who have a learning disability have been greatly influenced and shaped by political and societal agendas throughout history. England in the twenty-first century has been dominated by the influence of a learning disability strategy that promoted social inclusion; this strategy largely focused on connections that encouraged a contribution to mainstream society through friendships, education and paid employment.

This thesis has demonstrated how segregated services, friendships, and social events provide social connectivity that enabled a group of older women to have positive life experiences. Although at times on the margins of mainstream society, this was their community. This thesis has demonstrated the importance of listening to the views and experiences of women with learning disabilities and their life experiences, as these can be poles apart from the views of policy and practice leaders. Equally, the polarity of opinion that was evident has not resulted in this group of women living sad or lonely lives.

This thesis has demonstrated that ageing is far less traumatic and tragic than the images that have been portrayed by the media and society. On the contrary, the women participants told of their ability to overcome difficult and traumatic times and approach later life positively with energy. This period of their life was described as a better time when compared to life as a younger woman, symbolised by holidays abroad, having a circle of trusted friends, siblings who were there when they needed advice, and lots of activities and interests to keep them busy. The women felt valued and have what they described as 'a good life'. The women in this study had dreams and aspirations that, on the whole, painted a positive future where happiness was a key dominant feature: a life where they were independent, valued, active, and enjoyed good health and friendships in their chosen community. The connectivity that the women had with others from the learning disability community was central to their lived experiences as older women with learning disabilities. It was these relationships that enabled the women to feel that they belonged to a community with a shared history. I hope that other researchers will build on this thesis so that we can gain a deeper understanding of the lives of older women with learning disabilities living in England, thus gaining a greater understanding of how professionals can

facilitate older women to have a good life and enable their experiences to influence and drive future policy.

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Barnet **NHS**
Primary Care Trust

Alison Pointu
Barnet Learning Disabilities Service
313 Ballards Lane
London
N12 8LY
Telephone 020 8492 5454
Date

Dear

Research: This is my life – the experiences of women with learning disabilities

I am writing to invite you to take part in some research that I am carrying out in Barnet.

I want to find out what life is like for women who are getting older.

I am sending some information with this letter to help you choose if you want to take part in this research.

Please read the information and phone me if you have any questions.
Telephone number **020 8492 5454**

Many Thanks

Alison Pointu

Barnet **NHS**
Primary Care Trust
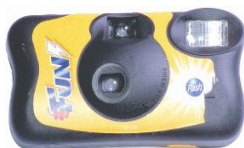
Information Sheet for people having their photographs taken

Research Study: What are the experiences of women with a learning disability who are growing older in England?

You are being invited to have your photograph taken as part of a research study. Before you decide it is important for you to understand why xxx wants to take your photo.

What is the purpose of the study?

We want to find out what are the good and bad things about life for women with learning disabilities.
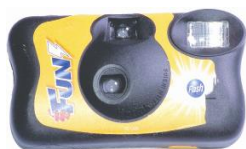
Why have I been chosen?

Because xxx is taking photos of people and places important to her. This will help her to talk to the researcher about her life.
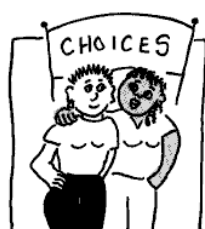
Do I have to have my photograph taken?

You do **not** have to have your photograph taken.

You can say 'Yes' or 'No' it is up to you.

What will happen to my photograph?

Once your photo has been taken xxxx will bring this to an interview with the researcher to help her talk about her life.
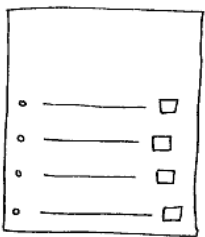
Will my photo be use in a report?

Your photo may be used in a research report.

Will my photos be used in a magazine?

The researcher will contact you to ask for your permission before using a photograph of you in a magazine or journal.

What do I have to do? If you would like your photo taken please fill in the consent form and give this back to xxx.

Thank you.

If you want more information about this study, please contact Alison see box below for details.

Alison Pointu

Barnet Primary Care Trust

Barnet Learning Disabilities Service

London

Telephone 020 8492 5454

Email Alison.pointu@barnet-pct.nhs.uk

Thanks to Photosymbols and Change Picture Bank

Appendix 2b
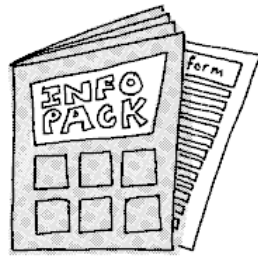
<u>Information Sheet</u>

"This is my life"

Research Study: What are the experiences of women with learning disabilities as they grow older?

You are being invited to take part in this research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time read this, and talk to others about the study.

What is the purpose of the study?

