

**‘This is the child I know, this is the child I love.’**  
**Older Parents of Adult Children with Learning Disabilities:**  
**Perspectives on Caregiving and Quality of Life**

**A thesis submitted for the degree of Doctor of Philosophy**

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# Abstract

**Objectives:** This study examined the experiences of older parents who provide long-term care for their adult children with learning disabilities and how they conceptualise their quality of life.

**Method:** Data were collected using semi-structured interviews during the period 2009 to 2012 with 27 older parent carers from four London boroughs and were analysed using framework technique.

**Findings:** Findings indicate benefits as well as challenges. Most participants appraised their quality of life positively, despite the challenges they had to negotiate on a daily basis. They reported rewards and benefits from caregiving, more so in later life, such as: a connected family from shared caregiving; having a sense of belonging; purposeful living; a reciprocal relationship with their adult children; and personal transformations from providing care which improved their quality of life.

The challenges that participants regularly encountered were: the added stress of the government's Personalisation Agenda of caring services (particularly through direct payments); struggles for access to services; multiple losses (sleep, career, identity and friends); worry about future care; fear of abuse when carers are unable to continue in their role; unhelpful attitudes of health and social care professionals; and a lack of empathy from friends as well as the public towards people with learning disabilities.

**Conclusion:** The findings indicate that caregiving and quality of life are inextricably linked. The difficulties that parent carers experienced were mainly associated with socio-structural barriers, rather than their children's disabilities. Importantly, the findings inform the practice of social workers and others who support this unique group of carers by providing new insights into how caring impacts on quality of life and how best these parents' needs can be met. This study makes a specific contribution to understanding the phenomenological realities of older carers and extends current conceptualisations of quality of life among older people.

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# Chapter 1 Introduction

This thesis explores the caregiving experiences and the quality of life of older parent carers of adults with learning disabilities. In this introductory chapter, first I provide the context of the study and highlight the importance of language. This is followed by an overview of the key constructs and a brief discussion of the policies affecting informal carers of adults with learning disabilities in England. I also explain the background to and motivation for conducting this study. Finally, I present the research questions, the contribution of the study and the structure of the thesis.

As life expectancy increases worldwide, it is projected that ‘by 2020 one in five people in England will be 65 or older’ (Department of Health, 2010: 13). However, longevity does not necessarily mean a good quality of life (Farquhar, 1995; Smith, 2000) as health can deteriorate in later life and threaten one’s independence (Schumacher et al., 2006). Additionally, the phenomenon of an ageing population has brought about an increase in the number of older people expected to need long-term care (Ross et al., 2008), as a consequence of which older people are perceived more as recipients of care than as providers (Arber and Ginn, 1990). Hence there is greater interest in their quality of life as care recipients (Smith, 2000), resulting in less attention being given to older people’s quality of life as caregivers, particularly their subjective understandings and experiences of quality of life (Hendry and McVittie, 2004). This is the case in the UK for older people with or without caring responsibilities, especially for older parents of adults with learning disabilities. While most research to date has focused on understanding quality of life from the perspective of younger parents of children with learning disabilities (Buzatto and Beresin, 2008), increased lifespan of adults with learning disabilities (Hubert and Hollins, 2000; Emerson et al., 2012) has extended the caring role for their parents (Cuskelly, 2006). Consequently, many adults with learning disabilities live at home (Ward, 1990; Seltzer, 1992; Yoong and Koritsas, 2012) with parents who are 70 years or over (Care Quality Commission, 2012).

## 1.1 The language of learning disability and carer

In the early 1990s, the term ‘learning disability’ replaced the term ‘mental handicap’ (Lloyd, 1993). Learning disability is conventionally defined as ‘a significantly reduced ability to understand new or complex information, to learn new skills and ... reduced ability to cope independently’ (Department of Health, 2001: 14) and is categorised as mild, moderate, severe or profound (World Health Organization, 1996 (ICD-10)). Consequently, many adults with learning disabilities need some level of care and support. As the respite care co-ordinator for a London local authority, I attended a stakeholder meeting with parents and their adult children with learning disabilities, during which the different terminologies used to describe service users were discussed. The discussion revealed that the general consensus was a preference for the term ‘learning disability’ rather than ‘learning difficulty’ because it describes their condition more accurately. In keeping with this consensus, when I presented this study to parents during the participant recruitment stage of the study, I used the term ‘learning disability’ and none of the parents expressed any concerns. Therefore, whilst I acknowledge that the term ‘learning difficulty’ is in keeping with the social model of disability, the term ‘learning disability’ is preferred by stakeholders in the current study and is used throughout this thesis.

Similarly, there has been a proliferation of the use of the term ‘carer’ within the literature on caring and related policies (Twigg and Atkin, 1994) over the last three decades. In the 1980s the term gained prominence with the rise of the feminist movement, whereby the notion of women as ‘natural’ caregivers and their role of providing unpaid care were debated strongly in feminist literature (Graham, 1983). The socially constructed term ‘carer’ (Ungerson, 1981) is taken to mean ‘someone who provides unpaid care by looking after an ill, older or disabled family member, friend or partner’ (Carers UK, 2014: 1). Policy documents and legislation relating to such informal care (the Carers Recognition and Service Act 1995, the Carers and Disabled Children Act 2000 and the Carers Equal Opportunities Act 2004) all include the term ‘carer’ in their commentary to

describe people who are providing unpaid care. Thus these legislative frameworks clearly endorse the term ‘carer’ as a recognised designation (Dalley, 1993). Similarly, the benefit system refers to entitlement for informal care as ‘carer’s allowance’.

Most people providing care in the familial context do not perceive themselves as carers; rather they see the care and support they provide as part of their family responsibilities (Twigg and Atkin, 1994; Finch and Mason, 1993; Squire, 2002; Kittay, 2002). Nevertheless, family members who do not readily accept the title of carer might reluctantly agree to such a label if they are actively claiming entitlements or seeking access to services. This is because the support available for addressing carers’ personal needs comes under the umbrella of carers’ services. For clarity and for consistency with the related literature in the field, throughout this thesis participants are referred to as older parent carers.

## **1.2 The constructs of caregiving and quality of life**

Caregiving as defined by Hermanns and Mastel-Smith (2012: 5) ‘is made up of actions one does on behalf of another individual who is unable to do those actions for himself or herself’. While caregiving for a child/adult with a learning disability can be a positive transformative experience (Hastings and Taunt, 2002; Green, 2002), traditionally stress and burden have been central in defining this experience (Grant et al., 1998). This deficit model perpetuates the notion that caregiving is problematic and that families struggle to cope in their caring role (Grant and Whittell, 2000). However, studies have increasingly emerged that report positive experiences of caregiving (Stainton and Besser, 1998; Grant et al., 1998; Scorgie and Sobsey, 2000; Jokinen and Brown, 2005; Green, 2007), providing a balanced picture and a more nuanced understanding of the complexities of caregiving (Miller and Lawton, 1997). Intertwined with this deeper understanding of the caring experience is the issue of the caregivers’ quality of life, as the caregiving role can either enhance or detract from the quality of life of carers (Carers UK, 2004; Ekwall et al., 2007; Yoong and

Koritsas, 2012). This complex interaction of positive and negative experiences and their impact upon quality of life has also been found to be the case for older parent carers of adults with learning disabilities (Walden et al., 2000; Chou et al., 2007; Caples and Sweeny, 2010; Yoong and Koritsas, 2012).

Quality of life is a contentious concept (Rapley, 2003) because it means different things to different people and is defined in different ways (Farquhar, 1995). It is difficult to define (Moons et al., 2006) and therefore there is no consensus about this definition (Smith, 2000). Consequently, researchers have sought to address this problem by choosing facets of quality of life that are appropriate for their particular study aims and objectives (Keith, 2001).

Although several researchers have attempted to define quality of life (Abrams, 1973; Andrews, 1974; Flanagan, 1978; George and Bearon, 1980; Ferrans, 1996), these definitions have received criticism for not incorporating all the constituents of quality of life (Smith, 2000). Moons et al. (2006), building on the work of Ferrans (1996), carried out a critical review of eight conceptualisations of quality of life in an attempt to provide a less ambiguous definition. They concluded that satisfaction with life, which is defined as ‘a subjective appraisal of one’s personal life’ (Moons et al., 2006: 898), was the most appropriate definition because it diffuses the conceptual ‘muddiness’ that surrounds quality of life. In addition, it refers to overall quality of life and is therefore not limited to the narrow focus of health-related quality of life (Moons et al., 2006). Other commentators have equated quality of life with happiness and the ‘good’ life (Aristotle, 1955), psychological well-being (Ryff and Singer, 1998) and subjective well-being (Diener, 1984).

Furthermore, quality of life has also been polarised into two dimensions (Cummins, 1997; Diener and Suh, 1997), with the objective component focusing on income and material possessions (McDowell and Newell, 1987) that can be partially or fully quantified (Mukherjee, 1989) and the subjective focus on individual ability to perform and enjoy work, family, social and community roles (Schipper et al., 1990). While Ryan et al. (2008) view these two dimensions as opposing constructs, other commentators argue that they are interrelated (Diener and Suh, 1997; Mukherjee, 1989).

### 1.3 Quality of life of older people

Historically, quality of life studies with older people have focused mainly on health-related quality of life (Idler et al., 2009) as a basis for health interventions (Hendry and McVittie, 2004). Alongside this health focus, researchers have become interested in global quality of life due to the prolonged life of older people (Farquhar, 1995; Hendry and McVittie, 2004; Gabriel and Bowling, 2004; Bowling and Gabriel, 2007; Borglin et al., 2005; Bowling et al., 2012). However, studies placing a stronger emphasis on the objective aspects of quality of life continue to use standardised quantitative measures to assess older people's quality of life (Farquhar, 1995; Walden et al., 2000; Perkins, 2009; Caples and Sweeny, 2010) and these have proven to be problematic (Bowling, 1995; Hendry and McVittie, 2004; Gilhooly et al., 2005) because they are inadequate for capturing what constitutes quality of life for older people (Hendry and McVittie, 2004). Therefore, older people's subjective quality of life remains under-explored in a general sense, and more specifically the voices of those with caring responsibilities are lacking in quality of life research and policies concerning caregiving in later life.

Understanding older people's subjective quality of life is important because there is a marked difference between their understanding of quality of life and the conceptualisations that have been included in the objective measures of quality of life (Hendry and McVittie, 2004). Indeed, the very nature of quality of life is subjective (Bowling et al., 2012), since each individual attaches his or her own meaning to their experiences (Calman, 1984). The subjective nature of quality of life is highlighted by the disability paradox, whereby people who live with profound disabilities or in adverse conditions report their quality of life as good (Albrecht and Devlieger, 1999). Therefore researchers must actively seek the views of older people in order to determine what contributes to their quality of life (Ziller, 1974; Fry, 2000), and instruments measuring quality of life should be grounded in people's experience (Bowling et al., 2012). Qualitative approaches are helpful in providing a deeper understanding of people's

perspectives (Mackenzie and Greenwood, 2012) and consequently are well placed to explore subjective quality of life of older people. With reference to the arguments outlined above (Moons et al., 2006), and for the purpose of this study, quality of life is self-defined by the older parent carers.

## **1.4 Policy context specific to carers of people with learning disabilities**

With the NHS and Community Care Act 1990, the shift from institutional care to care in the community placed informal carers at the centre of the debate on caregiving and social policy (Twigg and Atkin, 1994). This move reflected the policy-makers' assumptions that the most appropriate form of care is care given by family members (Sidell, 1994). Family carers make a substantial contribution to the economy of over £119 billion a year (Buckner and Yeandle, 2011); yet there has been no formal acknowledgement of their role and the importance of informal care has only recently been obtained after a long and sustained struggle (Stock and Lambert, 2011).

Successive governments have introduced legislation and policies in relation to informal carers. Although these are discussed fully in Chapter 2, a brief introduction is given here. The key policy initiatives 'Valuing People' (Department of Health, 2001) and 'Valuing People Now' (Department of Health, 2009) were ostensibly introduced specifically to support adults with learning disabilities and their family carers. 'Valuing People' was the first White Paper in 30 years which sought to bring people with learning difficulties and their families into mainstream society and address their needs (Department of Health, 2001). The stated aims of this White Paper were to improve the life chances for people with learning disabilities by working with social care services, health care providers, carers and adults with learning disabilities to provide opportunities, so that people with learning disabilities could 'lead full and active lives' (Department of Health, 2001: 1).

The 2001 White Paper embraced the four key principles of rights, independence, choice and inclusion (Department of Health, 2001), and was seen by some people as a positive initiative for people with learning disabilities (Foundation for People with Learning Disabilities, 2001). It included 11 objectives which focused on three main issues: improving health, employment and housing for people with learning disabilities. Two of the objectives were to set up national partnership boards and a learning disability taskforce, including people with learning disabilities and their carers, in order to give them a voice in key decision making about their lives. As a result, councils were encouraged to identify carers 70 years and older, and those from Black and minority ethnic communities (Department of Health, 2001), to be part of these initiatives. Some other positives that came about with the advent of the White Paper were: the implementation of the Carers' and Disabled Children Act, 2000, the development of the National Learning Disability Information Centre, the creation of a helpline in partnership with Mencap (one of the major national organisations that support people with learning disabilities and their parent carers) and an increase in the carer's allowance (Department of Health, 2001).

Despite these positive developments, there were some concerns. People with complex needs had not been prioritised and the objectives were over-ambitious and did not meet the intended goals. As a result the lives of many people with learning disabilities were not changed significantly (Mencap, 2009). Consequently, parent carers' expectations of improved life chances for their sons and daughters were dashed. A key omission from the 'Valuing People' White Paper was that no consideration was given to adults with learning disabilities who were themselves parents and in need of additional support in their parental role. These shortcomings had implications for carers because they continued to provide substantial care without adequate support and service provision.

The more recent policy initiative, 'Valuing People Now' (Department of Health, 2009), addressed some of these concerns, by according priority to the provision of services to people with complex needs. It sought to strengthen partnership working between various government departments, which was identified as one of the reasons that the 2001 White Paper failed to deliver

(Mencap, 2009). The 2009 White Paper was instrumental in promoting choice and control for people with learning disabilities through the personalisation of care. However, there remained concerns about the Personalisation Agenda (Lymbery, 2010) – more so, with the reduction in the social care budget (HM Treasury, 2010). Mencap (2009) argued that it would be difficult for people with learning disabilities to have choice, flexibility and control over their care, particularly those with complex needs, because services would be mainly resource led rather than needs led. Thus in order for service users' needs to be met adequately, family carers would need to make up the shortfall in funding in order to enable their adult children to access services. For older parent carers, in particular, the lack of adequate accommodation raised anxieties about planning for the future (Bowey and McGlaughlin, 2007).

The 'Valuing People' and 'Valuing People Now' policy initiatives of 2001 and 2009 were and still are of importance in laying the foundation for promoting the rights, independence and social inclusion of this marginalised group. However, more needs to be done at governmental level, so that appropriate services are provided to bring about positive changes in the lives of carers and their adult children with learning disabilities.

## **1.5 Motivation for conducting the study**

The study aimed to examine how older parents who provide long-term care for their adult children with learning disabilities conceptualise their quality of life. Interest in this study stems from my work with parent carers of adults with learning disabilities as the respite care co-ordinator for a local authority in a London borough. My role was to assess parents' needs with a view to offering respite to their sons and daughters, and to supporting parents in their caring role. I therefore had opportunities to engage with parents and to facilitate stakeholder meetings which provided a forum for parents to discuss issues of common interest and to share their experiences.

Over time, I gained an understanding of the complexity of caregiving and the demands placed on parents on an on-going basis. I also had a strong sense of the tremendous economic contribution they were making to social care in England. Through my work on an older carers' project, I observed that there were parents in their 70s and 80s supporting their adult children at home, mostly on their own. This observation reinforced my view that parents are experts by experience, often having a keener insight into their situation than professionals. In addition, parents not only put their adult children's needs before their own, but often failed to recognise and address their own needs. I felt these actions were motivated by love and a sense of duty. These observations gave me an insider's (emic) perspective (which is discussed further in Chapter 3) and sparked my interest in exploring the quality of life of these older parents.

The longevity of adults with learning disabilities and their older parent carers means that they are ageing together, with implications for health and social service provision (Caples and Sweeney, 2010). The long-term welfare of these adult children is dependent on the older parents' physical, mental, social and economic well-being (Burton-Smith et al., 2009). Since little is known about the subjective quality of life of older parent carers of adults with learning disabilities, there is an urgent need for more research, particularly qualitative studies, to understand the caregiving experiences of this unique group of carers and how they conceptualise their quality of life, and to inform policy and service delivery (Parmenter, 2004). It would therefore seem timely to examine the experiences of caregiving of older parent carers of adults with learning disabilities and how they conceptualise their quality of life in relation to their role.

## **1.6 Research questions**

The purpose of this study is therefore twofold: firstly, to examine the experiences of older parents who provide long-term care for their adult children with learning disabilities; and secondly, to explore how these parent carers conceptualise their

subjective quality of life experiences. Therefore the two main research questions are:

- What are the experiences of older parents who provide long-term care for their adult children with learning disabilities?
- How do older parents who provide long-term care for their adult children with learning disabilities conceptualise their quality of life?

In order to answer these questions, a qualitative study was designed, adopting a constructivist approach. The study draws on interviews with 27 older parent carers aged 60 years and over, who provide long-term care for their adult children with learning disabilities, living in four London boroughs. I chose 60 years as the lower age limit for including participants in the study, based on the World Health Organization's categorisation of older people:

*Sixty and over describes the older population, but acknowledges that chronological age is not a precise marker for the changes that accompany ageing as there are dramatic variations in health status, participation and level of independence among older people of the same age. (World Health Organization, 2002: 4)*

However, two parent carers who were just under 60 years identified themselves as older parents and were included in the study. This is discussed further in Chapter 3.

In constructivism, subjective reflexivity – meaning that the researcher is ‘constantly reflective and self-critical processes undergone by the researcher at all stages of the research process - replaces objectivity’ (Grbich, 2007: 10). As a reflexive researcher, I acknowledged that my influence was instrumental in shaping the research process (Ormston et al., 2014), so I used a reflexive journal to capture my feelings and thoughts throughout the research endeavour (see Appendix A). Extracts from my reflexive journal are interwoven into the

chapters of the thesis to illustrate my thinking processes. The extracts have been placed into boxes to differentiate them from the other text in the thesis.

## 1.7 Contribution of the study

It is expected that this study will make an important contribution by addressing gaps in research on older parents' caregiving experiences, and by providing a deeper understanding of their subjective quality of life. It is hoped that, having placed older parent carers' voices at the centre of this study, the findings will:

- provide additional evidence to develop an in-depth-understanding of caregiving and quality of life of older parent carers;
- provide insight for social policy-makers;
- inform social work practice with older parent carers of adults with learning disabilities.

## 1.8 Structure of the thesis

The subsequent chapters are organised as follows.

**Chapter 2** discusses of the main concepts and the general legislation and policies relating to informal carers and the research context. It then critically appraises the existing studies on parental caregiving for both children and adults with learning disabilities. It also evaluates studies on the quality of life of older people in general and more specifically on older parent carers of adults with learning disabilities.

**Chapter 3** provides a comprehensive account and justification for the ontological, epistemological and methodological positions, and how these were operationalised in the current study. It describes the theoretical models that informed the study. It discusses the ethical considerations that were taken into account in conducting the study and how they were addressed. The chapter also describes the recruitment procedures, the method used to collect data, and the

data analysis approaches. It concludes with a discussion of the challenges that were encountered while conducting the study, how these were overcome, and how the quality and rigour of the study were ensured.

**Chapters 4 and 5** present the findings from the thematic analysis, guided by the framework technique (Ritchie and Spencer, 1994), of 27 interviews with older parents supporting their adult children with learning disabilities. Chapter 4 presents the findings relating to the experiences of caring in later life for an adult child with learning disabilities, while Chapter 5 presents the findings that relate to how older parents conceptualise their quality of life in relation to their caring role.

**Chapter 6** provides an in-depth discussion of the findings in relation to the existing literature and the theoretical frameworks that guided the study. It also evaluates the strengths and limitations of the research.

**Chapter 7**, the final chapter, discusses the study's contribution to knowledge and the implications for policy, health and social care practice, education and further research.

The next chapter begins by providing a critical review of the studies on parental caregiving and quality of life of older people and older parent carers.

# Chapter 2 Literature review

## 2.1 Introduction

This chapter opens with a discussion of the main concepts of caregiving and caring, carers and quality of life. This is followed by a discussion of the general legislation and policies which support informal carers. A critique of existing studies on parental caregiving for adults with learning disabilities, the quality of life of older people in general and, more specifically, older carers of adults with learning disabilities concludes the chapter.

## 2.2 Literature search

An initial literature search was conducted in 2007 to identify studies on caregiving for adults with learning disabilities and quality of life of older people/older carers of adults with learning disabilities, using the electronic databases ASSIA, CINAHL Plus, PsycINFO, AgeInfo, Scopus, AMED, MEDLINE and Google Scholar. The literature reviewed includes publications from the period 1990 to 2014. This period was chosen because the National Health Service and Community Care Act 1990 is the landmark legislation that formalised informal care. However, seminal works on caregiving and quality of life published before 1990 are also included.

Manual and electronic searches used the terms ‘caregiving’, ‘older carers’, ‘learning disabilities’, ‘older people’ and ‘quality of life’ in different combinations. For example, in order to identify studies on caregiving, the combination of the terms ‘older carers’ and ‘learning disabilities’ was used in the search engines. The terms ‘quality of life’, ‘older people/older carers’ and ‘learning disabilities’ were used to identify the quality of life studies. Key journals were also searched, including *British Journal of Social Work*, *Journal of Intellectual Disability Research*, *Ageing and Society* and *Journal of Happiness and Well-being*. Reference lists for articles were reviewed in order to identify

further literature (James, 2013) and websites such as that of Carers UK were visited as part of the literature search.

For the duration of the project, periodic searches were conducted which yielded further papers. This was done to keep abreast of the new knowledge in the field relevant to the study and also to acknowledge that the literature review is an evolving and iterative process (Levy and Ellis, 2006). Moule's appraisal framework (Moule et al., 2003) was used as a guide for critiquing the existing literature (see Appendix B), and a critical narrative approach was adopted for the review (Pope et al., 2007). A narrative review allowed the inclusion of those papers that best reflected the area to be explored.

Although the main focus of the study is on older parent carers of adults with learning disabilities, studies on parent carers of children with learning disabilities and carers of other client groups (such as stroke survivors) have been included due to the paucity of studies on parent carers of adults with learning disabilities. Similarly, research on the quality of life of older people in general was included due to the dearth of research specifically on the quality of life of older parent carers of adults with learning disabilities. In order to address the scarcity of UK studies on caregiving by older people of adults with learning disabilities and their quality of life, studies outside of the UK have been included in the literature review. However, studies were excluded where the focus was on quality of life of older people in relation to health interventions, and the quality of life of adults with learning disabilities.

## **2.3 Discussion of main concepts**

### **2.3.1 Caregiving and caring**

Caregiving is a complex and multifaceted activity (Lane et al., 2003; Khan et al., 2007), and at a conceptual and operational level is difficult to explain (Grant and Ramcharan, 2001). Although the term is used widely, it has not been well defined (Arber and Ginn, 1990; Hermanns and Mastel-Smith, 2012) and the main

criticism of current definitions is that they tend to focus mainly on the procedural aspects of caregiving (Nolan et al., 1996b) and omit the affective dimension which is associated with a feeling of warmth, respect, nurturance and regard (Radsma, 1994). This task-oriented focus presents the concept as static and therefore fails to capture its dynamic nature (Langer, 1993). Several attempts have been made to define caregiving in order to provide a better understanding of the concept (Parker and Lawton, 1994), but these have not moved beyond the physical component (Nolan et al., 1996b).

This definitional difficulty is not surprising given the complex nature of caregiving (Arber and Ginn, 1990; Lane et al., 2003). Furthermore, Wenger et al. (1996) suggest that caregiving is better understood in terms of its purpose and outcomes.

From a feminist perspective, caregiving is seen as a 'natural female activity' (Barnes, 2006), and from a psychological perspective it can be perceived as offering a sense of fulfilment and an activity through which women demonstrate their femininity (Graham, 1983) as well as a form of identity (Lewis and Meredith, 1989). The changing gender profiles of caregiving and the social construction of women as carers (Ungerson, 1981) challenge the discourse on caring being synonymous with women, particularly as men over the age of 70 years are now more likely to be carers in the UK (Ross et al., 2008).

In relation to caring, it is envisaged that 'each of us will receive and provide care over the course of our lives' (England and Dyck, 2011: 37), and is an activity that takes place between family members, friends and colleagues, not only those who are in receipt of community services (Bowlby, 2011). Graham (1983) describes caring as a 'labour of love' because, more often than not, family members who provide care do so out of love and responsibility (Twigg and Atkin, 1994). This 'labour of love', referred to as emotional labour, can be experienced in parallel with the physical work that characterises caring (Twigg, 2006).

From an ethic of care standpoint, caring can be viewed from two perspectives: 'caring for' and 'caring about' (Tronto, 1993). At the affective level, 'caring for' focuses on the activities of looking after someone, and 'caring

about' refers to having concerns for someone (Graham, 1983). These two components are inextricably linked and are closely associated with motherhood (Dalley, 1996). For parents of children with learning disabilities there is an expectation that 'caring about' automatically extends to 'caring for' (Dalley, 1996) due to the additional needs of their children. In this context, the love that underpins caregiving (Dalley, 1996; Sims-Gould and Martin-Matthew, 2008) can change to feelings of obligation, burden and frustration (Dalley, 1996). The reciprocal relationship between adult children and their parents (Perkins, 2009; Grant, 2010; Perkins and Haley, 2013) also adds to the complexity of defining caregiving.

### **2.3.2 Carers**

In England and Wales there were 5.8 million carers in 2011 (Office of National Statistics, 2013), representing an increase of 35 per cent in older carers since the 2001 census (Carers UK, 2013). There were also 905,000 adults with learning disabilities (Department of Health, 2012) and 29,000 of these adults live with parents 70 years and over (Care Quality Commission, 2012). Some 13 per cent of carers are caring for a son or daughter with disability (Niblett, 2011). For parents of adults with learning disabilities, their extended caring role (Cuskelly, 2006) tends to consume the greater part of their lives (Yannamani et al., 2009), and for many family members it can be a lifelong career (Haley and Perkins, 2004; Perkins and Haley, 2013). Caregiving for adults with learning disabilities can be perceived as a continuation of a parent's childcare role (Twigg and Atkin, 1994; Perkins, 2009) and therefore differs from other caring situations, such as adults caring for their elderly parents and spouses, where family carers tend to take on the role gradually as dependency increases (Perkins, 2009).

As a consequence of prolonged caregiving, parent carers of adults with learning disabilities, particularly older parents, can develop a sense of mastery (Perkins, 2009). Mastery comes from trial and error, and a sense of coherence (SOC) develops from using a variety of coping strategies and being able to use the appropriate strategy to suit the particular situation (Antonovsky, 1987). In

essence, SOC is the ability to manage tension effectively without it becoming stressful (Ekwall et al., 2007). However, these parents may assume the caring role unprepared for what it involves (Nolan and Grant, 1989; Kellett and Mannion, 1999). Many do not realise the impact caregiving can have on their quality of life (Walden et al., 2000; Leung and Li-Tsang, 2003; Chou et al., 2007; Lin et al., 2009; Caples and Sweeney, 2010; Yoong and Koritsas, 2012). This is an important and under-researched area especially as caregiving and quality of life are interlinked, and impact on each other (Yoong and Koritsas, 2012).

### **2.3.3 Quality of life and related concepts**

The quality of life as a construct is not new, dating back to the ancient Greek philosophers (Chung et al., 1997). These philosophers had a great interest in how people lived, and therefore expended lots of energy teaching about happiness and the good life (Chung et al., 1997). Aristippus, a philosopher of the fourth century BC, described happiness as the sum total of hedonic experiences which focus on pleasurable pursuits as the ultimate goals of life (Ryan and Deci, 2001). This was seen as a vulgar ideal by Aristotle, who argued that true happiness was doing what is worthwhile (Ryan and Deci, 2001). This idea is associated with eudaimonia or the concept of the true self (Waterman, 1993) and is often described as psychological well-being (Ryff and Singer, 1998).

The notion of eudaimonia or psychological well-being was formulated to challenge hedonic well-being (Deci and Ryan, 2008). Hedonic enjoyment or subjective well-being (Diener, 1984) is perceived as transient, and can produce a life that lacks meaning, bereft of depth and a sense of community (Ryan et al., 2008). In contrast, eudaimonic living is associated with ‘life that is lived to the fullest in a deeply satisfying way, actualising one’s human potentials’ (Deci and Ryan, 2008: 2) and focusing on what is intrinsically good (Ryan et al., 2008).

The terms ‘well-being’ and ‘quality of life’ have been used interchangeably and are associated with a wide range of overlapping meanings (Gasper, 2010). Historically, well-being was used to describe how someone appraised his or her life, whereas quality of life referred to communities,

localities and societies (Gasper, 2010). A UK project, *Shaping Our Age*, explored how older people aged 65 and over understood and defined well-being.

Participants defined well-being as ‘feeling healthy, free from pain and able to lead a positive life. Some contributors to feelings of well-being were happiness, having sufficient personal finance, good physical and mental health, satisfaction and peace of mind, with self-worth and achievement also seen as influencing older people’s well-being’ (Hoban et al., 2013: 7).

Gilhooly et al. (2005:16) explained that the ‘shift in research interest from well-being to quality of life’ gained prominence due to an increased awareness of the level of unfairness that existed in society and had the potential to be detrimental to large groups of the people. The government’s response involved evaluating the quality of people’s lives to improve their situation without interfering in their private affairs (Gilhooly et al., 2005). This evaluation centred on the two main indicators of quality of life, which are the focus of the next section.

### **2.3.4 Indicators of quality of life**

In the late twentieth century, the term ‘quality of life’ was brought into wider use by economists and political scientists (Rapley, 2003), who used different indicators to assess how good or bad quality of life was for people on a national level. Quality of life has been measured using material living standards, GDP and a relative scientific index (Rapley, 2003). In the USA, economists who had previously used material well-being to measure quality of life shifted their focus to the quality of people’s experiences (Rapley, 2003). This meant that in the USA, quality of life developed from being a social-scientific index of the relative well-being of the whole population – ‘a state of states’ (an objective indicator) – to a state of the person (Rapley, 2003) which measured aspects of people’s subjective experience (a subjective indicator) (Camfield and Skevington, 2008). For the current study, quality of life has been taken to mean an individual, subjective experience and not a ‘state of states’.

### 2.3.5 Definitions of quality of life

The dichotomous nature of quality of life triggered many debates about objective and subjective quality of life (Mukherjee, 1989; Rapley, 2003; Moons et al., 2006). In defining quality of life, Farquhar (1994) identified two categories: expert and lay definitions. Within the expert classification are global, component and focused definitions. Global quality of life can be described as the degree of satisfaction or dissatisfaction in one's life (Abrams, 1973; Moons et al., 2006). The 'component' definition of quality of life has several dimensions, which highlight the multidimensional aspects of quality of life (Bond and Corner, 2004). This definition is captured by George and Bearon's (1980) four-dimensional model, which includes: general health and functional status (objective); and life satisfaction and self-esteem (subjective). It is also captured by Hughes's (1990) conceptual model of eight dimensions, comprising: personal autonomy, expressed satisfaction, physical and mental well-being, socioeconomic status, quality of the environment, purposeful activity, social integration and cultural factors. This comprehensive model takes into consideration all aspects of an individual's life, while the third expert definition, the focused definition, is often guided by political or professional agendas which tend to focus on specific domains (Bond and Corner, 2004). For example, in health services research on quality of life, the focus tends to be using measures to assess people's health and functional status (Bowling, 1996). The expert definitions of quality of life are generally utilised in population surveys of older people's quality of life (Bond and Corner, 2004).

Despite the view that lay definitions rather than expert definitions are more appropriate in assessing quality of life (Bond and Corner, 2004), very few studies on quality of life of older people have included their lay views (Gabriel and Bowling, 2004). This occurs despite older people talking freely about their quality of life when given the opportunity to do so (Andrews, 1974; Farquhar, 1994, 1995). How older people report their quality of life is influenced by their lived experiences (Bond and Corner, 2004), 'which are set in the context of time' (Farquhar, 1994: 153). Their stories are also shaped by the circumstances in

which they are told and the role of the listener (Bond and Corner, 2004). Similarly, from a social science perspective, quality of life embraces ‘the built, physical, economic and social environments, as well as the meaning of life to the individual, and the subjective experience of life quality’ (Bond and Corner, 2004: 2). From a social gerontology perspective, the absence of older people’s voices in quality of life research is not in keeping with the British social gerontology stance of listening to older people (Bond and Corner, 2004). In some instances, the way in which people report the subjective experiences of their quality of life may seem distorted, but these responses are nevertheless valuable because they provide an understanding of people’s perceptions of their quality of life (Clark, 2000), and these perceptions influence people’s actions (Abrams, 1976).

In summary, studies which draw on the lay views of older people are needed to provide a deeper understanding of what constitutes quality of life for them, to inform health and social care practitioners and policy-makers, and to contribute to the development of measures that are grounded in older people’s views. The need for quality of life measures to include both subjective and objective components has been acknowledged (Gabriel and Bowling, 2004); examples of these are the WHOQOL Group model (1993), OPQOL (Bowling and Stenner, 2011) and OPQOL-brief (Bowling et al., 2012). Both qualitative and quantitative approaches are important in assessing quality of life, and the approach chosen is highly dependent on what is being investigated (Keith, 2001). However, what is lacking in quality of life research with older people are studies that solicit their views by asking them directly (Fry, 2000) about what constitutes a ‘good’ or ‘bad’ quality of life for them. More importantly, there is a lack of research that seeks to understand the challenges, coping strategies and the fulfilment and enhancement derived from parental caregiving for adults with learning disabilities, and the interconnectedness of the experiences of caregiving and quality of life of older parents. Despite this paucity of studies, since the 1990s, which ushered in community care, informal carers have been the subject of much of the policy debate and there has been an increase in social care policies focusing support on informal carers (Twigg and Atkin, 1994).

## **2.4 Legislative and policy context for informal carers**

During the last 20 years national UK legislation and policies have been implemented to support and protect informal carers with a view to enhancing their role, so that they are able to continue providing care (Department of Health, 2010). In relation to welfare provision, family carers are seen as a ‘valuable resource for their relatives, the community and the government’ (James, 2013: 7). The three main Acts that previously supported informal carers are: the Carers (Recognition and Services) Act 1995; the Carers and Disabled Children Act 2000; and the Carers (Equal Opportunity Act) 2004. However, there are several other pieces of legislation and policy initiatives, such as the Work and Families Act 2006, the Equality Act 2010, the Care Act 2014 and the government’s Personalisation Agenda, which have influenced parent carers’ experiences of their role and quality of life, and these are discussed later in this section.

The three main Acts referred to above placed a duty on local authorities to assess carers’ needs and provide services to meet those identified needs. However, the implementation of the 1995 and 2000 Acts was problematic (Baggott, 2004; Scourfield, 2005b). For example, according to the 1995 Act, only informal carers who were providing regular and substantial care were entitled to an assessment. This meant that it was left to the local authorities’ discretion to decide what was ‘regular’ and ‘substantial’ care (Seddon and Robinson, 2001). This in turn created a post code lottery where services were more readily available to carers in some areas than in others (Yannamani et al., 2009; Carers Trust, 2012). Another issue was that the 1995 Act did not place a duty on local authorities to provide a service, only an assessment. Therefore, practitioners conducting carers’ assessments were concerned that they might raise carers’ expectations unduly as tangible outcomes could not be offered (Seddon and Robinson, 2001). This presented a dilemma for practitioners, as research has shown a link between carers’ satisfaction and service outcomes (Robinson and Williams, 2002). However, on the positive side, the 1995 Act

highlighted the importance of understanding informal carers' needs and afforded social care practitioners the opportunity to update their practice in conducting carers' assessments (Nolan et al., 1996a).

Five years later, the Carers and Disabled Children Act 2000 addressed the limitations of the 1995 Act (Seddon and Robinson, 2001) by giving the power to local authorities to provide a service for carers' assessed needs. Furthermore, it also afforded carers the opportunity to access services through direct payments by extending the Community Care (Direct Payment) Act 1996, which gave local authorities the power to provide direct payments to disabled people aged 18 to 65 (Gardner, 2011). Direct payments challenged the 'subordinate position of disabled people, in which they were recipients of arranged services' (Scourfield, 2005a: 470) thus giving them control over and flexibility in their care. Through direct payments the individuals might receive the cash equivalent of a directly provided service to purchase social care from a private/voluntary sector agency or become an employer by hiring their own staff (Glasby and Littlechild, 2009). However, due to the low uptake of carers' assessments nationally (Carers UK, 2003), the 2000 Act had little impact, as carers were largely unaware of their entitlement to an assessment (Keely and Clarke, 2002). The triggers for a carer's assessment occur mainly at transition periods (such as when young people move from children's services to adults' services) or when there is a family crisis (Robinson and Williams, 2002); thus assessments are offered more reactively than proactively (Weiss and Lunskey, 2010). The implementation of both the 1995 and 2000 Acts continues to be inconsistent (Stock and Lambert, 2011), which means that the assessment of carers' needs has not yet become standard practice (Glendinning et al., 2013).

In recognition of the needs and aspirations of carers, the Carers (Equal Opportunities) Act 2004 went a step further and placed a duty on local authorities to ensure that the wishes of carers to engage in work, training and leisure were taken into account by the professionals who were assessing their needs. However, Bowen (2004) found that in some cases, the post-assessment services that were offered were not tailored to meet carers' needs, resulting in carers not wanting most of the services offered, and the services they wanted, such as

respite care, training for personal care and information about job opportunities, not being made available to them. This situation again created many frustrations for carers and highlighted the need for carers to be supported by services that are directly beneficial and meaningful to them. Stock and Lambert (2011) have subsequently argued that creative approaches are needed to support carers, rather than seeking to fit carers into existing services, as the latter could prove disappointing and futile.

The Work and Families Act 2006 and the Equality Act 2010 both provide guidance for carers in relation to their right to request flexible working hours, and their right to protection against discrimination. In terms of support for carers, the Care Act 2014 has stipulated that local authorities no longer have the power, but rather a duty, to provide services to address carers' needs once they meet the eligibility criteria. The 2014 Act went a step further and removed the condition that carers needed to provide 'regular' and 'substantial care' in order to be eligible for an assessment, as had previously been the case. Therefore this Act broadens the scope of existing legislation and seeks to be more inclusive and comprehensive. This is a welcome change particularly for parent carers who provide mainly emotional support for adults with learning disabilities because it is difficult to quantify intangible support.

## **2.5 Personalisation**

While the policy changes should have improved parents' caregiving experiences and quality of life, in the current context of austerity it remains to be seen whether or not resources will be made available to make any marked or tangible difference to the quality of life for carers. In order for these Acts to have any significant impact, the way in which information is disseminated about carers' entitlement to assessments must be improved and prioritised (Stock and Lambert, 2011), so that carers can readily access services to support them in their caring role.

It has been shown that successive governments' responses to carers' needs have been criticised as being mainly rhetorical, due to the mismatch between the duty to assess and the lack of services available to meet identified needs (Baggott, 2004). In addition, carers encountered difficulties in both the interpretation and the implementation of legislation and policies. One such policy initiative which emerged in the 2006 White Paper (Department of Health, 2006) was the government's Personalisation Agenda. This was hailed as a different, and better, way of delivering adult social care (Lymbery, 2012), and was to be achieved through the route of self-directed support (Slasberg et al., 2012). Personalisation of services was described as 'a way of thinking and a way of doing' (Gardner, 2011: 18), in the modernisation of social care for the disabled, the sick and the elderly (Clements, 2008; Gardner, 2011). Personalisation placed 'an emphasis on providing social care services tailored to the individual needs of the service user rather than fitting people into existing services' (Harlock, 2010: 371).

The Personalisation Agenda has become an attractive option for politicians and policy-makers not only in terms of reorganising adult social care, but also as a cost-saving endeavour (Leadbeater et al., 2008; Needham, 2011), and has received cross-party support (Dickinson and Glasby, 2010). Direct payments and individual/personal budgets are the main levers through which the personalisation of services has been achieved to date. Similar to direct payments, described earlier, individual/ personal budgets offer choice, flexibility and control (Clements, 2008) to the carer (or their representative). The success of personal budgets hinges on 'recipients being informed about an upfront allocation of funding, enabling them to plan their support arrangements, and the construction of an agreed support plan which makes clear what outcomes are to be achieved with the money' (Poll et al., 2006: 25). Service users may choose to take cash as a direct payment, or services to the value of their budget (or a mixture of both) (Clements, 2008). Unlike direct payments, until recently there was no legislation associated with individual /personal budgets. However, under the Care Act 2014 personalisation has been endorsed as providing services that meet the service users' needs.

To date, the findings from personalisation research have been mixed in relation to carers, as evidenced by the studies by Williams (2003), Rosenthal et al. (2007), Glendinning et al. (2009) and Moran et al. (2011), and to some extent the outcomes have fallen short of the advantages envisaged by the 2008 English National Strategy for Carers, such as ‘more choice and control over what services best met their needs’ (HM Government, 2008: 61–3). In view of the current financial climate, it would be difficult for service users and carers to exercise choice and control, two main components of the personalisation initiative (Lymbery, 2012). Some small studies have reported the positive impacts of direct payments on carers (Williams et al., 2003; Carers UK, 2008; Blythe and Gardner, 2007) and individual budgets (Glendinning et al., 2009a), others have identified limitations in these initiatives, and the adverse effect on carers’ lives (Rosenthal et al., 2007; Rabiee et al., 2009; Moran et al., 2011).

Williams et al. (2003), in a qualitative study with 29 family members of people with learning disabilities in the UK, reported that parents played significant roles (as initiators, managers and supporters) in helping their children access direct payments. These roles involved managing the paperwork and identifying and recruiting personal assistants (PAs). However, the benefits of increased independence for their children and the reduction in their caregiving responsibilities were perceived as compensating for the additional tasks they took on to support their relatives. In another UK qualitative study with seven families of people with learning disabilities, Blyth and Gardner (2007) reported that parents also valued the flexibility and control offered via direct payments to employ a relative or trusted friend to provide services to meet both their children’s and the family’s needs.

Similarly, a study by Carers UK (2008) found that carers valued having the flexibility to purchase services that adequately met their children’s needs. The positive impact of individual budgets on carers was also reported by the IBSEN study (Glendinning et al., 2009a) piloted by the government. This study found that for carers of people with learning disabilities quality of life was enhanced; they reported a higher level of involvement in planning how their son or daughter would use their budget and they received more support from social

workers or external agencies with this role. Due to the interdependency between parent carers and their children, parents were happy once their children were happy, and like the parents in Williams et al.'s (2003) study the additional administrative responsibilities involved in accessing individual budgets were outweighed by the benefits. However, it is worthy of note that some parents reported in the IBSEN study (Glendinning et al., 2009a) that their concerns about their children were not taken into consideration in the planning process, which left them feeling undervalued. While these studies provide some insight for practitioners supporting family carers of people with learning disabilities, there are some limitations. For example, the sample size is too small for generalisation and therefore should be treated with caution. The findings also predate the government's cuts to social care funding in 2010, which have seriously challenged the notion of personalised or needs-led services, thus undermining the 'foundation' of personalisation (Boxall et al., 2009).

A large-scale Canadian study by Rosenthal et al. (2007) found that the added responsibilities of recruiting personal assistants and the general paperwork associated with individual budgets was referred to as 'managerial care' and increased the stress levels for some family carers. Unlike the small studies discussed above, this finding is more generalisable due to the large sample and therefore may be more representative of the experiences of carers supporting family members with individual budgets. However, these findings must nevertheless be treated with caution as the welfare provision in Canada may be organised differently from the UK despite the fact that the idea of individualised care (direct payments) was imported from Canada and the United States (Brandon and Towe, 1989; Salisbury et al., 1987) in the mid-1980s.

In the UK, Rabiee et al. (2009) also endorsed the negative impacts on carers that are associated with the responsibility incurred in managing and coordinating individual budgets. This problem was compounded by the shortfall in the money allocated by the Resource Allocation System (RAS), through which service users are told how much money has been allocated for their care, which meant that parent carers needed to provide the extra care themselves or 'top up' the money to pay for the care. In a further UK study, Moran et al. (2011) also

reported the stress endured by families from the fear of getting the process wrong. As evidenced in the IBSEN study (Glendinning et al., 2009a), specialist support for carers, such as having a carers' champion on local authority teams, and practitioners having an understanding of carers' issues, have been identified as contributors to positive experiences of carers supporting relatives with direct payments and individual budgets. Despite this, there is a sense that 'personalisation is still evolving in terms of policy, implementation and practice and how we can turn the rhetoric of personalisation into an effective reality is as yet unclear' (Harlock, 2009: 8). There also remain areas of concern, such as safeguarding and risk in relation to financial abuse (Manthorpe et al., 2009).

Although research acknowledges that informal carers play a vital role in caring for their relatives (Glendinning et al., 2009b) and are central to the successful implementation of personalisation, the impact on carers has not been widely explored (Larkin and Dickinson, 2011; Glendinning et al., 2013). Current findings are mainly incidental rather than explored in depth (Duncan-Turnbull, 2010). The IBSEN study (Glendinning et al., 2009a) is the exception, specifically examining the impact of individual budgets on carers of older people and people with learning disabilities.

While several Acts and policies have been implemented to support family carers in the UK, the net effect for carers appears to have been sporadic and fragmented. This raises serious concerns in the light of the general increase in the number of people providing care, and with the greatest increase (35 per cent) being older carers. Carers over the age of 70 are particularly at risk because they tend to care for 60 hours per week or more (Princess Royal Trust for Carers, 2011) and caring for more than 20 hours per week is recognised as the point at which caring starts to impact on the health and well-being of carers (Carers UK, 2012; Health and Social Care Information Centre, 2010). Many older carers are unable to consider retirement because they are heavily involved in caregiving and feel as if they are always on-call (Princess Royal Trust for Carers, 2011). This unique group of parents cannot be ignored because, with the de-institutionalisation of care, older parents are the main care providers for adults with learning disabilities (Yoong and Koritsas, 2012). Therefore policies for

informal carers must have a strong focus on enhancing their quality of life by ensuring that tangible support is given to meet their needs.