This study is to find out what life is like for you.

We want to find out what are the good and bad things about life for women. We want to find out how we can make services and life better for women like you.

Why have I been chosen?

We are inviting you to take part as you are a woman over fifty years of age. You will be one of a group of women who will be interviewed by the researcher.
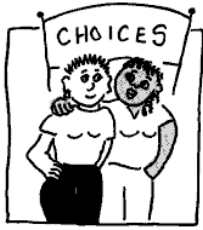
Do I have to take part?

You do **not** have to take part in this study

You can say 'Yes' or 'No' If you do say yes, you can change your mind at any time, without giving a reason. If you decide not to take part in this study, this will not affect the care or support you receive.
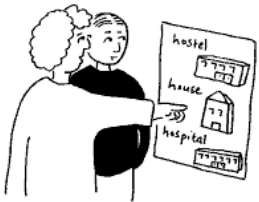
What will happen to me if I take part? If you do say 'Yes' you will be invited to come for two interviews. The interviews will be in a place of your choice. You can come alone, or bring a friend or relative with you.

The researcher will ask some questions and listen to your experiences.
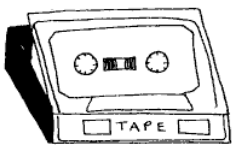
Each interview will be tape recorded. The interview will take about 1 ½ - 2 hours.

At the first interview you will be given a disposable camera, we will practice using them. Then you will be asked to take photographs of special people and places in your life. We will talk about your life and look at the photographs in the second interview.

Expenses and Payment Travel Bus or taxi expenses will be paid and drinks and light food will be provided at the interview.
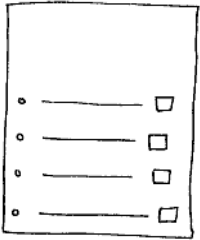
What do I have to do? If you are interested in taking part please fill in the consent form and post this back to me in the pre-paid envelope, or phone me to come and collect it. I will then telephone you and talk to you about the interview.

What are the disadvantages and risks of taking part? There are no disadvantages of taking part, although it will take time, and sometimes when we talk about our life it can bring out lots of different feelings; and this can make us feel happy or sad. If this happens you can talk to the researcher, a support worker or one of counsellors at the learning disability service.

What are the possible benefits of taking part? There are unlikely to be any personal benefits from taking part. However, we hope that this study will help to make services better in the future.

What if there is a problem? It is very unlikely that something goes wrong during the interview study, however if this does happen it will be sorted out immediately.

Will taking part in the study be kept confidential?

Yes, all information about you will be kept confidential. Your name will not be used in any of the reports, unless you want it to be.

Thank you for reading this information sheet

If you want more information see part 2 or if you want to discuss this study in any way, please contact Alison see box for details.

Alison Pointu

Barnet Primary Care Trust

Barnet Learning Disabilities Service

London

Telephone 020 8492 5454

Email Alison.pointu@barnet-pct.nhs.uk

(This is standard information that all NHS research studies have to explain)

Part Two – Information Sheet

If there is a problem? If you have a problem you can speak to the researcher (Alison) on 020 8492 5454, and she will try to answer your questions.
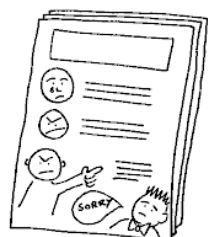
If you want to complain? If you want to make a complaint about this study you can contact Brenda Tomlin (PALS) she works at Edgware Community Hospital.

Patient Advisory Liaison Service (PALS)
Edgware Community Hospital
Deansbrook Road, London
Telephone 020 8952 2381

Will the information be kept confidential? All information collected during the study will be on secure computers, and will only be read by a small group of research staff. You will not be identified in any report or publication without your permission.

What will happen to the results? A summary report that will be easy to read and written for everyone that took part, when the study is completed.

A full report will be written about the study, and this may be presented at conferences and published in professional journals.

Who is organising and funding the research?

I am undertaking this study as part of a professional doctorate at the University of Hertfordshire.   I am not receiving any funding to do this research.

Who has reviewed the study?

All research in the health service is looked at by a group of people called a Research Ethics Committee who protect the safety, rights, and dignity of people taking part in research. This study was looked at by the Camden and Islington Community Local Research Ethics Committee.

Thank you for reading this information sheet.

Best Wishes Alison

Thanks to Change Picture Bank and Photosymbols

Barnet **NHS**
Primary Care Trust

Research Study: What are the experiences of women with learning disabilities as they grow older?