The following are critiques of studies on parental caregiving, quality of life of older people, and more specifically quality of life of older carers of adults with learning disabilities. The studies on parental caregiving are presented under two themes: 'challenges of caregiving' and 'enhancing factors of caregiving'. However, studies which have reported both the challenges and enhancing factors (Kearney and Griffin, 2001; Sloper et al., 1991; Pruchno and Patrick, 1999; Scorgie and Sobsey, 2000; Werner et al., 2009; Grant et al., 1998; Green, 2007; Grant, 2010; Dillenburger and McKerr, 2010) are discussed under the theme relevant to the dominant finding of these studies. In relation to quality of life, studies are critiqued under older people's quality of life in general, and specifically the quality of life of parent carers of children and adults with learning disabilities.

## **2.6 Challenges of caregiving**

### **2.6.1 Stress and 'care burden'**

Stress and care burden are experienced when the demands placed on someone are perceived to be greater than the personal resources available to cope (Olson, 1997). Burden has received considerable attention in the literature on the social experience of caring for a child with a disability and the quality of life of caregivers (Green, 2007). Care burden which is socially constructed (Green, 2007) has been conceptualised as being objective or subjective, where objective burden is associated with concrete events and activities, and subjective burden relates to the feelings, attitudes and emotional reactions of the carer (Morgan and Laing, 1991). To this end, stress and care burden have become synonymous with caregiving.

Studies on caregiver stress and burden present a static view of what is generally a dynamic process (Langer, 1993). The determinants of care burden

and caregivers' needs are not well understood (Mackenzie et al., 2007) and are generally linked to negative outcomes of caregiving (Hunt, 2003), such as isolation, disruption of leisure and employment time, depression, anxiety, physical illness and emotional disturbances (Dillworth-Anderson et al., 2002; Walden et al., 2000; Lin et al., 2009). This negative focus represents only one dimension of caregiving (Grant et al., 1998) and therefore does not provide a balanced understanding of carers' experiences (Miller and Lawton, 1997). For most parents, the impact of having a child with a learning disability can be stressful, as they tend to mourn the loss of the 'ideal' child – a notion which was formulated in pregnancy (Hobdell et al., 2007; Gordon, 2009). This experience can manifest itself as 'chronic sorrow', a phrase coined by Olshansky (1962) which is described as a pervasive feeling of sadness or grief (Olshansky, 1962; Burke, 1989). Research has shown that parents can experience this grief throughout the child's life span (Wikler et al., 1981), and this is seen as a natural emotional response to a tragic occurrence (Olshansky, 1962). This extended grief is characterised by loss of security, loss of the sense of community in family life, and loss of joy and recreation (Liedstrom et al., 2008: 310). The intensity of this sorrow varies between parents and families (Damrosch and Perry, 1989), and can be influenced by factors such as personality, ethnicity, religion and social class (Olshansky, 1962). Although not widely published in the caregiving literature, over the years, there has been a body of literature emerging which acknowledges the phenomenon of 'chronic sorrow' in relation to parents whose children have learning disabilities.

For example, researchers in the USA (Wikler et al., 1981; Damrosch and Perry, 1989; Mallow and Bechtel, 1999) examined in quantitative studies how parents of children with learning disabilities reported their adjustment process after becoming aware that their child had a learning disability. They found that it was common for parents to experience a form of grief which is consistent with chronic sorrow, and that mothers were likely to report a higher incidence than fathers (Damrosch and Perry, 1989). The intensity of grief and sorrow experienced by some parents did not decrease over time and occurred mainly at the child's developmental stages (Wikler et al., 1981).

However, in a small qualitative study, Kearney and Griffin (2001) explored the experiences of six parents of children with learning disabilities in Australia and found that parents can have mixed emotions, such as anguish, sorrow, hope, love, strength and joy in relation to parenting their children. Parents derived joy from their relationship with their children, and sorrow from the lack of understanding they received from others. They believed that they needed to be optimistic in order to function emotionally and they requested the support of professionals to help them to adopt a more positive outlook on life. These findings, although from a small number of participants, challenge the dominant perception that parents of children with disabilities are victims of personal tragedy and are generally ‘engulfed’ by emotional distress (Green, 2007). The strength of the study is that the design was clearly described, and a qualitative approach facilitated the exploration of the subjective experiences of parents. However, further exploration of the phenomenon of chronic sorrow is needed using larger samples to allow generalisation, and to complement the smaller studies which provide a deeper understanding for health and social care workers supporting families of children with learning disabilities. This will enhance health and social care practitioners’ knowledge, so they can identify parents who might be experiencing chronic sorrow and provide adequate support for them.

### **Ethnicity, culture and religious beliefs and caregiving**

For the UK population, along with the increase in life expectancy (Office of National Statistics, 2009) there is also an increase in diversity in relation to ethnicity, culture and religion (Raghavan, 2007). These factors have been reported to influence experiences of Black and minority ethnic families caring for a child/ adult with learning disabilities (Raghavan, 2007; Devapriam et al., 2008; Heer et al., 2012). Ethnicity, refers to the group a person belongs to as a result of certain shared characteristics including ancestral and geographical origins, social and cultural traditions, religion and languages (Mackintosh et al., 1998). Culture represents the values, beliefs, customs, behaviours, structures, and identity by which a group of people define themselves (Axelon, 1993). Religion is defined

by the Oxford dictionary as the belief in and worship of a superhuman controlling power, especially a personal God or Gods.

([www.oxforddictionaries.com/definition/english/religion](http://www.oxforddictionaries.com/definition/english/religion)).

In the UK, the focus in the literature on cultural issues tends to be mainly on South Asian Communities. Although a few studies have focussed specifically on Black Caribbean and Black African (Hubert, 2006), even less research has been done with other minority cultures. The prevalence of learning disabilities amongst South Asian families is reported as three times higher than any other UK community (Azmi et al., 1997). This higher prevalence is mainly associated with poor uptake on maternity services, higher genetic risk factors along with social and material disadvantages (Emerson and Hatton, 2004; Hatton et al., 2010). In addition, many difficulties have been identified for these families which include:

- poor access and reluctance to use respite services;
- language barriers in accessing and use of information;
- racism and
- stigma

(Raghavan, 2007).

While studies have reported overlaps in the caregiving experiences of white carers and carers from minority ethnic communities (Hubert, 1991; Devapriam et al., 2008; Raghavan et al., 2013), they have also identified stark differences that are specific to Black and minority ethnic communities which are influenced by factors such as ethnicity, cultural and religious beliefs (Mc Callion et al., 1997; Hubert, 2006; Raghavan, 2007; Devapriam et al., 2008; Heer et al., 2012; Raghavan et al., 2013).

Mc Callion et al (1997), in their qualitative study held a series of focus groups with African American, Chinese American, Haitian American, Hispanic/Latino American, Korean American and select Native American communities to explore the impact of culture and acculturation on older families caring for persons with developmental in the US. Acculturation is described as

the process by which immigrants and other persons from non-majority cultures, willingly or unwillingly, give up ethnic values, customs, and behaviours for those of the majority culture (Aponte and Barnes, 1995). They found that families demonstrating higher levels of integration in the majority culture had a better uptake and relationship with services. They further contend that these families did not experience language barriers and they were less likely to be overly influenced by religious and cultural explanation of disability. This study also reported that: every family is unique despite their cultural practices; there were mixed perceptions about disability whereby families in the same culture viewed it differently. For example, some families saw disability as the will of God, while others saw it as a punishment. In relation to support with caregiving, participants were of the view the extended family should not be assumed or ignored, as family support was highly valued. Also in some cultures support from faith-based organisations was deemed very helpful and cultural values were important to family members. In addition, Mc Callion et al (1997) found language barriers hindered access to services. This study was conducted in the US and although social services support systems may be organised differently, the findings may have some relevance for other contexts, as some cultural experiences and practices are similar regardless of context.

A UK qualitative study by Hubert (2006) with 30 older family carers (19 men and 11 women) co-residing with adults with learning disabilities from Black and minority ethnic groups living in a south London borough examined the services they received, the appropriateness of these services, what services they felt they needed, and whether they experienced any social, cultural or communication barriers in accessing, or trying to access, appropriate services, and information. The largest groups in the sample were African Caribbean and Indian who were mainly Christian, Muslim or Hindu and they cared for adults who had mostly moderate to severe learning disabilities.

The main findings reveal that access to day services was unproblematic as most adults with learning disabilities were attending day services and carers were generally satisfied with the quality of service provided, as carers felt the workers

were caring and respectful to their cultural and religious needs. On the contrary, accessing respite care was more difficult as 60% of families were not engaging in respite facilities. A range of reasons were identified such as the family carers being reluctant, feeling there was no need for respite care, and being unaware of respite provision for children and adults with learning disabilities.

In relation to assistance with personal care, families were reluctant because they felt that asking for help could be perceived as not coping, and the repercussions could be that their children would be ‘taken away’ and placed in residential or supported living accommodation. Therefore family carers were not actively seeking social services support. There was also a sense that even if family carers wanted to engage with services, many of them did not have a named contact, because the findings indicate that 70% of family carers did not have an allocated social worker which meant that seeking professional help such as advocacy would have been difficult.

One of the greatest problems many family carers experienced was the lack of access to information, particularly about future care arrangements. Although most of the family carers in the study were elderly and in poor health and this should have been an urgent need, 21 of the 30 families had no plans for the future and this situation was compounded by the lack of social worker support. Despite this, family carers felt strongly that sibling care in the future was not a viable option as they, the brothers and sisters had their own families to take care of, and while they had reservations about out of home placements for future care, for most families this seemed inevitable. Also reported were limited social networks more so for family carers from Black and minority ethnic communities and apart from their engagement with local church, temple or mosque which provided some form of social contact, other social connections were non-existent. For the carers who attended the mosque, they felt that the members were very supportive. Religious affiliation can be used to make sense of disability (Heer et al., 2012), and as a coping strategy (Raghavan, 2013) which is further discussed in section 2.7.2 on religious coping.

The barriers and problems encountered by family carers in the study may not be singular to them because carers from the white majority culture may have similar experiences. However, there are issues that affect specifically Black and minority ethnic communities, the most obvious one being the language barrier which in turn can bring about multiple disadvantages such as social isolation and lack of access to services. Some of these findings, for example lack of access to respite and being unaware of services that were available have been endorsed by later studies (Raghavan, 2007; Devapriam et al., 2008; Raghavan et al., 2013).

In a study commissioned by Mencap, Raghavan (2007) explored and identified whether there were any differences in accessing services and experience based on ethnicity with 25 older family carers (10 Pakistani, 9 White, 5 Indian, and 1 Bangladeshi) in Bradford. He found that whilst all white carers were satisfied with their housing situation, the Pakistani and Bangladeshi carers expressed the need for home adaptations or rehousing to facilitate them in providing personal care (for example a ground floor bathroom). Although family carers from both groups were co-resident with their son or daughter with a learning disability, the extended family lived with the Pakistani and Bangladeshi carers unlike the white and Indian carers. It was also reported that all family carers were involved in some form of day activities which were fashioned around their sons' and daughters' schedules. These activities included shopping, visiting friends and engaging in leisure and work. Notably, South Asian carers spent more time at home with the extended family.

In terms of short breaks for family carers, white carers seized the opportunity when their sons and daughters were at respite to go on short-breaks. This was not the case for South Asian carers, in fact they were reluctant to access respite services with the exception of Indian carers whose sons and daughters were accessing respite provision. Thus for Pakistani and Bangladeshi carers, holidays away from their children were not an option although some of them wished to get a break from their 24/7 caregiving role. Regarding carers' social life, South Asian carers reported most of their socialisation was with family and saw shopping as their main source of social activity in which they were able to meet

friends. In contrast, white carers reported a satisfactory social life with their friends when their children were at the day service and also on weekends. In the main, most carers reported having a good circle of friends. White carers reported having an established group of friends who were not their immediate family but interestingly, some of the Pakistani carers saw their immediate family and relatives as their friends.

The experiences of receiving support from services were mixed. While some white carers reported having good support from statutory services, others felt this was lacking. Carers also found that being part of the older parent group was a source of support. However, most South Asian carers were unaware of these support groups and their main source of support was their immediate family. Most carers from both groups had some form of contact with professionals (doctor and social workers) whom they found helpful.

It was also reported that almost all carers experienced some form of stigma and prejudice from society in relation to their children's disability. To this end, white carers learned to ignore these biases and managed to carry on with their activities and life in general. However, Pakistani carers in particular, experienced more stigma and racism. Another area that was problematic for South Asian older carers was the language barriers in accessing and use of information, particularly Pakistani and Bangladeshi carers who received most of the information in English and they had to rely on family members to help them make sense of the information. Indian carers also had information in English and although they found this less problematic than the other South Asian carers, they expressed the view that they would like information about services to be communicated to them in Gujarathi. White carers tended to receive information about services from several sources, namely their older carers support groups and when they attended meetings with day care services. Access to positive information is vital for all family carers because it helps them to make informed choices. For South Asian carers this may be particularly helpful as they may be able to view their circumstances in a more positive light and not as a tragedy

(Mir and Tovey, 2003) as culturally, South Asian families can experience stigma from having a child with a disability (Raghavan, 2007).

Notably, the Indian carers in the sample seemingly did not encounter the barriers reported by the other South Asian carers. For example, like the white carers, they were able to access day services and respite care. A possible explanation for this difference between the Indian family carers and other South Asian carers can be obtained from McCallion et al's (1997) observation of the link between the level of integration by minority cultures and access to services. It is possible that the Indian carers were more integrated into the white majority culture and therefore their experiences were different. .

The study provides valuable insight about the experiences of white and South Asians older carers and highlights the similarities and differences. The researcher provided a good audit trail of how the study was conducted. However, the sample is skewed towards Pakistani older carers. Some of these findings have been also reported in Devapriam et al's (2008) quantitative work in which they compared the stress levels and unmet needs in informal carers of South Asian and White adults with learning disabilities with 742 informal carers in Leicester. Similar to Raghavan (2007), they found that South Asian carers are less likely to access respite as a result of lack of culturally sensitive services, such as single sex respite provision for Muslim service users. Also South Asian carers are more likely to request housing adaptations to facilitate their caring role and they were less aware of services. In addition, Devapriam et al (2008) reported major stress levels in both groups particularly in carers with poor health, those caring for younger adults, carers who were caring for adults with challenging behaviour and carers who lack moral or service support. They found that South Asian carers were more likely to report physical stress than white carers. The higher level of stress in certain groups of carers suggest a lack of appropriate services for carers. It also highlights the need for services that are culturally sensitive for minority ethnic service users rather than a 'colour-blind' provision (Raghavan, 2009), that is a 'one size fits all' service.

As acknowledged by the authors, a limitation of the study is that the data might have been five to seven years old. However, its findings can inform the practice health and social care workers who support older carers from minority ethnic communities by helping them to devise interventions that meet the cultural and religious needs of minority ethnic community. This in turn will facilitate the uptake of services. In relation to service use, it is known that cultural and religious beliefs influence family carers' uptake of services, as they prefer services that take into consideration their cultural and religious beliefs (Raghavan et al., 2005).

In a more recent qualitative study with 43 family carers (16 White British, 24 Pakistani, 2 Bangladeshi, and 1 Black African) in West Yorkshire, Raghavan et al (2013) explored family carers' views and experiences on transition from school to college or to adult life with a special reference to ethnicity. The key findings suggest that although transition planning occurred, it was relatively later in the young person's school life. There were experiences that were common to family carers regardless of their ethnicity. For example all families reported lack of information about services and expressed a sense of being excluded. Also support from extended families was not common, despite the stereotypical thinking of supportive extended families in South Asian communities (Emerson and Robertson, 2002) and consequently they do not need help, as they look after their own (Mencap, 2006).

Also reported were experiences that were singular to South Asian family carers. These were associated with language barriers, cultural and religious beliefs which had implications for access and uptake of formal services. Although parents in general were often confused about the transition process and had limited information about future options for their son and daughter, South Asian carers, whose first language was not English, experienced greater confusion and lack of awareness of available options. There was also higher usage of respite services by Pakistani families because their sons' and daughters' care needs were more complex.

From a cultural perspective of duty and responsibility, there was an expectation among Pakistani and Bangladeshi families that siblings would take on caring responsibilities in the future, unlike British White carers. This finding on future care is in contrast to the family carers in Hubert's (2006) study, because family carers were of the view that siblings had their own families, and therefore providing care for their sisters and brothers with learning disabilities was not an option. That being said, the families in Hubert's (2006) sample were mainly Indian and African Caribbean origins and it must be acknowledged South Asian, likewise African Caribbean communities are not homogenous and within these groups there are cultural variations. There was also a preference in these two communities (Pakistani and Bangladeshi) that future care to take place in the home setting and not in supported housing or a residential setting although there was an expectation of their sons and daughters gaining independence. Thus the notion of independence for the South Asian families has different cultural meanings. Also, some families expressed the view that spouses of these adults will take over the caring responsibilities, because marriage is culturally significant and an expectation in South Asian communities.

For many South Asian families religious beliefs were used as a coping strategy in relation to the child's disability which they believe was God's will. This finding resonates with Hubert's (2006) work discussed earlier in this section where families used religious practices (for example attending temples and mosques) as coping mechanisms. Deviating from religious norms was a concern for Pakistani Muslim carers, and there was this sense that their sons and daughters might be caught up in situations whereby they over assimilate into the majority culture and disregard their customs when they are with their peers. The issue of shame and stigma of having a child with a learning disability was also reported by South Asian families.

Whilst both communities (South Asian and white) expressed similar needs, there was a greater need in South Asian families for financial and practical support such as home adaptations and getting help to complete claim forms and maximise their entitlement.

The study revealed that carers who were financially stable and in employment were more likely to access mainstream facilities, and were more confident in seeking information about leisure pursuits. The multiple disadvantages of economic and social deprivation, communication and language barriers, low education attainment and the severity of the child's disability made experiences of caregiving for Pakistani and Bangladeshi families more difficult.

The researchers provided a clear account of how the study was conducted and the findings give insight to practitioners supporting South Asians families particularly Pakistani and Bangladeshi family carers who provide day to day care for their sons and daughters, by highlighting the areas of disadvantage such as the communication and structural barriers alongside the lack of culturally appropriate service provision. As acknowledged by the authors, the sample did not have equal representation of all South Asians in the locality.

The focus on the studies reviewed so far, are on the experiences of white and Black and minority ethnic family cares, mainly South Asians. In a qualitative study in the UK, Heer et al (2012) used focus groups and interpretative phenomenological analysis, and explored the cultural context of caregiving amongst South Asian communities (Sikhs and Muslims) caring for a child with an intellectual disability. They also aimed to contribute to the development of culturally appropriate support and interventions in the children's disability services. The key findings suggest that they were similar as well as different experiences in both groups. Thus reiterating the point that the South Asian community is a heterogeneous group which is culturally diverse (Heer et al., 2012). For example, both groups relied on religious explanations to make sense of their children's disabilities. Mothers in the Muslim communities were more positive in their interpretations. They felt it was God's purpose and these children were given to them as a test. On the contrary, Sikh mothers regarded their children's disability as an adversity which they did not wish on anyone. They also viewed their children's health condition (epilepsy) as 'bad' behaviour.

For mothers in both groups, their perception was that their children lacked expression rather than understanding. This gave a sense of relief for parents

because they believed that communication was the main problem and if addressed could bring about positive change for their children. They also felt that an early diagnosis would have prepared them better for their caregiving role, and medical negligence in some instances, was responsible for their children's condition.

In relation to services, while Muslim parents felt let down by service providers in general, Sikh parents encountered difficulties mainly with 'Asian' providers. However, the consensus was that they preferred 'white' service providers, as they expected better support from their own. Both groups had hopes as well as concerns for the future of their children and expressed the wish that future care for their children to be provided at home. However, the issue at hand for Muslim parents was that they wanted services which were tailored to meet their needs because 'giving up' care was not an option.

The study finding that disability is God's will concurs with Hubert's (2006) work. Overall the findings clearly highlight the similarities and variations that exist in South Asian sub-cultures and provide useful knowledge for service providers and practitioners supporting South Asian families.

The studies reviewed on the experiences of Black and minority ethnic families were mainly qualitative and they were conducted in specific geographical areas. Therefore the findings may not be representative of all South Asian families. Despite this, they provide a valuable lens for practitioners supporting Black and minority ethnic families to devise culturally sensitive packages of care, and highlight the dire need for service providers to have a culturally competent work force as recommended by the Report of the faculty of the psychiatry of learning disability working group (2011).

### **Gender and caregiving**

Another known influence on caregiving experiences, is gender (Nolan et al., 1996b). In a quantitative UK study with 123 parent carers of children with Down's syndrome, Sloper et al (1991) investigated the factors related to stress

and satisfaction with life and found that fathers were less stressed than mothers and derived more satisfaction from parenting and family life. Mothers were also found to be more affected by the challenging behaviour of the child than fathers. In another study, using a quantitative approach to examine stress and gratification with 251 women and their husbands in the USA, Pruchno and Patrick (1999) also found that, although mothers experienced greater care burden, they reported more caregiving satisfaction than fathers, who were more affected by non-compliant and violent behaviours of their children. This is contrary to the findings in Sloper et al.'s (1991) study, in which fathers reported more satisfaction from parenting than mothers. Nonetheless, some of Pruchno and Patrick's (1999) findings are supported by Saloviita et al. (2003), who examined parental stress of 120 fathers and 116 mothers of children with learning disabilities in Finland. They too found that mothers experienced more satisfaction from their relationship with their children and coped better than men in handling difficult situations. As with Sloper et al.'s (1991) findings, the mothers in Saloviita et al.'s study were more distressed by the behavioural problems of the child.

These studies reported mixed psychological and emotional impacts for fathers and mothers. However, it is unclear whether the level of care provided by the mothers and fathers in Pruchno and Patrick's (1999) and Saloviita et al.'s (2003) studies had some bearing on the results. Only Sloper et al. (1991) indicated that the majority of fathers were employed (82%), in contrast to 49% of the mothers, which means that the majority of the mothers were the main caregivers. Also, both Sloper et al. (1991) and Saloviita et al. (2003) studied parents of children, whereas Pruchno and Patrick (1999) studied parents of adults. While there may be some overlaps in experience, age is known to be one of the factors that influence parent carers' coping strategies in mediating stress (Seltzer and Krauss, 1989). The cross-sectional design of the three studies limits conclusions about cause and effect and none of the studies reported the validity of the measures used. However, all the studies provided clear accounts of how they were conducted and the representations of fathers and mothers were fairly balanced. These cross-sectional studies provide insight for practitioners who

support families of both children and adults with learning disabilities, notably about gendered coping strategies and the impact of caring on men and women.

While these studies reported that care burden and parental stress were experienced differently by mothers and fathers, a more recent Canadian quantitative study found no significant difference between older mothers' and fathers' stress levels in relation to their caregiving experiences (Minnes and Woodford, 2005). Unlike the previous three studies, there were only 4 fathers out of 80 participants in Minnes and Woodford's study, therefore their findings should be treated with caution as fathers were under-represented in the sample.

### **Place of residence and caregiving**

In relation to place of residence of adults with learning disabilities and caregiver stress, McDermott et al. (1997) conducted a cross-sectional quantitative study of 99 US families of adults with learning disabilities (55 families of adults with learning disabilities living at home and the remaining 44 families living out of home) to identify differences in caregiver burden. McDermott and his colleagues found no difference in care burden and gratifications whether the person was co-resident or lived out of home. This indicates that care burden was experienced regardless of whether the adult with learning disabilities lived at home or out of home. However, this finding has been contradicted in later studies (Seltzer et al., 1997; Miltiades and Pruchno, 2001; Werner et al., 2009) as co-residence was found to contribute to family carers' stress.

For example, Seltzer et al. (1997) determined the antecedents and consequences of the end of co-residence in a longitudinal quantitative study in the USA with mothers 55 years or older who live with their adult children with learning disabilities ( $n = 308$ ) or mental illness ( $n = 73$ ). Adults with learning disabilities were likely to move out of home due to mothers' reduced caregiving capacity, old age and/or poor health. Psychiatric crises and parents becoming emotionally upset and venting their feelings were the likely reasons for adults with mental illness moving out of their parents' home. Seltzer et al. (1997) also

reported that the end of co-residence predicted significantly lower levels of maternal subjective burden for both groups of parents, although they continued to be involved in providing support for their adult children. The strength of this study was its longitudinal design, which enabled it to capture the changes in parents' experiences over a period of time and therefore to provide a more accurate perspective on parents' experiences; this is in contrast to McDermott et al.'s (1997) cross-sectional study.

Similarly, Miltiades and Pruchno (2001) in another US quantitative longitudinal study, with 305 older parents of adults with learning disabilities, noted that mothers who did not live with their adult children experienced less burden than those who co-resided with their adult children. This finding corroborates the earlier findings by Seltzer et al. (1997) and Heller et al. (1997) that parent carers of adults with learning disabilities are less burdened when they do not co-reside with them.

In a later qualitative study, Werner et al. (2009) also found that care burden decreased when co-residence ceased, and the quality of life of families improved. Werner and colleagues examined family experience and changes in family quality of life (FQoL) before and after placement away from home, with 16 Canadian families of adults who had behavioural problems and received services. However, feelings were mixed: although these families experienced a sense of relief from physical and emotional exhaustion, happiness and hopefulness, they also experienced feelings of worry and guilt. This study was unique in that it explored the impact of caregiving on the whole family rather than on the main caregiver. However, all the families in the study received services and therefore the sample is not representative of those families who are not in receipt of social services support. Another limitation of the study is that the interviews were done on-site at the day service. This could have biased the participants' responses, as they might have been more measured in what they had to say as a result of being in this formal setting.

However, some interesting findings have been reported in another qualitative UK study by Grant (2010), who explored not only 24 older carers' perceptions of stress and experiences of the longevity of caregiving, but also the

views of 14 adults with learning disabilities about their relationship with their parents. Grant, who also is a parent of a child with a learning disability, found that although parents experienced a high degree of stress mainly due to the behaviour of their adult children and the lack of continuity of services, their adult children provided practical help and companionship and were concerned about their parents' welfare. The adult children were also ambivalent about leaving home because they did not want their parents to be left on their own. This finding suggests that, while co-residence could be stressful, particularly when the adult child has challenging needs, parent carers experience several benefits such as practical help and companionship from living together with their adult children with learning disabilities. This highlights that both stress and rewards can coexist, a view supported by previous studies (Grant et al., 1998; Yannamani et al., 2009).

Some of these findings support earlier studies (Heller et al., 1997; Miltiades and Pruchno, 2001) that co-residence can be stressful for family caregivers, particularly when adult children have challenging behaviour (Unwin and Deb, 2011; Werner et al., 2009). Despite this, they also highlight the benefits that can be derived from co-residence. Benefits such as the reciprocal care between parents and their adult children with learning disabilities have been reported by Perkins (2009). However, Perkins contends that the level of reciprocity can vary and that parent carers of adults with learning disabilities gave more tangible and emotional support than they received. Moreover, as parents become older, the distinction between who is giving care and who is receiving care can become blurred (Perkins, 2009). The strengths of Grant's (2010) study include the insider perspective, as she has a child with a learning disability and therefore is reporting from an informed standpoint, and the rigorous research design. For example, how participants were recruited and the methodological approach were clearly outlined, and data from both individual and focus groups interviews were obtained from involving parent carers and adults with learning disabilities, which provided different perspectives. This is unique, as it is generally only the experiences of the carer or the adult child that are reported. Limitations relate to the observation that all the adults with learning

disabilities were in receipt of services and the small sample was skewed towards adults with mild learning disabilities from one geographical area. Therefore the findings are not representative of adults with moderate and severe learning disabilities.

### **Age and caregiving**

Like gender and co-residence, the age of the parent carers has been identified as a predictor of stress and care burden (Haveman et al., 1997; Kim et al., 2003; Minnes and Woodford, 2005).

In the Netherlands, Haveman et al. (1997) compared the service needs, time demands and subjective burden of parent caregivers of children and adults with learning disabilities across the life cycle in a quantitative study of 2,573 families using postal surveys. They also examined the extent to which family and child characteristics and service use contributed to parents' time demands and burden. The study found that care demands and subjective burden of parent carers of children and adults with learning disabilities varied across the life cycle, from childhood to adulthood, with burden being lower during adolescence than in earlier childhood and some years in adulthood (20–29 and 40 years and over). Although statistically significant, the group difference in burden was quite low ( $p < 0.01$ ). These findings suggest that perceived burden did not decrease for both younger and older caregivers, and resonate with the study by Heller et al. (1997) study, which reported no significant difference in burden between parents of children and parents of adults with learning disabilities. However, it differs from earlier work by Heller et al. (1992) which found that caregivers of adults over the age of 30 experienced less care burden than younger caregivers. Haveman et al. (1997) also found that families of older children used less formal services than those of younger children, indicating that family needs fluctuated depending on the age of their children. Although Haveman and colleagues used a population-based sample, their findings are not generalisable to the UK because of the

different context. However, the strength of their study is its large sample size, which provides greater insight into the families' experiences.

In contrast, a quantitative study by Kim et al. (2003) found that older carers are more likely to experience stress than younger carers. However, Perkins (2009) argues that older carers are better able to manage stress, as they gain extensive knowledge and expertise from their caring experiences, thus developing a sense of mastery from their extended years of caregiving, and therefore they are better equipped to meet the challenges of caregiving. Moreover, caring for their children is familiar territory because they have successfully adapted and adjusted to their caregiving situation (Townsend et al., 1989), and are therefore able to cope with caregiving demands, having learned from trial and error over time (Hubert and Hollins, 2000).

Minnes and Woodford (2005), utilising a mixed-method approach in combination with the Double ABCX model of adjustment and adaptation (McCubbin and Patterson, 1983), examined the well-being of 80 ageing parents of adults with learning disabilities (71 mothers and 9 fathers). They found that older parents aged 65 years and over did not perceive caregiving as more stressful than younger parents (those between the ages of 50 and 65 years). This finding supports Perkins' (2009) view that most older carers are able to adapt to caregiving stress over time by developing appropriate coping strategies (Seltzer and Krauss, 1989), or they accepted the way things were because they were more resigned to their caring roles (Grant and Whittell, 2000). However, it must be noted that the causes of and reasons for parental stress are not static or universally experienced (Grant, 2010).

We have seen that having a child with a learning disability can be devastating for parents and stressful for families as their initial hopes are dashed. Several predictors of care burden and stress have been identified, such as gender, place of residence, age, and behavioural needs of the adult child. Also ethnicity, cultural and religious beliefs can impact on the experiences of parent carers. The following section discusses struggles for services and fears for future care, which have been also identified as predictors of parental stress.

## 2.6.2 Struggles for services and fears for future care

Older parent carers contend with several issues on a daily basis which are potentially stressful, such as lack of support for their children and themselves, access to resources and fears about the future care of their adult children (Kenny and McGilloy, 2007; Bowey and McGlaughlin, 2005, 2007; Dillenburger and McKerr, 2009, 2010; Cairns et al., 2012; Bibby, 2012; Taggart et al., 2012). As parent carers become older, these issues are of greater importance because they fear what is going to happen to their adult children when they are no longer able to care.

Studies have reported that formal services were difficult to access and that there were difficulties in planning future care. For example, a UK study by Dillenburger and McKerr (2010) used mixed methods to explore the issues related to caring and future planning with 29 older caregivers (mainly parents), employing interviews and administering the General Health Questionnaire (GHQ-12) (Goldberg et al., 1996). The interviews were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1996). Parents reported that family support was integral in helping them provide care for their children, as sometimes they had difficulties in getting help or services. However, they derived considerable fun from living with their children, who were the most positive things in their lives. The findings indicate that most parents had not made any plans for the future and some of them were worried about the future care of their children. The strength of Dillenburger and McKerr's (2010) study is its phenomenological approach, which gives a voice to parent carers, who are generally marginalised in relation to social welfare issues (Scourfield, 2005b). The study also grounds the findings in the lived experiences of the parent carers and supports the behaviour analytic approach to ageing (Gallagher and Keenan, 2006) and caring (Dillenburger and McKerr, 2009). This approach views behaviour as an interaction between person and environment (Keenan and Dillenburger, 2004), which ensures that the blame for difficulties in coping and planning is laid not at the door of the older parent carers (Walker and Walker, 1998) but at the contingencies they have at their disposal (Dillenburger and

Keenan, 2005). The study's limitation is the use of a convenient sample which could have introduced a bias.

In a later UK study, Cairns et al. (2012) explored the experiences of eight older parent carers (six mothers and two fathers) providing prolonged care for their adult children with learning disabilities. The study aimed to gain an understanding of their caregiving experiences and their views on the future from the qualitative phase of a mixed study using a grounded theory approach. The study corroborated earlier findings by Dillenburger and McKerr (2010) which showed that parents lacked formal support, did not receive sufficient information or practical resources, and were worried about their child's future care and accommodation. Cairns et al. (2012) also found that parents continued to care despite their poor mental and/or physical health and therefore needed 'better alternatives' for their adult children.

There are a number of possible explanations why parents are reluctant to plan for future care. Parents have difficulty in 'letting go' of their adult children (Richardson and Ritchie, 1989; Taggart et al., 2012); they also believe that it is their responsibility to care for their children and that there are no alternatives (Llewellyn, 2003), and that their children's preference is to stay in the family home (Krauss and Seltzer, 1998). Furthermore, the interdependent relationship between adult children and their parents (Walmsley, 1996; Walker and Walker, 1998), resulting in reciprocity between them, such as children helping with household tasks and providing companionship, cements relationships and holds families together (Grant et al., 1998; Rimmerman and Muraven, 2001; Grant, 2010). A review of the literature on future planning for adults with learning disabilities who live with older parent carers by Bibby (2012) identified several barriers in addition to those previously mentioned: poor relationships with professionals; service users' fear of the unknown; that it was a painful and difficult subject to discuss; lack of information; and carer purpose and identity.

Both studies, Dillenburger and McKerr (2010) and Cairns et al. (2012), shed further light on the experiences of caring in later life for adult children with learning disabilities. The strengths of the study by Cairns et al. (2012) include its rigorous methodology, which is clearly outlined, and its use of a grounded theory

approach, which means that the findings are grounded in the parent carers' experiences. However, fathers were under-represented in the study, as there were only two fathers among the eight participants, so their voices were lacking.

Future support for adult children with learning disabilities becomes a major concern, and sometimes can cause anxiety as family carers get older (Walker and Walker, 1998). This concern is not confined only to parents, as adults with learning disabilities also worry about the future and their parents' welfare (Bowey and McGlaughlin, 2005; Grant, 2010). To this end, there is a growing interest in this area, and a number of studies have focused specifically on future planning of parents of adults with learning disabilities. Bowey and McGlaughlin (2005) in a UK study explored the views of 41 adults with learning disabilities about living at home with older parents and planning for the future. Most of them had concerns about ill health or the death of their parents and indicated that they helped at home. Only 27 per cent of the participants expressed the desire to live out of home. Some of them had discussed their plans for the future and were aware that their parents might not always be available. These findings highlight the symbiotic relationship that exists between parent carers and their adult children with learning disabilities and the reluctance of the adults with learning disabilities to leave home.

The strength of Bowey and McGlaughlin's (2005) study is that participants were involved in the design of the questionnaire, which was completed by the researchers using a range of communication tools, including pictures to engage and aid communication with the adults with learning disabilities. Therefore adults with limited verbal communication were able to participate. The study also addressed a gap in the literature by interviewing both the adults with learning disabilities and their parent carers in the same study, although this study reports only the findings from the adults. Limitations concern the lack of diversity in the sample – all the participants were Caucasian, so these findings may not reflect the views of adults with learning disabilities from Black and minority ethnic communities.

In 2007, Bowey and McGlaughlin reported the findings from the 62 parent carers who were interviewed in their 2005 study. Parent carers were given the

choice to be interviewed or complete a questionnaire: 56 carers opted to be interviewed and the remaining 6 completed a questionnaire. It was found that 55% of carers were not ready or willing to plan for the future, and that the barriers to planning related to a perceived lack of need to do so, especially when two parent carers were providing care, and lack of awareness of the time scales involved in securing housing. In addition, the study identified the difficulties parent carers had in letting go, lack of confidence in the available housing options, and the existence of mutually supportive relationships between them and their adult children. While Bowey and McGlaughlin (2007) provided a clear audit trail of the study design, their sample lacked cultural diversity, as all parent carers were Caucasian. That said, their findings on planning future care support previous studies (Kaufman et al., 1991; Freedman et al., 1997; Prosser, 1997; Gilbert et al., 2008) and later ones (Dillenburger and McKerr, 2010; Cairns et al., 2012).

In another UK study, Taggart et al. (2012) employed a mixed-methods approach to examine the support needs of ageing family carers in developing future plans for a relative with a learning disability. One hundred and twelve questionnaires were returned of the 200 distributed to parents/sibling carers and, in addition, in-depth interviews were conducted with 19 parents/sibling carers. Key findings indicate that the main preference of the family carers was for their family member with learning disabilities to remain in the family home with family and/or paid staff to support them. Several barriers were identified in relation to future planning which focused on: avoidance; lack of support and guidance; and lack of appropriate service provision. Solutions to future planning were: providing accessible information; offering one-to-one support; and preparing future plans early. The barriers Taggart et al. (2012) identified are consistent with the study by Cairns et al. (2012). The strengths of the study relate to the detailed account of how it was conducted, and that both the barriers and solutions to planning future care were identified. It would have been useful to analyse the parents' and the siblings' data separately to compare their perspectives on future planning. As evidenced by these studies, the reluctance of

older parents of adults with learning disabilities to plan for the future is well documented in the caregiving literature.

To this end, Walker and Walker (1998) suggest that contextual factors be taken into account in order to understand why parent carers, particularly older carers, delay planning for the future. They also argue that, according to Erikson's (1963) theory of psychosocial development, older people must master certain developmental tasks of resolving the conflict between ego-integrity and despair, as they tend to review what they have accomplished in life and how they have coped with loss, and prepare for their own death. From Erikson's perspective, older carers are viewed as being in despair, due to unaccomplished tasks related to their caring role. However, Dillenburger and McKerr (2009) provide a behaviour analyst's perspective on ageing; they report that the network of relationships that exist between older parents and their adult children is complex. Many parent carers regard their caregiving role as a full-time job which gives them a sense of purpose. Additionally, the symbiotic relationship between carers and their adult children makes planning for the future difficult.

In summary, from the studies reviewed above, there is a substantial body of evidence on the contributory factors associated with parental stress and care burden of adults with learning disabilities, which in turn present challenges for parent carers. With regard to the demographic factors (gender, place of residence and age), there was no clear consensus as the findings were mixed. In relation to the socio-structural barriers, lack of, and difficulties in accessing, formal services was seen as a major stressor, particularly for carers from the Black and ethnic minority communities. Similarly, contextual factors such as the presence of two parents sharing the caring role, and the interdependence between parent carers and their adult children, coupled with genuine concern for each other's welfare and well-being and the lack of information about accommodation, contributed to the difficulties experienced by parents in planning their children's future. Furthermore, Perkins (2009) contends that coping is central to caregiving, and in order to meet the demands and challenges of caregiving, parent carers utilise different coping strategies to alleviate the stress and care burden. Increasingly, researchers who have studied stress and coping among families of children with

learning disabilities have endorsed the validity of the transactional model of stress and coping (Hastings et al, 2002). Therefore the focus of the next section is on coping, coping strategies and coping inventories.

## **2.7 Coping, coping strategies and coping inventories**

Coping has been defined as ‘the person’s cognitive and behavioural efforts to manage the internal and external demands of the person–environment transaction that is appraised as taxing or exceeding the person’s resources’ (Folkman et al., 1986: 527). Coping mechanisms are grouped into two main strategies: problem-focused coping and emotional-focused coping (Lazarus and Folkman, 1984). Problem-focused coping is associated with solving and managing the problem that causes distress, and using strategies for gathering information, decision making, planning, resolving conflict and acquiring resources to address the underlying problem (Lazarus and Folkman, 1984). In contrast, emotion-focused coping is associated with changing the meaning of the situation by way of reappraisal or taking one’s mind off the problem for a while, which acts as a form of distraction (Ekwall et al., 2007). Much of the evidence on coping shows that men are more likely to use problem-focused coping, while women tend to use more emotion-focused coping (Endler and Parker, 1990; Blanchard-Fields et al., 1991; Ekwall et al., 2007). Problem-focused coping is associated with physical and psychological well-being and less stress, whereas emotion-focused coping strategies are associated with increased distress and more negative physical and psychological outcomes (Aldwin and Yancura, 2004).

In relation to coping strategies, Kling et al. (1997) in a US comparative study used a quantitative approach to examine the association between coping and psychological well-being in two samples of older women aged 55 years and over, who faced very different life challenges, in two on-going longitudinal studies. A total of 219 women were in the process of residential relocation (Smider et al., 1996) and 230 women were caregivers of adults with learning

disabilities (Seltzer and Krauss, 1994). Kling et al. (1997) hypothesised that the relocated women would report higher levels of well-being. This was not the case, with the exception of one scale (self-esteem). On the contrary, the caregiving sample reported higher levels of well-being on the purpose in life scores, which suggests that caregiving can have a positive impact on carers' well-being by giving them purpose and direction in their lives.

Regarding changes over time in well-being, the relocated group, as hypothesised, reported improvements in well-being in three areas: higher levels in environmental mastery and personal growth, and lower levels of depression. In the caregiving group, levels of well-being remained stable in all three areas. Another key finding was that the use of problem-focused coping was associated with improvements in well-being, while emotional-focused coping was linked to a decline in well-being. These findings indicate that there were more positive changes in well-being across time in the women who were relocated. For the women who were caregivers, a stronger relationship between coping and well-being was observed, thus highlighting the expertise that can be acquired from negotiating challenges over an extended period of time. The study's longitudinal design facilitated the observation of changes over time, and demonstrated that both changes in coping, and coping levels, can predict changes in well-being, showing the dynamic interplay between coping strategies and well-being. Despite the in-depth description of the measures used, the authors did not mention their reliability and validity, so caution must be used in the interpretation of these findings.

In relation to gender coping, Essex et al. (1999), in a quantitative longitudinal study, in phases 4 and 5 examined stress and coping among 133 older married mothers and fathers of adults with learning disabilities in the USA. They found no difference in the frequency of use of emotion-focused coping between mothers and fathers. However, mothers used more problem-focused coping strategies than fathers. This finding contradicts previous findings where men were more likely than women to use problem-focused coping (Endler and Parker, 1990; Blanchard-Fields et al., 1991) and the later work of Ekwall et al. (2007). Similar to Kling's (1997) study, problem-focused coping was associated

with better psychological well-being, and for mothers it acted as a buffer for caregiving stresses, but not for the fathers who utilised problem-focused coping. The strength of Essex et al.'s (1999) study is that the inclusion of both parents in the sample provides insight into gender coping strategies which is not captured by most studies, as the focus is generally on mothers who are generally the main caregivers (Kramer, 1997). Limitations of the study, as acknowledged by the authors, are that most of the parents were of Caucasian background, and therefore not representative, and the difference in the measures used: for example, the stress measure was highly specific whereas those for coping were more general. This difference in specificity could have impacted on the way fathers (who were not the main carers) reported, in that they rated their coping based on other problems rather than those associated with their children. Moreover, in phase 4 of the data collection, fathers completed only a self-administered questionnaire whereas mothers, in addition to a self-administered questionnaire, had the opportunity to participate in an in-home interview. This might have had some bearing on the findings relating to the fathers, as an in-house interview might have captured their experiences more closely than the self-administered questionnaire.

In Finland, Taanila et al. (2001) examined how families with physically and/or disabled children coped, the coping strategies they chose, and how families' coping strategies differed. Twenty-seven parents participated in the first set of interviews, after which eight parents (four with the lowest functioning scores and four with the highest functioning scores) were selected for a second round of interviews. The findings suggested that four families found ways of coping successfully, whereas the other four had many problems. The most frequently used coping strategies reported by families were: seeking information, acceptance of their situation, family cooperation and social support. Although families from both groups used similar coping strategies, those who coped successfully had a larger repertoire at their disposal. In the case of the families who experienced many problems, these were caused not only by the child with the disability, but by other family matters such as problems between spouses and between parents and other children. The families which coped successfully all

reported that they were given adequate information about the child's diagnosis and treatment, and shared an optimistic outlook towards the future. In addition, family cohesion, service support (for example, training courses), being open and honest about their feelings, and taking time out of their everyday duties all contributed to successful coping.

The families differed most from each other in parents' initial experiences, personal characteristics, effects of the child's disability on everyday family life and the level of social support. Although the study provided a clear audit trail of how it was conducted, there were no explicit statements in relation to ethical approval of the study and how consent was obtained from the families.

### **2.7.1 Mothers and coping**

In the UK, Hastings et al. (2002) used a self-report questionnaire with 41 mothers (a response rate of only 33 per cent) to examine the factors related to their positive perception of their child with a learning disability. Of the responses, three were completed by fathers, and these were excluded from the analysis because they did not represent a sub-sample large enough for differences to be reported. The mothers perceived their children as a source of: happiness/fulfilment; strength; family closeness; and personal growth and maturity. These positive experiences were instrumental in helping mothers to cope with the challenges of caregiving. In addition, the support of family and friends also helped in reframing their coping strategies. Due to the low response rate and the omission of the fathers' responses from the data analysis, these findings must be treated with caution.

In a later study in the USA, Kim et al. (2003) investigated changes over time in the way mothers coped with the challenges of caring for an adult child with disabilities and the effects of changes in coping on maternal well-being. A total of 246 mothers of adults with learning disabilities and 74 mothers of adults with mental illness participated in two longitudinal studies. The data were analysed from two points in time (waves 1 and 2).

Mothers of adults with mental illness were more likely to use emotion-focused coping strategies than mothers of adults with learning disabilities. With regard to the effects of coping on well-being, for both groups of mothers, an increase in the use of emotion-focused coping was associated with higher levels of subjective care burden and depression, and a poorer quality of relationships with their adult child. It was also observed that an increase in the use of problem-focused coping over time was associated with lower levels of subjective burden and depression, and better relationships with the adult child. However, for mothers of adults with mental illness, an increase in problem-focused coping was associated with better parent–child relationships, but there were no changes in subjective care burden and depression.

A possible reason for this difference is that mothers of adults with mental health problems were more likely to use emotion-focused coping and therefore regularly used a strategy which is associated with high subjective burden and depression. Their situation may have become chronic and therefore they were unresponsive to alternative methods even when they employed problem-focused strategies, which are generally associated with lower levels of subjective burden and depression.

### **2.7.2 Religion and coping**

In addition to emotional- and problem-focused strategies, religious coping has been identified as a coping mechanism for caregivers. Researchers examining the role of religion and spirituality in caregivers' stress have found that there is a connection between religious beliefs and the motivation to care (Guberman et al., 1992; Caffrey, 1992). Furthermore, studies have reported that carers who use religious or spiritual beliefs for coping derive benefits such as lower care burden stress, and hence lower levels of depression (Choi et al., 2008; Chang et al., 1998). Families who received support from their pastor, minister and other church members and were more likely to decide to care for the family member at home (Choi et al., 2008). Other benefits reported from the use of religious coping strategies were lower role submersion, a better relationship with care recipients

(Chang et al., 1998), and higher levels of caregiving satisfaction (Miltiades and Pruchno, 2002; Pearce, 2005).

Comparatively, Picot et al. (1997) found that caregivers of disabled or ill relatives, who engaged in religious/spiritual practices, derived greater benefits than those who did not use coping strategies based on religious beliefs. The literature on religion and coping highlights the benefits that carers can derive by using their religious beliefs as a coping mechanism.

The association between race and religion has been explored quantitatively in relation to caregiving by Miltiades and Pruchno (2002) in the USA. The authors found that Black women were more likely to use their religious beliefs as part of a coping strategy and experienced higher levels of caregiving satisfaction than White caregivers. However, the Black women had higher levels of caregiving burden. These results are valuable for practitioners who work with caregivers from different ethnic backgrounds because they can assist them in providing culturally sensitive support. The groups of carers are not homogeneous, however, and therefore the findings cannot be generalised and must be used with caution.

The studies discussed above provide greater insight into the coping strategies parent carers manage their stresses associated with caregiving. I will now focus on coping inventories which have been used to measure the stresses and rewards of caregiving.

### **2.7.3 Coping inventories**

In their seminal mixed-methods work, Grant et al. (1998) examined the stresses and rewards of caregiving with 120 families of children with learning disabilities in the UK. In the qualitative phase, semi-structured interviews were conducted with the primary caregiver and the themes that emerged were: the structure of family support, rewards, stress and coping, aspirations for continued support, and service evaluation. The methodology for this study is reported in Grant et al. (1994, 1995). Two further instruments were used to gather quantitative data about stress and rewards in caregiving: the Carers' Assessment of Difficulties

Index (CADI) and the Carers' Assessment of Satisfaction Index (CASI) (Nolan and Grant, 1992; Nolan et al., 1996b). The CADI was designed to establish the nature of problems faced by family caregivers and to identify which of these were seen to be most stressful; the CASI was designed to establish factors which were perceived as a source of satisfaction.

The main findings indicate that individual stress factors were half as prevalent compared with the rewards and gratification in the experiences of caregivers. Generally, satisfactions were mentioned much more often than stresses, which meant that very few caregivers had difficulty identifying rewards from their caregiving experience. In the case of both the CADI and the CASI, the results confirm the validity of the transactional model and that the negative views which are generally associated with caregiving are unlikely to reflect the perceived realities of caregivers.

Grant et al. (1998) identified a constellation of factors which were stressful for caregivers, including: the individual with learning disabilities; loss of sleep and lack of time to oneself; tending to the physical and personal care required by care recipient; lack of family support and failure of professionals to fully understand the problems facing families as well as perceived service shortfalls.

The strength of this study is that it acknowledges that stresses and rewards of caregiving – opposing experiences – can coexist. Although, where possible, the validity and generalisability of the findings have been strengthened by offering explanations based on links to theory or with other empirical studies, the authors indicate that the findings are preliminary because categories developed to aid analysis were still to be tested and confirmed statistically. In addition, further inductive analysis of the qualitative data was needed to establish the overall perspectives that 'shape' caregiving rewards and stresses. Another limitation is that, of the 120 families that participated in the study, only one transcript is referred to in reporting the findings of the study. A wider use of the qualitative data in reporting the results would have provided a more comprehensive account of participants' experiences.

In another UK study, Grant and Whittell (2000) used a case study approach to provide a description of the use of a coping inventory amongst 27 families of children or adults with learning disabilities to understand the differentiated nature of coping, to test the transactional model of coping and more specifically to explore which problem-solving, cognitive and stress reduction coping strategies the families found useful. Of the 27 families, 17 families were headed by couples and the remaining 10 were one-care families, 9 of whom were women. Semi-structured interviews were carried out with 41 people (26 females and 15 males) from the 27 families. The interview guide covered themes about caregiving histories, coping strategies and their relationship to stressors, general health questions, and carers' experiences with support services and care management. Also included were the two instruments: the Carers' Assessment of Managing Index (CAMI) for tapping into people's coping strategies; and the Carers' Assessments of Difficulties Index (CADI) for perceived stressors (Nolan et al., 1996b, 1998).

Family carers used a variety of problem-solving, cognitive and stress reduction approaches to caregiving. The evidence suggests that coping strategies (as measured by the CAMI) were differentiated into gender, life stage and family structure. The findings were that women coped slightly better than men, as they displayed greater self-belief and self-confidence in their ability to handle difficult situations. However, men were more likely to defer to the caring experience and expertise of their spouses. In terms of life stage, parents with pre-school children were less confident about their experiences and expertise, and seemed to have less self-belief, when faced with difficult situations. Parents of school-aged children and younger adults had similar coping strategies and reported more problem-solving methods, such as regular routine, working to a set of priorities, and finding solutions by trial and error. In contrast, older carers accepted the way things were because they were more resigned to their roles.

What is evident in Grant and Whittell's findings are the strengths and vulnerabilities in family coping. From a strengths perspective, families were considerably resilient in their everyday coping. However, in relation to their vulnerabilities, there were concerns for lone carers in particular as they were

more dependent on cognitive coping strategies when problem-solving approaches failed. An important observation was that men appeared to have less mastery over coping than women. As acknowledged by the authors, the study was carried out in Wales, where an All Wales Strategy (Felce et al., 1998) had provided a substantial investment in family services, and it was not known how far the effective coping strategies described were influenced by the support services. The authors having recruited through purposive sampling, it is not possible to generalise the findings. Despite this, the study provides some insight into differentiated family coping strategies used to meet the demands of caregiving.

Both Grant et al. (1998) and Grant and Whittell (2000) have highlighted the coexistence of stress and rewards, showing that the deficit models of caregiving are not representative of carers' perceived realities because many families are known to cope well in difficult situations (Hawley and DeHaan, 1996; Schumacher et al., 1998). Along with other researchers, they also report rewards and gratification which enhance their caregiving experiences (Grant and Nolan, 1993; Stainton and Besser, 1998; Scorgie and Sobsey, 2000; Jokinen and Brown, 2005; Green, 2007). Consequently, studies into the enhancing factors of caregiving are now discussed.

## **2.8 Enhancing factors of caregiving**

It could be argued that the benefits derived from caregiving have been under-reported (Hastings and Taunt, 2002; Hastings et al., 2005; Stainton and Besser, 1998) and de-emphasise the importance of caregiving for children with learning disabilities (Green, 2007). Caregiving satisfaction is seen as one of the benefits of providing care and represents the positive affect that parent carers derive from providing support (Miltiades and Pruchno, 2001). There is now greater awareness among researchers of the rewards and benefits, gratifications and transformations that families experience from caregiving (Stainton and Besser, 1998; Scorgie and Sobsey, 2000; Jokinen and Brown, 2005; Green, 2007).

Stainton and Besser (1998), in a qualitative study using group interviews, explored the positive impacts of children with learning disabilities on their families (six fathers and nine mothers, whose ages ranged from under 25 years to over 70). Key findings were that caring provided a source of joy and happiness, an increased sense of purpose and priorities, expanded personal and social networks, and community involvement; it was a source of increased spirituality and family unity, increased tolerance and understanding, personal growth and strength, positive impacts on others and the community, and positive interactions with professionals and services (Stainton and Besser, 1998).

These findings suggest that some families do have positive experiences in caring for their children with learning disabilities, and their optimism should be accepted as their reality rather than being seen as ‘in denial’ (Kearney and Griffin, 2001; Green, 2007). These findings represent a shift from the negative perceptions of parental caregiving for children with learning disabilities, which limit one’s understanding of the social experience of disability (Green, 2007). In addition, efforts were made to validate the findings by having an independent researcher review the transcripts and using coding to identify inconsistencies or omissions. However, only positive aspects of caregiving were explored by Stainton and Besser (1998) and consequently parents might have felt the need only to report their positive experiences, particularly as they were asked directly: ‘What are the positive impacts you feel your son or daughter with an intellectual disability has on your family?’ This question is leading and does not give parents the opportunity to express any negative experiences; thus it reports only one dimension of their caregiving experiences. Nevertheless, despite this bias, none of the parents had difficulties identifying positive experiences of caring for their children.

In a later Canadian study conducted in two phases, Scorgie and Sobsey (2000) explored the transformations in the lives of parents of children with learning disabilities. The first, qualitative phase determined how some parents who appeared to be managing life successfully would describe the positive aspects of parenting a child with a disability. Fifteen parents with children aged between 3 and 25 years with learning disabilities were interviewed about their

experiences as parents. Nine themes were identified from the data analysis of the interviews. The transcripts were mailed to participants for verification and clarification, thus confirming reliability.

In the second phase, a quantitative approach was used to determine the proportion of parents who would agree with the statements made by the original group of parents. From the nine themes identified in the qualitative interviews, a 59-item Life Management survey was constructed. A total of 189 questionnaires were distributed to families of children with learning disabilities, of which 80 were returned – a response rate of 42.3 per cent.

The findings indicate that parents had experienced positive or beneficial outcomes by parenting a child with a learning disability, as they agreed with most statements in the questionnaire. They experienced personal, relational and perspective transformations. Personal transformations are positive changes that parents observed in themselves. Parents of children with learning disabilities reported that their lives had changed by taking on new roles which benefited them. These new roles include becoming a group leader, advocating for their children and speaking at a conference. Parents also spoke of becoming more compassionate and less self-centred. Of all the traits they scored, they gave the highest rating to the ability to speak out on behalf of their children.

Relational transformation refers to changes in the way parents relate to other people. About half of the parents reported that their marriages had emerged stronger, as a result of parenting children with learning disabilities and working together. Conversely, the remaining parents reported that financial difficulties or personal health problems had placed a strain on their marriage. Therefore, while some parents reported that they were able to build strong relationships as a result of having a child with learning disabilities, others reported loss of friendships and relationship problems, which may be due to the difference in focus, and time constraints arising from their caregiving demands.

Perspective transformations refer to the way in which people view life. Parents had changed their perspective on the things that were important and valuable to life, such as being loved and valuing life.

All parents interviewed and the majority of those surveyed reported some positive transformations associated with having and caring for a child with learning disabilities. They also reported some negative changes, such as health problems, increased stresses, less trust in agencies (for example, government, healthcare providers and teachers), loss of friendship and reduced social life.

Scorgie and Sobsey (2000) provide a holistic view of the caregiving experience by reporting both positive and negative experiences of parenting a child with a learning disability, unlike Stainton and Besser (1998) who explored only positive impacts of parenting a child with a learning disability. These findings are supported by Lane et al. (2003), who also found that despite the high levels of stress experienced by caregivers, many carers were positive about their role and expressed a sense of personal worth and fulfilment.

More recently, Jokinen and Brown (2005) also investigated family issues with 15 volunteers in Canada, relating to maintaining or enhancing family quality of life using Brown et al.'s (2000) Family Quality of Life Survey. Parents reported overall satisfaction in a number of the quality of life domains, including satisfaction with leisure, life enjoyment and positive reflections about their sons and daughters and their experiences of life-long caregiving. However, these parents expressed grave concerns about the high degree of uncertainty of service provision. They also reported concerns about the health of family members, the social lives of the adult child, and the future roles of the siblings when the adults were no longer around to continue caregiving. Jokinen and Brown's (2005) findings corroborate the earlier study by Scorgie and Sobsey (2000). Limitations of Jokinen and Brown's study are that it did not confirm the validity and reliability of the Family Quality of Life Survey questionnaire and it was unclear how consent was obtained from participants.

In a later study, Green (2007), using a mixed-methods approach, examined the daily hassles, emotional distress and benefits experienced by a group of mothers of children with disabilities in the USA. The quantitative data were drawn from 81 mothers and 10 fathers who completed a survey. For the qualitative phase, 7 mothers from the initial survey were interviewed. In the interviews, mothers were asked to share their stories of their children's birth,

diagnosis, and their own and their children's interactions with family, friends, neighbours, service providers and the wider community.

Parents reported positive experiences of having and caring for a child with a learning disability, such as pride and joy, personal growth, learning to see beyond disability, developing a sense of courage and strength, and becoming experts by experience. Perceived stigma or objective burden had no direct effect on mothers' ability to find benefits in caregiving. For most mothers, the burden of care experienced was viewed in terms of social-cultural constraints (objective burden) rather than emotional distress (subjective burden). Subjective burden (emotional distress), which is associated with stigma, reduces perceived benefits, and stigma therefore has an indirect negative effect on parental perceptions of caregiving benefits. Green's (2007) findings resonate with Scorgie and Sobsey's (2000) and Grant's (2010) studies, which also found that children with learning disabilities enhance their parents' lives in many ways through their reciprocal relationship, and adds deeper understanding of the benefits parents can derive from caring for their children. Some of the origins of parental stress arise not from the child's disability, but from society's low expectations of parenting a child with a disability successfully (McKeever and Miller, 2004). This is because dependency in non-disabled individuals is usually confined to childhood, before they progress to independence and economic productivity in adulthood (Green, 2007). Children with disabilities who do not 'rise' to these expectations can be perceived by society as problematic and burdensome (Oliver, 1990; Priestley, 2003).

Green (2007) writes from an informed standpoint as she has a daughter with a learning disability and therefore offers an insider perspective. Although this may be seen as bias, from the perspective that parent carers of adults with learning disabilities become experts by experience (Nolan et al., 1996) being an 'insider' can add value to, and validation of, the study. However, these findings need to be treated with caution as the sample for the quantitative phase was relatively small (91) and the qualitative phase cannot be generalised.

Research on the experiences of caregiving and quality of life of older parents providing care for adults with learning disabilities is sparse. The

landscape of informal care for adults with learning disabilities and their parent carers has changed due to increase in life expectancy, so more studies are needed to provide nuanced understandings of caregiving and quality of life of older parents (Grant, 2010). Before evaluating the studies on older people's quality of life in relation to caregiving, an overview of the quality of life of older people in general is presented to provide some context to the ensuing critique of the quality of life of older people with caregiving responsibilities.

## **2.9 Quality of life of older people**

Traditionally, old age has been seen as a period of decline and dependency, particularly in Europe. This focus portrays ageing negatively and underestimates the quality of life of older people (Gabriel and Bowling, 2004), rather than viewing old age as a period of positive change and productivity (Bowling, 1995).

The interest in the quality of life of older people has grown significantly in the UK. An example of this is the Growing Old (GO) programme funded by the Economic and Social Research Council (ESRC), which spanned seven years and carried out 24 projects on the quality of life of older people. The studies extended beyond the traditional borders of health-related quality of life to encompass a range of other areas, such as transport, spiritual beliefs and loneliness (Walker, 2005). The findings of GO studies have added to the understanding of quality of life in old age and provided empirical evidence to inform policy and practice. However, there was a strong quantitative leaning with only three qualitative studies conducted, which indicates that the subjective quality of life was under-represented in the studies.

Researchers who have examined the quality of life of older people have identified several factors that influence how older people report their quality of life. These include social relationships with family, other social contacts, social activities, home neighbourhood, finances, psychological well-being, health outlook and functional status. Geographical location and gender can also influence older people's quality of life.

## **2.10 Factors that influence quality of life of older people**

Farquhar (1995) used a mixed-methods approach to identify lay definitions of quality of life among older people in the UK and to examine the relevance of available scales currently used to measure quality of life. In the quantitative phase, 210 older people comprising three groups, two from Hackney (an inner London city borough with high levels of deprivation) aged 65 to 85, and 85-plus, and the third group from Braintree, Essex (a semi-rural community with low levels of deprivation), aged 65 to 85, completed a survey. The qualitative phase was conducted utilising in-depth unstructured interviews with 40 older people (20 from Hackney and 20 from Essex).

Key factors found to enhance the quality of life of respondents were: social contacts, which included children and family; health/mobility/ability; material circumstances, which included financial situation; a good home; having the things they wanted; and activities. Unsurprisingly, most of the people in Braintree felt that their life was positive because of their material circumstances, health and mobility, and social contacts.

The findings of this study suggested that people are generally able to talk about their quality of life, and that geographic location plays a part in how people report their quality of life, with those who live in semi-rural areas being more likely to describe their quality of life in a positive way than those living in an inner city area. The very elderly were more likely to describe their quality of life in very negative terms than the younger elderly. The longitudinal design of the study was able to capture the changes in people's quality of life over time. However, all respondents lived at home, and it is not known whether older people who live in residential settings would have reported their quality of life differently.

In the UK, Gabriel and Bowling (2004) explored the quality of life from older people's perspectives in two phases. In the quantitative phase, 999 older people aged 65 and over completed a survey, while the qualitative phase was

conducted using in-depth interviews with 80 people. The main findings suggest that social relationships with family, friends and neighbours, home and neighbourhood, psychological wellbeing and outlook, social activities and hobbies (communal and solo), health, financial circumstances and independence were contributors to a good quality of life of older people. The findings provided a model of quality of life that is grounded in the subjective experiences of older people and resonate with Farquhar (1995), who also identified that family relationships and social contacts are integral to older people's quality of life. As in the study by Farquhar (1995), all participants lived in the community. The views of older people living in residential settings are not represented and therefore limit these findings.

Similarly in the UK, Bowling (1995) examined the dimensions of life that people perceive to be important in relation to quality of life and health-related quality of life. Quality was taken to encompass the social, psychological and physical domains of life, incorporating a subjective assessment of important life domains in relation to achieving satisfaction, and was operationalised as the things people regard as important, both good and bad.

The findings indicated that respondents acknowledged that relationships with family or relatives, their own health, the health of a (close) person, and finances/standard of living/housing were important. However, the order of importance changed when participants' responses were combined. Finance/standard of living/housing was given first priority, followed by relationship with family and friends, own health, health of close others and social life/leisure activities.

A limitation of this study was that casual prompting of respondents could have biased the responses. In addition, the scales used to measure health-related quality of life failed to include several items that were ranked as important by the respondents. These limitations demonstrate the difficulty encountered in using measures to assess quality of life, as no single measure is able to incorporate all the domains that people report as important to their quality of life. It also questions whether quality of life can be measured at all (Hendry and McVittie, 2004), despite the number of tools that have been developed. Nonetheless, the

findings of Bowling (1995) are supported by both Farquhar (1995) and a later study by Gabriel and Bowling (2004).

In another study, Bowling and Gabriel (2004) also explored the constituents of quality of life in older age in order to reach a better understanding of what quality of life means to people aged 65 or older. The findings indicated that the central tenets of quality of life in later life were psychological characteristics such as health outlook and functional status, and personal and neighbourhood social capital. Other aspects emphasised were the importance of financial circumstances and independence. This highlights the need to move from the narrow focus of functionalism to a broader perspective, including aspects such as finance and neighbourhood, in order to assess quality of life globally. Although this model of the quality of life was grounded in older people's experiences, a methodological limitation was that the sample lacked diversity because only White participants were included in the study.

More recent findings from Bowling and Gabriel (2007) illustrate that the respondents' quality of life was enhanced by: social relationships, social roles and activities, leisure activities enjoyed alone, health, psychological outlook and well-being, home and neighbourhood, financial circumstances, and independence. The reasons identified centred on freedom to do things they wanted to do without restriction, pleasure, enjoyment and satisfaction with life, mental harmony, social attachment and having access to companionship, intimacy, love, social contact and involvement, help, social roles, and feeling secure.

The study presents older people's perceptions of what they deem adds quality to their lives and the reasons why these factors are important. It addresses an important area in quality of life research that has been under-explored: that is, what constitutes quality of life for older people from their perspective. The strength of the study is that it used the value system of the older people who had been assessed rather than that of others. However, the structured measures used were unable to capture some areas, such as love, enjoyment and intimacy, which were mentioned by the respondents as enhancing their quality of life. These

domains were only revealed through qualitative exploration of the quantitative measure.

In Sweden, Borglin et al. (2005) used a qualitative approach to illuminate the experience of quality of life for 11 older people living at home. Four broad themes emerged as areas of importance to older people's experience of quality of life: anchorage to life, satisfied body and mind, access to significant relationships and conditioning. The meaning ascribed to these areas by the older people was that quality of life is about a preserved self and meaning in existence.

Importantly, areas that are not generally included in quality of life measures were reported, such as the meaning of home and thoughts about death and dying.

These findings indicate that quality of life is more complex than the commonly used quality of life measures capture, and that these tools need to measure other aspects of people's lives beyond health indices. They also highlight the importance of measures of quality of life being grounded in the subjective views of people whose lives they are meant to evaluate. This is a small qualitative study and therefore its findings are not representative. However, they provide useful insights into aspects of older people's quality of life that measures fail to capture, and support Hendry and McVittie's (2004) point that what quality of life instruments measure is different from what older people report about their subjective quality of life.

## **2.11 Gender and quality of life**

Research has shown that men and women prioritise different things when appraising their quality of life. In a quantitative study, Wilhelmson et al. (2005) investigated what 141 older people in Sweden considered to be important for their quality of life, and explored the impact of gender, education and health status on individual perception. Participants were asked to choose three statements from cards about the things that might influence their quality of life, without ranking them.

The results showed that for the open-ended question the most frequently mentioned domain was social relations, followed by health, activities, functional ability, well-being, personal belief and attitudes, their own home, and personal finances. The frequency differed greatly between men and women. For example, social relationships were cited by 72 per cent of women and 44 per cent of men. The results for health were also different but to a lesser degree (52 per cent of women and 38 per cent of men). The most frequently selected card domain for both men and women was functional ability, followed by physical health, social relations and being able to continue to live in one's present home. The second most common domains chosen by men and women were physical health and social relations respectively. An interesting result was that both men and women who were 80 years and over selected functional ability and remaining living in one's home relatively more frequently than their younger counterparts.

There are two main points to be considered about the findings of this study. Firstly, the study was conducted in Sweden and one has to be careful when comparing studies of quality of life from different countries due to cultural differences. The limitations of the study are that the findings might not be representative of older people in Sweden because the sample was drawn from a relatively small geographic area. The use of show cards could also present a bias in the participants' responses. Despite this, it is worth noting that the main findings of Wilhelmson et al.'s study are consistent with UK studies (Bowling, 1995; Farquhar, 1995; Gabriel and Bowling, 2004).

In the UK, Scott et al. (2009) conducted a mixed-approach study to explore people's own perception of quality of life, and how quality of life perception of men and women differs across the life course. Some of the findings from the longitudinal analysis suggest that people's perception of quality of life changes over time. These changes occur after important life transitions such as partnership and parenthood. Key findings identified as being important to quality of life were: health, family and finance. Regarding health, a significant finding was that the well-being of individuals was affected by the health of other family members. This is a factor that had not been considered in the quality of life literature, as the focus had generally been on the individual's own health (Scott et

al., 2009). Health was seen as an important factor in assessing quality of life and this was more so for people in their mid-thirties and upwards. This may be due to a decrease in functioning and energy level, or it may be significant when people have children.

In relation to gender, 25 per cent of the men between the ages of 15 and 19 mentioned health as being important to quality of life, in contrast to 70 per cent of the women between the ages of 56 and 65. In general, women with the exception of the age group over 75, saw health as being more important to quality of life than men. This finding concurs with Wilhelmson et al. (2005) and indicates some consistency in how older people report their quality of life, regardless of where they live.

Similarly to health, women viewed family as being more important to quality of life than men, particularly older men. Women mentioned children more than men, in relation to their quality of life. Men linked family to their role as breadwinners and therefore finance was mentioned as a factor in their quality of life by men of all ages. It is important to note that all the areas identified are interlinked, as individuals need good health to care for others, both financially and emotionally.

The findings of this study provide an insight into what contributes to a good quality of life for men and women. The longitudinal design of the study was very useful in demonstrating changes in quality of life over time; more importantly, it shows that quality of life is not a static, but a dynamic concept, and the focus of what is important may change with age. The study used a population based sample, and therefore its findings could be generalised for the UK. The limitations of the study were that the measures used did not take into consideration the environment and community, which had been seen as two major factors that impact on quality of life (Rapley, 2003).

## **2.12 Caregiving and quality of life of older parent carers of adult children with learning disabilities**

Seven studies which were mainly quantitative were identified in the literature search concerning the quality of life of older parents caring for an adult child with a learning disability (Walden, et al., 2000; Leung and Li-Tsang, 2003; Chou et al., 2007; Lin et al., 2009; Perkins, 2009; Caples and Sweeney, 2010; Yoong and Koritsas, 2012).

Walden et al. (2000), in a quantitative study, compared the quality of life of a UK sample of 62 parents (58 women and 4 men), whose ages ranged between 37 and 86 years, and who provided care for adults with learning disabilities, with selected reference groups in the USA. The psychological well-being of UK parents was significantly lower than reported in a previous study of the US mid-life mothers of adult children without disabilities (Ryff et al., 1994). There was also a particularly large difference on the personal growth and purposive life subscales. With regard to positive affect between parents and their children, similar results were found to those reported in US studies of parents of adults with learning disabilities (Greenberg et al., 1993). Parents' stress was higher in the UK parents than in a US sample of parents with adults with intellectual disability (Krauss and Seltzer, 1993) and those in the Republic of Ireland (Seltzer et al., 1995). However, levels of stress were similar to parents in Northern Ireland (Seltzer et al., 1995). In UK parents, depression was also reported at a higher level compared to the normative US sample of adult women (Derogatis, 1994), but there was no difference in the level of anxiety.

The quality of life of parents was affected by challenging behaviour, as they experienced stress, anxiety and depression. Informal support also impacted on parents' quality of life, in that the lower levels of informal support were associated with higher levels of parental stress, anxiety and depression. Conversely, informal support was also related to positive affect, as the higher levels of informal support were associated with higher levels of positive affect. It was also reported that physical dependency contributed moderately to parental

stress and positive affect. For example, the more able the adult with a learning disability, the lower the level of parental stress and the higher the positive affect. Similarly, higher levels of emotional support were associated with greater levels of psychological well-being. It is important to note that formal support did not contribute significantly to any of the quality of life indices. This suggests that informal support has the potential to reduce stress as well as enhance quality of life, unlike formal support which may reduce stress but has little positive impact on quality of life.

Walden et al. (2000), using Todd and Shearn's (1996b) framework of captive and captivated parents to differentiate parents, posed the open-ended question to parents: 'How different do you think your life would be if (name) was not living at home?' Some 29 per cent of the parents' responses were coded as captive parents with 61 per cent coded as captivated. The remaining 10 per cent were along the continuum between captive and captivated. Captive parents reported higher levels of stress than captivated parents. In contrast, the parents who were captivated scored higher on environmental mastery, a subscale of psychological well-being, indicating greater control over their environment and the external world. This in turn had a positive effect on their lives, as their scores were lower for depression and higher for positive affect and purpose in life. Captivated parents were seen as tending to 'lower the bar' in relation to their personal goals and they found positive meaning in their parental role. In contrast, captive parents experienced the tasks of parenting as restricting and were more likely to give up. Their difficulties lay, according to the authors, in the fact that they had invested in a lifestyle that was becoming less and less realisable.

These findings suggest that the UK mothers experienced more stress, less sense of personal growth or development and less sense of purpose and directedness than the US mothers with and without adult children with learning disabilities, with the exception of Northern Ireland. However, most of the UK mothers (61 per cent) were described as captivated parents, which means that despite their higher levels of stress, seemingly they were functioning fairly well. Although Walden's aim was to examine the factors that contributed to the quality of life of the parents, what was actually measured was psychological well-being

(Yoong and Koritsas, 2012). Also, no demographics were given of the reference groups and fathers were under-represented in the sample, comprising only four out of 62 parents.

Lin et al. (2009) used a quantitative approach to examine the quality of life of 597 parents of children/adolescents with intellectual disabilities in Taiwan using the WHOQOL-BREF questionnaire. Parents' physical capacity, psychological well-being, social relationships and environment were lower than among the general population but slightly higher than among the parents of adults with learning disabilities.

This finding supports Walden et al. (2000), who also found that the psychological well-being of older parents of adults with learning disabilities in the UK was lower than parents in the general population and also parents of children with learning disabilities, and suggested that older parents may be affected by their extended years of caregiving. This finding suggests that younger parents may experience less stress than older parents. The findings on age of parent carers in relation to stress and care burden were inconclusive. Kim et al. (2003) supports Lin et al. (2009) in finding that older parents are likely to experience more stress than younger parents.

In contrast, Heller et al. (1992) argue that older parents of adults with learning disabilities experience less stress than younger parents. This view is supported by Perkins (2009), who suggests that as parents get older, they develop expertise which helps them to negotiate stress better than younger parents. However, Minnes and Woodford (2005) found no difference in the stress levels between younger and older parents of adults with learning disabilities. They argue that stress levels varied across parents' caregiving life span. Self-perceived health status, household income and stress from insufficient family support were also predictors of how parents reported their quality of life. The strength of this study is that WHOQOL-BREF incorporated the subjective experiences of parents. The limitations of the study include an observation that the severity of the children's disability was skewed towards severe, which means that parents of children with mild disabilities were under-represented. Similarly, fathers (27 per cent) were under-represented in the sample.

In Hong Kong, Leung and Li-Tsang (2003) also explored the quality of life among 71 parents of children with disabilities and 76 parents whose children were not disabled, using the WHOQOL-BREF (HK) questionnaire. Parents of the children with disabilities scored lower on all domains of quality of life than parents of children without disabilities from similar backgrounds. There were significant differences between the two groups of parents in the social relationships and environmental domains, but not in physical health and psychological domains. The latter finding may be due to parents with children with disabilities developing coping strategies over time, and contrasts with Walden et al. (2000) and Lin et al. (2009). However, the level of children's disability impacted on parental quality of life, with parents of children with more severe disability scoring lower on physical, psychological and environmental but not on social relationships. This suggests that parents' participation in social activities may not be restricted by the severity of the child's disability, but is seemingly influenced by their attitudes to life in general (Li-Tsang, Yau and Yuen, 2001).

Chou et al. (2007) in a quantitative study examined the quality of life of 792 family caregivers of adults with learning disabilities who resided together and also investigated background variables such as age, perceived health of the caregiver, adults' severity of disability and cultural context, using the questionnaire WHOQOL-BREF Taiwan version. Family caregivers reported that they experienced a higher quality of life when their adult relatives were at school. The main predictors of quality of life of caregivers were health status, their family income and the level of severity of the adults' disability. A notable finding was that the caregivers' quality of life was higher for adults with severe learning disabilities and lower for those caring for adults with mild learning disabilities. This is inconsistent with other studies (Leung and Li-Tsang, 2003; Wang et al., 2004). An explanation for this result is that, in Taiwan, adults with severe learning disabilities are more likely to receive higher levels of government subsidy and formal support than adults with mild learning disabilities, and this in turn impacts positively on caregivers' quality of life. These findings are specific to Hsin-Chu city and are therefore not generalisable to the whole of Taiwan or

the UK, and important variables such as family structure and composition were left out and these can influence family caregivers' quality of life.

Support or the lack of it has been associated with caregivers' quality of life (Walden et al., 2000; Chou et al., 2007). In the UK, Caples and Sweeney (2010) in a quantitative study using the Family Quality of Life Survey (FQOLS) (Brown et al., 2006) investigated the quality of life of 49 parents of children and adults with learning disabilities who were receiving respite care with the view to inform the development of respite services and examine parental needs and preferences for respite care. The majority of the family reported their quality of life as good or excellent. Most of them were also satisfied with their health and financial circumstances. In relation to family relationships, the majority made considerable effort to maintain family connections. However, many parents reported a lack of support from other people, which limited their social contacts. They were generally satisfied with the formal services. Many parents faced a lengthy period of waiting for respite care as the demand exceeded the supply and it was not necessarily what parents felt would improve their quality of life. Loss of career was seen as impacting on financial well-being as well as loss of social contacts. Family values such as religious beliefs were useful in helping parents cope with the challenges of having a child with a learning disability.

The findings of this study suggest that parents were generally positive about their quality of life and their main concerns were about the lack of and delivery of respite care for their children. In the main, parents highlight the benefits derived from parenting a child with a learning disability. These findings are not representative of people with learning disability, however, as many of the children were diagnosed with Down's syndrome and this may have influenced the positive outcome of the study. Hodapp and Urban (2007) have described a Down's syndrome advantage, whereby many of the people with this diagnosis have mild disabilities. The limitations of the Caples and Sweeney (2010) study include the low response rate (38 per cent), and the fact that all the children were receiving respite care, so parents who do not receive services – 'hidden' parents (Horne, 1989) – were not represented in the study.

It is evident that the impact of caregiving can influence how parents report their quality of life. Yoong and Koritsas (2012) in a qualitative study explored the impact of caring for adults with learning disabilities on the quality of life of 12 parents in Australia. Caring had benefits as well as drawbacks which enhanced or reduced parents' quality of life. For example, by being involved in parent carers' groups, parents gained opportunities to develop friendships from which they derived support, a sense of belonging and mutual understanding. Their adult children also provided companionship and support in difficult times such as during loss and bereavement. Some parents were able to participate in leisure activities with their children. Overall, most parents felt that caring for their adult children gave them personal satisfaction and a sense of accomplishment.

Conversely, some parents experienced their time being restricted by their caring role, which meant that it was difficult to engage with other family members such as grandchildren and meet the needs of their other children. Caring also restricted their time for leisure and employment, and some parents stopped working to care for their children, which impacted negatively on their financial situation. Most parents had difficulty in accessing formal services and, when they did, the quality of the services was poor and failed to meet their needs. Fears about the future care and accommodation for their adult children provoked high levels of stress and anxiety for older parents, which impacted negatively on their quality of life.

The findings of Yoong and Koritsas (2012) clearly suggest that there are benefits from having and caring for adult children with learning disabilities, which enhance older parents' quality of life in many ways. However, there are restrictions that are imposed by the caring role, and also by the lack of formal support, which reduce the quality of parent carers' lives. These findings corroborate earlier research on caregiving and quality of life by Caples and Sweeney (2010). The study provides a balanced picture of caregiving and its impact on older parent carers' quality of life. However, the findings represent only parents whose children were in receipt of services and therefore the views of those who were not accessing services, which may be different, are missing.

Most of the adults had mild learning disabilities, which means their parent carers may report their quality of life differently from parents who provide care for adults with severe and profound learning disabilities, or who are compound carers, which means they are caring for more than one person.

Perkins (2009) conducted a quantitative study in the USA to investigate the relationship between compound caregiving and reciprocity to the well-being of 91 older carers of adults with learning disabilities (34 of these older carers were compound caregivers, having multiple caring roles). Compound caregivers were likely to opt for residential care for the adult with learning disability. There was no difference in life satisfaction, depressive symptomatology, global physical health or mental health between compound and non-compound caregivers. In relation to reciprocity, it was found that caregivers gave more emotional support than they received. The findings suggest that older carers develop their expertise from prolonged caregiving and therefore compound carers were able to multi-task because they were familiar with their roles. Heller et al. (1992) argue that older carers experienced less stress and care burden than younger carers. This may be due to their adapting to caregiving stress over time by developing appropriate coping strategies (Seltzer and Krauss, 1989), or their acceptance of the way things are because they are more resigned to their roles (Grant and Whittell, 2000). Perkins' (2009) study provides a deeper understanding of caregiving and reciprocity, and the theoretical underpinning is clearly stated.

A critique of Perkins' (2009) work relates to the methodological limitation that the validity and reliability of the instruments used were not reported. In addition, the use of a convenience sample may have introduced some element of bias and the cross-sectional design was not able to observe changes in quality of life of carers over a period of time. A complementary qualitative phase to explore life satisfaction, rather than using standardised measures, would have enhanced the study findings as much debate has been generated about the use of measures in assessing quality of life (Hendry and McVittie, 2004; Gilhooly et al., 2005).

## 2.13 Summary

In summary, this chapter has reviewed quality of life of older people in the context of caregiving for adult children with learning disabilities. The dilemmas of defining quality of life and caregiving and the complex nuanced features of these two constructs were highlighted to provide context. Differences in age, gender, socioeconomic background and health circumstances all contribute to how older people report their quality of life in relation to their caregiving role.

The chapter also critically appraised studies relating to caregiving and its impact on the quality of life of older parent carers who provide long-term care for their adult children with learning disabilities. The literature suggested that caregiving has its rewards and challenges, and older parent carers of adults with learning disabilities have similar experiences which can either enhance or reduce their quality of life.

The contributory factors were: formal and informal support, the severity of the child's disability, challenging behaviour, negative societal attitudes and the socioeconomic background. There is strong evidence to suggest that the quality of life of older people is being investigated, as the number of published studies has grown since 1995. However, the review also noted that there are very few studies, particularly in the UK, on the quality of life of older people providing care for their adult children with learning disabilities. Specifically, there are no qualitative studies that have explored the quality of life and subjective experiences of older people caring for adults with learning disabilities in the UK. Most of the studies on the quality of life of parent carers focus on parents, mainly mothers, of children and adolescents. Therefore the fathers' voices are lacking in caregiving and quality of life research. Moreover, little is known about the subjective understandings of quality of life of older parent carers who provide long-term care for their adult children with learning disabilities in the UK. Although the studies reviewed are methodologically diverse, there is a strong emphasis on quality of life measurements, which have their limitations. Therefore the current study adopts a constructivist qualitative approach to

examine the experiences of older parent carers of adults with learning disabilities and how they conceptualise their quality of life.

The questions that emerged from the literature review and which are addressed in this study are:

1. What are the experiences of older parents who provide long-term care for their adult children with learning disabilities?
2. How do older parents who provide long-term care for their adult children with learning disabilities conceptualise their quality of life?

The methodology and rationale for selecting a constructivist approach, along with methods and the theoretical models that informed the study, are discussed in the next chapter.

# **Chapter 3 Methodology and models that informed the study**

## **3.1 Introduction**

This chapter discusses the ontological, epistemological and methodological premises underpinning the study. It presents and discusses the selection of theoretical models that informed the study: the six stages of caregiving (Nolan et al., 1996b) and the Double ABCX model of adjustment and adaptation (McCubbin and Paterson, 1983). These models are revisited in Chapter 6 to discuss their relevance to the study's findings. This is followed by a discussion of the ethical issues that were considered in conducting the study and how these were addressed. The chapter also provides a detailed account of the sampling technique, data collection and data analysis process. It concludes with the challenges that were encountered in conducting the study and how rigour was ensured.

This study adopts a qualitative constructivist approach which is located in an interpretivist paradigm and is guided mainly by the works of Rodwell (1998), Guba and Lincoln (1989, 1994), Appleton and King (2002) and Denzin and Lincoln (2000a, 2011, 2013).

## **3.2 A qualitative approach**

The main aim of this study was to examine the experiences of older parents who provide long-term care for adult children with learning disabilities and how they conceptualise their quality of life in relation to their caring role. This involved the exploration of multiple meanings and realities of the older parent carers (Rodwell, 1998). A qualitative approach was considered appropriate because the researcher's aim was to understand the complexity and richness of people's experiences and subjective interpretations, how meanings are negotiated within a social context, and how the same event can be interpreted in multiple ways

(Denzin and Lincoln, 1994 and therefore can be viewed pluralistically (Appleton and King, 2002). Mason (1996: 4) argues that ‘qualitative research is concerned with how the social world is interpreted, understood, experienced or produced’.

### **3.3 A philosophical perspective**

A myriad of philosophical perspectives are included within the qualitative paradigm and researchers therefore draw on ideas from selected research philosophies or paradigms to inform their philosophical position (Finlay, 2006). Denzin and Lincoln (2000b: 19) posit that ‘all qualitative researchers are philosophers’, and draw on the seminal work of Bateson (1972: 320), who describes philosophers in ‘that universal sense in which all human beings ... are guided by highly abstract principles’. Lincoln and Guba (1985:14-15) suggest that ‘these principles combine beliefs about ontology (What kind of being is the human being? What is the nature of reality?), epistemology (What is the relationship between the enquirer and the known?), and methodology (How do we know the world, or gain knowledge of it?)’.

Furthermore, philosophical deliberations are implied in social research, as researchers ‘philosophy and theory offer us a lens through which we can view our participants and the research process ... they give us tools to analyse our data and assess the impact of our relationship with participants’ (Finlay, 2006: 25). Echoing this sentiment, Ponterotto (2005) argues that it is important for researchers to fully understand the philosophical assumptions that underpin their worldview, and a sound understanding of philosophy and methodology enables researchers to produce a richer and more robust study (Appleton and King, 2002).

Therefore, in order to choose a philosophical approach for this study, the philosophical bases of the five major paradigms (Table 3.1) were given thorough consideration, and this formed the groundwork for the epistemological and methodological choices for this study. Traditionally, research has been categorised into two main paradigms – positivist or realist, and interpretivist or

relativist (Finlay, 2006). Given the nature of this study, a constructivist approach which is aligned with the interpretivist/relativist paradigm was selected. This is discussed more fully below.

According to Denzin and Lincoln (2000b), ontology, epistemology and methodology are interrelated activities that combine to form a paradigm or an interpretive framework, which is described as a set of ‘basic beliefs that guides action’ (Guba, 1990: 17). These paradigms set the context for the investigator’s study (Ponterotto, 2005) and at the same time guide the research endeavour (Denzin and Lincoln, 2000b). Creswell (2003) views qualitative research as fundamentally interpretive and therefore everyone has his or her own interpretation. Finlay and Ballinger (2006) support this view, making the point that people have different perspectives and therefore what one person perceives as true may not be true for another person. To this end, the interpretivist or relativist researcher believes that there are multiple constructed realities which are subjective and influenced by context, the social environment and the researcher–participant interaction (Ponterotto, 2005).

Therefore, in order to choose a research approach within the interpretivist framework, both the constructivist and participatory paradigms were considered. The two approaches share some similarities (Appleton and King, 2002) from an ontological standpoint, in that they both view reality pluralistically (multiple realities) (Lincoln and Guba, 1985) and they both adopt a subjectivist epistemology (Lincoln et al., 2011). Nevertheless, the constructivist approach was found to be the more suitable for this study because conducting a full participatory enquiry with older parent carers would have meant involving them in the design of the study. This was not practical because time constraints are one of the major issues that parent carers experience as part of their caring role.

Table 3.1 Basic beliefs of alternative paradigms (adapted from Lincoln et al., 2011: 100)

<b>Issue</b>	<b>Positivism</b>	<b>Post positivism</b>	<b>Critical theory et al.</b>	<b>Constructivism</b>	<b>Participatory</b>
Ontology	Naïve realism: ‘real’ reality but apprehendable	Critical realism: ‘real’ reality but only imperfect and probabilistically apprehendable	Historical realism: virtual reality shaped by social, political, cultural, economic, ethnic and gender values; crystallised over time	Relativism: local and specific co-constructed realities	Participative reality: subjective-objective reality co-created by mind and given cosmos
Epistemology	Dualist/objectivist; true	Modified dualist/objectivist; critical tradition/community findings probably true	Transactional subjectivist; value-mediated findings	Transactional/subjectivist-created findings	Critical subjectivity transaction with cosmos; extended epistemology of experiential, propositional and practical
Methodology	Experimental/manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental manipulative critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/dialectical	Hermeneutic/dialectical	Political participation in collaborative action inquiry; primacy of the practical; use of language grounded in shared experiential context

This concern was expressed by the older parent carers at the meeting I attended to present the study. The following extract from my reflexive journal illustrates my thoughts on choosing my methodological approach:

Today has been a struggle for me. I have read several texts and I had several discussions with colleagues on my methodology. I need to choose an approach that answers my research questions. I am sure that they can be answered by a purely qualitative approach, but which one? I am drawn towards both constructivist and participatory action research. However, the parent carers I presented to a few weeks ago, all seemed to be advocating for more services and expressing that they have very little time for themselves. Genuine action research needs the carers to commit a substantial amount of time to attend group sessions to contribute to the design of the study. I think the constructivist approach is better suited for the study as it still captures participation but is less time consuming. This is my final decision. Although I have a good grasp of this approach having read Rodwell (1998), I need to fully immerse myself in constructivist literature.

### **3.4 Constructivism as the chosen methodological approach**

Constructivism has philosophical roots connecting back to the works of Heidegger, Gadamer, Guba and Lincoln and is described as an ‘alternative to the ‘received view’ or positivist paradigm’ (Ponterotto, 2005: 129). It adopts a relativist position which embraces multiple realities that are valued equally (Schwandt, 1994) and that are socially constructed (Bryman and Teevan, 2005). Furthermore, relativism emphasises that the multiple realities are located and specific to individuals or groups that hold these constructions (Denzin and Lincoln, 1998). Constructivism therefore ‘assumes a relativist ontology (there are

multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic (in the natural world) set of methodological procedures' (Denzin and Lincoln, 2013: 27). Researchers adopting this stance are interested in disentangling how these shared worldviews of the researcher and the participants are constructed, and how they gain acceptance (Ballinger, 2006). Therefore the relativist researcher is aware that his or her understandings are viewed as one many equally plausible perspectives (Ballinger, 2006), each of which makes a significant contribution to a fuller and more complete understanding (Nolan et al., 2003) of people's interactions within their social environment (Appleton and King, 2002).