Consent Form
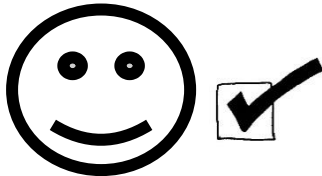
I have read the participant information sheet ☐

I understood the participant information sheet ☐

I understand that my information will be kept ☐
   i. in a safe place
   ii. confidential
   iii. and it will not have my name on it

I agree to have my interviews tape recorded ☐
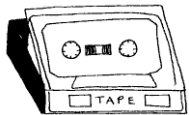
I agree to take photographs ☐

I agree to take part in the research ☐

I understand that I can change my mind at ☐

anytime

Name...

Date..

Barnet **NHS**
Primary Care Trust

Would you like to be a member an Expert Reference Group?

Research: Experience of getting older

Researcher: Alison Pointu

You are being invited to be a member of an expert reference group for this research study. Before you decide, it is important for you to know what it is and what it will include.

What is an expert reference group?

This is a small group of women who will initially meet with me (Alison) every week for 4-6 weeks, for about one hour in June. The meetings will take place in a room at the Space. Once the first set of meetings has taken place, other meetings will be agreed during the year. These will take place every month for or an hour, and will be held at the Space.

What will the expert reference group do? This group will help me (Alison) and be expert partners that help to improve this study.   The expert reference group will try out the questions and make sure that the words are easy to understand, and **not** confusing. The group will also take photographs of people and places to see how this might help the research.
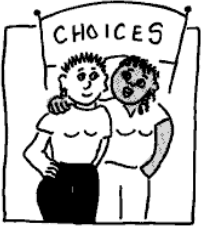
Do I have to be a member of the expert reference group? You do **not** have to take part in this expert reference group. You can say 'Yes' or 'No' this is up to you.

Expenses and Payment Travel expenses will be paid, and drinks will be provided at the meetings. At the end of the research the expert reference group will receive a voucher for a store of their choice as a thank you for their work.

Thank you for reading this information about the expert reference group.

If you want more information or want to talk about it, please contact Alison see box for details or talk to Pat Harris, Manager at SPACE.

Alison Pointu

Barnet Primary Care Trust

Barnet Learning Disabilities Service

Telephone 020 8492 5454

Email Alison.Pointu@barnet-pct.nhs.uk

Thanks to Change Picture Bank

Appendix 5: Research Governance Approval

Barnet **NHS**

Primary Care Trust

Our Ref:	**ACB/LGE**	**3rd Floor**
Your Ref:		**Westgate House**
Direct Line:	020 8937 7690	**Edgware Community**
Fax:	020 8937 7650	**Hospital**
e-mail:	andrew.burnett@barnet-pct.nhs.uk	**Burnt Oak Broadway**
		Edgware
		Middlesex
		HA8 0AD

7 November 2008

Alison Pointu
Director of Nursing/Nurse Consultant
Barnet Primary Care Trust
313 Ballards Lane
London
N12 8LY
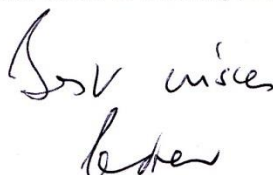
Re: What are the lived experiences of women with learning disabilities as they grow older?

Thank you for sending me the research protocol for the above project which you propose to undertake in the Barnet Primary Care Trust area. All research within Barnet PCT is undertaken in accordance with the Department of Health Research Governance Framework for Health and Social Care. Operational issues of research governance and management processes are undertaken on our behalf by Camden PCT.

The PCT assesses that the proposed research is consistent with strategy and service management issues. I confirm that I am willing to support your proposed research project in this context.

This letter does not constitute approval to commence research. I am copying this letter to Camden PCT who will give approval if all requirements of research governance and ethical review are met.

I look forward to receiving your outcomes when your research has finished.

Dr Andrew Burnett
Director of Health Improvement / Medical Director

cc   Mabel Saili, Research Registrar, Camden PCT

Appendix 6: Research Ethical Approval

Provider Services

Camden **NHS**
Primary Care Trust

North Central London Research Consortium
3rd Floor. West Wing
Camden PCT, St Pancras Hospital
4 St Pancras Way, London, NW1 0PE

Telephone: 020 7530 5375

Facsimile: 020 7530 3235
www.camdenproviderservices.nhs.uk

16th December 2008

Alison Pontu
313 Ballards Lane
London
N12 8LY

Dear Alison Pointu

Title: What are the lived experiences of women with learning disabilities as they grow older?

LREC Ref: 08/H0722/96

R&D Ref: 08PC165

I am pleased to confirm that the above study has now received R&D approval, and you may now start your research in Barnet PCT. May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Ethics Committee and R&D Office as soon as possible.

Please ensure that all members of the research team are aware of their responsibilities as researchers. For more details on these responsibilities, please check the R&D handbook or NoCLoR website:
http://www.noclor.nhs.uk

We would like to wish you every success with your project

Yours sincerely,

Angela Williams
Research & Development Manager