From the constructivist position, it is expected that the older parent carers in the study would report the multiple self-created realities that they ascribe to their caregiving experiences and their quality of life (Rodwell, 1998) as people attach different meanings to the same things or experiences (Crotty, 2003; Grbich, 2007). The subjectivist epistemology acknowledges the joint enterprise in co-creating understandings between researcher and participants (Guba and Lincoln, 2004; Grbich, 2007). For this study, the collaborative endeavour of meaning making and interpretation would take place between the older parent carers and myself. The dialogue, which would occur in their own home or a place of their choice – a natural setting – is characteristic of the constructivist approach (Rodwell, 1998; Denzin and Lincoln, 2013).

Constructivism has a strong interest in the ideologies and the values that lie behind research findings (Denzin and Lincoln, 2000b), such as the social structures and the assumptions ingrained in our thoughts that inform how we view the world, while seeking to understand the personal constructions that participants and the researcher hold in relation to their particular experiences (Guba and Lincoln, 1994). To this end, the constructivist researcher is a passionate participant (Guba and Lincoln, 1994) who actively engages in constructing meaning (Silverman, 2011) in a sustained way with research participants (Creswell, 2003; Grbich, 2007). Thus, one of the main endeavours of the constructivist researcher is co-creation of knowledge jointly with participants (Denzin and Lincoln, 2013) to find common 'ground' and at the same time to

acknowledge new perspectives (Guba and Lincoln, 1994) and constantly engage in reflection. Self-reflexivity is viewed as fundamental to the constructivist approach, and researchers adopting this orientation generally engage in critical self-reflection by acknowledging their influence on the research process (Finlay, 2006) and their prejudices (Kiesinger, 1998). As mentioned in Chapter 1, self-reflexivity was aided by my keeping a reflexive journal and making copious field notes. The following is one of my reflections:

This is my first major research project and I derived some comfort from the fact that I had worked with the older parent carers of adults with learning disabilities before in my capacity as the respite care co-ordinator for a local authority. However, I quickly realised that I had embarked on a journey where it was imperative for me to change hats from a practitioner and lecturer to a researcher. This meant engaging thoroughly with the methodological literature in order to gain a firm grasp of the different paradigms and make informed choices about my approach and to establish myself as a researcher.

Rodwell (1998), Guba and Lincoln (1989) and Charmaz (2000) note that within constructivism there is scope not only for action and change, but also for knowledge development and understanding (Nolan et al., 2003).

I am interested in the unique experiences of caregivers both individually and collectively and the multiple meanings they attach to their quality of life in relation to their caring role. These meanings and constructions would be negotiated between the parent carers and myself, facilitating participant empowerment through this joint endeavour (Rodwell, 1998). Therefore both my values and the carers' values are instrumental in the research process as 'a mutual shaping takes place which is influenced by both the researcher's and the respondent's own value systems' (Lincoln and Guba, 1985: 100). The features described above are in keeping with my relativist view of the world which embraces multiple realities, and therefore this approach was well placed to answer the research questions.

Constructivism having been affirmed as my methodological choice, the next section discusses the assumptions that underpin this approach, which are based on: values in research, constructed realities, inquirer–participant relationship, generalisation and causality (Rodwell, 1998).

## **3.5 Assumptions of the constructivist inquiry**

### **3.5.1 Values in research**

Social research is known to be influenced by a variety of factors, including values which are the researcher’s inner feelings and behaviour (Bryman and Teevan, 2005). In the constructivist inquiry, values are important to the creation of knowledge (Lincoln and Guba, 1985) and therefore the assumption is that the inquiry is value-bound, which means that the constructivist researcher must be explicit in acknowledging the impact of his or her values on the research process if the results of the inquiry are to be judged meaningful (Rodwell, 1998). This view is endorsed by May (2011), who also believes that the values and their relationship to the decisions made must be openly acknowledged throughout the research process, in order to provide justification for systematic and credible research. The involvement of participants iteratively in the research process helps to affirm their values and adds credibility to the study. As suggested by Rodwell (1998), one way of doing this is member checking, which involves giving participants the opportunity to review their interview transcripts. This advice was heeded and the transcripts were returned to the parent carers so that they could check them for accuracy. I also engaged in constant reflection, which is evidenced in the reflexive accounts provided throughout the thesis, acknowledging my impact on the research process.

### **3.5.2 Constructed realities**

The constructivist researcher assumes that people hold multiple realities which are constructed and that these reflect their worldview and who they are in relation to it (Rodwell, 1998). These constructions are negotiated between the inquirer and participants through a consensus (Guba and Lincoln, 2005) and participants should be facilitated to share their views to gain a consensus about the area being investigated, without anyone's experiences being privileged over another, and all contributing to what is agreed (Rodwell, 1998). For this study, during the interviews with participants consensus was sought by sharing the experiences of other participants and myself, with a view to finding out whether the participants interviewed had a similar view/experience or not. All parent carers' voices are reported in the findings of the study, thus placing equal value on their accounts.

### **3.5.3 Inquirer–participant relationship**

In the constructivist approach it is assumed that there is no objectivity, whereby there is a separation between the observer and the object of the inquiry (Rodwell, 1998). On the contrary, the relationship between the inquirer and participants is premised on the notion that they are inseparable, as they both interact and influence each other to such an extent that it is difficult to separate the knower and the known (Rodwell, 1998). Furthermore, the inquirer–participant relationship is preferred over observer–observed, and participants and inquirer are actively involved in the co-construction of reality (Rodwell, 1998). In this study, meaning was co-created between the participants and myself, so this joint enterprise facilitated mutuality.

### **3.5.4 Generalisation**

Generalisation refers to whether the findings from a study based on a sample have any relevance beyond the sample and the context of the research itself (Lewis and Ritchie, 2003). Qualitative researchers vary in the meaning they

attach to generalisation, and it is contentious whether qualitative research findings are deemed capable of supporting wider inference because epistemological and ontological assumptions are known to influence generalisation (Lewis and Ritchie, 2003). This view is echoed by Shaw and Gould (2001), who purport that qualitative research is not robust enough, and therefore its findings cannot be generalised. It must be observed that generalisation for constructivist researchers is problematic because it is unable to provide the extent of people's experiences necessary to depict the full picture of the area that is being explored (Rodwell, 1998), and because generalisation by its very nature is unable to accommodate the multiple perspectives which are characteristic of the constructivist inquiry (Grbich, 2007).

Furthermore, Rodwell (1998) believes that it is left to the reader, not the researcher, to establish whether the findings are relevant to a particular context. She explains that the researcher has the role of producing a comprehensive description of working hypotheses and preparing the final report, and this report should encompass the detail and richness of information necessary for the reader to decide whether it is relevant to another context. Therefore, heeding Rodwell's advice, the aim of the current study was to provide richness through 'thick descriptions' (Ballinger, 2006), so that readers can decide whether the work has relevance to other environments. Extensive quotes are used from the participants' accounts of their experiences, providing a nuanced understanding of caregiving and quality of life.

### **3.5.5 Causality**

Constructivism does not embrace the concept of causality, as it sees it as irrelevant (Rodwell, 1998), and it may also be perceived as misleading and simplistic (Appleton and King, 2002). Furthermore, Guba and Lincoln (1982) explain that all entities are in a state of mutual simultaneous shaping, and that all things influence each other, so cause and effect are inextricably linked. It must also be emphasised, as endorsed by Appleton and King (2002), that the constructions and meanings that are articulated by the parent carers in this study

are unique to their settings and may never happen in exactly the same way in another setting.

### **3.6 Critique of constructivism**

Having discussed and justified the choice of methodology, it must be acknowledged that constructivism, like all other methodological approaches, is not beyond criticism. Guba (1990) is of the view that, although other methodologies embrace a relativistic viewpoint of multiple meanings, constructivism has received the strongest criticism for adopting this stance. For instance, Pawson and Tilley (1997) contend that due to constructivism's relativist position, and the differences in power relations between stakeholders, it will be difficult to arrive at a 'common' understanding.

In defence, Appleton and King (2002) point out that what Pawson and Tilley (1997) have not taken into consideration is that Guba and Lincoln (1994), proponents of the constructivist approach, hold a moderate view of this relativist position. For Guba and Lincoln (1994), different levels of power exist among stakeholders but these power differentials could be acknowledged through meaningful dialogue and negotiation. However, it remains unclear how a research endeavour based on partnership, equality and respect could be achieved when power differentials exist between the enquirer and participants but remain obscure (Lincoln and Guba, 2000). Nevertheless, it is constructivism's moderate ontological stance, coupled with its acknowledgement of its inherent problems, that makes it an attractive methodology (King and Appleton, 1999). The debates and difficulties highlighted by commentators in the field serve to remind the enquirer about the necessity of a careful and ongoing consideration of these issues as the research process unfolds.

As the present study was explicitly premised on a joint endeavour between the parent carers and myself, constructivism was considered an appropriate methodology. Moreover, to the extent that it is possible, an equal value was placed on the meanings that the parent carers ascribed to their quality of life, as

they were seen as the experts with regard to their situations (Nolan et al., 1996b); no one meaning was privileged over any other (Ballinger, 2006).

### **3.7 Reflection on my methodological journey**

I presented the proposed study at the University's Research Day, with a view to obtaining feedback on a possible methodological approach to answer my research question. Although I received copious feedback, I remained unenlightened in my search for a methodological fit for the study. As a matter of fact, I felt more confused, and after a lengthy discussion with my first supervisor I realised that I needed to immerse myself in the literature on methodologies. After six months of reading key texts such as Denzin and Lincoln (2000a), Guba and Lincoln (1994), Miles and Huberman (1994), Finlay and Ballinger (2006), Charmaz (2000) and Rodwell (1998), and by an elimination process of the possible qualitative approaches, I finally decided that a constructivist approach was well suited for the study, having considered grounded theory (Glaser and Strauss, 1967; Charmaz, 2000), interpretative phenomenological analysis (IPA) (Smith and Osborn, 2008) and participatory action research (PAR) (Kemmis and McTaggart, 2000) in my deliberations.

From engagement with the literature, I realised that bracketing, which is not having any preconceived ideas and being able to separate one's known ideas, is a feature of both grounded theory and IPA approaches. This would have proven difficult for me to achieve, as I had already worked extensively with parent carers of adults with learning disabilities. These approaches were therefore not feasible options for me due to my 'closeness' to the data. I needed an approach that was suitable to answer the research questions and which also acknowledged the tacit knowledge that I had gained from my insider perspective and therefore my impact on the research process, which could be addressed by being a reflexive researcher. Having an insider or emic perspective as the researcher was regarded as a strength, but this position also presented challenges which are discussed further in Chapter 6. With regard to PAR, due to the

commitment that was needed from participants – in this case, older parent carers – I decided that it would have been difficult to carry out participatory research that involved several engagements for these parent carers because the anecdotal evidence suggests that time is one of the major constraints in their caring role.

However, I felt deep down that I needed to choose an empowering approach, as carers' contribution to the social care model in the UK is generally undervalued. I was able to achieve this through the constructivist approach because there are many similarities between the participatory and the constructivist approaches, which have been discussed in earlier this chapter. In addition, a core feature of the constructivist inquiry is 'member checking'. Therefore the parent carers' transcripts from their interviews were sent to them to check the accuracy and to add any other information that they felt was relevant to their story.

The following section discusses how the constructivist approach was operationalised in the current study, taking into account the methodological requirements that must be addressed for the inquiry to be deemed constructivist.

### **3.8 How the constructivist approach was operationalised**

In the constructivist inquiry, the researcher conceptualises the study design (Rodwell, 1998), this includes the 'fit, focus and feasibility', a chain of events, which Guba and Lincoln (1989: 186-187 ) describe as the 'flow' of this approach. This school of thought is further extended by Rodwell (1998: 52 and 54) who points out that:

*the inquiry form is not static .....Instead, it is interactive, going back and forth in a constant process of data collection and verification, of theory construction and verification. The inquiry and knowledge creation are on a course of continuous shaping involving discovery and validation. The process is always interwoven from the entry into*

*the enquiry, through to the co-construction of meaning, to the construction and negotiation of an inquiry product.*

In addressing the methodological requirements of the constructivist inquiry, Denzin and Lincoln (2013) strongly recommend that researchers conduct their research in a natural setting, as reality cannot be separated from its context (Rodwell, 1998). The researcher is expected to have some prior knowledge of the subject under investigation in order to establish what constitutes the natural setting for the researcher's foreshadowed questions (McMillan and Schumacher, 1993). These are questions that are shaped by the researcher's knowledge of the subject area and experience (Rodwell, 1998).

These guidelines were adhered to in this study, as the parent carers were interviewed in their own homes, with the exception of one carer who chose a Carers' Centre. My prior knowledge and experience of working with parent carers of adults with learning disabilities informed the data collection process. I also had informal discussions with practitioners and colleagues which helped me in conceptualising and designing the study, and preparing for field access, as recommended by Appleton and King (2002). These discussions aided me in the selection of my methodological approach.

Having discussed the methodological framework for the study, I will now outline the theoretical models that informed this work.

### **3.9 Models that informed the study**

Caregiving and quality of life are inextricably linked, as caring is known to impact on the quality of life of parent carers (Walden et al., 2000; Lin et al., 2009; Perkins, 2009; Yoong and Koritsas, 2012), and the coping strategies that they employ influence how they experience their caring role and report their quality of life. Several models were given consideration, but the frameworks of Nolan et al.'s (1996b) six stages of caregiving and the Double ABCX model of adjustment and adaptation (McCubbin and Patterson, 1983) were identified as the

most appropriate models for underpinning the study, as they best reflect the caregiving and quality of life experiences. Nolan et al.'s (1996b) model identifies six stages of family caregiving that can be applied to older parent carers of adults with learning disabilities. The Double ABCX model (McCubbin and Paterson, 1983) has been used widely with families of children with disabilities.

### 3.9.1 Nolan et al.'s six stages of caregiving

Nolan et al.'s (1996b) six stages framework builds on Wilson's (1989a, 1989b) model, using the findings of the study with caregivers of people with dementia which was conducted by Keady and Nolan (1995a, 1995b). The findings of this study suggested that the transition points in the caring journey can be used to determine the specific support that carers need at that point in time.

*Table 3.2* Nolan et al.'s six stages in the caring journey for parents of children with learning disabilities (adapted from Nolan et al., 1996b: 109)

<b>Stage</b>	<b>Description</b>
1 Building on the past	Drawing on past experiences influences the quality of family support that parent carers may have for their child with a learning disability
2 Recognising the need	Realisation of the level of commitment parent carers need to make to care for their child with a learning disability
3 Taking it on	The conscious effort to take on the caring role where there is really no choice
4 Working through it	Parent carers embracing the caring role and learning from trial and error the different strategies to adopt in negotiating the challenges they encounter
5 Reaching the end	Planning for the future when parent carers' own health does not permit them to continue to care

6 A new beginning	Difficult for parent carers of adults with learning disabilities to see a new beginning; this period may signify multiple losses
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### **Building on the past**

For parents of adults with learning disabilities, building on the past seems irrelevant. There is no past to build on (Nolan et al., 1996b) because caring has just begun (Grant et al., 2003), and for these parents the focus is likely to be on the future rather than on the past (Nolan et al., 1996b). However, prior to the birth of the child with the disability, the relationships between parents and other siblings, if this is not their first child, are important and tend to inform the quality of the family support, as past support does influence the future (Nolan and Grant, 1992). Therefore building on the past is seen as both an antecedent to care and also an integral part of the caring journey (Nolan et al., 1996b).

### **Recognising the need**

At this stage, the parents are made aware that their child has a learning disability. This realisation brings sadness and a feeling of loss (Hobdell et al., 2007). Recognising the need may heighten parents' awareness of the level of commitment involved in caring for a child with a learning disability and may also bring about some uncertainty for both the present and the future (Grant et al., 2003).

### **Taking it on**

The notion of taking on caregiving raises the question of whether parents have the choice of caring for their child with a disability. It could be assumed that they do not, as this role begins like any other childcare role; unless there is some reason why the parent is not available through sickness or death, there is no decision to make (Nolan et al., 1996b). Braithwaite (1990) argues that there is

more to learn about becoming a carer than becoming a parent. This has some resonance for parent carers of children with learning disabilities because what begins as taking normal childcare responsibilities (Taraborrelli, 1993) then becomes a lifetime of caring.

### **Working through it**

This stage involves active caregiving, whereby carers focus on the positive aspects of caregiving whilst seeking to minimise the negatives, and they generally learn from trial and error and become experts of their situation (Nolan et al., 1996b). Motenko (1989) suggests that the longer the caring role has been undertaken, the less stressful it becomes. This is very pertinent to older parent carers in the study as research has shown over time that parent carers adapt to their caregiving role (Seltzer and Krauss, 1989), gain a sense of mastery through their experience (Perkins, 2009) and generally give up this role due their frailty or the challenging behaviour of their children (Kim et al., 2003).

### **Reaching the end**

For some carers, reaching the end of the caring role is dictated by their own healthcare needs or their inability to cope with severe challenging behaviour of their sons and daughters (Kim et al., 2003), and as a result residential accommodation is sought as an alternative. For most older parent carers of adults with learning disabilities, making such a decision can be stressful (Bowey and McGlaughlin, 2007; Nolan et al., 1996b), as 'letting go' (Richardson and Ritchie, 1989; Taggart et al., 2012) is difficult and this feeling of separation can become more acute as parents get older (Grant, 1990). As a result, most parent carers maintain active involvement in the care of their adult children (Dellasega and Mastrian, 1995; Seltzer et al., 1997; Davys and Haigh, 2007).

## **A new beginning**

A life after caring has been rarely considered by most carers and therefore they are often ill-prepared, especially those who have been caring for a long time (Nolan et al., 1996b). When a carer is no longer able to care, it does not mean that he or she automatically becomes a non-carer (Hancock and Jarvis, 1994). The period following active caring can, however, prove quite daunting. For parent carers of adults with learning disabilities, who devote the greater part their lives to the caring role, reaching the end could bring multiple losses. Examples of these are loss of identity, loss of purpose and loss companionship (Grant, 2010). It must be noted that for some carers, caring involves loving attention and provides both activity and a sense of identity (Nolan et al., 1996b). However, it is not uncommon for carers to experience negative emotions such as guilt in having had to relinquish their role and this does not facilitate a new beginning (Nolan et al., 1996b). It can be argued that for parent carers, particularly older carers, a new beginning may be difficult.

This model is intended to identify the key transition points that occur over time in the caregiving journey, which can inform different help and support that will be most useful at those times. During these stages, carers employ different coping strategies, having appraised their stress levels. Although all six stages are relevant to parent carers in the current study, stages 5 and 6 are possibly pertinent because this group of older parents, having worked it through by embracing their role and providing active care, are now reaching the end and are making decisions about the future. For this unique group of older parent carers and their adult children, planning for the future can be a very stressful activity because of the reciprocal nature of their relationship.

The temporal and longitudinal aspects of caregiving have been highlighted as the major deficits in the caregiving literature by Nolan et al. (1996b). They contend that these aspects of caregiving must be considered because they identify how carers' needs change over time and the key transition points throughout the

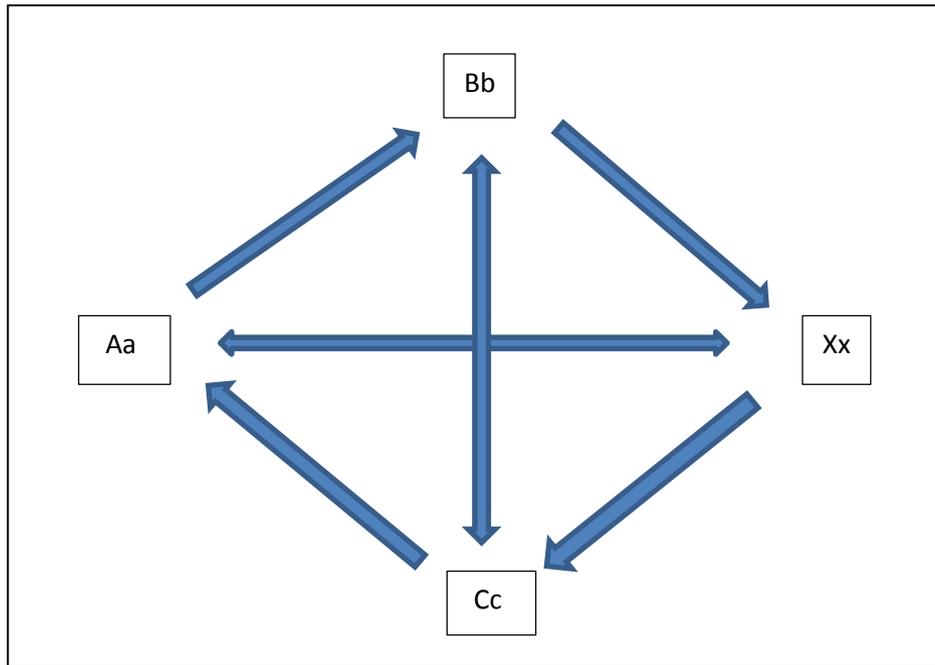
caregiving journey. This model has relevance to the older parent carers in this study who have been caring over a long period of time and is well grounded empirically.

### **3.9.2 Double ABCX model of adjustment and adaptation**

The Double ABCX model of adjustment and adaptation (McCubbin and Patterson, 1983) complements Nolan et al.'s (1996b) model because integral to the six stages of caring are the coping strategies that family carers use to meet the demands of the caring role. The Double ABCX model has been used extensively to measure stress and coping of families of children with disabilities. As shown in Figure 3.1, the family's use of resources is referred to as B, their perception of the stressor event is referred to as C and both the resources and the event are examined to establish their relationship to the stressor, which is A, and the stress experience, X. Orr et al. (1991) tested this model with families who care for people with learning disabilities and found that the flow of the model was ACBX, rather than ABCX (McCubbin and Patterson, 1983). The importance of this flow is that the resources for coping are dependent not on the objective nature of the stressor, but on how 'the stressor is perceived and appraised' (Nolan et al., 1996b: 56).

The two models described above complement each other and seek to explain the relationship between coping, caregiving and the impact on quality of life. However, it must be acknowledged that the complexities and intricacies of caring, coping and quality of life are not mutually exclusive; they must therefore be viewed together in order to obtain a holistic perspective.

Figure 3.1 The Double ABCX model (McCubbin and Patterson, 1983; cited in Jacques, 2003: 1)



Aa: build-up of stressor events; Bb: resources build up to deal with situation; Cc: family perception of this and previous stressor events; Xx: outcome in terms of family adaptation

### 3.10 Ethical issues

Researchers need to be fully cognisant of research practice and must strive to ensure ‘ethics of care’, which are ethical decisions based on care, compassion and the desire to bring benefit to the individual or group rather than following rules blindly (Mauthner et al., 2002). The research participants in this study are older parent carers who have been caring for their sons and daughters with learning disabilities from birth, and they are the experts on their situation. However, they are seen as a vulnerable group due to both their age and their role as carers, and there is potential for them to be exploited in research endeavours. Therefore, ethical approval was sought and obtained from Brunel University’s Ethics Committee for this study (see Appendix C).

Research involving human participants must be conducted in an ethical manner that recognises the responsibilities of researchers and respects the dignity, safety and rights of the research participants (WHO, 2002). Gilhooly (2002) recommends that the research endeavour be supported by the four principles of ethical research, which are non-maleficence (do no harm), beneficence (do positive good), justice (treat people fairly) and autonomy (have respect for people). These are embedded in the constructivist process, which emphasises its value-laden nature and has at its core ‘the notions of respect for human dignity, fairness, honesty and justice’ (Rodwell, 1998: 102). Therefore, these ethical principles were adhered to throughout the research process.

Abbott and Sapsford (2006) implore researchers to stay alert and ensure ethical issues are addressed throughout the ‘life’ of the project and not only at the outset. This principle was implemented by ensuring that the older parent carers who participated in the study were treated with respect and dignity. This was demonstrated by being courteous in my interaction with parent carers and ensuring that the information leaflets were comprehensive so that they could make informed choices about their participation. Carers were also given contact numbers in the event that they needed further clarification and information about seeking emotional support after the interviews.

The parent carers are 60 years and over and this was given particular consideration in recruiting participants for the study. Although most older people live independently and are self-determining and able to decide whether or not to participate in research, they are more likely to suffer from physical and/or mental impairments, and this might affect their competence to consent to research (Gilhooly, 2002). In order to engage in research, it is imperative that researchers obtain informed consent from participants (Hammersley and Traianou, 2012). Therefore, parent carers with cognitive impairment were not included in the study. Cognitive ability was determined by observing the parent carers’ level of engagement prior to and during the interviews. All the parent carers who volunteered for the study were able to give informed consent and engage fully in the research process. They were also asked to sign a consent form (see Appendix D). Before I began the interviews, the purpose of the study was carefully

explained to the participants, and they were given the opportunity to ask questions. Parent carers were also reminded that they could withdraw from the study at any time without giving any reason. This was explicit in all my interactions with the parent carers, and therefore there was no coercion.

Barnes and Warren (1999) suggest that, in carrying out research with older people, genuine effort must be made to bring about a balance of power, as failing to do so could be viewed as tokenistic and could have a disempowering effect (Carter and Beresford, 2000). However, Morse (2002) indicates that qualitative interviewing has the potential to bring about self-reflection, self-disclosure or catharsis. These considerations were deliberated on, and it was acknowledged that the ‘caring journey’ for some carers might be difficult, and that an interview could be a distressing experience for them, as it might ‘unearth’ or bring to the fore feelings of sadness associated with the circumstances surrounding the birth of their son or daughter with a learning disability. When three carers became tearful during the interviews, I responded appropriately, as indicated in section 3.16, by giving them the opportunity to end the interview and encouraging them to seek emotional support if they needed to do so. Every effort was made to protect the carers’ privacy and dignity by giving them the choice of where the interviews would take place. For example, one parent carer asked to be interviewed at a Carers’ Centre, while the others requested to be interviewed at home.

Due consideration was given to the fact that I had worked in the field as a respite co-ordinator for adults with learning disabilities, and in presenting the study to carers my previous role was discussed. I was very careful not to raise carers’ expectations about services, by clarifying my role as a researcher to the carers throughout the research process, particularly during the interviews.

Confidentiality and anonymity were also considered in conducting the current study. In social science research, confidentiality means that no real names or other identifying information about persons and places of the inquiry will be reported (Lofland and Lofland, 1995). This was adhered to in the current study by anonymising the parent carers’ identities in the transcripts and research report. Parent carers were informed that their real names would not be used for any

direct quotes and also it is not my intention to name the boroughs from which they were recruited. In addition, the information tape recorded during the interviews was downloaded to a computer and given a code and the transcripts were stored in a locked cupboard.

Qualitative researchers must provide criteria by which their work can be judged (Meyrick, 2006). Due to the nature of qualitative research, it cannot be replicated, which means that someone following the exact steps is unlikely to get the same results, since people's experiences are dynamic and what they report at a given point in time may change when they are asked the same question on another occasion (Appleton and King, 2002; Guba and Lincoln, 1982). For qualitative research to be trustworthy and authentic, researchers need to demonstrate how they arrive at their findings (Richards, 2009). The next section discusses how quality was assured in the current study.

### **3.11 Locating and recruiting participants**

Participants were recruited from four boroughs in south-east England. Two of the boroughs were predominantly White and the participants were mainly upper-middle-class professionals. The other two boroughs were more diverse and the participants mainly working class. Boroughs are units with local governance and they interpret national guidelines in different ways. I contacted the Carers Development Managers in these boroughs, requesting to attend one of their monthly carers' meetings to present the proposed study (see Appendix E). Harris and Dyson (2001) suggest that personal contact with the researcher to gain information enhances recruitment. Therefore, carers were given the opportunity to ask questions during the presentation. The general consensus was that due to the ageing population the carer's role is extended, and little is known about caregiving in old age and its impact. Therefore research is needed to explore the experience of caregiving with parent carers aged 60 years and over. Parent carers were given information packs, which included leaflets containing information about the study and a form to complete and return in a self-addressed stamped

envelope, if they met the inclusion criteria and were interested in participating (see Appendix F). Inclusion and exclusion criteria are given in Figure 3.2.

*Figure 3.2 Inclusion and exclusion criteria*

<p><b>Inclusion criteria</b></p> <ol style="list-style-type: none"><li>1. Parent carers 60 years and over who are supporting adults with learning disabilities living at home or out of home. Adult children living out of home must visit at least once a month.</li><li>2. Parent carers must be able to talk about their experiences comfortably in English.</li><li>3. Parent carers must be able to give valid consent to participate in the study.</li></ol>
<p><b>Exclusion criteria</b></p> <ol style="list-style-type: none"><li>1. Non-parents of adults with learning disabilities.</li><li>2. Parent carers supporting adults with learning disabilities who are unable talk about their experiences in English.</li><li>3. Parent carers with cognitive impairment or severe communication problems.</li></ol>

It was evident that there were carers who were still very much involved in caring for their sons and daughters with learning disabilities, even though they did not live at home. These parents identified themselves as carers and continued to be active members of the carers' group. One carer from this group described her role as caring by remote, due to the level of care she provided on a regular basis while her daughter lived in a residential setting. This became very apparent as the study progressed. There was a strong interest in the study from this group of parent carers, so I took the decision to include in the study parent carers whose adult children lived out of home and met the criterion of visiting home at least once a month.

### **3.12 Sampling approach**

The parent carers were recruited using a non-probability purposive sampling technique. This sampling approach is employed in qualitative research, whereby participants are selected to meet the criteria (Ritchie and Lewis, 2003) that will generate appropriate data when interviewed (Green and Thorogood, 2004).

Purposive sampling is a component of the constructivist inquiry which is aimed at obtaining a wide range of perceptions (Rodwell, 1998). In order to achieve this, I endeavoured to recruit older parent carers from White, Black and minority ethnic communities who were caring for an adult child with a learning disability.

### **3.13 Characteristics of participants**

The participants comprised 17 females and 10 males and the average age of the parent carers was 69 (see Table 3.3). However, 10 of them were 70 years and over and 2 were under 60. The 2 parent carers aged 58 and 59 were included in the study because they had substantial years of caring, 33 and 40 years respectively, and they identified themselves as older parent carers. It is known that 'how 'old age' is determined or defined is not uniform' (McIntyre, 2013: 17) and an individual's perceptions and experiences of ageing can be influenced by several factors, including social norms (Steverink et al., 2001). Both carers were of Indian background, and culturally it is possible that for them, people in their late 50s may be perceived as being older. Five of the parent carers (2 males and 3 females) were sole carers; however, all of the married couples with the exception of one identified the mothers as the main carers. A total of 70 per cent of the carers (19) were White British and 30 per cent of carers (8) were from Black and minority ethnic backgrounds.

The majority of the parent carers were home owners. With regard to educational level, 1 parent carer did not have any formal education; of the remaining 26, 12 had a university degree and the other 14 were educated to

secondary school level. Sixteen of the parent carers were co-resident and the others were out-of-home parent carers.

In line with current diversity figures in the UK (Office for National Statistics, 2012) there was a fair balance between the parent carers from White and from Black and minority ethnic backgrounds (70 per cent and 30 per cent respectively). Most of the parent carers were mothers, which is in keeping with the national statistics and the general trend in caregiving (Ward, 1990). More parents were co-resident carers (16 out of 27) and most were educated to secondary level and above.

### **3.14 Pilot**

In order to test the interview questions and ensure that they were understandable and asked in the correct order, a pilot study was carried out with four older parent carers. This small-scale trial conducted before the main investigation aimed to establish whether the research design and data collection instruments were adequate (Wilson and Sapsford, 2006). Having a few participants to test the interview questions is recommended, as this can reveal flaws which can be addressed before months of work are destroyed (Locke et al., 2007).

The pilot interviews provided the opportunity to modify and change the order in which the questions were presented. For example, the questions on quality of life, which were asked at the beginning of the interviews in the pilot study, were asked lower down the order during the main study. These questions seemed better placed after carers had described their caring role. The demographic questions, such as age and educational qualifications, were asked at the end of the interview. Wilson and Sapsford (2006) suggest that such questions are uninteresting and sometimes sensitive. They therefore advise that it is better for the researcher to engage the participants' interest as early as possible in the interview process. The interviews that were piloted were included in the main study as there were only minor adjustments.

Table 3.3 Characteristics of participants

<b>Participants (pseudonyms)</b>	<b>Age</b>	<b>Ethnicity, marital status</b>	<b>Caring for</b>	<b>Education</b>	<b>No. of years of caring</b>
1. Mr Smith	72	White/ British, Widower	Son with moderate learning disability and daughter with mild learning disability living in residential and supported housing respectively	Secondary school	40
2. Mr Brown	67	White/ British, Married	Son with moderate learning disability living in supported housing	University	40
3. Mrs Patel	60	Indian, divorced	Son with mild learning disability living at home	University	33
4(a). <b>Mr Sylvester</b>	61	White/ British, married	Daughter with moderate learning disability living in residential	University	27
4(b). <b>Mrs Sylvester</b>	68	African Caribbean, married	Daughter with moderate learning disability living in residential	University	27
5(a). <b>Mr O'Connor</b>	62	White/ British, married	Son with severe learning disability living at home	University	18
5(b). <b>Mrs O'Connor</b>	65	White/ British, married	Son with severe learning disability living at home	University	18
6. Mrs Jones	60	White/ British, married	Daughter with moderate learning disability living in residential	College	26

7. Mrs Collins	76	White/ British, widow	Son with mild learning disability living at home	Secondary school	45
8. Mrs Carter	63	White/ British, married	Son with mild learning disability living in supported housing	University	41
9(a). <b>Mr James</b>	64	White/ British, married	Son with mild learning disability living at home	Secondary school	32
9(b). <b>Mrs James</b>	66	White/ British, married	Son with mild learning disability living at home	Secondary school	32
10. Mrs Wilkinson	81	White/ British, married	Daughter with mild learning disability living in supported housing	Secondary school	41
11a. <b>Mr Johnson</b>	80	White/ British, married	Son with mild learning disability living in residential	University	50
11(b). <b>Mrs Johnson</b>	82	White/ British, married	Son with mild learning disability living in residential	University	50
12. Mrs Steiner	79	White/ German, married	Daughter with a mild learning disability living at home	University	53
13a. <b>Mr Whittle</b>	76	White/ British, married	Daughter with moderate learning disability living in residential	Secondary school	43
13b. <b>Mrs Whittle</b>	78	White/ British, married	Daughter with moderate learning disability living in residential	Secondary school	43

14. Mrs Wood	62	White/ British, married	Daughter with mild learning disability living in residential	Secondary school	31
15a. <b>Mr Halcyon</b>	69	White/ British, married	Son with mild learning disability living at home	University	28
15b. <b>Mrs Halcyon</b>	66	White/ Italian, married	Son with mild learning disability living at home	University	28
16. Mr Cullen	61	White/ British, widower	Daughter with mild learning disability living at home	Secondary school	21
17. Mrs Singh	71	Indian, married	Son with moderate learning disability living at home	Secondary school	54
18. Mrs Rahim	58	Indian, widow	Son with mild learning disability living at home	Secondary school	33
19. Mrs St Bernard	83	African Caribbean, married	Son with mild learning disability living at home	Secondary school	50
20. Mr Ramdeen	80	Asian, married	Two sons with mild and severe learning disabilities living at home	University	51
21. Mrs Ali	59	Indian married	Daughter with severe learning disability living in residential	No formal education	40

Note: the names of the six couples who participated in the study are indicated in **bold**.

### **3.15 Data collection method**

Semi-structured interviews were conducted with parent carers using open-ended questions. This allowed me the scope to probe beyond the initial answers, thus engaging in conversation which could yielded rich insights into parent carers' biographies, experiences, attitudes and feelings (May, 2011). An interview is a guided conversation whereby researchers listen with intent to hear the meaning of what is said (Rubin and Rubin, 1995) and participants are viewed as meaning-makers (Holstein and Gubrium, 1995). Meaning making holds a central position in the interpretive process (Warren, 2002). In keeping with this line of thinking, May (2011: 159) acknowledges that 'the data derived from interviews ... provide the researcher with a means of analysing the ways in which people consider events and relationships and the reasons they offer for doing so.'

### **3.16 Conducting the interviews**

The parent carers who expressed an interest in participating in the study were contacted by telephone to arrange a date and time that were convenient for them. As indicated above, all carers with the exception of one opted to be interviewed at home when their sons and daughters were either at college or the day centre. The interviews lasted between 1 and 2 hours and ended when carers' responses were exhausted and no new information was forthcoming (Rodwell, 1998).

I called the day before each interview to confirm the time and date, as conducting research with older people requires more time and planning (McMurdo et al., 2011). I ensured that I arrived on time for each interview, which demonstrated respect and value for the carers' time and contributions to the study. I also gave them the opportunity to ask any questions about the study and I explained the purpose of the interview. This provided the opportunity to build rapport. Prior to beginning the interview, the consent form was signed and I sought the permission of the carers to tape record the interviews. I also reminded

them that their participation was voluntary and that they were free to withdraw from the study at any time. As recommended by Rodwell (1998), I used an interview guide with foreshadowed questions as shown in Figure 3.3.

*Figure 3.3 Interview guide*

1. How long have you been caring for your son/daughter?
2. Could you tell me about your caring role?
3. Does anyone else help with caring for your son/daughter?
4. Could you tell me what things do you find helpful/unhelpful in your caring role?
5. What aspects of your caring role do you find pleasant/rewarding and/or difficult?
6. What were your thoughts when you found out that your son/daughter has a learning disability?
7. How would you describe your quality of life? (Why do you say so?)
8. Could you tell me what things add quality to or take away from your life?
9. Does caring impact on your quality of life?
10. Can you recall any memorable events in your caring role?
11. How do you see the future?

The interviews were conducted in a relaxed and conversational manner. This was due to familiarising myself, prior to meeting the parent carers, with the areas I needed to cover in the interviews and to drawing on interviewing skills which I had acquired from fieldwork. I made sure that my body language was appropriate by being very engaged with what the parent carers had to say about their experiences and, when appropriate, sharing my experiences. This ensured that a joint understanding was established between the parent carers and myself, and meanings were negotiated through a consensus (Grbich, 2007). I sought clarification when responses were vague and summarised what was being said at the end of the interviews to check that my interpretation was correct.

In keeping with the hermeneutic process, a feature of constructivism, parent carers' constructions that emerged from previous interviews were compared within the current interview. This was done by asking carers their views on particular experiences that other carers had expressed, in order to find out whether or not they had had similar experiences. This process aided in gaining a better understanding of participants' constructions and enhanced the study's credibility (Rodwell, 1998). I engaged fully with each new carer, giving him or her the opportunity to express his or her views before seeking a consensus. A consensus was sought at the end of the interviews when recapping to ensure that I did not influence parent carers' responses by asking leading questions.

On three occasions during the interviews, parent carers became tearful and they were given the opportunity to compose themselves or withdraw from the study. Both carers expressed the wish to continue. However, they were encouraged to seek emotional support through counselling from their GP, if they felt the need to do so. They were also given the option to call me to discuss their feelings.

Towards the end of the interview, I summarised what the carers said, to check for accuracy, and I asked if they had anything else they would like to talk about. On several occasions, parent carers spoke about the Coalition government's direct payments and personal budgets initiatives in relation to service delivery. I used this opportunity to discuss these issues because in my previous job in a local authority I had worked as a direct payments champion. I deemed this engagement to be important for demonstrating to the parent carers that I was interested in their concerns and for clearly indicating that the interview process was conducted in the spirit of partnership.

I thanked all the parent carers for participating in the study and asked whether they were comfortable with the questions I had asked. All of the carers felt that the questions were fine and expressed the opinion that the interview had afforded them the opportunity to tell their story, which for most of them was a cathartic experience, and reaffirmed their commitment and dedication to caring for their adult children (Langer, 1993).

The experience of conducting the interviews was highly varied from being very nervous to being very relaxed. Although I was able to draw on my skills from carrying out assessments as a respite care co-ordinator, I found that using tape recorders raised my level of anxiety because I was constantly wondering if they were working properly. Therefore for the first few interviews, particularly the first one, I was glancing regularly to see whether the light on the recorder was on. I felt that this detracted from the flow of the interview. However, the more interviews I did, the more confident I became, to the extent that I even forgot that I was using a recorder. Some parent carers' stories 'tugged on my heart strings' as their reports their about struggles for support were very vivid. The following is my reflection after one of my interviews.

This experience is different from my previous experiences of assessing parent carers' needs for services. Then, I was able to give a service as the respite care co-ordinator. I am now a researcher. I am actually taking something, their stories. I am not able to give anything tangible now, other than offering a keen listening ear which I believe that parent carers appreciate because so many times they are not listened to or heard. This parent is clearly struggling for services. She is very aware of the government's modernisation agenda for services and feels quite strongly about the lack of consultation with parent carers, she gives the impression that she is at the end of a cul de sac, with no way forward, she sounds like the 'fire' in her has gone out, just resigned to her role. I am left feeling powerless in relation to her needs.

### **3.17 Verifying accounts**

After each interview I wrote field notes in a reflexive journal. These notes captured my thoughts and feelings (as demonstrated in the above extract), how the interviews were conducted, their contexts, and any other observations I felt that were important in the operationalisation of the study. These notes were written mainly on my return journey after conducting an interview to avoid what

Rodwell (1998) describes as the natural reshaping that occurs when experiences become part of the memory. Penning my thoughts and feelings after conducting interviews was cathartic.

### **3.18 Member checking**

After transcribing the interviews, the previously mentioned practice of ‘member checking’ was put into operation, whereby the transcripts along with pre-stamped self-addressed envelopes were sent to carers to check their accuracy and for them to add any additional comments if they wished to do so. Most carers responded and some had minor corrections, but on the whole they were all satisfied that the information was accurate. I assumed that the carers who did not respond did not have any additional comments and deemed the transcripts to be representative of what they had shared in their interviews. Some carers took the opportunity to wish me success with the study when returning their comments.

### **3.19 Data analysis**

Rodwell (1998) asserts that data analysis is a planned activity which occurs in parallel with data collection. Therefore, preliminary analyses were conducted as the data were collected to explore the themes that were emerging. There are several approaches to analysing qualitative data. Having chosen the constructivist approach, one potential choice of data analysis was the constructivist grounded theory approach, as recommended both by Charmaz (2000) and by Rodwell (1998). However, framework analysis rather than grounded theory was used to analyse the data. Framework analysis was developed by Ritchie and Spencer (1994) and is described as being ‘widely used by qualitative researchers’:

*It is a matrix based analytic method which facilitates rigorous and transparent data management such that all the stages involved in the ‘analytical hierarchy’ can be systematically conducted. It allows the*

*analyst to move back and forth between different levels of abstraction without losing sight of the 'raw data'. (Ritchie et al., 2003: 220)*

The choice of using framework analysis was made due to its flexibility, in that it is not wedded to any particular epistemological, philosophical or theoretical stance and therefore can be adapted for use with any qualitative approach aimed at generating themes (Gale et al., 2013). The framework method also has distinct benefits for the participants of the study, which are discussed in the next section.

### **3.19.1 Analytical technique: framework analysis**

The framework method falls within the broad family of thematic analysis (Gale et al., 2013). However, there is a strong focus throughout the analysis on 'preserving the integrity of the participants' accounts' (Green and Thorogood 2004: 184). This was a very important consideration for this study because the parent carers should be able to recognise themselves in the findings, thereby placing value on their contribution. Grounded theory has a requirement of no preconceived ideas (Glaser and Strauss, 1967) for undertaking data analysis. Therefore 'bracketing or the effort to suspend previous assumptions or understandings' (Finlay, 2006:187) is recommended. A researcher in my situation, who has worked extensively with carers of adults with learning disabilities, is inevitably very 'close' to the data and bracketing would have presented a challenge for me due to my preconceived ideas. To this end, Finlay (2008) endorses the notion of preconceived knowledge and suggests that, in order for researchers to make interpretations, they need prior understanding to gain insight while at the same time being reflective.

One of the intentions of the study is to inform the practice of both social care and health professionals by providing new insights into working with older parent carers caring for an adult child with learning disabilities. Framework analysis assists this goal, as it is geared to producing findings that are policy and practice oriented (Ritchie and Spencer, 1994). Having justified the data analysis approach, I will describe how the data were managed and analysed.

Qualitative data analysis has, as its main focus, detection and the various tasks of defining, categorising, theorising, explaining, exploring and mapping (Ritchie and Spencer, 1994). In total 21 interviews were conducted, six of which were carried out with couples. The transcribed data collected from the individual interviews were managed using the ‘framework technique’ developed by the National Centre for Social Research (Ritchie and Spencer, 1994), which is a matrix-based analytic method used to manage and organise data according to key themes, concepts and emergent categories (Ritchie et al., 2003). The process was aided by field notes which helped make sense of the emerging themes.

The data from the couple’s interviews were analysed separately using a participant-based group approach, where each parent carer was allocated a row with an identifier, male (M) or female (F) (Ritchie et al., 2003). This was to ensure that each parent voice was captured in the analysis and subsequently in the report. The data were managed in five steps that are characteristic of framework method, as shown in Figure 3.4.

*Figure 3.4* The five stages of framework analysis (adapted from Ritchie and Spencer, 1994)

- |  |
|--|
| <ol style="list-style-type: none"><li>1. Familiarisation</li><li>2. Identifying a thematic framework</li><li>3. Indexing</li><li>4. Charting</li><li>5. Mapping and interpretation</li></ol> |
|--|

### **Familiarisation with data**

I listened to the audio recordings of the interviews several times, during the transcribing and after completion, and I also read the field notes several times in order to familiarise myself with the data. In reading the transcripts and field notes, I made reflective notes in the right-hand margins. These included my thoughts and any connections with other pieces of data.

## Identifying a thematic framework

Themes were identified from a few of the transcripts that had rich comprehensive data and ‘Post-it’ notes were used to record the descriptive themes. Once the initial list of themes was generated, they were grouped thematically and then sorted according to different levels of generality so that the index would have a hierarchy of main and subthemes (see Appendix G). These were re-sorted several times until I felt I had a workable structure or a conceptual framework, as shown, for example, in Table 3.4.

*Table 3.4* Example theme and subthemes

<b>Theme</b>	<b>Subthemes</b>
Experiences of the caring role	Details and nature of caring role. Facilitators of caring role. Demands of caring role.

## Indexing

Having constructed an initial conceptual framework, the next task is indexing. These indexes were applied to all the transcripts (raw data) by recording the indexes manually in the margins of the transcript, where I also made reflective notes about my ‘hunches’ or any surprises that I inferred from the data. This involved reading each phrase, sentence and paragraph in great detail.

## Thematic charting

Thematic charting involved summarising the data and at the same time trying to retain its context and language, and placing the summarised data in a thematic matrix (see Appendix H). I was very careful to ensure that the data captured accurately what participants said. I had to make a judgement as to how much data to include as too much data could make the matrix unmanageable, while over-

reduced data could lack richness (Ritchie et al., 2003). I also noted the particular quotes demonstrating the themes, and these were highlighted so that they were easily identifiable when synthesising the findings. The charts were read several times to ensure that the themes and subthemes were placed appropriately. At this stage a comparison was done within cases and between cases.

### **Mapping and interpretation**

During mapping and interpretation, several descriptive categories were identified and recorded on A4 sheets of paper. Connections were made and elements were reassigned to different categories as more meaningful classification developed. This is the final stage of the data management, and is a descriptive analysis. This was followed by a more abstract or theoretical classification which yielded the main themes and subthemes, which were reviewed against the entire data set. At this stage, some of the themes were renamed to provide a more accurate representation.

The following is a reflection of my thoughts during the data analysis:

For the last three days I have been reading transcripts. As I read each transcript I was taken back to the day I conducted the interview. This is an important stage of my research. I know I need to go into the depth of the data. I am getting excited. Some really interesting categories are emerging and I need to go through each stage thoroughly. However, the framework approach requires that interpretation comes after data management. I know data management is iterative. I can see the joint constructions between the parent carers and myself, and I can truly feel that I have used a constructivist approach. However, there are some feelings of ambivalence: Do I have too many categories? Do I group both positive and negative themes together? Am I doing this correctly? I think I need to revisit the chapter on framework data analysis. I think this will boost my confidence.

### **3.20 Challenges encountered in the research process and how these were addressed**

In one borough during a discussion following the presentation of the study, the Carers Development Manager told carers that a PhD takes many years and therefore the findings of the research would not be known for a long time. This seemed to impact on the motivation and recruitment of participants, and although many seemed interested in the study and over 50 information packs were distributed at the meeting, only two parent carers from that borough volunteered for the study. Significantly, the carers who volunteered were not at the meeting and got to know about the study from a meeting we attended at a voluntary organisation. I reflected on this, and on the other occasions when I presented the study I told carers the time it took to complete a part-time PhD, and that this was the usual period of time for in-depth research studies. I then left the carers to decide whether they wanted to participate. Many of them later volunteered to participate in the study by contacting me.

Another challenging situation occurred when I presented the study at a carers' meeting immediately after a representative from social services had announced the cuts to services for people with learning disabilities. The parent carers were very angry and I felt that this might impact on their interest in volunteering for the study. I was given only 10 minutes for my presentation, and I therefore decided to remain after the meeting to answer any questions parent carers might have about the study. This strategy paid off, as the parent carers welcomed the opportunity to ask questions and seven of them opted to take part in the research.

While the interviews with parent carers were being conducted, on several occasions couples presented themselves to be interviewed when only one parent carer had signed the returned form. This presented a challenge for me because this only became apparent when I arrived to conduct the interviews. On the first occasion, the parents were interviewed together. As the interview progressed I

realised that one parent was very dominant while the other seemed to be struggling to contribute. Their caring experiences were quite different, although they were caring for the same person. Therefore, I needed to ensure that I facilitated the parents to take turns in expressing their views. Initially it was difficult but I was able to draw on interviewing skills that I had used previously when I interviewed families. One option would have been to interview the parents separately, but the fact that they presented themselves as a couple connoted to some extent that this was the way they perceived their role, as sharing (division of labour), and this was quite evident during the interview. Having reflected on the challenges of this first interview with couples, I made some adjustments, such as placing the tape recorders strategically to ensure the responses from both parents were captured, and allowing sufficient time between questions to give each parent the opportunity to respond.

Although it was my initial intention to interview two focus groups, it was only possible to carry out interviews with individuals and couples. This was another challenge encountered in the recruitment process because only one carer volunteered to be in a focus group. This carer also opted for an individual interview, so I interviewed her individually, as there were no other volunteers to form a group. A focus group would have given parent carers who felt comfortable in a group setting the opportunity to have a 'voice'.

### **3.21 Rigour and quality of the study**

Demonstrating rigour and quality of qualitative research pose challenges for researchers (Seale, 1999; Ballinger, 2006). This is due mainly to the perceptions held by some commentators (e.g. Silverman, 1989; Atkinson, 1997) that qualitative work is romanticised and therefore lacks rigour. However, Meyrick (2006) contends that there must be criteria for evaluating qualitative research. To this end, some researchers have replaced the components used to judge the rigour of quantitative work by their qualitative equivalents. For example, Denzin and

Lincoln (2000b: 21) acknowledge that in qualitative research, terms like ‘credibility, transferability, dependability and confirmability replace the usual positivistic criteria of internal and external validity, reliability and objectivity’. They further offer ‘trustworthiness and authenticity as replacements for internal and external validity, which characterises positivistic work’ (Denzin and Lincoln, 2000a: 158). These two criteria are in keeping with Rodwell’s criteria (1998), which include trustworthiness and authenticity as qualities that must be demonstrated in the constructivist inquiry in order for it to be judged as rigorous.

For the current study, Lincoln and Guba’s (1985) criteria were used to evaluate trustworthiness, which they describe as ‘methods that can ensure one has carried out the process correctly’ (Lincoln and Guba, 1985: 245). How the current study ensured trustworthiness is discussed in the following section.

### **3.21.1 Credibility**

Credibility is concerned with the ‘accuracy of the results and interpretations’ as observed by the participants (Rodwell, 1998: 98). For the research to be deemed credible, it is very important that the researcher’s analysis, constructions and interpretations are believable to the participants who were co-creators in the construction of reality (Rodwell, 1998). For the current study, this was demonstrated by sending the transcribed data and a general summary of the research findings to the carers to check their accuracy and for them to add any comments.

Lincoln and Guba’s (1985) naturalist criteria to determine credibility include prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis and member checks. Prolonged engagement as described by Rodwell (1998: 98) ‘involves lengthy, purposive, intensive contact with the context and the stakeholders connected to the phenomenon or problem of interest for the investigation’. Interaction with the participants for this study took place over several months, starting with the presentation of the study to carers’ group where carers were afforded the opportunity to ask questions,

through to contacting carers to set up the interviews and finally returning the transcripts to check for accuracy.

Persistent observation is ‘an in-depth, focused pursuit of information found to be salient from prolonged engagement’ (Rodwell, 1998: 98). Although, over a period of time, I engaged with the parent carers who participated in the study, I was unable to observe them for any prolonged periods while presenting the study and conducting interviews, as there were time constraints.

Triangulation involves comparing two data sources with each other (Rodwell, 1998). However, Guba and Lincoln (1989) do not consider triangulation to be a credibility check, and they have expressed the view that the term is closely aligned to the positivistic approach. For this study, I was able to demonstrate credibility in several areas of the research process: for example, I used peer debriefing, which required me to discuss the research with someone who was not involved with the research process, but who has expertise in the methodological approach and was able to ‘ask the difficult questions, offer advice, explore the next step, support and listen’ (Rodwell, 1998: 99). This role was undertaken throughout the research by several people: namely, my supervisors and colleagues, and the independent members at my annual reviews. Member checks were also made during the interviews by recapping on what was being said to ensure that I had the correct understanding, requesting carers to comment on their transcripts and engaging in the hermeneutic process.

### **3.21.2 Transferability**

Transferability refers to whether the findings have relevance in a different context and how well they are understood, so that they can inform decisions about their usefulness in other settings (Rodwell, 1998). According to Guba and Lincoln (1989), the onus of transferability rests with the consumers (readers) of the research, as they are in a better position to know if the findings can be applied to their situation. However, Ballinger (2006) suggests that the researcher should provide ‘thick’ descriptions which offer a comprehensive account of the participants and the context of the study.

The study has provided detailed accounts of the setting, the participants, the problems and the findings, which should provide the reader with a holistic picture from which to determine whether the findings are applicable to their own situation.

### **3.21.3 Dependability**

Dependability is assured when all procedures used to collect, analyse and interpret data are within the expectation of constructivist research practices (Rodwell, 1998). This was demonstrated by keeping a reflexive journal throughout the period of the study, discussing key issues such as data collection and analysis, and recording the way in which decisions were arrived at with supervisors.

### **3.21.4 Confirmability**

Confirmability is achieved when an outsider is able to follow the steps taken by the inquirer from the raw data to the final product (Rodwell, 1998). An audit trail should therefore be provided, which Ballinger (2006: 239) describes as ‘the ability of the researcher to demonstrate how his or her work progressed throughout the project with the use of verifiable documents such as a research diary, and dated computer files’. Richards (2009: 152) supports this view, stating that ‘good qualitative research gets much of its claim to validity from the researchers’ ability to show convincingly how they got there’. This is demonstrated by keeping a reflexive journal and in Chapters 4 and 5, where direct quotes from the carers are used to illustrate and substantiate the themes that emerged from the data, confirming that the findings are grounded in the experiences of carers who are the main stakeholders in this research.

### 3.21.5 Authenticity as a criterion to demonstrate quality

Authenticity is one of the criteria by which qualitative research is judged. According to Rodwell (1998), in the constructivist approach it refers to research rigour and quality. In order to achieve quality, Guba and Lincoln (1989) in their seminal work identified five dimensions which they described as fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity. These dimensions were renamed by Nolan et al. (2003) as shown in Table 3.5.

This model is closely aligned to the constructivist approach, which seeks to include and empower, rather than alienate, the participants who have actively engaged in the research process. Therefore, this model is appropriate for this study, whereby the parent carers as active participants and a wider audience including professionals, policy-makers and academics are able to judge the quality of the study using Nolan et al.'s (2003) criteria.

*Table 3.5* Criteria for quality (adapted from Nolan et al., 2003)

<b>Guba and Lincoln's (1989) original criteria</b>	<b>Nolan et al.'s (2003) renamed criteria</b>
Fairness	Equal access
Ontological authenticity	Enhanced awareness of the position/views of self/own group
Educative authenticity	Enhanced awareness of the position/ views of others
Catalytic authenticity	Encouraging by providing a rationale or impetus for change
Tactical authenticity	Enabling action by providing the means to achieve, or at least begin to achieve, change

This study adopts a qualitative approach as discussed earlier in this chapter, whereby the qualitative researcher 'systematically reflects on who he or

she is in the enquiry and is sensitive to his or her personal biography and how it shapes the study, thus acknowledging biases, values, and interest' (Creswell, 2003: 182). Although, the qualitative researcher's 'presence is seen as a contamination by positivistic quantitative researchers ... it is recognised that the presence and influence of the researcher is unavoidable, and indeed a resource which must be capitalised upon' (Holliday, 2002: 145). What is important is that the researcher is aware of his or her effects on the study (Hammersley and Atkinson, 1983). Throughout the stages of this study, I constantly reflected on my influence on the research process in terms of the shaping of the design and the interpretation of the findings. Reflexivity contributes to the integrity and quality of the research by questioning the researcher's credibility and the impact on the meanings generated (Patton, 2002). The following extract captures one of my many reflections after interviewing parent carers.

I felt that I struggled today in this interview to remain focused. This parent seems to be overwhelmed with the caring role and her experience of receiving services is very negative. This made me feel like I need to offer some sort of explanation as this took me back to my role as a respite co-ordinator in a local authority. I know exactly what she is saying about the service being unreliable. I needed to keep on the researcher's hat and I also needed to acknowledge the parent's feelings, which is a balancing act. My body language clearly indicated that I am aware of the challenges and I have a strong sense that I might be influencing the responses.

### **3.22 Summary**

In summary, this chapter has given a clear account of the methodology and methods used to address the research questions, and it has justified the decisions taken throughout the study, by drawing on the relevant methodological literature. It has also provided a clear audit trail of how the study was conducted and the way in which the ethical issues and challenges were addressed. Additionally,

consideration has been given to the quality of the study by demonstrating its trustworthiness and authenticity.

The following two chapters present a synthesised account of the findings in regard to the two research questions. The next chapter begins with a consideration of the experiences of older parents who provide long-term care for their adult children with learning disabilities.

# Chapter 4 Findings: experiences and consequences of parental caregiving

## 4.1 Introduction

The findings from the in-depth analysis of interviews with parent carers who shared their experiences of providing care for their adult children with learning disabilities are presented in Chapters 4 and 5. This provides space for the participants' voices to emerge clearly without being overlaid with the findings of the literature on caregiving and quality of life. An integrated analysis of these two chapters will be presented in the discussion chapter (Chapter 6). This chapter addresses the first research question:

*What are the experiences of older parents who provide long-term care for their adult children with learning disabilities?*

The major themes and their corresponding subthemes, as shown in Figure 4.1, emerged from the analysis using the framework technique (Ritchie and Spencer, 1994) as described in Chapter 3. In addition to the demographics of the participants presented in Chapter 3, a brief summary of participants' salient characteristics is provided.

## 4.2 Participants' profiles

A total of 27 older parent carers (17 mothers and 10 fathers) participated in the study; of these 6 were couples; 8 were from the Black and minority ethnic communities and 5 parents were sole carers (2 widows, 2 widowers and 1 divorced person). All mothers with the exception of two (Mrs O'Connor and Mrs St Bernard) left work to care for their children. In contrast, but in line with traditional gender roles, all fathers with the exception of one (Mr Cullen, who

was retired on medical grounds) continued to work full time after the birth of their children. At the time of the interviews, all participants were retired with the exception of Mr and Mrs O'Connor. Two participants, Mr Smith and Mr Ramdeen, had two children with learning disabilities. The majority of the adult children were described by their parents as having mild learning disabilities (14 of the 23 adults); of the remaining 9 adults, 6 had moderate disabilities and 3 were severely learning disabled. These categories are in keeping with the classification of learning disabilities described in Chapter 1.

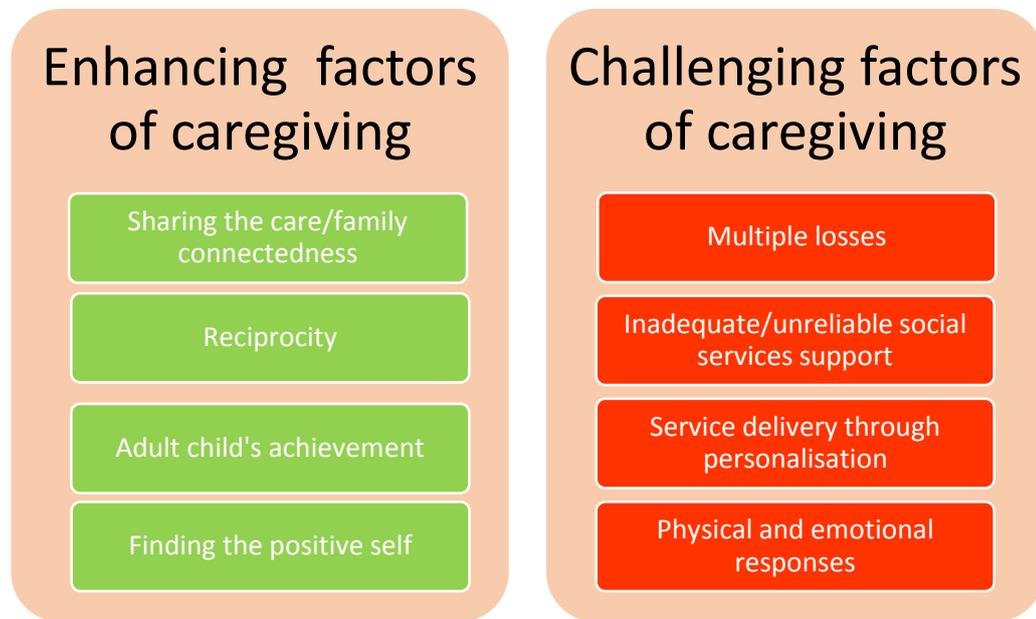
All the adults with learning disabilities were receiving social services support at the time that their parents were interviewed.

### **4.3 Experiences and consequences of caregiving**

The caregiving experiences explored here were categorised into two main themes: 'Enhancing factors of caregiving' and 'Challenging factors of caregiving'. These factors can be viewed on a continuum and the analysis suggested that the older parents' caregiving experiences were enhancing as well as challenging, and can be best understood in terms of the interaction of a number of the factors shown in Figure 4.1. This figure provides a summary of the older parent carers' experiences of caregiving and how these shaped their lives. An overview of the themes is presented before discussing their corresponding subthemes, and extracts from participants' accounts are used to illustrate these subthemes. In this chapter and the next, I have endeavoured to include as many of the 27 participants' extracts as possible to demonstrate these themes, in keeping with the constructivist approach described in Chapter 3. Constructivism is interested in multiple meanings and therefore is premised on relativity (Rodwell, 1998; Ponterotto, 2005). Therefore, no one's story is privileged over another (Ballinger, 2006) and the 27 voices of participants are all represented in these findings. In addition, as discussed in Chapter 1, I have included reflexive accounts in both findings chapters (Chapters 4 and 5), to emphasise my 'contribution to construction of meanings throughout the research process'

(Willig, 2008:10), which was facilitated through the joint enterprise in meaning making between the participants and myself (Guba and Lincoln, 2004).

*Figure 4.1* Themes and subthemes of experiences of caregiving



#### **4.4 Overview: enhancing factors of caregiving**

This overarching theme captures the different enhancing experiences of caregiving among the older parent carers. These were centred on family connectedness fostered through shared caregiving; the mutuality of the relationship between parent carers and their adult children; the pride they felt when their children realised their potential; and the satisfaction and rewards derived from providing long-term care for their adult children. They also valued the opportunities caregiving afforded them to become involved with different groups or organisations, whereby they were able to use their experience and expertise. Although participants acknowledged the challenges of caregiving, they equally articulated the factors that enhanced their caregiving experiences, which for the overwhelming majority of these older parent carers ‘outweighed’ the challenges they encountered. The subthemes of enhancing factors of caregiving

are: sharing the caring role/family connectedness; reciprocity; adult child's achievement; and finding the positive self.

#### **4.4.1 Sharing the caring role/family connectedness**

This subtheme relates to sharing the caring responsibilities for the adult child between parents and other family members, and the closeness or family connectedness that resulted from shared caring. Most participants reported that, due to the complexity of the task, caring was best done by more than one person. Therefore, they shared the caring role with other relatives. This division of labour meant support for each other, in addition to caring for the adult with learning disabilities. Some parents were of the view that the stresses associated with caregiving have the potential to divide couples and family members, but for these families, this was not the case. On the contrary, shared caring fostered family connectedness. Parent carers expressed the view that sharing the care responsibilities was integral to caring for adults with learning disabilities, particularly in the light of the few services that were available when their children were born, most in the 1960s. However, due to changes in some parents' circumstances over time, a few parents in this study were caring for their adult child on their own.

Parent carers acknowledged that formal services became more available for people with learning disabilities in the 1990s with the advent of care in the community; however, care was mostly provided by family members. Parents felt that sharing the caring responsibilities with spouses and/or family members enhanced parental caregiving experiences, as it fostered a sense of togetherness. For example, Mr O'Connor, whose son was severely learning disabled and lived with him, recounted:

*I personally retired from full-time work almost three years ago now to provide a bit more support. I wanted to do a manual lifting course*

*because [son] is awkward to handle, and [my wife's] knees are now playing up. I am very conscious that I am the [one] to do the lifting around here so I obviously want to know how to lift people who needed care. So I spent one morning training [in lifting and manual handling]. (Interview 5, pp. 3 and 4)*

This demonstrates that this couple made a conscious effort to share the caring role. Mr O'Connor was aware of the aspects of the caring role that he needed to help with, and he sought the necessary training to support his son. His account also gives a sense that he was not only caring for his son but cared about his wife by taking on the lifting tasks and reducing his work to part time to complement her in the caring role.

Similarly, Mr Sylvester shared the caring responsibilities with his wife. He explained:

*You see this is what I mean by adjustments. In my job I had to work away as part of my job involved travelling, but fortunately I was able to fly to Scotland for example and return on the same day and be on time to put my [daughter] to bed. But it meant a lot of planning as I had to get up early in the morning to catch the first train. (Interview 4, p. 4)*

The above demonstrates a level of planning and negotiation between parents in order to meet their children's needs. It was also evident that there was a sense of togetherness between these couples. Caring for a child with a learning disability at home at that time would have been very difficult, as most people with learning disabilities were being cared for in residential settings and parents therefore had minimal support.

Apart from parental sharing of the caring role, participants spoke of other family members sharing the caring responsibilities, as was the case in Mr Johnson's family:

*He [their son with learning disability] had three other siblings and they have been very supportive in the purest way, which held the family together. (Interview 11, p. 4)*

This sibling support was further endorsed by Mr Johnson:

*His [son's] older sister is very helpful and has more or less taken over the immediate dealings with the [service providers]. (Interview 11, p. 4)*

The involvement of these siblings in their brother's care is a family affair which enhanced the caregiving experiences of the parent carers, who were both over 80 years old.

In relation to family care, an interesting idea emerged from Mrs St Bernard's narrative when she was asked if anyone helped with caring for her son. She responded:

*Everybody, everybody; it is a family community. (Interview 19, p. 1)*

The notion of a 'family community' highlighted the family's commitment to caring for their relative with a learning disability. This relates to the familiar phrase, 'care in the community', which generally means the family. Mrs St Bernard had five able-bodied adult children who 'shouldered' the caring responsibilities along with herself and her husband, and unlike most of the other mothers in the study, she continued to work full time until retirement.

It was evident that Mrs St Bernard's nursing profession helped to shape the way in which she went about caring. She recounted her working experiences:

*[As a nurse] it was one community and if you are finished your duty, [that is,] my time is up, I go to somebody else [and] take over [their task] and finish it. (Interview 19, p. 3)*

Clearly, Mrs St Bernard organised her family care as a team. In other words, caring was everyone's business. Shared caring with family members resonated with my personal experience of caring for a relative who was terminally ill and I reflected as follows:

Parent carers who shared the caring responsibilities for their adult children with other family members, apart from helping the adults, they also sent out a positive message that the family as a whole was interested in their welfare and well-being. Shared caring was beneficial to families as they derived a sense of togetherness through team work. This reminded me of my situation when my family took turns to care for my uncle. Some of us travelled long distances to do our share of caring which clearly was too much for one person on a continuous basis. This sharing of the caring responsibilities strengthened the bonds between us which helped us to prepare for the inevitable when it happened, and more importantly my uncle felt 'secure' and valued by having several family members caring for him.

Apart from family members, there was interconnectedness between parent carers and their adult children with learning disabilities, which is discussed under theme of reciprocity.

#### **4.4.2 Reciprocity**

Reciprocity relates to the mutual support that existed between parent carers and their adult children, which was expressed in differing ways, such as providing companionship for each other, and the adult children doing household chores and making simple snacks for their parents. For this group of parents, their caring role has been extended as they are actively caring in their later years due to the increase in life expectancy for their children and themselves. Reciprocity was prevalent across the participants' accounts and many older parent carers valued their adult children's company and the mutual support they derived from being

together. To this end, reciprocity was one of the main factors that parent carers reported as enhancing their caring experiences and quality of life. This was particularly so for the older parent carers whose adult children were co-resident. Although some adults, due to the severity of their disability, were unable to reciprocate in a tangible way – for example, making a cup of tea – their presence meant a lot to their parent carers as they provided companionship, especially for parent carers who were widows or widowers. For these parents, their adult children played a vital role by ‘filling’ the void left by the death of spouses.

This is captured very well in the extensive account from Mrs Collins, a 76-year-old widow whose son lived with her. She explained:

*It's good to have someone else in the house now I'm on my own. I don't always see a lot of him. He'll come home and as I said have a shower and have dinner. He will stay with me until roughly around about half past seven and I'll be in here and he'll vanish in there, and he'll be playing videos in there. But he's there, there's someone in the house. And also he always makes sure all the doors are locked up at night, that's his job and I let him do it. And we've got bird feeders in the garden which my husband used to keep topped up. He has taken over that job, so I let him do it. Because you have to let him do as much as he possibly can. And also if I've used something out of the larder or the fridge, anything like that, and I put the packaging in the recycling bin – because we've got a recycling bin – the next thing I know he's taken the packaging out, he's written down what it is, he's put the packaging back. He's got a shopping list! I get given shopping lists. So, I'd miss him terribly if he wasn't here, because he is good company, he's good fun. And we can talk about steam railways.*  
(Interview 7, p. 4)

Mrs Collins appreciates her son's company and the tangible help he provides. Mutual sharing and caring are very evident in this extract and demonstrate the

symbiotic relationship that generally exists between adults with learning disabilities and their older parent carers (Prosser, 1997). The household chores that Mrs Collins' son helped with had previously been done by his father. This gave a sense of him taking over his father's role.

The level of reciprocity in Mrs Collins' situation is unique in relation to other participants' experiences. For example, Mrs Whittle described the help given by her daughter:

*She is very good at cake and biscuit and tea and sometimes you [may] get her to do a coffee, but it did not come very often. But she can do it, you know. (Interview 13, p. 4)*

These two extracts demonstrate different levels of reciprocity between parents and their adult children. In Mrs Whittle's case, her daughter lived in a residential home but visited on a regular basis, highlighting that adult children can reciprocate even though they do not live at home.

Interestingly, Mrs James viewed reciprocity as akin to co-residency and she feared that the symbiotic relationship she enjoyed with her son living at home would be lost if he went to live in a residential setting. She reasoned:

*He does make a nice cup of tea, yes, yes you know. I don't really want him to go into a home. (Interview 9, p. 11)*

Mrs James's case highlights some of the possible factors that influence older parent carers' decisions about seeking out-of-home placements in planning future care for their adult children with learning disabilities (Grant, 2010).

#### **4.4.3 The adult child's achievements**

This subtheme relates to the skills that adult children acquired beyond the life skills they acquire at home. These ranged from participation in sporting events

and learning photography, to reaching their full potential academically. In relation to these skills, some parent carers spoke of their children's achievements and the gratification and sense of pride they felt when their children realised their potential. Mrs Patel recounted her son's achievements as follows:

*At one stage we thought he [son with disability] would have been able to hold on to a job and he used to read ... not a lot of speech, but he had more than he has now, definitely. He also won a gold medal at a special Olympics in [local area]. I will show you the photograph; his picture came out in the newspaper. (Interview 3, pp. 12 and 13)*

Mrs Patel's extract indicates that she had great expectations of her son and felt at one point that he might be able to work. She spoke about her son's achievement with great fondness and looked quite pleased at his obtaining of a gold medal and being acknowledged in the local newspaper. What was very interesting about Mrs Patel's account is that she also went on to speak about her able-bodied son, who had achieved academic excellence in the medical field. The fact that she spoke of the achievements of her two children together gave the impression that she derived the same level of pride from both, as she made no distinction between their abilities.

Like Mrs Patel, Mrs Rahim described her son's award as follows:

*He did a photography course and was awarded a camera. He went to London with his older brother. He was [dressed] very smart in his tie and coat. He was very happy to be given the award because he did not know he was going to be given one. He was very happy. He came home and said, 'Look mom, I got a camera.' (Interview 18, p. 5)*

In listening to Mrs Rahim I could discern the immense pride she felt from her son's achievement. Her other two children were professionals and there was a

sense that she supported her son in his personal development as she did with her other children.

Interestingly, although Mr Cullen and Mrs Wood found caregiving quite challenging, particularly Mrs Wood who described her caring role metaphorically as ‘carrying the most incredibly heavy boulder up a mountain’, their children’s achievements were seen as the ‘highlights’ of their caregiving experiences. Similar to the parent carers whose caregiving experiences were less challenging, they too felt a deep sense of pride and were pleased to report their achievements. Mrs Wood explained:

*[Her daughter] was a member of a voluntary organisation ... something that was a bit like girl guides and boys scouts for young people with learning disabilities in [borough] and they were fantastic ... and they got her through her Duke of Edinburgh awards, bronze, silver and gold ... All of that. (Interview 14, p. 3)*

This indicates that, with adequate support, adults with learning disabilities can engage in mainstream activities and achieve similarly to their friends and peers who do not have a learning disability, which can instil pride in their parent carers.

Mr Cullen, who was the sole carer for his daughter, also recounted her achievements:

*When she was passing all her subjects, that was really wonderful and it was nice to see all of her certificates. [She] likes to see that I was there, even more so after my wife had died. I would be going to the prize giving in July. She was really chuffed that I was there and she knew that people were watching her. She was really pleased. That’s great for me that she is doing well. (Interview 16, p. 8)*

Despite his tiredness, which was constantly mentioned throughout his interview, Mr Cullen was quite eager to talk about his daughter's achievements because he saw these as the 'high moments' of his caregiving and quality of life experiences. His extract indicates the strong bond between him and his daughter, as she wanted him to be present, and he publicly demonstrated his support by attending her prize-giving ceremonies. All the parent carers who spoke of their children's achievements indicated that their caregiving experience and quality of life were enhanced by marking and celebrating their children's accomplishments.

Parent carers' accounts indicate that they were interested in their children's personal development regardless of their level of ability, and they supported them to realise their full potential and give them the best chance in life. For this group of adults, gaining life skills and pursuing their areas of interest were important in promoting independence and self-confidence about their future care. Their parents were caring in later life and were reaching the end of their caregiving trajectory due to the increase in their own needs. It may be important to understand that for these parents the celebration of their children's accomplishments and the development of self-confidence perhaps offered some sense of existential comfort and hope for an anticipated future when their capacity to care would inevitably diminish.

#### **4.4.4 Finding the positive self**

This subtheme relates to a range of positive coping strategies that participants employed to parent and care for their children successfully. One of these strategies included 'giving of self' – that is, parent carers getting involved with and committing to organisations that supported people with learning disabilities. In this study, all participants spoke about their initial feelings of devastation when they realised that their children had a learning disability and the implications for them as a family. However, most parent carers reported that over time their emotions changed from despair of what seemed to be a personal tragedy, to hopefulness and acceptance, having re-appraised their situation by looking beyond their children's disabilities and focusing on the positive aspects

of parenting and caring. They therefore seized opportunities to get involved by being advocates for their adult children, and sharing their experiences with other parent carers in group meetings and conferences. Being part of these activities, and sharing their experiences, helped parent carers to cope with their situation, as described in this extended extract from Mr O'Connor, who had two children with a rare learning disability:

*Once we knew what it was, we then found out there was a charity that actually included that particular condition. It actually turned out that there are two children's charities so we joined both of them.*

*Obviously, we liaised with them and in terms of the caring and the support, I think those charities do have a role that is particularly important. They have annual conferences. At the time that we joined, there were lots of area representatives and little get-togethers. There were opportunities where you can share experiences, and I've taken the view of trying to get this out of my system by actually writing about it, and my wife has been supportive. I wrote a short paper about contrasting the two ways that we have been looking after [our children] and we took that to a conference. (Interview 5, p. 10)*

Clearly Mr O'Connor's involvement helped him to cope with his situation, and he and his wife were keen to share their experiences with other parent carers. Through giving their time and sharing their experiences, parent carers were able to focus on the positives of caregiving, which in turn provided opportunities for self-development.

Similarly, Mr Sylvester and Mr Johnson became involved with organisations that supported people with learning disabilities. Mr Sylvester explained:

*I got involved in [charitable association] and I feel I've been able to make a great contribution there, being a trustee for about 16 years. I*

*have also been involved locally since I retired, now I chair the group that you came to meet [with parent carers] and that's very rewarding because you feel you are helping people, getting them up to date. So I'm now giving a lot of time into helping and supporting parent carers, and I find that very rewarding. And it's even more rewarding when I meet people and they hail me and say 'oh you are [daughter's] dad'. (Interview 4, p. 14)*

There is a sense from this quote that Mr Sylvester derived personal satisfaction by serving on the committee and was happy to be involved with the organisation rather than engaging in self-pity. As he went on to explain:

*I feel in many ways that you can wring your hands and moan all the time. It's much better to do something. (Interview 4, p.14)*

Mr Johnson also recounted his involvement:

*Well I was the chairman of [organisation], and what I did as the chairman was to get the authorities, now this is quite important, to accept that autism came under learning disability. Because if you're dealing with the authorities, it's very important to know with whom you're dealing and if the NHS agrees it is part of learning disability, a lot of things follow. (Interview 11, p. 4)*

Both Mr Johnson and Mr Sylvester used their expertise and influence for the greater good of adults with learning disabilities and their parents.

Besides being involved with organisations, parent carers expressed the 'positive self' through acceptance of their situation. For example, when Mr Brown was asked about caring for his son, he replied with gusto:

*Absolutely brilliant to be honest [raises his voice]. I once said to someone who told me it must be awful having a child with handicap, I said no. If I had a choice now, and if someone could say unwind, you can have [my son] as he is or you can have [a son] who can talk and express himself, I would have [my son] as he is. This is what I know and love and that's important to me. (Interview 2, p. 20)*

This demonstrates the unconditional love that parents have for their children. From Mr Brown's narrative, I surmised that he had moved on from his initial disappointment and accepted his situation. This acceptance can be viewed as parent carers finding the 'positive self', whereby they have moved beyond the disappointment they initially felt, to accepting their situation and feeling positive about their children.

Similar sentiments were echoed by Mr Smith, who had two adult children with learning disabilities. He reasoned:

*We are lucky that we've got them ... I am lucky to have them ... one or two of my friends had children with disabilities and they died. Things could have been a lot worse. (Interview 1, p. 12)*

Listening to Mr Smith, there is a sense of emotional maturity in seeing the positives in parenting and caring for his two adult children. He felt fortunate to have them. Generally, caregiving is framed mainly around adversity – that is, stress and burden – but these parent carers' accounts captured both the stresses and positive changes in their lives, and this was heartening, as their stories inferred a sense of survival and mastery. The notions of parent carers being 'survivors' and gaining mastery over their situation are explored further in the discussion chapter (Chapter 6).

On hearing the parent carers' stories of how they had changed adversity into opportunities for personal growth and transformations, I was reminded of my own situation, where I was able to change adversity into opportunities when

the volcano in Montserrat stamped its authority on the island and I had to relocate to England. I reflected on this:

Most parent carers spoke of the positives they derived from what started off as an adverse situation, as their expectations were dashed when they first realised that their children had a learning disability. Their stories captured the stresses as well as the personal gratifications and transformations they derived from caring for their adult children. I felt that I was truly getting a balanced picture of parents' caring experiences and most importantly they seemingly had 'survived' some difficult times. This mirrored my own situation, having been 'caught up' in a volcanic crisis which was stressful and having to leave familiar territory where I was living comfortably, and exchange landscapes in seven hours from Montserrat to England where I had no connections. Similar to the parent carers in my study caring for a child with a learning disability was not something they had planned for, my situation was also unplanned. Like some the parent carers, I managed to turn adversity into opportunities by using different coping strategies, one of which was focusing on education which provided the opportunities for self-development and personal transformations, in short [I became] 'a survivor'.

Parent carers also reported the flip side of caregiving and quality of life experiences – the challenges. They rarely spoke of the subjective burden, apart from expressing their sadness when they were told that their children were learning disabled; more prevalent in their accounts was the objective burden: the unreliable and inadequate formal services and the negative professional and societal attitudes (socio-structural barriers and challenges) they had encountered in caring and trying to access formal services for their adult children. These are discussed in the following section.

## **4.5 Challenging factors**

This second overarching theme encapsulates the challenges that parent carers experienced, having made the choice to provide long-term care for their children. These were: multiple losses, inadequate/unreliable social services support, service delivery through personalisation, and physical and emotional responses to caregiving.

### **4.5.1 Multiple losses**

This subtheme concerns the negative impact of caregiving on parents, and has several strands which focus on the various losses that were experienced as a result of providing long-term care for their adult children with learning disabilities. The losses reported were centred on loss of sleep, loss of career, loss of career identity, and loss of friends. All participants experienced some form of loss; however, a few of them experienced a combination of the losses identified. These were generally the parents who were ‘immersed’ in their caregiving role, and who were very dependent on formal services due to having few or no informal support networks.

#### **Loss of sleep**

This theme concerns the sleep deprivation experienced by most parent carers. While it could be argued that many parents’ sleep is disturbed during the early years of caring for their children, the caveat is that, for this group of parents, loss of sleep was cumulative as the loss of sleep that is generally associated with caring for children in their infant years continued into their children’s adulthood. To this end, sleep deprivation was reported as one of the main challenges that older parent carers faced in their caregiving trajectory, and without adequate support it had the potential to impact negatively on their health and general well-being. The reasons for sleep interruptions varied from attending to personal care, to providing reassurance due to panic attacks, and erratic sleep patterns. Mrs

Jones's sleep was being interrupted to provide care and, coupled with the situation of no respite support, this impacted negatively on her mental health. She related her experience:

*I was not getting any sleep with the baby being awake half the night and [daughter with disability] being awake the other half. I wasn't getting any sleep at all and I was cracking up gently ... I was really cracking up and I asked for help and they said there isn't any respite. (Interview 6, p. 3)*

The above highlights the psychological impact of sleep deprivation on Mrs Jones and the shortage of respite services. Respite is generally valued by parent carers because it allows them to get a break from their caring role; it usually involves overnight stays and therefore allows parents to 'recharge their batteries' so that they can continue in their caring role.

For some parent carers, like Mr Cullen, Mrs Singh and Mr Ramdeen, loss of sleep was viewed as synonymous with the caring role and therefore it was only mentioned after they were prompted. For these parent carers, sleep deprivation was seemingly a natural part of caregiving. Mr Cullen went on to describe his situation in caring for his daughter as follows:

*She is still very frightened at nights. She is frightened of noises and quite often she comes into my bedroom to wake me up because she is upset. And I have to put her back into bed and sit and wait at the side of the bed until she goes back to sleep. (Interview 16, p. 5)*

Providing care at nights proved to be very difficult for Mr Cullen because he was trying to cope with his own health needs and also being the sole carer for his daughter, who in some respects was quite able, but needed constant emotional support. In this case, having to comfort someone who is frightened can be

physically and emotionally draining, and it impacted on Mr Cullen's physical and emotional health as he constantly spoke of being tired and feeling depressed. Mrs Singh, who was caring for her 54-year-old son and was awakened several times at night to attend to his personal needs, also felt tired. She related:

*Too much waking up, three, four times a night. (Interview17, p.4)*

Similarly, Mr Ramdeen, who was 80 years old and had two sons with learning disabilities, was awakened several times to look after one of his sons. He explained:

*We [he and his wife] are always awakened. As far as [son] is concerned, about four to five times, he goes several times per night and every time my wife has to awake me. With my other son, if he has any difficulty at nights, he would tell us. (Interview 20, p. 6)*

Mr Ramdeen indicates that he is responsible for attending to his sons' personal needs. Apart from the gendered caring, which could be cultural, what is also apparent is the frequency of his sleep interruptions, which can have serious implications for Mr Ramdeen's health.

Mrs Patel, a sole parent carer who cared for her 33-year-old son, had experienced multiple losses which included loss of sleep. She related a very emotional account. She described her experience as follows:

*I could not sleep for two nights because he was restless. I get up every time he wets so I have to change him. Sometimes he soils, so I have to shower him at four o'clock in the morning. Nobody wants to know. (Interview 3, p. 8)*

Clearly for Mrs Patel, the impact of sleep deprivation for consecutive nights left her feeling tired and burnt out. Having to provide personal care meant that Mrs

Patel was also actively caring in the early hours of the morning. Therefore for her, caring seemed relentless and she felt that no one was interested in her situation, as she was on her own without any tangible or emotional support. For many parent carers, sleep deprivation due to continuous night-time caring was an ‘invisible’ burden which seemed to have been magnified at nights and contributed a sense of isolation and detachment from the world.

While most parent carers acknowledged that loss of sleep was problematic as it impacted negatively on their health, one parent carer, Mrs St Bernard, did not see it as a problem. She responded as follows when asked whether her sleep was interrupted at nights.

*Mrs St Bernard: ‘Oh yes he is incontinent, twice a night sometimes.’*

*Researcher: ‘So your sleep is interrupted?’*

*Mrs St Bernard: ‘No well I put it this way, it is not interrupted ... that is no problem, because in the days when I worked in the hospital when they [patients] were wet and dirty I would clean them and put them back to bed.’ (Interview 1, p. 4)*

From Mrs St Bernard’s extract, it is clear that she did not find being awoken at nights problematic; she was a nurse and worked on night shifts, so she was accustomed to being awake at nights. However, for the other parent carers who were not accustomed to working during the night, being interrupted several times at night to provide care over a prolonged period presented health challenges that are associated with sleep deprivation. I reflected on this, as I was very concerned about the impact this deprivation could have on parent carers’ health, particularly for those who were on their own. The following are my thoughts:

Providing active care during the day and night must be a ‘shattering’ experience and can have serious consequences for one’s health. I am particularly concerned for all parent carers who are deprived of sleep over the years but particularly so Mrs Patel, Mrs Jones, Mr Cullen and Mr Ramdeen as they indicated quite strongly that loss of sleep is problematic and have inferred that they are tired. I am wondering, what were the outcomes from their carers’ assessments, as they were all assessed? Without adequate sleep it would be difficult for parent carers to continue in their caring role as they would ‘burn out’ and their health would deteriorate. The answer here must be more respite support for these parent carers and a reassessment of their needs.

### **Loss of career**

This theme refers mainly to mothers who had to leave paid employment when they realised that their children would need extra care. Most mothers, with the exception of two who continued to work full time, left their jobs to care for their children with the hope of returning to work at some point. However, this did not happen as they continued to provide active care into their children’s adult years. With mothers giving up paid employment, this meant that there was less family income and they were also at risk of isolation, as being out of work reduced their social contacts. A few mothers compensated for the loss of income by doing part-time work, which in most cases was menial work when their children went to school or college. They reported that this was only possible because their employers understood their situation. However, most of the mothers stayed at home; although they were reluctant to give up paid work, they had no other choice. They also joined parents’ groups which helped to extend their social contacts and gave them the opportunity to share their experiences of caring for their children. While these social contacts were welcomed by most mothers, a few mothers expressed that they did not join parent carers’ groups because they did not have anyone to help with their adult children.

Loss of career surfaced several times in Mrs Wood's narrative because she felt very passionate about being in paid employment. Having to give up full-time work, she felt at a disadvantage in many ways, such as not being able to socialise with work colleagues. She also felt that her professional development was adversely affected. She lamented:

*I haven't been able to go out to work which I think has [pause] there is a whole part of me that feels as if it hasn't been lived, which I very much regret. (Interview 14, p. 6)*

Mrs Wood's account illustrates the value and meaning she placed on paid work and having a career. She saw work as the avenue through which she could develop her full potential. Later on in her interview, she indicated that work was not about the money, because financially they were well off with her husband's salary, but work gave her an identity, boosted her self-esteem and confidence, and provided opportunities for her professional development.

Likewise Mrs Jones left work to care for her daughter. She said:

*I am [a] teacher and [I] gave up work the summer after my daughter was born because it was clear she needed me and I didn't want to give her to a child minder or anyone else to look after because I thought they're not going to do much. And I did look around [but] there was no real childcare for people with learning disabilities. (Interview 6, p.2)*

From Mrs Jones's extract it is evident that she had no option but to give up work to care for her daughter. Seemingly she could not find someone who was suitable to care for her. From her account she seems to convey that she was the best person to care for her daughter when she said that her daughter needed 'her', implying a mother's care. At the same time, she was torn between continuing on

her career pathway or leaving work to take up a new career, albeit an imposed one.

Mrs Patel also gave up her career to care for her son, and throughout her interview she referred several times to her profession and the contribution she made to her country of origin by setting up a child welfare clinic. She explained:

*Once we came here, I had to give up my career because I found absolutely nothing to help me. Nothing, nobody guided me, my GP practice knew obviously [son] was disabled. (Interview 3, p. 8)*

From Mrs Patel's extract it is clear that in order to continue working she needed support and she was unaware of the formal support systems in England.

However, even when mothers had both formal and informal support, they chose to give up their careers due to the extra care their children needed. This was the case with Mrs Sylvester, who also valued the benefits of work. She explained:

*I would leave the job I am doing and stay at home for some years and start thinking again later about employment. I never got back to work. (Interview 4, p. 3)*

Mrs Sylvester shared the care for her daughter with her husband and also accessed formal support. She clearly saw work as an outlet, as she felt constrained by being at home. She expressed that she took the 'brunt' of the caring, a view which was endorsed by her husband. She explained further:

*For me it [caring] makes me feel isolated without a doubt because I never got back to work and it was difficult. (Interview 4, p. 3)*

## Loss of career identity

Apart from the financial reward and the opportunity to socialise, parent carers linked their identity to their career, so having lost their career by giving up their job to care for their children, they also experienced loss of their career identity. Ironically, having lost one career, they gained another, as a parent carer. However, for some participants this transition was not smooth because parents had the hope of returning to work. They were therefore in limbo for a while, until the harsh reality set in that it was difficult to sustain a career and the caring role at the same time.

For Mrs Jones, who like many other mothers gave up her job to care for her child, her identity was clearly linked to her profession. When asked about returning to work, she responded:

*I am a frustrated teacher ... I had to give up work, something that I am really passionate about. I love teaching and I love kids. To give up all that was quite hard, it was very hard and financially of course it's very hard. (Interview 6, pp. 12 and 13)*

This response clearly sums up Mrs Jones's feelings and more importantly it shows how she views herself as a frustrated teacher, not a frustrated parent carer. This gives the impression that, even though Mrs Jones has not taught for many years, she still identifies herself as a teacher.

Similarly, Mrs Wood and Mrs Patel had to give up their jobs to care for their children. Mrs Wood said:

*Well working, I have always had a huge interest in the personal development world, so I have gone on courses, done training ... many things like that, but always on weekends or evenings you know. (Interview 14, p. 7)*

This quote indicates that Mrs Wood values being employed, as she feels it is through the avenue of paid work that she can develop herself, particularly her identity. Her current role as a parent carer was seemingly not as fulfilling and this was very strongly articulated during her interview.

Similarly, Mrs Patel found that, having given up her career in the health field to care for her son at home, because she could not predict when he would be ill and her working conditions were not flexible, she became isolated and felt that her sole purpose was to care for her son. She explained:

*Once we came here, I had to give up my career because I found absolutely no help ... I couldn't return to work because he was falling ill and I could not do a 9.00 [a.m.] to 5.00 [p.m.] job. (Interview 3, p.3)*

Mrs Patel's life changed considerably when she relocated to England. She was unable to work, and without her familial support she became isolated. During her interview, she spoke about her professional career several times and clearly derived a sense of self-worth and identity from her work in the health field. It was difficult for Mrs Patel to come to terms with not being able to continue in her profession and with the loss of her professional identity.

### **Loss of friends**

This is the final strand to the subtheme 'multiple losses'. Many participants spoke of the loss of friends after their children were born. When the differentials between their children and their friends' children became apparent, their friendships waned, and as a result they drifted apart. Although some parents wanted to maintain this friendship, others did not. For example, Mrs Steiner found it difficult to continue with her circle of friends when her daughter was diagnosed with a learning disability. She said:

*It's completely unlike me, I completely changed, my whole personality changed. I knew that, you know. For instance, I was a nanny before I got married and I even had a girl staying with me after I was married, the girl I looked after. But then you know I did not want to be in touch with those people any more, and they didn't either, so it is really strange. It changes, it just changes your life. (Interview 12, p. 4)*

In Mrs Steiner's case, she chose not to remain in contact with her previous friends and they did want to continue the friendship. Seemingly, having a child with a learning disability invoked a feeling of being different and she felt more comfortable with parents of children with learning disabilities, as she further explained:

*Researcher: What things do you find helpful in your caring role?*

*Mrs Steiner: 'I get together say 3 or 4 times a year with other carers, they become [my] friends and that helps a lot.'* (Interview 12, p. 3)

This extract indicates that Mrs Steiner values other parent carers' friendships because she does not have to explain her situation. This could be one of her coping strategies for dealing with the situation.

In contrast, Mrs Halcyon wanted to keep in touch with her friends but it seemed that there was a 'natural fading' of friendships after she had her son with a learning disability. She reported:

*We make the best of it [caring], but the fall off in friends and family [pause]. I think one day there is just going to be me and him [husband]. (Interview 15, p. 10)*

This extract indicates that Mrs Halcyon was feeling isolated and 'cut off' from her friends. In her case, she was not keen on the carers' groups because she

wanted to continue with the circle of friends she had before her son was born. Thus she was resisting relationships that forced her to break with the past and was seemingly reluctant to take on her new identity as a parent carer.

#### **4.5.2 Inadequate/unreliable social services support**

This subtheme was prevalent across all the interviews and focuses on services which were resource-led rather than needs-led. Such services failed to meet the needs of parent carers and their adult children. Participants reported that they all had at least one occasion when the service they accessed was inadequate. For many participants, inadequate services were seemingly the rule rather than the exception because they experienced difficulties in getting appropriate services on a continuous basis. For example, respite services for their adult children were in great demand, but in many instances these services were not available. As a result, parent carers did not get the regular respite they anticipated; hence they were disappointed.

Mrs Jones recounted her experience of accessing respite as follows:

*It was a great relief to have a bit of respite, because it meant that I could have a [good] night's sleep, because she [daughter] did a lot of waking at nights. But it [respite] wasn't often to be honest. There was one time which will be interesting for you, I think. They said to me, oh you've got to have one night [in a month]. I got to the top of the list and that was the allocation. I said I don't need one night. If there is somebody that is desperate (like I was) please give them. I'll rather go once every fortnight. No, you can't do that. This is the system and if you don't want it you will go to the bottom of the list and you will have to climb back up again. I said it is awful for me with very young kids. They said, 'take it or leave it' and I just couldn't believe it, so she went one night per month. (Interview 6, pp. 6 and 7)*

The above highlights the attitude of service providers and the inadequacy and inflexibility of respite services. Clearly, the respite allocation did not meet Mrs Jones's needs and there was no room for negotiation. This highlights that respite was resource-led rather than needs-led.

Mr Halcyon felt strongly about the contribution parent carers make by caring for their children, which provides a huge saving for the government. He experienced a different difficulty from Mrs Jones in accessing respite for his son. He said:

*Respite, that is another problem ... There were occasions when respite was withdrawn at short notice. We prepared him. We got him to agree. We would tell him respite is on Friday. On Friday we would have them [respite providers] saying, 'we've got an emergency [another person needs the respite] and it is off'. Having told him and built him up for the whole week and got him ready to go, this is a problem as they push aside pre-planned respite, and in the case of someone with autism, it is very difficult. (Interview 15, p. 4)*

This account highlights the unreliability and limited availability of the respite services for adults with learning disabilities for some participants. Respite is a much needed service because it gives parent carers a break from their caring role, and while the needs of all families must be met, cancelling one family to accommodate another creates problems. This sends the wrong message to the families whose respite has been cancelled because they perceive that their needs are not a priority and this can bring about a feeling of being devalued.

In Mr Halcyon's case, the family's hopes were dashed at the last minute. Managing services in this manner leads to a lack of trust. Mrs Jones echoed Mr Halcyon's experience of having his respite services cancelled at the last minute.

Apart from respite services, which the majority of older parent carers had difficulty in accessing at the times convenient to them, some parent carers spoke

of other services such as day services and schools which were inadequate. For example, Mrs Steiner explained:

*I don't know if you know [day centre]. It is for the very disabled ... wheel chairs and things like that. She [daughter] did not fit in. She did not do the things they were trying to do. She didn't take part in anything and she walked from one room to another. You could tell she was really confused. (Interview 12, p. 6)*

Mrs Steiner's account clearly conjures a picture of a service that did not meet her daughter's needs and gives a sense that the service operated on the basis of 'one size fits all'.

Like Mrs Steiner's daughter, Mr Johnson's son accessed a day service that did not meet his needs. He said:

*It [day service] was wholly inappropriate for my son. He once had a tantrum, in my knowledge where he completely lost his mind. And we have two reports in his life, I think, where he had a tantrum, and on one occasion was a physical assault. But the centre was totally wrong for him, which is one of the reasons why we earnestly sought another place for him. (Interview 1, p. 3)*

This extract indicates that the staff at the centre might not have been trained to deal with challenging behaviour and also that the wrong day service may have been offered to Mr Johnson's son. I reflected on the service situation, particularly the respite services, as follows:

I felt angry and drained listening to participants' difficulties in accessing services, respite in particular. This was very poignant for me as I worked as a respite co-ordinator for adults with learning disabilities in a local authority. As an insider at one point and now an outsider I thought about the 'good old days' of arranging respite breaks, with parent carers having an allocation of thirty days per year which was pre-planned. In addition, their adult children were given a week at a holiday village so that parent carers could have a break from their caring role. Seemingly, the government's cuts to services are having serious implications for respite services for adults with learning disabilities and their parent carers. This clearly is a mismatch in relation to the objectives set out in the White Paper Valuing People 2001 and more recent Valuing People Now 2009. No wonder older parent carers feel let down, it seems like promises have been broken.

#### **4.5.3 Service delivery through personalisation**

This theme relates to the government's Personalisation Agenda, which includes direct payments and personal/individual budgets. The difficulties encountered in accessing these initiatives surfaced regularly in participants' narratives and most parent carers felt that personalisation, especially direct payments, was burdensome as it added another 'layer' of stress to their caring role. There was a sense that they were given little information about this agenda and it was forced on them without proper consultation.

Personal budgets can be taken as a direct payment, which is money given to families to purchase their care, or can take place through service users having a say in how they want the money to be spent on their behalf. Of the parents who accessed direct payments, only one couple reported that they were satisfied, as they were able to have flexibility and control in meeting their son's needs. The other parent carers did not experience these benefits; on the contrary, they struggled to manage the paperwork and the recruitment of personal assistants, which increased their stress levels.

Mrs Carter, the main parent for her son with a mild learning disability, described her views on direct payments as follows:

*I am fearful that what wouldn't be helpful is the special direct payments that is being awarded to our sons and daughters. I know that the borough are leaders in this and it will go nationally at some time, but it seems to me, quite a few people I know in the system are already on direct payments. So for some people, they say it is the best thing since sliced bread, but for our sons and daughters, I know it is going to be a nightmare ... I can understand it would be extremely helpful for adults who maybe have a physical disability and like to take charge of their lives and the way they want the money to be spent, but certainly with my son, awarding him money and saying ok, this is your money ... Well certainly, he wouldn't be able to look after the money himself, so that presents a problem. If he is not going to look after it, then we'll [older parents] have to look after it, and we'll have to be his accountants and arrange his care. And now we are getting on in life we don't want the hassle. (Interview 8, p. 4)*

Mrs Carter seems to be ambivalent about direct payments for people with learning disabilities and their parent carers. She highlights the additional responsibilities that older parent carers would have to take on, which she is not willing to do at this stage of her life. She feels that this initiative might be more helpful for people who can manage it themselves: for example, people with physical disabilities.

Mr Halcyon also reported that direct payments were burdensome and unhelpful. He recounted:

*Well, the unhelpful thing is all the administration that is associated with direct payments and personalisation. It puts a big burden on carers. My wife does most of this. For example, the woman that we*

*pay to look after [son] when he goes to his college courses, we pay her the fee and we work through an agency to do the financials to deal with Inland Revenue. But my wife still has to write cheques regularly ... Effectively, you become an employer with all the liabilities of an employer. If you get it wrong, the Inland Revenue comes down on you. This is a problem. Now, my wife is a graduate. She knows what she is doing, but a lot of people aren't. And even she finds it heavy going. We are here to care for our son. We are actually saving the state a lot of money ... But they load things on top of us. This is definitely unhelpful. They try to make out that they are doing us a favour. They are giving us choice. (Interview 15, pp. 5 and 6)*

Mr Halcyon clearly sees direct payments as an added burden, due to the level of accountability it entails, and he explains that if parent carers do not get it right, they will be held culpable. Although he receives direct payments, it does not seem likely that he would recommend it to other parent carers because of his experience.

Mrs St Bernard was very vocal about direct payments, as she too felt the system was burdensome. She said:

*I don't want it. No chance there. Too much paperwork. That's what I tell them. I don't want it. Not a chance, you know ... It did not matter because I don't want that money. (Interview 19, p. 8)*

Mrs St Bernard echoed the sentiments of Mr Halcyon regarding the administrative tasks associated with direct payments. Mr James and Mrs Patel endorsed their concerns about direct payments. Mr James's perception of direct payments was as follows:

*I mean this direct payments scheme is a prime example of people not knowing what's going on. [Son] is not on it because nobody ever said*

*you've got to fill in this form. Some people fill in forms and some people don't. (Interview 3, p. 5)*

For Mr James, the direct payments system is very vague, as no one has given him sufficient information or explained to him exactly what it is.

In contrast, Mrs Patel has direct payments and she knows what they involve, but has encountered several difficulties. She recounted:

*They [the borough] have taken on this thing which government is now starting. That everybody be in charge of their money, direct payment. They are giving all the responsibility and doing nothing to help. I refuse, but they said you have no escape, you have got to take it. I said I can't take on any more. (Interview 3, p. 5)*

This extract gives the sense that Mrs Patel took on direct payments and the associated responsibilities reluctantly. She further explained:

*I honestly cannot take on any more responsibility. I cannot go on chasing who will come and work. They say you will have better control because [you] will be paying them yourself. No, it does not work like that. If I have someone coming and I pay, then suddenly they say I am going home, my son is not well. Then I am completely on my own. I have to find a new one from somewhere else. I can't do that every day because ... So I would much rather go to Social Services. Even though it means I don't have any control, at least I know they [care workers] will listen to Social Services and they will come [to work]. On top of that they [Social Services] give me the money and they want me to keep each and every receipt ... I don't want all those additional things. I really can't, I have enough on my plate as it is. (Interview 3, p. 11)*

Here Mrs Patel explains her feelings about direct payments, which she clearly had difficulties in managing. Being the employer, she feels powerless in recruiting care workers. She believes that Social Services are better placed to enforce contractual arrangements with care workers. Therefore, for Mrs Patel, direct payments are having the opposite effect to that intended: rather than giving her control and flexibility, they are a source of stress.

In relation to personal budgets, Mr Whittle acknowledged that while services for people with learning disabilities had evolved over time, he was quite sceptical of direct payments and personal budgets. His preference is for accessing services by the traditional means – that is, with Social Services being the purchaser of services. He explained:

*And I mean the old system, the day centre, the great positive thing was that they met up and they socialised with all their friends and that sort of thing. But in terms of developmental work we were always critical. I mean I was always critical that there was not anything meaningful going on ... They say [daughter] got a personal budget, they've basically given up ... in some respects it might be what is convenient for staff. (Interview 13, p. 7)*

This indicates that Mr Whittle was not in favour of personal budgets and from his account he did not seem to make a distinction between direct payments and personal budgets. He was seemingly not involved, as he referred to the residential home where his daughter lives as 'they'. This could mean that the decision to access services via a personal budget and direct payments was made without the family being fully involved.

These examples of older parent carers' experiences of direct payments and personal budgets indicate the level of resistance to this particular mode of service delivery. However, Mrs O'Connor, a health professional, was one of the two mothers who managed to work full time and the only parent who found direct payments useful for her son, when respite was not available. She explained:

*The borough does not have adequate respite for young people over 18 ... What they try to do is to give us a budget to see if we can make our own arrangements. (Interview 5, pp. 3 and 4)*

Later in the interview, Mrs O'Connor said:

*You need your support. [The borough] does not have respite care, but at least we have money so we can pay a carer and we can go to [activity] which is something we do together. (Interview 5, p. 13)*

From Mrs O'Connor's accounts, direct payments were offered to purchase respite because respite was not available from the borough for adults with learning disabilities, and she willingly accepted it, which gave herself and her husband a break from their caring role, to do things together. It seems that the rationale for offering direct payments to Mrs O'Connor was different because it was the option to purchase an unavailable service. This is unlike other participants' accounts, in which direct payments seem to have been mandatory for purchasing social services. This meant that parent carers felt that direct payments were imposed on them, and many of them did not want the additional responsibility of organising their children's care. There also seemed to be a lack of support with the administrative tasks for those who were accessing direct payments. These tasks were perceived to be overwhelming by parent carers and made direct payments an unattractive option.

Having worked successfully in supporting older parent carers of adults with learning disabilities as a direct payments champion in a local authority, I was surprised at this finding. However, I was pleased that participants felt comfortable to voice their experiences about how they were offered direct payments and the lack of support from professionals, as sometimes older people find it difficult to talk about the negative aspects of service delivery in face-to-face interviews (Atwal and Caldwell, 2005). This is my reflection on participants' accounts of direct payments:

As someone who has encouraged older parent carers of adults with learning disabilities to access services on direct payments both for themselves and their children, I felt saddened by parent carers' difficult experiences of accessing direct payments. Their experiences were different from my experience of working with older parent carers. This led me to reflect on my role in supporting families – for example, having meetings with bank workers to explain direct payments and to assist families with the paperwork in setting up bank accounts. Also I attended meetings with the direct payments team to provide feedback from the families who were accessing direct payments and discussed any difficulties with direct payments advisors with a view to resolving them. I realised from participants' accounts, times had changed and the philosophy of choice, flexibility and control that underpins direct payments was not realised by these families. As a matter of fact, direct payments were perceived as a burden by most of the participants. I questioned what went wrong, and it was evident families were thrown into the 'deep end' without support and there was a sense that direct payment was mandatory, and if they were assessed for formal services it was imposed on them. I believe that this area of service delivery needs further exploration.

#### **4.5.4 Physical and emotional consequences of caregiving**

This subtheme relates to the physical and emotional consequences experienced by older parent carers of adults with learning disabilities. The main physical consequence of caring that was reported centred on 'feeling tired', which is captured as 'exhaustion', and the emotional consequences were lack of appreciation by professionals and politicians, being perceived as unintelligent or lacking in understanding by professionals, and feelings of guilt and being stigmatised by society due to the adult child's challenging behaviour.

## **Exhaustion from caring**

Although most participants expressed a strong commitment to caring for their sons and daughters, a few parents expressed feelings of being tired from providing care. For Mr Cullen, this was a recurrent theme throughout his interview. As a widower, he was the sole parent carer for his adult daughter and it was evident in his narrative that providing active care had taken its toll. He explained:

*I am finding that I am getting more tired as the years go on.  
(Interview 16, p. 3)*

He further related his experiences:

*Caring is tiredness that just keeps coming back over and over again. At the moment I feel tired, no energy, and I feel unhealthy. In fact I went to the doctors because I am going to sleep during afternoons and mornings. One morning this week I was back in bed at 10 o'clock and I was out for an hour and a half because I was just tired.  
(Interview 16, p. 8)*

For Mr Cullen, this level of tiredness is clearly impacting on his ability to care for his daughter, who is very dependent on him. Although he has a substantial care package from Social Services, he is still finding it difficult to coordinate the care. He expressed that his preference was supported housing for his daughter and that he would continue to be involved in her care but would have some more time for himself. He was very articulate in stressing that he still wanted to be involved, but wanted to promote his daughter's independence in preparation for the future.

Mrs Wood also reported that she felt tired caring for her daughter. Although, unlike Mr Cullen's daughter, her daughter lived in a residential home,

she was still involved in her daughter's care more or less on a daily basis. She said:

*Life with her [daughter] physically present [pause] it's like all the energy is sucked out of you. (Interview 14, p. 2)*

This extract indicates that Mrs Wood is extremely tired and possibly burnt out, to the point where her energy level is very low. She went on to elaborate:

*It [caring] [has] become so much more of a slog and it's taken its toll in terms of one's ideology and one's oomph. (Interview 14, p. 5)*

In this account Mrs Wood conveys the fact that she was not only physically tired but mentally 'drained'. This gave the impression that she was at the end of her tether. Similarly, Mrs Patel reported low energy levels. She said:

*My energy level is going down and what I used to do even five years ago I can't do now because my own health is deteriorating, but I try. (Interview 3, p. 9)*

The impact of caring on Mrs Patel is similar to the experience of Mr Cullen and Mrs Wood, whereby over time tiredness is defining their role and may be signalling the end of their ability to continue providing active care. However, relinquishing their role could be equally difficult due to the interdependence between them and their adult children.

While the feeling of tiredness was reported as the main physical consequence of caring, to a lesser extent parent carers spoke of feeling devalued by the lack of appreciation shown by professionals, politicians and society – for example, being perceived as unintelligent or lacking in understanding by professionals, and being taken for granted by politicians who see them mainly as a resource.

## **Lack of appreciation**

Most participants' accounts indicated that their input into their adult children's care was not appreciated by professionals and politicians and was seen as a given. This sentiment was articulated strongly by Mr and Mrs Halcyon in their interview. Mrs Halcyon expressed that:

*I just feel we are so unappreciated [for] the work we do as parents, nobody knows, friends and relatives think they have got an idea what it is to be 24-7. Yes, yes and there is no point in moaning about it.  
(Interview 15, p. 9)*

Mr Halcyon supported his wife's view, adding:

*And one does not want praise all the time but one would like to be appreciated. The people [professionals and politicians] ... and I am bringing this up all the time, every time I go to these meetings with [council representatives] and the likes, my mantra is carers care and that is their primary function, to care, not be administrators, not to be responsible for this, that and the other. Just a little bit of appreciation on the part of the powers that be. We [carers] contribute loads.  
(Interview 15, pp. 12 and 13)*

Mrs Halcyon's and her husband's accounts sum up their feelings of being undervalued. This is due to the lack of appreciation by professionals and politicians for their input in their children's care and the expertise they have acquired over time as parent carers. While families and friends may have some idea of the level of demands placed on parent carers of adults with learning disabilities, the reality is that no one seems to acknowledge this. These sentiments were endorsed by most of the participants.

In addition, Mrs Collins expressed a different view of how professionals perceived parent carers of adults with learning disabilities, which also conjures a feeling of being devalued. She explained:

*And it is a worry, we [parent carers] do get the feeling that a lot of officers from Social Services don't really give much thought to parent carers. Whether they mean to come over like that or not I don't know but I always tended to get the impression that some of them seem to think that because we've got sons and daughters with learning disabilities we are not very bright ourselves. (Interview 7, p. 5)*

This extract sums up Mrs Collins' feelings about how parents who have children with learning disabilities are perceived by some professionals and the assumptions that are made about parent carers. These perceptions prompted me to reflect:

I found the perceived link between the adult child's level of ability and the parent's aptitude very concerning because it has the potential for practitioners to discriminate against parent carers unknowingly, and reduce the quality of engagement. It also has an overtone which devalues the parent carer's contribution and undermines the foundation of support for people with learning disabilities. I wondered whether practitioners are aware of this perception.

Participants also reported feelings of guilt and being stigmatised by society because of their children's challenging behaviour, especially when their children's learning disability was not evident. For most of the parent carers who spoke of difficulties in managing behaviour, their children were diagnosed with autism. Mr Cullen shared his experience of an incident which involved his daughter who had autism:

*Society can't seem to cope with someone with a disability when they themselves are not well behaved ... In a shop, we were queuing up to pay for an item, a man and little girl came up behind [daughter] and bumped into her ... and [daughter] shouted and complained. The guy started to get on his high horses and started to throw his weight around, and was pushing and shoving me, telling me to clear off and it's none of my business that he was pushing [daughter]. And I said it is, she is my daughter and she has disabilities, if you can't see and this is the thing that annoys me, a lot of people say I didn't know she has a disability ... that makes me down, and [daughter] is down, so of course it makes the day bad. (Interview 16, p. 5)*

From Mr Cullen's account it is evident that he became upset when he had to defend his daughter's behaviour. Members of the public seem to be oblivious to people with learning disabilities and respond negatively when they present with challenging behaviour. For older parent carers, having to advocate for children by asking society to be more aware of their needs can be difficult. Mr O'Connor, whose son has challenging behaviour, endorses the view of society being unaware. He said:

*Again it is about trying to find a society which understands people with learning disabilities and supports them. (Interview 5, p. 15)*

Mrs Steiner, Mrs Jones, Mrs Wilkinson, Mrs Wood and Mr Halcyon all spoke about their feelings when their children exhibited challenging behaviour in public. They felt guilty and stigmatised and judged for having a child with a learning disability. Mrs Steiner explained:

*You get those funny looks from other people, 50 years ago. So you become a bit withdrawn. (Interview 12, p. 4)*

This extract highlights how some people respond to parents whose children have learning disabilities and the impact it can have on parents, such as feelings of guilt and stigma.

Mrs Jones also spoke of the embarrassment she and her husband felt when their daughter challenged in public. She recounted:

*Her tantrums again, you know, come and go at the most awkward times. We've had horrendous do's with her in very embarrassing situations and [it got] to the point where her [father] can't really cope with all the embarrassment. (Interview 6, p. 10)*

This extract indicated the lack of public empathy for parents whose children have challenging behaviour and how parent carers feel when they constantly have to explain their child's behaviour in a society where people with learning disabilities are living longer and there should perhaps be a more heightened public awareness around disability.

Older parent carers are not 'new' to the caring landscape of their children. They are experts by experience and have a lot to offer in developing services for adults with learning disabilities. However, they need to feel that their contribution is valued and that they are equal partners in a collaborative endeavour of providing care for their adult children. Equally important, carers need to feel that they are part of society, not in a situation of 'them and us'.

## **4.6 Summary**

This chapter has presented an analysis in relation to the caregiving experiences of the participants. The key findings presented above illustrate a rich picture, with a myriad of perspectives found in the participants' accounts which highlight the complexity, challenges and conflicts of caring for their adult children over their life span and in the later stages of their lives. However, these were experienced in different measures, depending on how well the parent carers

were able to work through the challenges that they faced. This was influenced mainly by the quality of support they were able to access, their formal and informal support networks, the severity of their children's disability and whether they presented with difficult behaviour.

Despite the challenges that participants had to negotiate on an almost daily basis, most participants appraised their caregiving experience positively, which in turn enhanced their quality of life. For these participants, caring in their later years had brought about significant benefits, such as personal development and a sense of gratification and satisfaction in caring for their adult children, with whom they had fostered a unique relationship, and these benefits seemed to outweigh the challenges. Their accounts gave a sense that most of the participants had worked through their difficulties successfully and had emerged as 'survivors', having started out with a situation that society tends to view as a personal tragedy. Having made the choice look after their children at home, they had to adapt. Their lifelong experiences of caregiving had enabled them to become equipped for their role in later life as they had acquired expertise, a sense of mastery and coherence over their situation.

However, for a few parents this was not the case, as they felt 'stuck' in their caring role and that their lives were 'on hold', not having been able to realise their potential. Notably, these participants were 'immersed' in care by virtue of being the main or sole carer, and they had various difficulties which were ongoing, such as: little or no informal support; difficulties in engaging with formal services; and receiving low-quality formal support which did not meet their needs. As a result, their situation affected their caregiving experience and quality of life adversely. This is discussed in Chapter 5.

Participants' narratives were very powerful and highlighted the complex and dynamic nature of caregiving. Many of them used metaphorical language to describe their experiences. What became apparent in analysing their accounts is that caring for their adult children with learning disabilities in their later years had added some positive dimensions to their lives, and the difficulties they encountered were not primarily associated with their children's disabilities; rather they were socio-structural barriers, such as lack of access to, and the poor

quality of, formal services, and poor societal and professional attitudes. The impact of the caregiving experiences discussed in this chapter is explored further in relation to parent carers' quality of life in Chapter 5.

Chapter 5 therefore focuses on the findings related to the second research question: How do older parents who provide care for adult children with learning disabilities conceptualise their quality of life?

# Chapter 5 Conceptualisations of quality of life

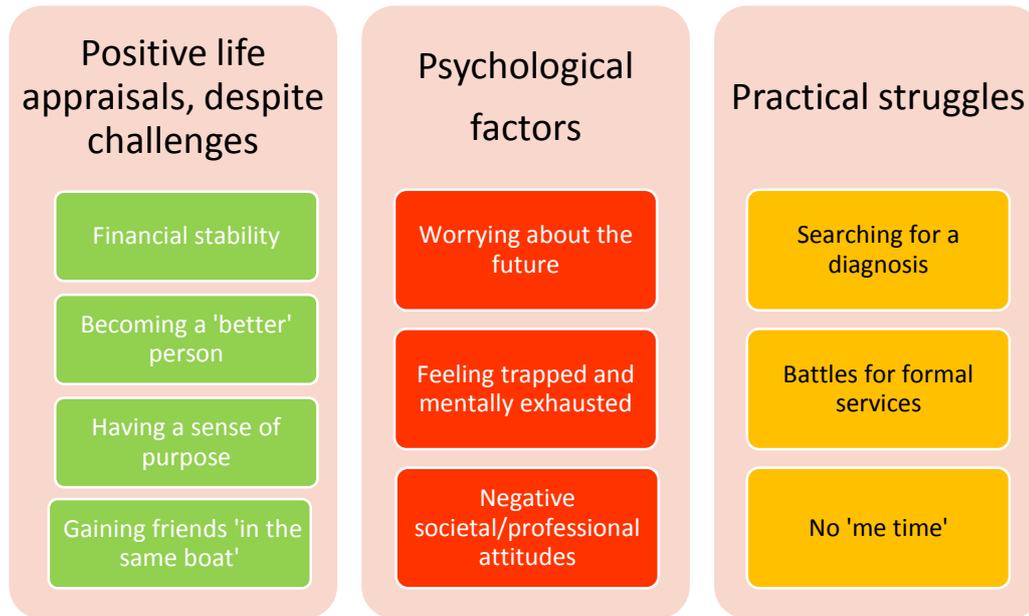
## 5.1 Introduction

Chapter 4, the first findings chapter, examined older parent carers' experiences of caregiving for their adult children with learning disabilities. This second findings chapter seeks to examine these older parent carers' conceptualisations of their quality of life in relation to their caregiving role by answering the second research question:

*How do older parents who provide long-term care for adult children with learning disabilities conceptualise their quality of life?*

Three major themes were identified in relation to how the participants conceptualised their quality of life, from the analytic process described in Chapter 3. These are: positive life appraisals, despite challenges; psychological factors; and practical struggles. These themes with their corresponding subthemes are shown in Figure.5.1. As in Chapter 4, this figure is intended to guide the reader and provide an understanding of the parent carers' conceptualisations of their quality of life in relation to their caregiving experiences. Each theme is presented and discussed in turn. An overview of the major themes is presented before discussing the corresponding subthemes. Extracts from participants' accounts are used to illustrate these subthemes.

Figure 5.1 Major themes with subthemes of conceptualisations of quality of life



## 5.2 Overview: positive life appraisals, despite challenges

This theme captures the essence of how the majority of participants described their overall quality of life. The dynamic nature of caregiving and quality of life was articulated clearly in parent carers' accounts as they related the changes that occurred overtime on their caring journey. Through prolonged caregiving, older parents developed expertise which gave them the confidence to face new challenges. In this study, parent carers' confidence was boosted by financial stability which helped them to take control over their lives, and therefore most parent carers' narratives were centred on positive life appraisals which added value to their quality of life. These positive appraisals can be themed in the following ways: financial stability; becoming a 'better' person; having a sense of purpose; and gaining friends 'in the same boat'.

### 5.2.1 Financial stability

This theme relates to participants' assessments of their financial status and confirmation that they were able to meet their financial commitments. Most

participants spoke of being financially stable and expressed the view that having sufficient money to meet their needs contributed to a good quality of life. Although some participants (mainly women) had to give up work to care for their children and most of them never returned to work, they were able to meet their financial needs comfortably on one income, because one parent in each household (mainly men) worked full time and had a steady income, as acknowledged by Mr Smith, who was 72 years old and had two children with learning disabilities:

*Our quality of life overall, it wasn't bad. Financially, we weren't badly off; I had a job which paid above the average. We did not want for anything basically, and I could afford the odd luxuries. We went on holidays together. We went mostly on caravan holidays which were much more acceptable for [son]. (Interview 1, p. 4)*

Mrs O'Connor also felt that having sufficient money among other things, such as a good education, enhanced her quality of life and she is one of the two mothers who were able to manage a career alongside caring responsibilities. In appraising her quality of life, she compared her situation with others and acknowledged that she had been lucky. She described her quality of life as follows:

*I'd say pretty good because I think I have been pretty lucky. I was born in the twentieth century in the UK and I have had a good education and good family. My family are all loveable and supportive. I have some great friends and lots of interest. I've been very lucky with my career. Money has never been a problem because we always worked jolly hard, both of us. We live in a nice house. Apart from my horrible knees, I would say yes, I am an awful lot better off than some. (Interview 5, p. 11)*

Being able to support one's family and having financial stability were important to Mr Smith's and Mrs O'Connor quality of life. Mr Smith had agreed with his wife that he would work full time while she stayed at home to care for their two children who had learning disabilities because he felt caring was a full-time job in itself, and therefore felt that it was not practical for his wife to seek paid employment. Mrs O'Connor, on the other hand, was one of few women who managed to balance the two roles, caring and paid work. This was achieved with her husband being the main parent carer.

Mrs Johnson, like Mrs O'Connor, felt that her husband and herself were lucky to have had a privileged education, and although Mrs Johnson remained at home, they were able to live reasonably well on her husband's salary. For Mrs Johnson, being financially well off contributed to having a good quality of life. She summed up her quality of life as follows:

*I think we are lucky that we are reasonably well off, so that what wasn't provided by the state, we could buy. I think ... yes we sent him to private schools because there wasn't a suitable school. (Interview 11, p. 8)*

This above quote indicates that Mrs Johnson had the money to pay for private educational provision when the state was unable to meet her son's needs. Having the ability to pay for services meant that parents were not solely dependent on the state and this reduced the level of stress that is generally associated with unmet needs.

Mr Whittle, similarly to others, quite clearly expressed the view that having a good quality of life meant having sufficient money to meet his financial needs. He said:

*It's quite good, we have no money worries, we are, what's the word, self-sufficient. (Interview 13, p. 16)*

While in most of the parent carers' narratives, having sufficient money was explicitly referred to as adding quality to their lives, Mrs Collins and Mr Sylvester offered different perspectives about money and its relation to quality of life. For example, Mrs Collins' reasoned:

*We had a reasonable quality of life ... [However,] you could be a millionaire with no ties and have no quality of life. You work your quality of life out, I think, according to your own ideas, [and] your own finances obviously. (Interview 7, p. 6)*

There is a sense from Mrs Collins' quote that money on its own does not enhance people's quality of life, but rather there are other attributes which influence how people manage their lives. Mr Sylvester had another viewpoint:

*I have been able to have a good quality of life in the things we do. Even though you are a pauper you can still have a good quality of life. (Interview 4, p. 13)*

Mr Sylvester felt that he experienced a good quality of life and that this was dependent not on the amount of money he had, but on the personal adjustments he made, and the fulfilment he derived from caring for his daughter.

Data from the present study support the view argued by Farquhar (1995) that quality of life means different things to different people. In this study even couples who were caring for the same adult child differed in the way in which they conceptualised quality of life. For example, Mr and Mrs Sylvester appraised their quality of life from different perspectives. Mr Sylvester reported that his quality of life was enhanced by caring for his daughter. He felt he had become a 'better person' through his experiences of caregiving. This theme is discussed in the following section. In contrast, Mrs Sylvester felt that caring restricted her personal development and therefore reduced her quality of life. Seemingly, a good quality of life for her meant being able to realise her potential through paid

work. I found these differing perspectives interesting, and they highlight the subjectivity of the concept of quality of life.

I was surprised that most parent carers in the current study reported that they were financially stable, as this is the opposite of what is generally portrayed in policy/social services circles, which often give the impression that all carers struggle financially (Yeandle et al., 2007). These parents are older carers, so looking at the data through a generational lens deepens our understanding about the importance of not treating all carers as the same. There are not only individual differences, but also generational differences in the kinds of things that older parent carers prioritise and value in their lives. I reflected on this issue:

I was surprised by this finding that the majority of parent carers reported that they were financially stable, especially as most households had only one source of income. Although many parents were professionals and some of them lived in affluent areas, from listening to these parent carers' stories, in particular the mothers, I got a sense that they were quite resourceful and thrifty and not that money was in abundance. Thrift seems to be a 'dying' quality in the modern generation as borrowing tends to be encouraged by most financial institutions. For this group of parents, seemingly they lived within their means.

### **5.2.2 Becoming a 'better' person**

This theme parallels the caregiving theme in Chapter 4 'finding the positive self', in that it can be seen as another coping strategy which parent carers employed while caring for their adult children. In describing how they had become a 'better' person, they spoke about personal transformations such as being aware of the needs of others and having a sense of humility. These different positive experiences brought about a change in parent carers' focus, as acknowledged by Mr Johnson:

*Quality of life is not expressed in sea cruises and river cruises and the like, because quality of life is one's contribution towards their fellow man. (Interview 11, p. 8)*

For Mr Johnson, a good quality of life was about doing something for humanity rather than focusing only on enjoying oneself. He explained that his privileged background and the academic successes of his family could have made him haughty and selfish, but caring for his son with a learning disability has grounded the family in reality, which Mr Johnson summed up as follows:

*[Son's name] helped the family to come together. It's a privilege to have [him] in many ways. All our lives are different because of him. That's astonishing. (Interview 11, p. 6)*

Similarly, Mr Sylvester described his quality of life from the perspective of having and caring for his daughter. He explained:

*It is a term I have difficulty with, it is banded about, 'quality of life', and I have used it. I am very careful. A lot depends on the individual, what you want out of life, what you are expecting. I would tend to say we have had to make many more adjustments than we ever thought we would have to make, and there have been more restrictions. As to quality of life I get the same pleasure. (Interview 4, p. 4)*

The above quote indicates that quality of life is an individual experience and is influenced by the extent to which people re-align their expectations, depending on their circumstances. For Mr Sylvester, caring for his child with a learning disability warranted several adjustments which he had made successfully, and by so doing he had added value to his life. He elaborated:

*My conclusion about quality of life might shock you and everybody else but I think having a disabled daughter (daughter's name) has improved my quality of life. It made me a better person. I may not have some material things. I may not be able to go out as much as possible. There may be physical demands but as a person, it makes me always aware that there is somebody in the household we have to do extra catering for, and in that way, it made me think of everybody else in the household. (Interview 4, p. 7)*

There is a sense that Mr Sylvester made not only physical, but also psychological adjustments, which were manifested in personal transformations such as his perception of others' needs and his concerns for their well-being.

Both Mr Sylvester and Mr Johnson focused on their caregiving role while describing their quality of life, and related the transformations which had taken place in their lives. Mrs Ali also spoke of re-adjusting her life when she realised that her daughter need extra care. She described her quality of life as follows:

*It [quality of life] is good, we have to be patient, we have to be calm to look after a person like this. You have to learn, you have to be strong. You need to love, to show the person because that person is damaged, body and brain and everything, you have to look after a person like this. Be caring, very caring from the heart. (Interview 21, p. 5)*

From Mrs Ali's account it is evident that she invested a lot of time and energy in the care of her daughter. She says her quality of life is good because she cares 'from the heart'. There is a sense here that caring is deconstructed as love, and the fundamental traits of being patient, strong, calm and adaptable are integral to 'successful' caregiving.

Another personal attribute that enhanced parent carers' quality of life was identified by Mr Brown:

*Humanity, humanity, an understanding of what life is about really, it is quite fundamental, philosophical. That makes me less of a machine and more a human being. (Interview 2, p. 2)*

This extract indicates the psychological changes that some parent carers undergo in adjusting to their changing circumstances of having a child with a learning disability. Similar to Mrs Ali, Mr Brown highlights the intrinsic values that enhance people's quality of life and stresses the importance of the fundamental understanding of caring as an undertaking that has the capacity to 'open up' what is important to life. He is arguing that caring has enriched his life and added to its quality rather than taken it away.

Parent carers spoke of the different changes (practical, psychological, developmental) that occurred in their lives, having had children with learning disabilities. Some spoke of the life-changing adjustments they had made and the acquisition of personal attributes that helped them to meet the demands of caring, while other parent carers spoke of becoming more humane through their experiences of caring for their children.

For the parent carers who conceptualised their quality of life from the perspectives of personal transformations/modifications, these experiences were centred mainly on the different coping strategies they used, having appraised their situation of having and caring for an adult child with a learning disability.

For some parents, providing long-term care for their adult children added quality to their lives by enabling them to do something worthwhile, and afforded them opportunities to meet other parent carers, despite the fact that some parents had lost their friends along the way. This is discussed under the themes of having a sense of purpose and gaining friends 'in the same boat'.

### **5.2.3 Having a sense of purpose**

In the context of the study, having a sense of purpose concerns the feeling of being 'needed' which many older parents derived from active caregiving, well beyond the period when their ordinary child-caring role would have ended. Mrs

Steiner, aged 79, who was caring for her 53-year-old daughter, described as follows her quality of life in relation to having a sense of purpose:

*Well you feel needed. One of my sisters always said, although they've all got children, they grow up and they leave home, and they said for instance I am needed. You have a feeling that you are still needed. And I like to be needed, that is why I wanted to be a nurse. I always loved children so much anyway and when you choose a career like a nurse, you know. It is caring, you know ... you are so needed.*  
(Interview 12, p. 9)

This extract demonstrates how she feels about her contribution to her daughter's care. The fact that Mrs Steiner feels needed gives the sense that the care provided contributes to her daughter's welfare and well-being and she clearly derives a sense of purpose through caregiving.

Mrs Collins also expressed her view:

*You got to keep going, you know, you can't [stop]. A lot of elderly people start stagnating, but I can't stagnate, I've got to keep going. It [caring] is good for me.* (Interview 7, p. 4)

For Mrs Collins, active caring in her later years gave her a sense of purpose because she was making a positive contribution to her son's life. She makes the point that in her view there are some older people who just sit and do nothing, and therefore their lives lack purpose.

Mrs Rahim, whose son was 33, explained:

*I feel rewarded as I look after him, I cook for him, and see he is ok, dropping and picking him up to the college or from the college. I feel that he is with me. I don't leave him alone.* (Interview 18, p. 4)

As seen from Mrs Rahim's extract, caring for her son gave structure to her day. This made her feel needed as she was doing something worthwhile for her son. Many parents felt that caring in later life gave them a sense of purpose. Although they lost friends when it became evident that their children had a learning disability, they also made friends with other parent carers who had children with learning disabilities. This is discussed in the following section under the theme of gaining friends 'in the same boat'.

#### **5.2.4 Gaining friends 'in the same boat'**

In the study, parent carers referred to establishing new friendships with other parent carers of adults with learning disabilities, having lost some of the friends they had had before their children were born. This theme was discussed in Chapter 4 as one of the multiple losses which parent carers experienced from having and caring for a child with a learning disability.

Mr Smith spoke about the value of making friends with other parents who had children with learning disabilities. He felt that having these friends provided a support network and social outlets for him and his wife over the years, and helped them to cope with their situation. Throughout his account he referred to the support group they had formed and what it meant to him, especially after he had lost his wife. He also spoke of the many visits they made to friends from the group who had moved to the south. He said:

*We used to visit them with other friends and it was a big social event. We used to go there two or three times a year with all our children down there. There was a big bungalow with a swimming pool. It was really something then. Over the years that has kept us sane, because we have had that support. When you know that there are other people [friends] having the same problems as you are, you know you are not on your own. (Interview 1, p. 5)*

For Mr Smith, making friends with other parent carers of people with learning disabilities gave him a sense of solidarity and possibly identity; he felt they would understand the challenges of caring for a child with a learning disability because they were in a similar situation.

Mrs Steiner, like Mr Smith, valued the friendship of other parent carers. Apart from extending her social circles and also providing a sense of solidarity, it facilitated social inclusion and provided a sense of belonging. Her extract illustrates this:

*Saturday we have a jumble sale for Mencap, for her club. So I get together say 3 or 4 times a year with other carers, they become friends, and that helps a lot, we'll talk to each other. Like tomorrow, we'll go and have, sort of set everything out, but we'll have lunch together, and that is really the best help. (Interview 12, p. 3)*

Mrs Steiner clearly valued peer support, and she was asked to elaborate on what she meant by 'the best help'. She responded:

*Well it boost you up, because you get depressed sometimes, you feel very alone, you give up a lot of your friends in the beginning, I have found it takes you about two years to get over the [diagnosis] ... well it's a shock when you're told your daughter has Down's syndrome. (Interview 12, p. 3)*

Mrs Sylvester also endorsed the view of gaining a sense of solidarity. She explained:

*So I kept up with a few people, and beyond that you just keep up with a few people whose children are in your child's school. They are in the same boat as you. (Interview 4, p. 6)*

This extract highlights that there is a normal tendency for some parents to gravitate to parents who understand their situation, connoting a shared identity as they too have children with learning disabilities. This view was echoed by Mrs Wood:

*I was just chatting to another parent on the phone this morning, she rang me about something. It is of course one's community that understands where you are at and where you are coming from.*  
(Interview 14, p. 4)

While discussing this notion of befriending other parents, Mrs Sylvester went on to describe her experience of befriending parents from her son's school whose children were not learning disabled. She referred to:

*School holidays when they [parents of her son's friends] may have organised trips. Because they knew I had another child who might not fit in, the invitation did not come our way. That kind of thing.*  
(Interview 4, p. 6)

This extract clearly demonstrates the attitudes of some parents whose children did not have a disability and is representative of the social exclusion that many parents and their children with learning disabilities encounter in their daily lives. For Mrs Sylvester it must have been very hurtful: both her children were excluded, her daughter with a learning disability and her son who did not have a disability. This gave the impression that he was punished for having a sibling with a disability.

Mrs Wood also reported that friends whose children did not have a disability tended to move away. She said:

*What becomes very apparent is that very good friends that you have ... the friends that you have with young children, as the differential*

*between your child and the others grow, they zoom off on their own lives. And people who I would have thought, who lived on our road, understood a little, never invited her [daughter] round to tea or play or anything. It's quite shocking actually. (Interview 14, p. 4)*

This extract highlights the social exclusion that families with children with learning disabilities face as a result of negative societal attitudes, which can be quite devastating. This social exclusion is representative of the experiences of many people with learning disabilities (Department of Health, 2001).

It became clear from listening to parent carers that befriending parents in a similar situation protected them from 'hurt' and provided a 'safe haven'. I reflected on this; the following are my thoughts:

Hearing parent carers' accounts of how their children and themselves were socially excluded I wondered if this exclusion has been perpetuated by the education system whereby children with learning disabilities attend special needs schools rather than being supported in mainstream school. While they need extra support, there may be some merit in integrating children with learning disabilities in mainstream schools with the focus being on inclusion. Although these accounts refer to when the adults with learning disabilities were much younger, I believe this situation holds true for them as adults, because parent carers related the negative societal attitudes they experienced on a daily basis towards their adult children. There needs to be a serious re-think on social inclusion, as diversity is still perceived as a deficit by a society.

Most parent carers in the study conceptualised their quality of life by drawing on the positive experiences of providing long-term care for their children and therefore appraised their quality of life as good. They gave a sense of being in control of their situation, while at the same time acknowledging the struggles they encountered, such as accessing formal services and obtaining a

formal diagnosis, which are discussed later in this chapter. However, a few participants viewed their quality of life principally as either a psychological or practical struggle, or in some cases both, and these experiences also influenced how they appraised their quality of life.

## **5.3 Psychological factors**

In the current study, the theme ‘psychological factors’ relates to the negative feelings that participants experienced in providing care for their adult children with learning disabilities, and how these impacted on their quality of life. Many participants in the study spoke of a range of psychological factors they experienced. While most parent carers were able to devise coping strategies to address these, a few were unable to do so, and ‘grappled’ with different emotional stressors on a daily basis. Their quality of life seemed to be conceptualised principally from these negative experiences. These psychological factors include: worrying about the future; feeling trapped and mentally exhausted; and negative societal and professional attitudes.

### **5.3.1 Worrying about the future**

This subtheme was prevalent across parent carers’ accounts, and it reflects the worry that older parent carers experienced about planning future care for their adult children when they are unable to carry on caring. Their main worry centred on who will take over the caring ‘baton’. Most participants worried about future care, even those whose children were already living in a residential setting. These parents felt they needed someone to take over the ‘vigilance’, to be as watchful and alert as they had been for all these years. The general consensus among the parent carers whose adult children were living at home was that a sibling would take over the caring role. Anecdotal evidence suggests that it is mainly Black and minority ethnic (BME) communities who take this option, but I was surprised that the findings from this study indicate that both indigenous and BME parent

carers were thinking of sibling care. I later discerned what could be the possible reason, as fear of abuse surfaced in some of the interviews. This will be discussed later in the chapter. While future care for their adult children ‘lingered’ at the back of many parent carers’ minds, for a minority, this thought consumed their lives because they felt they were left with few or no options. Mrs Patel’s account exemplifies this:

*Even though we were full of anguish, and I said that I don’t know what the future has for him and I was wondering what would happen if I die ... if both of us [non-disabled son] go what will happen to my son [with learning disability]? That is the ultimate thing that worries me ... it [the future] gives me sleepless nights. (Interview 3, p. 10)*

This extract indicates the level of worry for Mrs Patel about her son’s care in the future. Although she had a discussion about future care with professionals from Social Services, she was opposed to the thought of her son going into a residential home and did not continue with the plans. I asked Mrs Patel if she had discussed the future care of her son with his brother. She responded:

*Yes of course, he is very aware. He of course says I will look after my brother, but I have to be pragmatic. He may say anything now because he is emotionally involved with his brother, but tomorrow he will have a wife, he will have his children, his brother cannot be the main focus like it is for me. I know that if he does not go before me. That is my prayer to God. Let him go first. I would go at peace then. If he goes I am quite ready to go ... If he is here and I die, I will die a very tortured soul. (Interview 3, p. 20)*

It is evident that Mrs Patel has a dilemma about who is to take over the care of her son when she is no longer able to care for him, and it seems that finding a solution is difficult. She gives the impression that she is the only person who can

care for her son, and she would rather he died than to trust a stranger with his care. It is important for professionals to understand that some elderly carers may feel this way. Worrying about their children's future is one of the stressors for older parent carers of adults with learning disabilities, which tend to overshadow parents' worry about their own future. I reflected on Mrs Patel's situation as follows:

The extended caring role brought about benefits for most older parent carers in this study, and as a result their quality of life has been enhanced. For Mrs Patel this is not the case – apart from the several challenges she has experienced, caring in later life has presented her with the dilemma of planning the future care of her son. Forty years ago adults with learning disabilities very rarely outlived their parents, therefore future care was hardly an issue. Now that adults with learning disabilities are outliving their parent carers, this is no longer an exception, but an expectation. Therefore it is imperative that older parent carers think seriously about the future care of their adult children and as described by one parent this could be the elephant in the room.

In contrast, Mr Cullen was quite eager to plan his daughter's future care. He opted for supported housing as he felt he was getting to the end of his tether and it was in his daughter's best interest that, while he is alive, she is supported to live independently. His feelings are summed up in the following extensive extracts:

*There will come a point when I die, she is going to have to be independent of me and she's going to have to get on with it herself. So we've been discussing things like housing, etc., but the only people who are positive about finding [daughter's name] housing is [voluntary organisation]. My local council housing department seems to be averse to finding people with learning disabilities housing ... So*

*any delays in sorting out housing I think is adverse to her independent living. And we are told about how people have got to be independent, but that is a lot of words about it, lip service, but there isn't a lot of movement. (Interview 16, p. 6)*

Mr Cullen is evidently trying to be proactive but seems not to be getting the necessary professional support. Although there is a lot of talk by politicians about promoting independence for adults with learning disabilities, and policy initiatives such as Valuing People 2001 and 2009, in Mr Cullen's case, making this a reality is seeming to present challenges and to be quite daunting. As he further explained:

*She [his daughter] was offered a shared house by [voluntary organisation] and it turned out that she couldn't move because her assessment wasn't up to date and there was no funding options available to her, so she couldn't move even if she wanted to. And I think that says something about the service. We are talking about independence, but independence isn't there when people want it, and that's the big thing. (Interview 16, p. 9)*

Mr Cullen is trying to work in partnership with Social Services to promote his daughter's independence and at the same time address the issue of future care, as he is the sole parent carer. The situation, as related by Mr Cullen, created a level of uncertainty and frustration about the future care of his daughter.

Apart from planning alternative accommodation for the future, some parent carers' fears about future care were compounded by fear of abuse. These thoughts were very unsettling for them, and appeared to be barriers to planning for future care. Mr Halcyon was one of the parent carers who had this feeling. He recounted:

*We had reason to believe that he was assaulted. Now, I don't know if that was behind why we found it difficult for him to go to respite unless he is comfortable with the people he's with. (Interview 15, p. 5)*

Mr and Mrs Halcyon's past experience of their son being abused clearly shaped their views about future care and they looked forward with trepidation to the time when they are unable to care for their son, as they had very little confidence in the quality and safety of care that is available.

Similarly, Mrs Patel found planning future care for her son a challenge because he had also been abused. Witnessing her son being physically abused was a deterrent to planning his future, which is quite understandable. She explained:

*My son was getting bullied, physically abused by another client ... It happened in front of me one day ... (Interview 3, p. 4)*

While all parent carers worried about the future, for some it remained the 'elephant in the room', as expressed by Mrs Halcyon. For Mr and Mrs Halcyon and Mrs Patel, planning future care for their adult children presented double challenges based on their previous negative experiences. On the other hand, Mr Cullen was willing to promote his daughter's independence, but he felt disillusioned due to lack of professional support. Like some other parent carers, he felt trapped in his caring role and mentally exhausted. This theme is discussed in the following section.

### **5.3.2 Feeling trapped and mentally exhausted**

The feelings of being trapped and mentally exhausted were expressed by some participants who were 'heavily' involved in caring for their adult child. This subtheme highlights how these parent carers felt, and describes the physical and mental stresses and strains that parent carers experienced due to the demands of

providing care. These participants were either main or sole parent carers and therefore provided substantial care for their adult children. They felt that caring for their children as adults had ‘consumed’ their lives, and this was particularly so for Mrs Wood and Mr Cullen, who constantly referred to caring as a full-time job. For Mrs Wood, even though her daughter lived in a residential home, she visited home on a regular basis. She related her experience:

*I bear the brunt of the connection with [daughter's name]. I think it has affected my quality of life hugely. It meant that when my friends were going out and having lunch together, whatever, I couldn't. Having still to care actively when she comes home [from residential care], and by 'remote' [while she is at the residential home] in terms of always keeping one's antennae open as to how she is, and what needs to happen ... she [daughter] not being able to wear a pair of trousers because the button is off and no one is sewing it on. So they [trousers] come back and I have to sew on the button. (Interview 14, pp. 6 and 7)*

Mrs Wood's extract gives a sense of her being ‘trapped’ in her caring role because it limited her social interactions, which impacted negatively on her quality of life. The feeling of being in constant demand persisted even when her daughter was living away from home, at a time when society may feel that the ‘burden’ has been lifted. Although the physical presence may have gone, the emotional and ‘cognitive’ or mental ‘weight’ remained because caring is by ‘remote’, as recounted by Mrs Wood.

The feeling of being physically and mentally trapped was also expressed by Mr Cullen and Mrs Patel. All parent carers in the study saw their responsibilities to care for their children as a long-term contract that they could not get away from, as acknowledged by Mrs Carter:

*We still have that ... emotionally you can never really cut yourself off. Physically there is a distance between you, but mentally I think am very [involved]. (Interview 8, p. 6)*

Parent carers who were not able to realise their own potential, or get a reprieve from their caregiving role, felt 'trapped' in caring, which in turn gave them a feeling of being a 'captive' of care, as described by Todd and Shearn (1996b). For example, in Mr Cullen's case, his daughter felt the need to have him constantly around. He described his situation as follows:

*Sometimes if I haven't said to her [daughter] where I am, I'll find her running round the house looking for me, because in her words she can't hear me. (Interview 16, p. 6)*

This demonstrates the high level of dependency and the interconnectedness between Mr Cullen and his daughter. While this has its benefits, as the sole carer, he felt trapped. Similarly, Mrs Patel felt 'trapped' in caring and this surfaced several times during her interview. She explained:

*I have given up on my life. I have finished. I have a son, that's my responsibility. I will do it. [Son's name] is my eternal baby, he will always be like this, so I do not expect my life to change very much. (Interview 3, pp. 6 and 7)*

This extract gives the feeling that Mrs Patel had resigned herself to a life of caring and therefore offers a sense of her being 'trapped' both mentally and physically. Although Mrs Patel's son accessed formal services, the lack of an informal support network compounded her feelings of having total responsibility for her son. The following was my reflection after interviewing her:

This is my third interview, however this is the first mother. I found this interview very different from the previous two. The feelings expressed by Mrs Patel were in line with Olshanky's (1962) chronic sorrow, which describes feelings of sadness that parents experience as a result of having a child with a learning disability. Although I had read the literature on chronic sorrow, I still was taken by surprise when Mrs Patel's account mirrored this feeling because her account was very vivid. During her interview, she said that she welcomed the opportunity to tell her story and the experience was cathartic. For me, listening to Mrs Patel heightened my awareness of the profound impact of having and mothering a child with a learning disability. I wondered if I had offered sufficient support during the interview. With the subsequent interviews I need to be aware of other parents who might be experiencing this form of sadness and acknowledge their distress more than I did for Mrs Patel. On this occasion I was a bit 'frozen'.

Apart from the feelings of being trapped in care and the 'disappointment' that some parent carers experienced from having a child with a learning disability, parent carers felt that their stress was compounded by the way they were perceived by some members of society and health and social care professionals. These experiences are discussed under the subtheme negative societal and professional attitudes.

### **5.3.3 Negative societal and professional attitudes**

This subtheme relates to the hurtful feelings that some participants experienced as a result of negative societal and professional attitudes towards their children and themselves. Parent carers felt quite hurt by the negative attitudes of some of their friends, other parents with non-disabled children, professionals and the general public. Mrs O'Connor related her painful experience:

*Sometimes there's this really hurtful exclusion. One of the most hurtful things for us was that one of my really good friends was getting married down in [name of place] and we got an invitation to the wedding. She had written in it I hope you don't mind this is just an invitation for you and [husband's name], not [son's name] because children are not being invited to the wedding. At the wedding we went to the reception, there were at least 20 children there. I find it extremely hurtful, and this is someone who is a very good friend.*  
(Interview 5, p. 6)

Mrs O'Connor clearly did not expect such rejection from a close friend and this must have been doubly painful for her because one normally looks for support from close friends. The fact that other children attended the wedding gives the impression that Mrs O'Connor's son was singled out, possibly because he had a learning disability.

Mrs Wilkinson also related her experience of rejection from another parent at her daughter's school. She said:

*[Daughter's name] and this girl were friends, she was the only friend [daughter's name] had but the mother was very cunning in the way she tried to separate them. And it was hurtful, I remember.* (Interview 10, p. 6)

This extract demonstrates the rejection and unpleasantness that many families with disabled children experience, from people whose children are able-bodied.

Parent carers were also subjected to insensitive remarks, as explained by Mrs Wood:

*When you are waiting to pick your children up. They [other parents] go on about how incredibly well their son is doing, and how he's passed his scholarship ... And I also remember another mother saying*

*to me how pleased she was that all her child's marbles were in the right place. I mean this was not said intentionally, but it is insensitive, and you are sensitive, you have to develop a very thick skin.*  
(Interview 14, p. 5)

Mrs Wood felt that, although the other parent's careless remarks were not intended to offend, they were hurtful, and in order for parent carers to survive this marginalisation, they need to become thick skinned or 'lamine' themselves, and develop strategies to diffuse society's negative attitudes.

The feeling of being marginalised came not only from other parents, but also from health and social care professionals, as related by Mrs Wilkinson:

*I had a paediatrician who was a monster, I am sorry, he was a monster. Being in the [name of organisation], I don't think he had any ... well he didn't have any understanding of parents anyway ... there was no reassurance, no gentle way of putting it, no nothing. I mean, I would turn up ... well I always left in tears when I had seen him. I usually cried all the way home ... he really was the worst man in my life. (Interview 10, pp. 1 and 2)*

Mrs Wilkinson expressed her feelings about the doctor's behaviour and the impact he had on her, which conjured a feeling of deep hurt, due to his insensitivity and lack of compassion and the power imbalance.

These experiences were echoed by other parents. For example, Mrs Collins described her encounter:

*We didn't know he had a learning disability until he was three years old. And to be honest the way in which we were told was very bad. We are actually told definitely when he was nearly five and I had to see the doctor at the clinic, and he just said that he has a learning disability, he'll never go to ordinary school, goodbye. You can*

*imagine how I felt. He was my only child. I mean I went round to my mother's from there. I know I cried all the way round. (Interview 7, p. 2)*

Like Mrs Wilkinson, Mrs Collins felt humiliated by the way in which the doctor interacted with her and told her about her child's disability.

Similarly, Mrs Wood and Mr Johnson experienced the cold and inhumane way in which the doctors dealt with parents whose children had a learning disability. Mrs Wood said:

*And we were told that she had a learning disability and might never walk or anything like that, in front of a group of twenty-five other people, by Dr [name], which I think is the most appalling way. It was done in front of twenty-five strangers, yes. So that was, you know, I am glad he's dead now. (Interview 14, pp. 4 and 5)*

This extract highlights the negative experiences of parent carers and the unhelpful relationship that existed between them and their doctors. Mr Johnson recounted his experience as follows:

*He [son with learning disability] was born at home and the family doctor as soon as he saw him said put this one in a home and forget him. (Interview 11, p. 6)*

Mr Johnson was told quite bluntly about the condition of the child and where his needs would apparently be best met. This means of communication could be quite disheartening for parents, in view of the anticipation and excitement that may have preceded the birth of the child.

There are two issues concerning the doctors' engagement with these parent carers. First, the doctors' demeanour and apparent lack of social skills impacted on parents' feelings. Secondly, little value was placed on people with

learning disability at that time. While there is an expectation that the medical professionals would have dealt with parents in a sensitive manner, in the mid- to late 1960s, children with learning disabilities were marginalised and cared for mainly in institutions. Therefore for the parents who wanted to care for their children at home, there was very little support and society's attitude to disability was very poor, which compounded the distress of parents whose children had a learning disability. The terms used to describe people with learning disabilities, such as 'invalid' and 'mentally handicapped', indicated society's perception of children with learning disabilities at that time.

For participants who experienced psychological struggles, while these impacted negatively on their experience, most of them were able to move on and focus on the positive aspects of their lives when reporting their quality of life. However, for some the impact 'tarnished' their experiences and influenced their conceptualisation of their quality of life.

## **5.4 Practical struggles**

This theme describes the objective burden (socio-structural barriers) experienced by parents caring for their adult children. Participants in the study had little or no choice in taking on the caring role. They had no knowledge of the magnitude of the task ahead, and most if not all encountered several difficulties along their caring trajectory. These have been captured in three sub-themes: searching for a diagnosis, battles for services and no 'me time'. For some participants, one or more of these practical struggles have continued throughout their caregiving experience and have shaped the way in which they describe their quality of life.

### **5.4.1 Searching for a diagnosis**

Searching for a diagnosis is a prevalent theme across the interviews. It relates to the difficulties parents had in getting formal diagnoses for their children when

their learning disability was not as easily detectable as in the case of Down's syndrome, where the person has characteristic features. Most participants spoke of being aware that something was wrong, but they needed a formal diagnosis to confirm their suspicion and the validation that would enable them to obtain the appropriate support. Whether they suspected that their child had a disability or not, they all reported that they felt devastated, but it was better to know rather than 'groping' in the dark. Mrs Wilkinson explained:

*But because she never had a diagnosis, she never had any financial help and don't know of any that was available , but she was about ... well eight or nine years ago now, she got referred by the GP for incapacity benefit, which she got a [diagnosis] and we could have done with that thirty years sooner. (Interview 10, p. 11)*

Mrs Wilkinson's daughter was given a formal diagnosis of autism after 30 years, which meant that it was difficult to get specialist input and support, and that the family remained unsupported for a very long time. It is only within the last two decades that autism (which spans a wide spectrum of behaviours) has been recognised as a learning disability.

Mrs Wood recounted a similar experience:

*She would lie outside the door just drumming her heels on it and you know it was very very tough. We had no social worker and we were a good middle class family who I think they felt we would manage. But we were very near the edge, or I was particularly, actually. And I think that it was ... she wasn't diagnosed with Asperger. I mean obviously she had [a] learning disability , but she wasn't given a diagnosis until she was about twenty-three I think and it was only because we threatened [Social Services] with a judicial review that we managed to get a diagnosis that explained her very very difficult behaviour. (Interview 14, p. 2)*

Mrs Wood was unable to make sense of her daughter's behaviour due to the lack of a formal diagnosis, and as a result she did not have the specialist support to manage her daughter's challenging needs. This presented a very difficult situation for the family and almost brought them to 'breaking point'.

Having a diagnosis was clearly very important to both Mrs Wilkinson and Mrs Wood. Apart from giving an entitlement for benefits, it also gives 'peace of mind' to parents by providing a better understanding of their children's difficult behaviour. Other participants shared the experience of searching for a diagnosis. For some, like Mrs Jones, this search was still ongoing at the time of the study. She explained:

*She's still undiagnosed really to be honest, which actually comes to another thing which has not been helpful for me. Because I have friends with Down's syndrome or Rett syndrome children and they all had support groups. They go away for the evening, and they have an evening and they all chat about Down's syndrome or Rett syndrome or whatever syndrome. They go away for weekends and they have wonderful ... and I didn't have a support group because she was undiagnosed, so there was nothing for me. The only support I could get was through [national voluntary organisation] ... (Interview 6, p. 12)*

Mrs Jones expressed the feeling of being left out by not having a formal diagnosis for her daughter. Although she could receive support from the global organisation for learning disabilities, belonging to a specialist group was important to her, to share experiences and draw on support from other parents whose children had a similar diagnosis.

For Mrs Jones, a formal diagnosis would have offered the family social inclusion by enabling them to identify with a particular group. She reasoned:

*They'd [other parents] say oh we we're going off to Brighton for the weekend for a [...] week. And I'm going 'oh that's nice' ... Oh we've got all this stuff happening, putting on all this stuff for them to do, lovely food and all that. And I used to think, ah how wonderful. And with Down's syndrome my friends did the same, and there was nothing for us, so you know we did not cash in on any. (Interview 6, p. 12)*

The feeling of being excluded by not having a formal diagnosis impacted on the support Mrs Jones received and seemingly placed her at a disadvantage.

However, although a diagnosis can give an entitlement to a service, even parent carers who had a diagnosis still struggled for formal services.

#### **5.4.2 Battles for services**

This subtheme focuses on the difficulties parent carers encountered in accessing formal services. Most of the participants in the study began caring for their children with learning disabilities when services were not very well established.

Mr Whittle in his narrative endorsed this view:

*We went from nothing basically, and really fighting ... [then] we saw the services evolve and become stable and steady. (Interview 13, p. 1)*

However, gaining access to services for some participants was a 'battle'. In order to access services, children needed to have a statement from the educational department that they had a learning disability. Participants who had the experience of 'battling' to get services expressed that it was tiring and for many

they just used their informal support and struggled on or sought support from the voluntary sector, which was more accessible. Mrs Wood explained:

*It's like getting blood out of a stone with the borough. It's as if you are a criminal in terms of asking for facilities for your child like social groups, or respite, or all those sort of things. You are made to feel you know, you're brought up before boards of people who treat you in the most appalling way really. (Interview 14, p. 4)*

This extract highlights the humiliation that Mrs Wood experienced in advocating for services to meet her child's needs.

Like Mrs Wood, other parents had difficulties in accessing formal services. Mrs Patel described it as:

*A battle, it [accessing services] has been a battle, I tell you. I am trying to get a day centre working. (Interview 3, p. 14)*

The view that attempts to access formal services could be described as a battle was also shared by Mr Brown. He said:

*To be honest we were frustrated with [the] authorities, social services and education. We were not going to take no for an answer. We wanted the best. We found the level was mediocre. People jumped to rapid conclusions without understanding what was going on. That was tough. So we lived a battle. (Interview 2, p. 12)*

These extracts highlight parent carers' experiences of trying to obtain services for their children as a life-long, bruising campaign. The impression given by Mr Brown, as his son's advocate, is that he was prepared to 'champion' his cause relentlessly because it became apparent that parents who insisted, and refused to give up the 'fight', eventually received a service for their children. The

contention is whether these services were reliable and met their children's needs. These issues are discussed later in the chapter.

Apart from the difficulties in accessing services, parents reported that the government cuts had affected the quality of support they received. Mr Ramdeen related:

*They wanted to cut down [services.] I said no, no way because it is the only centre where [son] has shown progress so far and you can see it. So we insisted. (Interview 20, p. 3)*

For Mr Ramdeen, the cuts to day services meant that his son was unable to attend a centre that met his cultural needs. His experience was very different from that of Mr Smith, who said:

*[Name] borough was second to none ... Absolutely second to none. It was so good people were moving from other boroughs ... But when [son's name] was in need there was never a question. If anybody proposed, he was in. Not a problem. (Interview 1, p. 3)*

Mr Smith's experience presents a different picture from what most of the other participants related, even those who were living in the same borough as Mr Smith. The caveat here could be that Mr Smith was caring on his own for two adults with learning disabilities, and anecdotal evidence suggests that Social Services are more responsive to men supporting families than to women in similar circumstances.

The demands of caring and the difficulties that parent carers experienced in obtaining formal services impacted on their time. Some who used their informal support networks were able to alleviate the situation. Others, such as Mrs Carter, Mrs Wood, Mr Cullen and Mrs Jones, had no informal support and very little time to meet their own needs. This is discussed under the next subtheme.

### 5.4.3 No 'me time'

This theme relates to parents not having sufficient time to address their own needs and to get a break from their caring role. The lack of time that parents described was prevalent across the interviews, as most participants spoke about not having time to meet their own needs. Although with adequate formal and/or informal support participants were able to set aside some time in their busy caring schedule, for some this was not always possible. The restriction reported varied for participants, but the 'me time' that was available seemingly depended on the level of care they provided: for example, whether they were the main or sole parent carer. Mrs Carter, who is the main parent carer for her son, said:

*One needs space and time for yourself, and if you don't, you almost feel like a 24 hour nurse ... Because, if you're in a caring role 24/7, it means you can't plan, you don't have time for yourself, you can't have uninterrupted sleep, sometimes you neglect yourself health wise, and mentally as well, so yes it does. (Interview 8, p. 7)*

Mrs Carter acknowledged putting her adult child's needs before her own. One may argue this is what most parents do when their children are younger. However, for this group of parents the caring role has been extended into old age and some have continued to make these sacrifices by prioritising their adult children's needs at the expense of their own well-being.

Others, like Mrs Wood, who placed their aspirations and needs aside to care for their children, were unable to realise their full potential. Mrs Wood's feelings are summed up in the following extract:

*I haven't been able to go out to work, which I think has....., there is a whole part of me that feels as if it hasn't been lived, which I much regret. Although I would have always stayed at home to look after my children in the early years certainly till secondary school. But I would*

*say that when you talk about my quality of life as a carer, that is who I have been. That is what my life has been about really, that comes first and everything else has always had to be fitted around that, and it falls mainly on my shoulders. (Interview 14, p. 6)*

For Mrs Wood, having no 'me time' meant that, apart from being unable to socialise, she was unable to do things that would bring quality to her life, such as having a paid career. Caring dominated her life and there was little time left for anything else. Her identity as a carer is prominent in her life, and there is a part of her that has never been able to develop or flourish; the regret seems to be for the person she might have become if she had not had caring responsibilities.

Mr Cullen also felt very restricted by his caring responsibilities, and not having time for himself surfaced several times during his interview. This was his response when asked to describe his quality of life:

*Not brilliant to be perfectly honest. I don't have a lot of me time, and as you can see from the mess I don't have a lot of time getting round the house, which I know is important to do, but I just seem to be running out of energy. (Interview 16, p. 6)*

It was evident that Mr Cullen neglected his health and environs because his time was consumed by caregiving and he was experiencing burnout.

Having the time to attend to one's basic needs was very important for participants because, due to the demands of caring, time was a scarce commodity. Therefore, the things that most other people take for granted, such as being able to sleep without being disturbed and having time to take a bath, for some participants were nearly a luxury. Mrs Jones, in describing her quality of life, said:

*... I think being able to go out you know, being able to have a bath perhaps when you want. I mean I've got out of the habit now, just run into the shower, quick shower and out. (Interview 6, p. 14)*

Mrs Jones's response seems to suggest that having the time to meet their basic needs adds quality to parent carers' lives. This was endorsed previously by Mrs Carter who spoke of having uninterrupted sleep, which is also a basic need.

## **5.5 Summary**

This chapter has presented the analysis in relation to the way in which the participants conceptualised their quality of life, in the context of long-term caregiving for their adult children. The key findings are that an overwhelming majority of participants appraised their quality of life as good despite the challenges of caregiving, and that having a child with a learning disability enhanced their quality of life, particularly in their later years. These have been summarised in ten themes. The enhancing factors are: financial stability; becoming a better person; having a sense of purpose; and gaining friends 'in the same boat'. The challenges are: worrying about the future; negative societal and professional attitudes; feeling trapped and mentally exhausted; searching for a diagnosis; battles for services; and no 'me time'.

Parent carers reported wide-ranging impacts of caregiving on their quality of life and the changes that occurred over time at a personal level and in the areas of service provision. Some of the changes in their quality of life were more subtle than others because of differing experiences of caregiving. What is evident from these findings is the subjective nature of quality of life, as demonstrated by couples who were caring for the same adult, but who reported their quality of life from different perspectives. It was apparent that the carers who appraised their experiences of caregiving as negative also appraised their quality of life as poor. These parent carers had similar characteristics, such as that they were main or sole carers with little or no formal support and the rewards they experienced from

caring were transient, as the demands of caregiving superseded their positive experiences.

The overall consensus in parent carers' stories offers a counter-narrative to the dominant discourse on caring for an adult child with a learning disability, which generally emphasises stress and care burden as the defining characteristics of caregiving.

Chapter 6 will present a discussion of the findings of Chapters 4 and 5, which will be framed around two overarching themes. The rationale for creating these overarching themes, and how they were developed, are presented at the beginning of the chapter.

# Chapter 6 Discussion of the findings

## 6.1 Introduction

This chapter discusses the main findings from Chapters 4 and 5 in relation to current knowledge about caregiving and quality of life, and the theoretical frameworks that guided the study. The chapter also critically appraises the study design and its robustness.

In Chapter 4, the findings focused on participants' experiences of caring for their adult children with learning disabilities. These were centred on two themes: enhancing factors of caregiving; and challenges of caregiving. In relation to the enhancing factors of caregiving, participants related the benefits they derived from caring in later years, such as family cohesion by sharing the caring role and caring experiences, the symbiotic relationship with their children, and seeing their children realise their potential and the transformations in their lives by having and caring for a child with a learning disability. The challenges they recalled were multiple losses such as loss of sleep, paid work and friends, the struggles for, and the unreliability of, formal social care services, and the physical and emotional consequences of caring for a child with a learning disability, which were compounded by negative societal attitudes. While most participants were able to devise coping strategies to overcome these challenges, and therefore reported their caregiving experience positively, for a few participants these challenges remained unresolved and impacted adversely on their experiences of caregiving and their quality of life.

Chapter 5 captured the participants' conceptualisations of their quality of life in the context of providing long-term care for their children. Three themes were identified: positive life appraisals, despite challenges; psychological factors; and practical struggles. As with their caring experiences, most participants appraised their quality of life positively and recounted the various factors that added quality to their lives. These factors focused on being able to meet their financial commitments, developing qualities such as humility and being aware of

others' needs, purposeful living, and gaining a sense of solidarity through new friendships. However, they also acknowledged the challenges that impacted negatively on their quality of life. These were centred on: worrying about future care, negative professional and societal attitudes, the feeling of being trapped and burnt out by the demands of caregiving, having no time to meet their own needs, constant struggles and battles for services on behalf of their children, and in some instances, the frustrations experienced in obtaining formal diagnoses of their children's condition. As with their caregiving experiences, a minority of participants were unable to 'rise' to these challenges and therefore appraised their quality of life as poor.

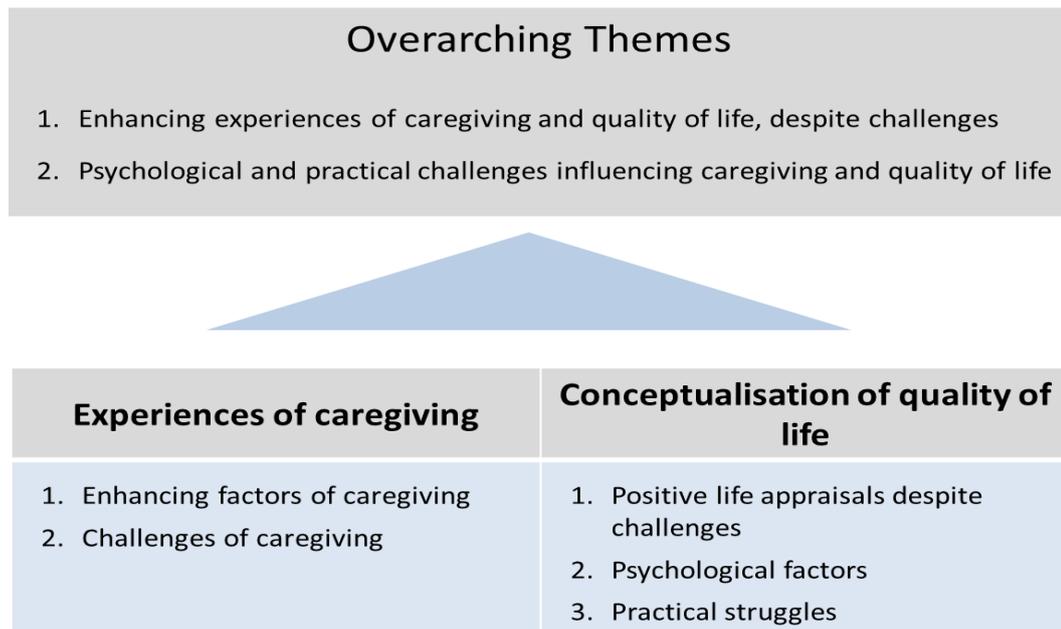
Evident from participants' narratives were a number of overlapping themes which emerged from their caregiving and quality of life experiences. Significantly, the same participants reported their caregiving experiences as negative and their quality of life as poor, thus highlighting the interconnectedness of caregiving and quality of life and the influence one construct has on the other. To this end, the rationale for creating two overarching themes was underpinned by the 'fluidity' with which participants spoke about their caregiving experiences and their quality of life.

Therefore the findings are structured around two overarching themes:

- enhancing experiences of caregiving and quality of life; and
- psychological and practical challenges influencing caregiving and quality of life.

These were created from the five themes and their corresponding subthemes that were presented in the findings chapters (Chapters 4 and 5) on experiences of caregiving and conceptualisations of quality of life, as shown in Figure 6.1 (see Appendix I).

Figure 6.1 Experiences of caregiving and conceptualisations of quality of life



This discussion foregrounds the enhancing factors of caregiving and quality of life for two reasons. First, overall participants’ appraisals of their caregiving experiences and their quality of life focused mainly on the benefits they derived from caring in later years and the positive impact these had on their quality of life. Secondly, as highlighted in Chapter 5, these findings offer a counter-narrative to the dominant discourse on caregiving, in which commentators use a pathological framework (Green, 2007; Kenny and McGilloway, 2007) that emphasises the negative aspects of caregiving by focusing on stress and care burden to portray parental experiences of caring for children and adults with learning disabilities (Saloviita et al., 2003). They also challenge the notion that parents who have positive experiences of parenting and caring for a child with a learning disability are ‘in denial’ or are failing to accept their ‘tragic’ circumstances (Grant et al., 1998; Kearney and Griffin, 2001; McKeever and Miller, 2004).

However, the intention of acknowledging these positive experiences first is not to ‘downplay’ or deny the significance of the many challenges which are discussed later in the chapter – what the participants had to ‘work through’ on a daily basis in order to provide care for their children. In fact, the literature

recognises that the enhancing experiences of rewards and gratification can coexist with the challenging experiences of stress and care burden (Grant et al., 1998; Todd and Shearn, 1996a, 1996b, 1996c; Yannamani et al., 2009; Milne and Larkin, 2014). Therefore the caveat here is that, despite these challenges, most participants ‘emerged’ as ‘survivors’ and experts by experience after several years of caring, and reported caregiving benefits that have enhanced their quality of life.

## **6.2 Enhancing experiences of caregiving and quality of life**

As illustrated above, the first overarching theme is the merger of two themes: ‘enhancing factors of caregiving’ and ‘positive life appraisals, despite challenges’, which were presented in Chapters 4 and 5 as separate themes. It concerns the ‘high points’ of participants’ caregiving and quality of life experiences and relates to the tangible and intangible benefits that participants derived from caring for their adult children. These were manifested as:

- the family bonds they cemented through shared family caring;
- the opportunities to share their experiences with other parent carers;
- a sense of purpose derived from caring in their later years;
- the feelings of gratification;
- reciprocity- the help they received from their adult children;
- having financial stability; and
- the expertise, mastery and sense of coherence they acquired over the years.

Many participants, in appraising their caregiving experiences and quality of life, spoke of the factors that enhanced their role and their quality of life, while acknowledging the challenges they encountered in this life-long career (Haley and Perkins, 2004). The participants’ accounts provided a rich tapestry of

interwoven ‘highs’ and ‘lows’, which illustrated the enmeshed experiences of caregiving and quality of life. This interconnectedness is represented in Figure 6.2 as tectonic plates to demonstrate the stresses and strains associated with caregiving, and the dynamic interplay between caregiving and quality of life. These stresses and strains, if not alleviated by appropriate carers’ support (for example, planned regular respite care services), have the potential to impact negatively on their caregiving experiences and quality of life.

*Figure 6.2* Enmeshed experiences of caregiving and quality of life



The study revealed that caregiving and quality of life are enmeshed, multifaceted, complex and dynamic constructs. To this end, participants reported that caring impacted on their quality of life and vice versa. The participants are older parents who have been caring over a prolonged period, and personal and structural changes such as the ageing process and the reduction in social care services that occurred over time helped to shape their experiences.

Participants reported that sharing the care for their adult child with their spouse/partner and other family members fostered a sense of connectedness and family cohesion which enhanced their quality of life. These findings resonate with the family unity described by Stainton and Besser (1998) and Jokinen and Brown (2005) in Chapter 2. Sharing the caring role was integral to caring for adults with learning disabilities, particularly for parents caring in their later years, due to the demands placed on them. Participants expressed the view that it would have been difficult to provide care without the support of their spouses or other family members. Mr Sylvester articulated very strongly that he could not care for

his daughter on his own and he appreciated the significant input from his wife as the main parent carer. In some families, such as the Johnsons, Jameses and St Bernards, siblings were highly involved in sharing the care for their adult brothers and sisters. These shared responsibilities were instrumental in cementing strong bonds within families, particularly for couples.

This is in contrast to the families in the study by Yoong and Koritsas (2012), who shared the caring role and reported that their relationships were negatively affected. A possible explanation for this difference is that, whereas the families in the current study perceived the caring role as a shared family experience, this may not have been the case for the families in Yoong and Koritsas' (2012) study, as they reported that other family members, such as siblings, felt neglected. Therefore shared caring can be a protective as well as a risk factor for families, as it has the potential to connect people or create tension and division.

In addition to sharing the physical tasks of caring, participants felt that sharing their experiences with other parent carers in group meetings facilitated social interaction and enhanced their quality of life. This finding concurs with Yoong and Koritsas' (2012) study, which found that social contacts enhanced the quality of life of older parent carers of adults with learning disabilities. It also supports studies which explored the quality of life of older people and found that social contacts contribute positively to their quality of life (Farquhar, 1995; Gabriel and Bowling, 2004; Bowling and Gabriel, 2007). Family ties and social contacts are perceived as some the interpersonal qualities that enhance caregiving experiences (Greenberg et al., 1993), which in turn impacts positively on carers' quality of life.

Apart from having social contacts, participants experienced a sense of belonging by participating in the parent carers' groups. The need to belong has been identified as an important component of quality of life (Lyons et al., 2002). This finding also resonates with Yoong and Koritsas (2012), in which older parent carers reported that being involved in support groups gave them a sense of belonging and added value to their lives. Similarly, taking a valued role with, and for, others fosters connectedness, which gives a sense of belonging, purpose and

meaning that affirms self-worth (Duncan, 2004: 198). Social inclusion and a sense of belonging are particularly important to parent carers of adults with learning disabilities because they tend to be marginalised in society (Milne and Larkin, 2014) and in social welfare issues (Scourfield, 2005b).

In addition, providing long-term care gave many participants a sense of purpose as they were making a valuable contribution to their adult children's welfare and well-being, and felt needed by them. This sense of purpose is described by Borglin et al. (2005) as finding meaning in one's existence. For example, Mrs Steiner, Mrs Collins and others explained that providing care added meaning to their lives. This resonates with several other studies (Stainton and Besser, 1998; Yoong and Koritsas, 2012; Haley et al., 2009). Both Stainton and Besser (1998) and Yoong and Koritsas (2012) found that a sense of purpose was one of the positive impacts on parent carers of children and adults with learning disabilities. Furthermore, Haley et al. (2009) reported that family caregivers of stroke survivors felt that they derived a sense of purpose from providing care for their relatives. For the participants in this study, having a purposeful life helped them to structure their day, which in turn enhanced their quality of life by affording them opportunities to engage in meaningful activities. These included being part of carers' groups, which facilitated a sense of solidarity.

Most participants reported positive changes or personal transformations from providing care for their adult children, corroborating Scorgie and Sobsey's (2000) study. In the current study, Mr Sylvester, Mr Brown and Mr Johnson described their experiences of personal transformations as becoming a 'better' person, which included having a greater awareness of other people's needs, becoming more in touch with humanity, developing stronger family values and acquiring virtues such as humility and empathy. The feeling of 'becoming' a better person is described as an intrapersonal quality (Greenberg et al., 1993) that parent carers acquire through caregiving, and can be explained by taking an occupational science stance and drawing on Wilcock's (1998) tripartite theory of doing, being and becoming, where providing care can be linked to 'doing', which is synonymous with occupation (Wilcock, 1999). Therefore, caregiving could be

seen as an occupation, albeit an imposed occupation for most participants, as they had little or no choice in taking on this role. Having a sense of being refers to being true to one's self and the uniqueness one brings to his or her relationship with others, in what he or she does (Wilcock, 1999). Becoming is associated with potential and growth, personal transformation and self-actualisation (Fidler and Fidler, 1983). For many participants, the notion of 'becoming' was driven by the sense of belonging (Hammell, 2004), which is a human desire (Wilcock, 2006) and is important for well-being (Andonian and MacRae, 2011) and contributes positively to one's quality of life, as it acts as a 'buffer' for stressful situations (Holt-Lunstad et al., 2010).

Participants also spoke of their personal transformations in relation to their development. For example, they took on new roles such as advocating for their children and attending conferences to share experiences of having and caring for a child with a learning disability. Similarly, Scorgie and Sobsey (2000) reported that parents of children with learning disabilities experienced personal transformations by virtue of caring for their children, which provided them with opportunities to take on new roles such as advocacy. Participants in the present study reported that they were able to see beyond their children's disability and focus on their ability. This resonates with Green's (2007) work, in which participants reported that having and caring for a child with a learning disability had helped them to see their children as people first, rather than focusing on their disability. Furthermore, parent carers strove to find opportunities for their children to realise their full potential, which is in keeping with the parents in Grant et al.'s (1998) and Kenny and McGiloway's (2007) studies, who supported their children with learning disabilities to meet their goals and aspirations. Adopting a positive attitude towards their children helped parent carers to derive rewards and gratification from the caregiving role which are discussed in the following section.

There is a growing body of evidence in relation to the rewards and gratification of caregiving, as researchers endeavour to gain a better understanding of the complexities of this phenomenon (Grant et al., 1998; Scorgie and Sobsey, 2000; Kearney and Griffin, 2001; Green, 2007). This study

supports the findings of these studies as the overwhelming majority of participants in this study reported that they derived rewards, satisfaction and personal growth from caring for their adult children, which in turn brought a sense of fulfilment, happiness and enjoyment. In short, caring for their adult children enhanced their caregiving experiences and their quality of life in many ways. This echoes findings which endorse the view that providing care for children and adults with learning disabilities can be experienced as a source of joy and happiness, and can have many rewards (Sloper et al., 1991; Kearney and Griffin, 2001; Hastings et al., 2002; Grant et al., 1998; Jokinen and Brown, 2005; Scorgie and Sobsey, 2000; Stainton and Besser, 1998; Green, 2007; Grant, 2010; Caples and Sweeney, 2010; Yoong and Koritsas, 2012). This perspective is also in keeping with what Redmond and Richardson (2003) refer to as ‘corrective portrayals’ to the doom and gloom that pervades the literature on caring for children with learning disabilities, and adds to the emerging body of literature on the positive experiences of caring for children and adults with learning disabilities.

In this study, most fathers (seven out of nine) reported more sources of rewards and gratification than mothers. This finding to some extent mirrors Sloper et al.’s (1991) study in relation to gender caring, where fathers derived more caregiving satisfaction and greater rewards, and it is also similar to the mothers in Heller et al.’s (1997) study who were heavily involved in care and reported less satisfaction and fewer rewards than the fathers. For the purpose of this study, parent carers are described as being at the ‘heavy’ end of caring if they are the main carer or provide care over 20 hours a week, the point at which caring impacts on carers’ health and well-being (Carers UK, 2012). Similar to fathers in Sloper et al.’s (1991) study, most fathers in the current study were not the main parent carers and were therefore at the ‘light end’ of caring. Interestingly, the two fathers Mr Cullen and Mr Ramdeen who were main carers and therefore were at the ‘heavy end’ of caring by providing substantial care reported fewer rewards and less gratification, just like the mothers who were at the ‘heavy end’ of caring. However, the two mothers who were employed full time and therefore were not main parent carers reported like the fathers who were

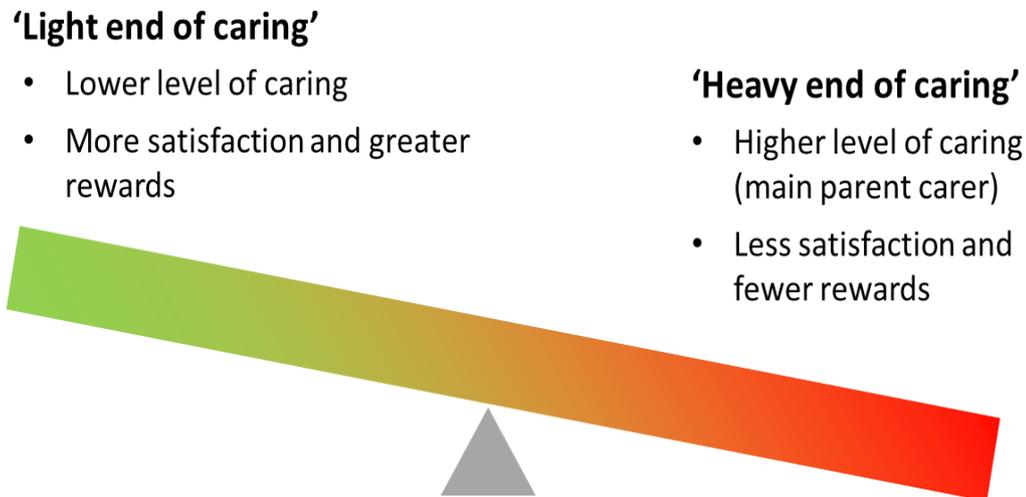
also at the 'light end' of caring. This finding indicates that satisfaction and rewards from caregiving may be closely associated with the level of care provided and not necessarily with the gender of those providing the care.

Another possible reason might be the difference in the mothers' and fathers' coping strategies, as coping is central to caregiving (Perkins, 2009). It has been observed that men are more likely to use problem-focused coping (Blanchard-Fields et al., 1991), which is linked to problem solving and resolving conflicts (Lazarus and Folkman, 1984). This form of coping is associated with less stress and more positive psychological well-being (Aldwin and Yancura, 2004) and lower levels of perceived burden (Kim et al., 2003), which can influence the level of rewards and gratification derived from caregiving. On the contrary, women tend to use emotion-focused coping (Endler and Parker, 1990), which is premised on changing the meaning of the situation as a form of distraction (Ekwall et al., 2007). This can result in higher levels of stress and burden (Kim et al., 2003) and negative psychological well-being (Aldwin and Yancura, 2004), which are associated with fewer rewards and less gratification. However, parents are known to use a variety of coping strategies, including emotion- and problem-focused coping in stressful situations (Lazarus and Folkman, 1984; Folkman et al., 1986; Essex et al, 1999; Folkman and Moskowitz, 2004; Kenny and McGilloway, 2007), and therefore gendered coping may not be a reliable predictor of caregiving rewards and gratification.

Therefore, in this work the concept of gender caring and coping in relation to satisfaction and gratification in caregiving were seemingly superseded by the level of care provided. Thus gender might not be as influential in determining caregiver satisfaction and rewards as previously thought. This study also highlights that practitioners need to provide reliable formal support for carers who are at the 'heavy end' of caregiving, who are generally sole carers with no informal support, to enhance their caring experiences and quality of life. This is of particular importance as the number of older parent carers is likely to continue to grow with the increase in life expectancy (Carers UK, 2012). There is also the possibility of more men over the age of 70 caring for their adult children with learning disabilities, as men are more likely to be providing care in their later

years following retirement (Ross et al., 2008). The relationship between levels of care and rewards and gratification is shown in Figure 6.3.

*Figure 6.3* Levels of care versus satisfaction and rewards



Through prolonged caring, many participants gained a sense of mastery which boosted their self-confidence and derived benefits from their reciprocal relationship with their adult children. Gaining a sense of mastery is linked to acquiring expertise over time, and mirrors the findings on the experiences of older parent carers of adults with learning disabilities (Perkins, 2009; Kling et al., 1997) and on carers of stroke survivors (Greenwood et al., 2009). For parent carers of adults with learning disabilities, particularly older parents, the caring landscape is familiar by virtue of caring for their children from birth, unlike 'new' carers for other client groups. Research indicates that older parent carers tend to be more confident and gain self-awareness from prolonged caregiving (Schwartz and Gidron, 2002).

In relation to reciprocity, most participants perceived that the interdependence between themselves and their adult children enhanced their caregiving and quality of life. They spoke of reciprocity as an important aspect of their experiences and felt that this mutuality became stronger as they got older. This resonates with Prosser and Moss (1996) and Grant (2010), who highlighted that the reciprocity between parent carers and their adult children was stronger in parent carers' later years. In the current study, reciprocity was manifested in

tangible and intangible ways. For example, Mrs Collins and Mrs James described the help and companionship received from their children, such as preparing the shopping list, ensuring that the doors were locked at night, making cups of tea and importantly having someone to talk to. Even when their adult children are not able to give tangible help, their presence means a lot to their parents as they provide companionship, particularly for parents caring on their own. Grant's (2010) and Perkins and Haley's (2013) studies similarly reported that adults with learning disabilities provide both tangible and emotional support for older parent carers. However, Perkins and Haley (2013) found that parent carers gave more emotional support than they received. It could be argued that the quality of the relationship and the benefits that both parties derive from reciprocating are more important than how much they contribute to the relationship.

Several studies on caregiving have highlighted the interdependency and reciprocity between adult children with learning disabilities and their older parent carers (Walker and Walker, 1998; Williams and Robinson, 2001; Grant, 2010; Cairns et al., 2012). However, with the exception of Perkins (2009) and Perkins and Haley (2013), this finding was not explicit in the studies reviewed on caregiving and quality of life of older parent carers of adults with learning disabilities (Walden et al., 2000; Lin et al., 2009; Leung and Li-Tsang, 2003; Chou et al., 2007; Caples and Sweeney, 2010). To date, studies reviewed on the quality of life of older people have not identified reciprocity as a component of quality of life (Farquhar, 1995; Gabriel and Bowling, 2004; Bowling, 1995; Bowling and Gabriel, 2004; Bowling and Gabriel, 2007; Borglin et al., 2005; Wilhelmson et al., 2005). Therefore this study's finding, which identifies the relationship between caregiving, reciprocity and quality of life, provides a unique contribution to the existing body of research findings.

Furthermore, in keeping with previous research (Twigg and Atkin, 1994; Grant, 2010), this study revealed that caregiving takes place in a relationship which is not uni-directional but is a mutual giving and receiving process to meet each other's needs. This reciprocal relationship challenges the binary notion of carer and cared for (Williams and Robinson, 2001), and the term 'caregiving' which implies that one person only provides care, and the other only receives,

thus disregarding the interdependency/mutuality that exists between the parent carers and their adult children. It also highlights the need for practitioners to view older parent carers and their adult children with learning disabilities as a dyad, when planning services and preparing for the transition of adults with learning disabilities into residential or supported living. This is discussed further in Chapter 7 under implications for practice.

Financial stability was viewed as an enhancing factor in most participants' quality of life and this concurs with Caples and Sweeney (2010), who found that older parent carers of adults with learning disabilities deemed that being financially stable was important to their quality of life. Likewise, other studies on older people's quality of life reported that having adequate finance enhanced their quality of life (Bowling, 1995; Farquhar, 1995; Gabriel and Bowling, 2004; Jokinen and Brown, 2005). For participants in this study, having sufficient money to meet their family's needs was integral to their quality of life, as it helped to reduce some of the stresses and strains of caregiving. For example, Mrs Johnson was able to purchase specialist services for her son when Social Services were unable to meet his needs.

Even though many participants (mainly women) had to leave work to care for their children, families were able to live comfortably on one income. One explanation could be found in the nature of jobs that the men did, as main 'bread winners'. Many of them were university graduates (see the demographics in Chapter 3) and therefore their higher earnings helped the family to meet their financial commitments. However, another reason could be that families were thrifty and managed their finances well.

Overall, participants reported their quality of life positively and they articulated very strongly in their narratives that their experiences of caregiving and their quality of life were enhanced by the personal gratification and rewards of having and caring for their adult children. These findings corroborate Caples and Sweeney (2010), who surveyed the quality of life of parent carers and found that most parent carers rated their quality of life as 'good' or 'excellent'.

In appraising their quality of life, participants reported attributes that mirror eudaimonic and hedonic quality of life as described by the Greek

philosophers Aristotle and Aristippus. These philosophers devoted much time and energy to providing guidelines for living and explaining how to achieve optimum functioning (Chung et al., 1997). Most participants in the current study, in describing their quality of life in relation to their caregiving role, focused on aspects such as self-fulfilment, personal growth, purposeful living, gaining mastery and a sense of coherence, which are associated with eudaimonic quality of life. Ryan et al. (2008) argue that eudaimonic living pursues intrinsic goals and values such as personal growth, relationships, community, health, behaving in autonomous volitional ways, satisfying basic psychological needs such as competence, relatedness and having a sense of awareness (mindfulness).

However, for a few participants their descriptions of their quality of life were consistent with hedonic quality of life. These were centred on aspects of their lives that were not fully realised, such as not being able to find quality time, and feelings of being disadvantaged by not being able to engage in paid work, thereby feeling unfulfilled. Although these participants reported rewards and gratification from caregiving, these were not long lasting. Ryan and Deci (2001) posit that hedonic quality of life has as its main goal the pursuit of pleasure, which tends to be transient and can produce a life that lacks meaning, bereft of depth and a sense of community (Ryan et al., 2008). This new finding has not been reported in the studies reviewed on caregiving and quality of life of older parent carers of adults with learning disabilities and none has considered these philosophical perspectives of eudaimonia and hedonia.

The participants in this study described a range of experiences that enhanced their quality of life in relation to their caregiving: sharing the care and caregiving experiences, the mutuality between participants and their adult children, feeling a sense of belonging from their interaction with other parent carers, personal and relational transformations, opportunities for self-actualisation, and rewards and gratification. In this vein, research has indicated that 'belongingness, connectedness and interdependency are positively correlated to human well-being' (Hammell, 2014: 39). In addition, the enmeshed nature of caregiving and quality of life was evident within participants' stories. These findings extend earlier works on caregiving and quality of life. The approach to

the present study is unique because its findings are grounded in older parent carers' experiences of caring and quality of life. Having adopted a qualitative approach in which quality of life was self-defined, the findings here offer a more nuanced understanding of the quality of life of older parent carers of adults with learning disabilities than hitherto has been the case. The exception is the Australian study by Yoong and Koritsas (2012), who also explored the impact of caregiving on parents of children and adults with learning disabilities using a qualitative approach. However, the present study differs from Yoong and Koritsas' in that fear of abuse was one of the concerns parents expressed around the future care of their adult children, particularly in residential settings, and this amplifies the reservations of older parent carers in planning future care.

Most of the literature reviewed on caregiving experiences and quality of life of older parents of adults with learning disabilities were quantitative studies (Walden et al., 2000; Lin et al., 2009; Leung and Li-Tsang, 2003; Chou et al., 2007; Perkins, 2009; Caples and Sweeney, 2010). The studies by Walden et al. (2000), Lin et al. (2009), Leung and Li-Tsang (2003) and Chou et al. (2007) reported mainly on the negative impact of caregiving on older parents' quality of life, identifying lower psychological well-being and higher levels of stress, in relation to the general population, and to parent carers in the USA in Walden et al.'s (2000) study. The present study is in line with Perkins (2009), Caples and Sweeney (2010) and Yoong and Koritsas (2012) in highlighting the positive as well as the negative aspects of caregiving. It therefore attempts to address the imbalance in the literature by offering a balanced view of caregiving and quality of life of older parent carers of adults with learning disabilities, which is more representative of carers' experiences (Miller and Lawton, 1997; Green, 2007).

It could be argued that recognition of the benefits of providing care for people with disabilities has taken longer than for other client groups (Green, 2007) because of the preconception that parents should be emotionally burdened by caring for their adult children with learning disabilities (McKeever and Miller, 2004). However, Green warns that this negative perspective presents 'a distorted picture of parenting a child with a disability and our understanding of the social experience of disability' (2007: 151). This notion also portrays disability as a

deficit, and therefore fails to acknowledge benefits that can be derived from parenting and caring for a child with a learning disability, and the positive impact this can have on parents' quality of life. Nonetheless, negative experiences were recounted by participants in the present study and, to offer a balanced view, the next section discusses the 'low points' or challenges of caregiving and quality of life of older parent carers of adults with learning disabilities.

### **6.3 Psychological and practical challenges influencing caregiving and quality of life**

The findings discussed now relate to the second overarching theme: psychological and practical challenges influencing caregiving and quality of life. This theme was created by merging the three themes: challenges of caregiving, psychological factors and practical struggles. The impact of these challenges on parent carers' quality of life was manifested as:

- multiple losses and constraints;
- socio-structural barriers to formal services;
- consequences of no formal diagnoses;
- uncertainties and fears about future care; and
- negative societal and professional attitudes.

Participants reported on the psychological and practical difficulties that adversely affected the quality of their caregiving experiences and their lives. These experiences depended on the resources that participants were able to access, their coping strategies and how they 'worked' through these challenges. Although most participants described themselves as resilient and gained control and mastery of their situation, through trial and error (Hubert and Hollins, 2000), a few participants were not able to do so because of the limited resources they had at their disposal.

Within the literature, parents have reported several losses as a result of caring for their children (Caples and Sweeney, 2010). Likewise, all participants in the present study acknowledged that they had experienced some form of loss. Most of them reported that their sleep was interrupted at nights and in some instances several times each night. A few participants indicated that their health was affected as they felt low in energy and lethargic. They recounted loss of sleep as one of the ‘lows’ of their caregiving experience. This finding of loss of sleep mirrors that of Grant et al. (1998) and the Carers’ Survey (Survey of Carers in Households, 2010). Although this theme has not been reported explicitly in the studies reviewed on caregiving and quality of life, researchers exploring the quality of life of parents of children and adults with learning disabilities have reported lower psychological well-being and depression in parent carers in comparison to the general population (Lin et al., 2009; Leung Li-Tsang, 2003; Chou et al., 2007) and parent carers in the USA (Walden et al., 2000). It is possible that loss of sleep and tiredness over a prolonged period could have led to burnout and contributed to these health conditions. For example, Mrs Jones expressed her wish for a good night’s sleep because she had to get up several times during the night to care for her daughter and felt that she was ‘cracking up’.

Some participants reported that the frequency of respite that they were accustomed to when their children were younger was not available in adult services. Therefore opportunities to access overnight breaks to address their sleep deprivation were significantly reduced and this impacted negatively on their quality of life. For most participants, loss of sleep was cumulative because it extended from childhood to adulthood. Some participants perceived sleep deprivation as a natural experience as it became the ‘norm’ of their caregiving experience.

Another loss, which mainly affected women, was loss of career, as most mothers had left work to care for children, and although they had intended to return to work, they were never able to do so because their caring role had extended into their children’s adulthood. In some instances, they felt that their personal development was negatively affected and their opportunities for social

contacts were limited, which reduced their quality of life significantly. While most mothers in the study were able to adjust their expectations, a few remained unfulfilled. For example, Mrs Wood articulated very strongly how she felt, described her situation in this way: ‘I haven’t been able to go out to work which I think has [pause] there is a whole part of me that feels as if it hasn’t been lived, which I very much regret.’ From this extract, one can discern the negative impact on Mrs Wood’s life. This finding is consistent with studies by Yoong and Koritsas (2012) and Caples and Sweeney (2010), where parents gave up paid employment to care for their children. For some participants in the present study, this had a negative impact on their quality of life in many diverse ways, such as not being able to achieve their career dreams and desires, and not having the psychological benefits that are associated with paid work.

Coupled with loss of career was loss of identity, as many participants’ identity was closely associated to their career. For example, Mrs Jones, a teacher, recounted how her identity was ‘threatened’ when she had to give up work to care. Work provided her with an identity and an avenue for socialisation, and enhanced her self-esteem.

Some participants, having stopped working to care for their children, had lowered their aspirations in relation to their career, and used their caring role to provide opportunities for personal development and gratification. These adjustments mirror the characteristics of ‘captivated’ parents as described by Todd and Shearn (1996b), whereby parent carers choose to reframe their personal goals, and find more meaning in their parental roles. However, a few participants who were mainly lone or sole parent carers found it difficult to re-focus their personal aspirations due to the meaning they had attached to their personal development from paid employment and the coping strategies they used to meet the demands of caregiving. Therefore they felt restricted by their caring role. These parents are referred to as ‘captive’ parents (Todd and Shearn, 1996b) because they became so ‘immersed’ in caring that their lives were dominated by their caring responsibilities and they struggled to find meaning and purpose in their lives beyond caring. These findings also confirm Grant and Whittell’s study (2000) in relation to family coping, as they found that lone/sole parents were

more vulnerable than, and did not cope as well as, families where caring responsibilities were shared. In relation to quality of life, the findings in the present study extend the work on factors that influence the quality of life of caregivers in general and, more specifically, older parent carers of adults with learning disabilities.

Furthermore, captive parents experienced feelings of sadness and disappointment at having a child with learning disability. This is in keeping with what Olshansky (1962) refers to as chronic sorrow, which is a form of grief that is experienced by parents of children with disabilities at various times during their caring trajectory (Wikler et al., 1981; Olshansky, 1962) as they mourn the loss of the child they had expected (Hobdell et al., 2007; Gordon, 2009) and their imagined possible futures. Over the years, caring for their children had consumed their lives and they found it difficult to ‘buoy’ themselves up, having ‘surrendered’ themselves to a life of caring. Seemingly for these parents, there was no way out as they contended with several challenges (advocating for adequate and reliable support, coping with unhelpful professionals and dismissive societal attitudes, and ‘searching’ for formal diagnoses of their children’s condition) which are discussed later in the chapter.

These parent carers’ experiences mirror those of the families in Taanila et al.’s (2001) study who did not cope successfully. Taanila and colleagues examined how families with disabled children coped, and how their coping strategies differed. They found that families with inadequate support and family problems did not cope as well as those who received good formal and informal support, who obtained adequate information about their children’s diagnosis, who took time out of their caring duties and who held optimistic views about the future.

Having a support network of friends has been identified as helping parent carers of children with learning disabilities to cope successfully (Hastings et al., 2002). Many participants in the current study reported that they had lost friends along the way, due to the difference in focus of their lives. For example, while they were advocating for services for their children, their friends were supporting their children through university. Similarly, Scorgie and Sobsey (2000) found

that loss of friendships was one of the negative impacts of caring for a child with a learning disability. The negative attitudes and the distancing by close friends who had children without disabilities were distressing for most participants in the present study. However, for some, this loss was compensated for, by making new friends with other parent carers, from whom they derived a sense of solidarity, collective resilience and social identity (Haslam et al., 2008).

In addition to participants' multiple losses, they also reported the constraints that caregiving imposed on their quality of life. In the current study, lack of time was considered to be one of the major constraints, particularly for sole carers with little or no informal support, as in the case of Mr Cullen and Mrs Patel, on whom the demands of caregiving were so great that it was difficult for them to balance their caring responsibilities and find any quality time for themselves. Despite this, they continued to provide care and hoped for what Cairns et al. (2012) referred to as 'better alternatives', such as services like respite care that responded to their children's needs and theirs. Similar to the older parent carers in Cairns et al.'s (2012) study, the participants in the present study felt that they needed better access to services for their adult children with learning disabilities, as they encountered many socio-structural barriers which are discussed below.

Green (2007) argued that socio-structural barriers, such as lack of access to services, and unreliable and inadequate services, are the main sources of stress for parent carers of adults with learning disabilities. Most participants regardless of ethnicity had to struggle to get appropriate and adequate services for their adult children, which left them exhausted and made their lives more stressful. Similar findings have been reported by Yoong and Koritsas (2012) and Grant (2010), where parent carers of adults with learning disabilities found that they needed to advocate strongly on their children's behalf for them to access services and that in some instances services were just not available. For example, the demand for respite services was greater than the availability, and hence parent carers were unable to get a break from their caring role. This is consistent with Caples and Sweeney (2010), who reported that respite availability was insufficient for parent carers of adults with learning disabilities. In the current

study, Mrs Jones requested respite to get a break from her caring role because her sleep was disturbed frequently to provide care for her daughter, and she was offered one night which clearly did not meet her short- or long-term needs.

Another concern was the unreliability of the service, as planned respite was often cancelled at very short notice, which left parent carers disappointed and more importantly not being able to get the break they anticipated or needed. For example, Mr Halcyon's son's respite was cancelled at the last minute, which meant that he had to cancel his plans for taking a break with his wife. It is apparent from participants' accounts that services provided by local authorities in the traditional way were poorly coordinated. This mirrors Green's (2007) study of mothering a child with a learning disability, where services were either not available or unreliable, and it also highlights how parent carers' needs are not considered by those who plan and provide services for adults with learning disabilities. These socio-structural constraints or objective burden (Green, 2007) adversely affected participants' caregiving experiences and their quality of life.

In relation to family carers from Black and minority ethnic communities, the literature suggests that their experiences mirror those of white family carers in many respects such as lack of information about services and a sense of being excluded (Raghavan et al., 2013). Also, the socio-economic status and level of education influence access to services regardless of ethnic origin (Raghavan et al., 2013), but there are experiences specific to these communities which are shaped by their ethnic origin and cultural and religious beliefs (Hubert, 2006; Raghavan, 2007; Devapriam et al., 2008; Raghavan et al., 2013). These experiences include mainly communication and language barriers, lack of awareness or poor access to services, services that are not culturally sensitive and lack of information (Raghavan, 2007).

In addition to ethnicity, culture, religion, socio-economic status and educational attainment (Raghavan et al., 2013), acculturation has been reported to impact on caregiving experiences of family carers from Black and minority ethnic communities (McCallion et al., 1997).

Regarding the experiences of the older parent carers in the current study from Black and minority ethnic groups, the findings indicate that their experiences were largely parallel to those of the white older parent carers. Taking into consideration the economic climate in which the study was conducted and drawing on the literature reviewed on family carers from Black and minority ethnic communities several explanations are offered. A major factor that impacted on the older parent carers' experiences of caregiving and quality of life regardless of ethnicity was the austerity measures imposed by the Coalition Government in 2010 which resulted in cuts to funding of adult services in local authorities. An example of this impact was reported by Mr Ramdeen, a South Asian parent carer, whose son's day service in an Asian day centre was withdrawn after the government funding to adult social care was reduced, and replaced by a local service which was not specifically for Asian service users. The experience reported here is due to lack of funding and not necessarily the unavailability of culturally appropriate services.

The literature indicates that Black and minority communities which are well integrated into the majority community experience better service usage and access (Mc Callion et al., 1997). The older parent carers in the current study from Black and minority ethnic groups were well integrated into the majority culture (White British) and therefore they were able to articulate their needs and express their views confidently and comfortably in English, an inclusion criterion for the study (see figure 3.2 in section 3.11). Also, they were mainly middle-class professionals who were financially stable and were educated to secondary level or above, apart from Mrs Ali who had no formal education. Nevertheless she was a self-made business owner. They also attended carers support groups which have been identified as a source of valuable information for informal carers (Raghavan, 2007). In the current study the socio-structural barriers, struggles for respite care, the overwhelming paper work from direct payments and the fear about future care for their adult children were not singular to parent carers from the Black and ethnic minority groups but these were experiences reported across all families. Studies also indicate that South Asian families use

religious beliefs as a coping mechanism (Raghavan, 2013) and to find meaning or to make sense of disability (Heer et al., 2012). This was not the case for the Black and minority ethnic parent carers in current study. The experiences specific to Black and minority ethnic communities reported in the literature did not emerge in the findings of the current study because the Black and minority ethnic parent carers were mainly from a middle class background with generally high educational attainment. This is a limitation of the study and which is discussed in section 6.6.2.

Service delivery under the government policy of personalisation of services – specifically, the policy of direct payments which was introduced under the 1996 legislation and involved service users and carers receiving money to purchase social care from the private or voluntary agencies, or to employ their own support worker (Glasby and Littlechild, 2009) – also proved problematic for most participants. In this study, participants indicated that they perceived personalisation to be a complex concept, a view which has been endorsed by Dickinson and Glasby (2010). For example, parent carers were not clear about what personalisation was trying to achieve because of the drastic cuts to services. They were also confused about the different terms involved, such as direct payments, personal budgets, individual budgets and self-directed support, because they had been used interchangeably by professionals and providers.

Personalisation was promoted as a different way of organising adult services, with the main ‘drivers’ being more choice and control (Lymbery, 2012). However, there was an ‘undercurrent’ as proponents of personalisation were promoting it as a cost-saving exercise (Leadbeater et al., 2008; Needham, 2011) and at the same time services were being cut. This added to the confusion because fewer funds were available for adult social care and the choice and control promised by personalisation seemed rhetorical (Boxall et al., 2009). Therefore parent carers were presented with a dilemma: fewer services meant they had little or no choice. Another dilemma was that many parent carers perceived direct payments as adding a layer of stress because they were responsible for managing direct payments while providing care. They voiced

strongly the view that accessing services with direct payments was burdensome for several reasons:

- the administrative tasks involved were overwhelming;
- the recruiting of personal assistants was daunting because effectively they had to become employers and felt they did not have the expertise;
- there was a lack of clarity about what services they were able to purchase with the money;
- there was a lack of support when they encountered difficulties;
- the level of responsibility was too great; and
- the fear of getting it wrong made them feel very vulnerable due to the financial and legal implications.

These issues created high levels of stress and anxiety and the general consensus, with the exception of one parent carer, was that direct payments did not give them the control, choice and flexibility that they were meant to provide; instead they felt ‘saddled’ with an arrangement that was burdensome.

The finding of stress and anxiety associated with these administrative tasks (mainly paperwork) concurs with the Canadian study by Rosenthal et al. (2007), which identified the paperwork associated with direct payment as ‘managerial care’. Importantly, the fear of ‘getting it wrong’ supports the study by Moran et al. (2011), which was the first to report that parent carers were afraid of getting the process of accessing direct payments wrong. This is an important finding as it highlights the added pressure that personalisation can place on parent carers in the absence of support.

On the other hand, the present study’s findings contradict the findings from the government pilot study (IBSEN) (Glendinning et al., 2009a) that parent carers’ quality of life was enhanced by their children accessing services on personal budgets and direct payments. Actually, parent carers in the present study found direct payments, in particular, very stressful and this detracted from their caring experiences and quality of life. Moreover, unlike the studies by Williams

et al. (2003) and Carers UK (2008), which reported that there were more benefits and positives than problems in accessing direct payments, importantly, the current study found that the problems encountered by participants managing direct payments far outweighed the benefits. Similarly, participants found that managing direct payments and recruiting personal assistants proved to be a daunting and disempowering experience. This is in contrast to Blyth and Gardner (2007), who reported that carers welcomed the opportunity to select and recruit people in whom they had trust to support their children.

A possible explanation for the difference in findings between this study and the studies by Williams et al. (2003), Carers UK (2008), Glendinning et al. (2009a), and Blyth and Gardner (2007) could be the financial climate in which the studies were conducted. These studies were conducted at the height of the promotion of personalisation and more importantly before the government's cuts were implemented in 2010. Additional money was also given to 'pump prime' the implementation of these initiatives (Gardner, 2011). Therefore, it is likely that participants' experiences of personalisation were different because more money was available to meet their needs and more support structures were in place, particularly in 2009 when the government piloted the IBSEN project (Glendinning et al., 2009a). For the present study, the data were collected mainly in 2011 and 2012, when Social Services budgets were being reduced by central government and the objectives of personalisation were clearly being undermined (Boxall et al., 2009).

Furthermore, the literature suggests that direct payments are generally favoured by articulate and well-educated service users and carers (Spandler, 2004; Clarke et al., 2007; Lymbery, 2010). However, the present study refutes the notion that those who are well educated are more likely to opt for direct payments, as dissenting views about direct payments were expressed by all participants, including those who were well educated and articulate. Indeed, they were very much aware of the austerity measures imposed by the Coalition government and how adult social care funding was significantly reduced by the cuts to Social Services budgets. These parent carers were therefore not interested in direct payments, which for them offered little choice or control. Moreover,

parent carers who were already managing direct payments for their adult children before the cuts to services implied that they were not likely to recommend this mode of accessing services to other parent carers because of the stresses involved in operationalising direct payments (see Chapter 4).

For some families, the cuts meant that they were forced to access services where 'one size fits all', thus eroding the very premise on which personalisation was introduced as an alternative to the traditional way of providing services (Boxall et al., 2009; Slasberg et al., 2012). For example, Mr Ramdeen received direct payments to purchase day services for his son at an Asian day centre which met his cultural needs. However, his son's care package was reviewed, the transport to the day centre was removed and it was recommended that his son access a local day centre which did not meet his cultural needs.

The notion that direct payments are favoured mainly by those who are more educated highlights the inequality in the implementation of this policy initiative, as there will be many eligible adults with learning disabilities and parent carers who are in need of services, but who may not be able to manage the system and thereby exercise choice and control (Lymbery, 2010). For these people, social workers should provide support to create a level playing field, so that they can access direct payments for their children and themselves if they wish to do so. Despite the view that social workers may have a minimal role in working with service users who are receiving direct payments (Lymbery, 2012), it could be argued that the transformational changes for service users that were envisaged through personalisation, which were associated with fairness and justice, fit well with the core principles of social work (social change, social well-being, human rights and social justice). However, this has been mere rhetoric as, in implementing personalisation, practitioners have found themselves in a difficult situation, due to government cuts to social care funding (HM Treasury, 2010) combined with the increased financial pressures for social care brought about by changing demographics (Lymbery, 2012). Therefore the role of social workers in adult services has moved closer to the margins (Lombard, 2011), reduced to one of surveillance and safeguarding (Lymbery, 2012).

From the situations participants described, the premise on which direct payments were established seems to have been forgotten since the cuts have been introduced (HM Treasury, 2010). Beresford (2011/12: 39) reminds us:

*Direct payments are a ground-breaking development rooted in pioneering philosophy, values and theory. They grow out of the social model of disability and the independent living movement. Their essential aim was to put disabled people, and then other service users, in control of their support as part of a broader independent living approach.*

This view is supported by others (Priestley, 1999; Kestenbaum, 1992). The principles of choice, flexibility, control and inclusion are in keeping with social work values and good practice, and therefore should be promoted in the delivery of adult social care. However, concerns arise from the imposition of personalisation on service users and their parent carers, and the difficulties in its implementation, which have created more stress than benefits for families. The apparent shift of the Coalition Government from the wider emancipatory framework of empowerment, inclusion, rights and citizenship, which personalisation is meant to enhance, to a more self-centred activity (Boxall et al., 2009) may lead to the agenda not having much effect on professional practice or impacting negatively on families (Kestenbaum, 1999; Spandler, 2004). Morris (2011: 10) makes a very important contribution to the personalisation debate, arguing that:

*the purchasing power and control over resources afforded by the use of direct payments or personal budgets are important ways of gaining control over how support needs are met. However, it is not sufficient in many ways and not the only way to achieve choice and control.*

Taking on board the points raised by Beresford (2011/12) and Morris (2011), there seems to be a need for policy-makers to revisit the ‘blueprint’ of personalisation and to undertake meaningful consultation with those who have experience of using and managing direct payments and personal budgets. Thus a possible way forward is to adopt a bottom-up approach which includes the experiences of service users and carers. However, resources are needed to give families genuine choice and control, and given the mismatch between the Conservative government’s ambitions for personalisation and its proposed further cuts to funding for welfare provision, it remains to be seen whether personalisation is the main vehicle for modernising adult social care.

These are important findings as they are grounded in the older parent carers’ experiences of managing direct payments and individual budgets for their adult children, and provide new insights into the impact of personalisation on older carers, particularly in times of austerity. They also indicate that direct payments as a lever of personalisation are just as much about stress, burden, anxiety, risk and imposition as they are about flexibility, choice and control, and highlight that the relationship between care, the state and families is changing without meaningful consultation.

Although participants encountered difficulties in the availability and reliability of formal services, some participants reported easier access to specialised services and parental support from charitable organisations that were associated with their children’s diagnoses. These organisations acted as a ‘buffer’ for families because they were able to get advice in managing their children’s condition and they received support that was tailored to their needs. However, this created some discord for parents whose children did not have a formal diagnosis, or had a late diagnosis, as they were unable to benefit from specialised input and services. These participants felt that they were doubly disadvantaged because they were not only unable to access the specialised services and support, but also excluded from some benefit entitlements. Furthermore, their experiences in trying to get a diagnosis were stressful because they found social and health care professionals unhelpful and dismissive. This was reported by Mrs Wilkinson, whose daughter was diagnosed with autism in her mid-30s and who

has difficulties in accessing services, as it was not until the late 1990s that Social Services included autism as a learning disability and therefore offered services to families. This finding does not seem to have been reported in either the literature about caregiving for adults with learning disabilities or the literature concerned with caregiving in relation to quality of life. This new knowledge provides a more in-depth understanding of the challenges/barriers that parent carers face in trying to access timely and relevant services when their child does not have a definitive diagnosis.

The barriers to planning for the future care of children, and the fears of parent carers about the future care of their adult children with learning disabilities, have been widely reported (Prosser, 1997; Kenny and McGilloway, 2007; Bowey and McGlaughlin, 2007; Dillenburger and McKerr, 2010; Grant, 2010; Cairns et al., 2012; Yoong and Koritsas, 2012). This present work supports these authors' findings, as most participants reported that they were worried about the future care of their adult children and cited several reasons, such as lack of support from professionals, worry about the quality of care in residential care and supported living, difficulty in letting go, the reciprocal relationship (interdependence) between older parent carers and their adult children with learning disabilities, and lack of housing information.

An important new finding, fear of abuse, was reported in the present study. This has not been reported in the previously published literature on caregiving. In Mrs Patel's case, she had sleepless nights worrying about the care of her son when she was no longer able to care for him, as he had been physically abused at the day centre. Similarly, Mrs Halcyon described her worry about her son's future care as the 'elephant in the room', as there were suspicions that he had been sexually assaulted. This fear could have been propagated by the spate of abuse of people with learning disabilities that occurred in residential and nursing homes, which was being widely reported in the media at the same time as the present study was undertaken. For example, the landmark case of Winterbourne View Care Home which was broadcast in 2011 on the BBC *Panorama* programme (Care Quality Commission, 2012) raised public consciousness through national media coverage and in some instances from

parent carers' personal experiences of their children being abused. To this end, the fear of abuse might have been one of the reasons why most participants whose adult children were co-resident saw sibling care as the main option for the future care. This initially came as a surprise, as anecdotal evidence suggests that it is mainly Black and minority ethnic (BME) families who tend to use sibling care. However, in this case, White indigenous as well as BME participants were considering sibling care when they are unable to continue providing care for their adult children. This resonates with a Canadian study by Jokinen and Brown (2005).

Participants found that planning future care impacted negatively on their quality of life, as it was anxiety provoking and stressful. While the increase in life expectancy of adults with learning disabilities has proven to be beneficial to older carers in many ways, such as the provision of mutual support, planning future care has nonetheless presented parent carers with a dilemma. These findings support the calls of Mencap (2002) and Yoong and Koritsas (2012) for practitioners to be proactive in supporting older parent carers in planning future care rather than being reactive when there is a crisis situation.

In addition to these challenges, participants reported that negative societal attitudes towards them and their children impacted on their quality of life. Similar results have been reported in research focusing on caregiving and quality of life (Caples and Sweeney, 2010) and on caregiving of older parents (McKeever and Miller, 2004; Green, 2007) whereby intolerance of disability and challenging behaviour restricted parent carers' engagement with their adult children in mainstream activities and thus impacted negatively on their quality of life. An example of this is the distress experienced by Mr Cullen, who constantly had to explain his daughter's behaviour in public and was left exasperated by the lack of public empathy.

Most participants also reported that the negative attitudes of professionals impacted on their quality of life. In a similar vein, research by Grant (2010) highlighted the unsupportive attitudes which older parents encountered from health and social care professionals. These were related to access to formal services and the difficulties of having their voices heard, and the manner or lack

of sensitivity with which they were told about their children's diagnoses. For example, in this study, Mrs Wood felt like a 'criminal' while advocating for services on behalf of her daughter, and Mrs Collins felt belittled (perceived as not bright) by social care professionals and insulted by the paediatrician when her daughter was born. These negative attitudes evoked feelings of hurt and created adversarial relationships between professionals and parent carers.

The psychological and practical challenges influencing caregiving and quality of life have been widely reported (Green, 2007; Grant, 2010; Caples and Sweeney, 2012). However, Green (2007) reminds us that these challenges present only half of the picture of the experiences of caregiving and its impact on quality of life.

Therefore the conceptual model developed from the findings (see Figure 6.1) is grounded in parent carers' experiences by the use of a qualitative constructivist approach (Rodwell, 1998) and provides a deeper understanding of the experiences of prolonged caregiving by older parents and their conceptualisation of their quality of life in relation to their caregiving role. Furthermore, it highlights the complexities of caregiving and quality of life and the need for adequate and reliable formal support at both the service delivery and professional levels to enhance these parent carers' quality of life. This model makes an innovative contribution to the knowledge of health and social care practitioners, as it provides new insights into the experiences of caregiving and quality of life of older parent carers and how these parent carers can be supported by professionals through timely interventions, and reliable and adequate services to meet not only their children's needs but also their own needs.

## **6.4 Conceptual model**

The findings of this work are informed by two theoretical models: Nolan et al.'s (1996b) modified six-stage temporal model of family caregiving, which was

initially developed by Wilson (1989a, 1989b) in dementia care, and McCubbin and Patterson's (1983) ABCX model of adjustment and adaptation. These models, which were described in Chapter 3, are now discussed in relation to the study's findings.

#### **6.4.1 Nolan et al.'s modified six-stage temporal model**

Nolan's et al. (1996b) identified a range of caregiving situations that parents experience, namely:

1. Building on the past
2. Recognising the need
3. Taking it on
4. Working through it
5. Reaching the end
6. A new beginning

In the context of this study, all six stages are discussed because the parent carers' accounts provided a longitudinal perspective of caregiving, as they recounted their experiences from the birth of their children. However, the final two stages are most relevant, as at the time of the interviews, the average age of parent carers was 69 and, as would be expected, parent carers were at different points in these stages.

##### **Building on the past**

As discussed in Chapter 3, Nolan's et al.'s (1996b) view of 'building on the past' refers to the recognition of the foundations of the caregiving relationships with family members, professionals and society as an antecedent to, and an integral part of, the caregiving trajectory (Nolan et al., 1996b). The findings of the present study resonate with Nolan et al.'s view, as parent carers spoke about the impact of having a child with a learning disability on families and the negative

experiences in engaging with health and social care professionals and society, which influenced their decision to provide care for their children at home. These experiences determined the quality of relationships with family members and with professionals. Generally, family members came together with the notion that providing care was a family responsibility. However, the negative responses of professionals from the outset instilled a lack of trust and confidence in parents. Parents' perceptions of society's intolerance of disability and the general feeling that having a child with disability was a personal tragedy (Green, 2007) also created resentment for these families, causing them to feel alienated. All parents in this study reportedly took the decision to care for their children at home, in some instances against professional advice.

### **Recognising the need**

This refers to the stage when parents realise that something is wrong and that the child will need extra care. Having the knowledge that the child is learning disabled, raises the issue of the uncertainty of care for the present as well as the future (Grant et al., 2003). Data from the current study are consistent with Nolan's et al.'s (1996b) description of this stage, as parents acknowledged that due to their children's disability, the nature of the care they needed to provide was different from ordinary child care. This was an emotional time for most parents. However, the parents who had a formal diagnosis were able to adjust their lives to accommodate caring responsibilities. This adjustment was more difficult for the parents who were searching for a diagnosis. This landscape was unfamiliar territory for parent carers, and in many instances they had no alternative but to 'take it on'.

## **Taking it on**

Having had the realisation that extra care is needed, in Nolan et al.'s model, relatives tended to weigh up their options before taking on the caring role. Similarly, in the current study parent carers needed to make this decision and had no choice, as Nolan et al. (1996b) acknowledged. Parent carers were obliged to adjust their lives, making sacrifices such as leaving their paid employment in order to 'take it on'. Although parents' hopes were dashed at the birth of their child with a learning disability (Hodell et al., 2007), they 'moved on' and committed to caring and loving their children, going on to derive benefits from their role (Grant et al., 1998; Scorgie and Sobsey 2000; Kearney and Griffin, 2001; Green, 2007). In addition, parents took on their caring role without knowing the implications (Nolan et al., 1996b). This was evident in the current study as parent carers did not appear to have been aware of the full impact of providing care long term at the outset, but later discovered that caring brought about feelings of being trapped, low energy levels, time constraints, loss of sleep and loss of friends. These were captured under the themes of feeling trapped and mentally exhausted, no 'me time' and 'multiple losses'. However, as time went on they were able to 'work it through'.

## **Working it through**

This stage refers to active caring, which for many parent carers in the present study meant making the best of their situation by seeking out the positives while trying to minimise the negatives. Closely linked to 'working it through' was the formal/informal support that parents either received or did not receive. There was a sense that parents, having developed expertise (Nolan et al., 1996b), mastery (Perkins, 2009) and sense of coherence (Antonovsky, 1987) by caring for their children, had become confident and were therefore able to advocate for services on their children's behalf. Also critical to their experiences of caregiving was informal support from family.

Data from the current study reflected Nolan et al.'s (1996b) analysis whereby, on a daily basis, families caring for their relatives tried to find a balance and meaning by working through their situation. Thus several themes emerged from parents' accounts that corroborated Nolan and colleagues' ideas concerning the positive side of finding meaning: family cohesion from shared caring, deriving a sense of purpose, becoming a 'better' person and gaining friends 'in the same boat' all contributed positively to parents' caregiving experience and their quality of life. Among the challenges of 'working it through' were the battles for formal services and service delivery through personalisation, which in some instances left parents frustrated and impacted negatively on their quality of life. Therefore the findings from the current study build on Nolan et al.'s (1996b) ideas, and extend the notion of 'working it through' by providing a more nuanced understanding of carers' experiences of providing care on a daily basis, in light of the changing landscape of policy initiatives such as personalisation.

### **Reaching the end**

The finding from this study discussed under the theme of worrying about the future in Chapter 5 is in keeping with Nolan et al.'s (1996b) description of 'reaching the end' and its relation to planning alternative caregiving arrangements. The average parental age was 69 and all parents acknowledged that uppermost in their thoughts was the future care of their adult children. Parent carers were quite worried about who would take over from them and, more importantly, about the quality of care that would be provided. The evidence here suggests that the struggles for services, particularly respite, the lack of trust in others including professionals, the fear of abuse from support workers and giving up the caring role or 'letting go' contributed to their worries. The fear of abuse of adults with learning disabilities is of great concern to parents and has made planning for future care more difficult, now that they are reaching the end of their caring trajectory. Some parent carers, despite feeling tired and burned out, are continuing in their role as they have not been able to find suitable alternative care

that will give them peace of mind. Fear of abuse adds to the challenges identified by Nolan et al. (1996b) and others, in planning future care of adults with learning disabilities ( Bowey and Mc Glaughlin,2005 and 2007; Taggart et al. 2012).

### **A new beginning**

In Nolan et al.'s (1996b) model, this stage represents a new caregiving role for the carers or their life after they have given up the role. Data from this work concur to some extent with this thinking. Now that older parents of adults with learning disabilities are providing active care into their later years, this extension of their caring role (Cuskelly, 2006) can be viewed as 'a new beginning'.

A new beginning was manifested in the current study in both positive and negative ways. On the positive front, for many parent carers, reciprocity, purposeful living, family connectedness and personal transformations were reported as the benefits that parents derived from caring in their later years. For example, the reciprocal relationship was not as apparent when their children were younger, but as their children became older, and were able to help with household chores and provide companionship, this brought about new dimensions to parent carers' lives. These changes in the relationships between parent carers and their children heralded a new beginning as parents and their adult children became a dyad through their symbiotic relationship. This closeness was very evident in the case of parents who were sole or main carers.

In contrast, 'a new beginning' for a few parents who were not coping very well was a time of extreme worry about their children's future care. Forty years ago this was rarely an issue, as parents generally outlived their children with learning disabilities. Moreover, the imposition of personalisation brought another layer of stress for parents. As discussed previously, parents who were 'captives' of care (Todd and Shearn, 1996b) in the current study experienced this negative 'new beginning', due mainly to their coping strategies and the constraints on their resources.

Therefore, in this work, parent carers experienced 'a new beginning' either positively or negatively, and this influenced how they appraised their

quality of life. By re-examining Nolan et al.'s (1996b) idea of 'a new beginning', the current study provides an amplified understanding of caregiving in later life and how it impacts on older parents' quality of life. It is evident from the above findings that Nolan et al.'s (1996b) framework was useful, and helped to shape the current study.

### 6.4.2 The Double ABCX model of adjustment and adaptation

In relation to the Double ABCX model, a modified version (McCubbin and Patterson, 1983) (see Figure 6.4) is considered as it captures the findings of this study more closely than the model described in section 3.9.2. This model extended Hill's (1949, 1958) two-stage model of stressor and crisis to include post-crisis variables and coping strategies. It provided a useful framework for the current study and complements Nolan et al.'s (1996b) framework. The Double ABCX model, which is based on the study of families whose husbands/fathers were held captive or unaccounted for in the Vietnam War, focuses on family events over time and is helpful in guiding research into the range of factors that predict families' successful adaptation in caring for a child with a learning disability (Hodapp, 1995).

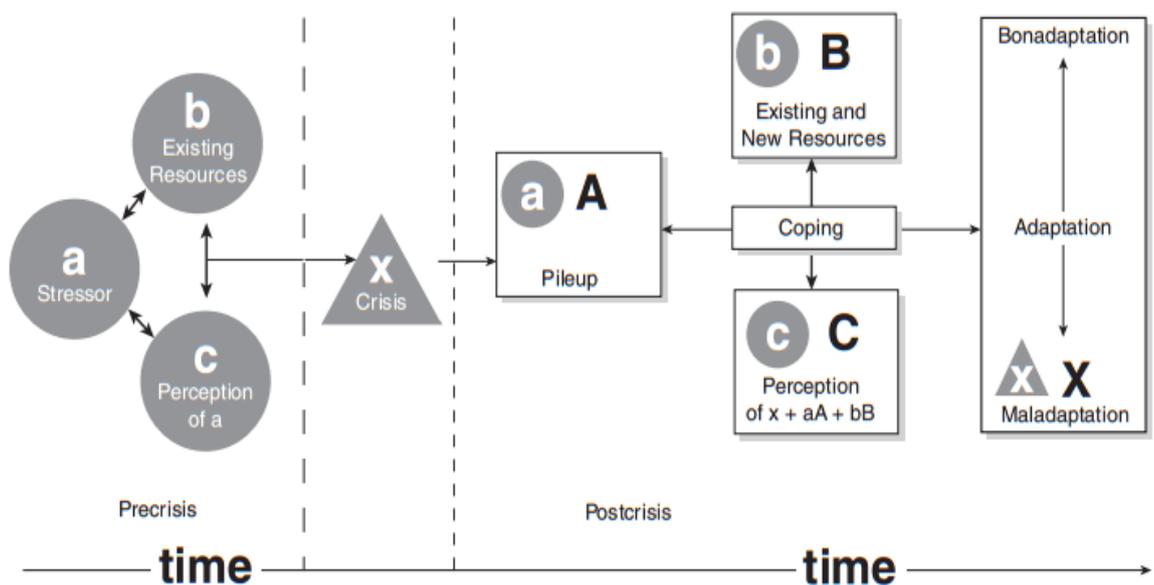


Figure 6.4 The Double ABCX model (McCubbin and Patterson, 1983: 86)

The Double ABCX model (see Figure 6.4) has three main parts: pre-crisis, crisis and post-crisis.

In the pre-crisis stage, 'a' represents the initial stressor, 'b' is the existing resources, which include psychological/individual and social/community as well as intrafamilial /family resources, and 'c' is the perception of the stressor 'a'. In the crisis stage, 'x' refers to the crisis and the post-crisis variables include: the pileup of stressors (aA); existing and new resources (bB); perception (definition) of the initial stressor, pileup, and existing and new resources (Cc); coping; and adaptation to the post-crisis variables.

In this study the initial stressors (a) were: the parent being told, or suspecting, that their child had a learning disability; the decision to take on the caring role, knowing that the child would need extra care, and in some instances searching for a diagnosis in order to access specialist services. The family resources (b) centred mainly on informal support from family and friends. Access to formal services proved difficult for many parent carers, and in the case of services like respite, which were intended to give parents a much needed break from their caring role, demand outweighed supply. This left parent carers feeling that they were on their own. Although formal services evolved over time, for these parent carers government cuts to services precipitated a crisis (x) as they 'battled' to get the appropriate support for their children. Therefore, the stresses perceived by parent carers (c) were not their children's disabilities, as they had moved on from their initial disappointment, but the socio-structural barriers which they had to contend with on a daily basis.

In the post-crisis period, these were compounded by the negative and unhelpful attitudes of health and social care professionals and society's lack of empathy towards people with disabilities, particularly when they were accessing public services, referred to as pileup in the ABCX model. However, most of the parent carers were able to draw on existing and new resources. They were resilient because they had developed expertise and gained a sense of mastery over their situation and, demonstrating a sense of coherence, used an array of coping strategies such as: being part of parents' groups; making new friends with

like-minded parents who were in a similar situation; gaining a sense of solidarity; replacing the friends whom they had lost along the way; personal development by advocating for their children; and personal transformation by acquiring positive attributes like humility, empathy and self-awareness.

Having worked through the challenges using appropriate strategies, most parent carers perceived their situation as positive and as a result adapted well (bonadaptation) to their caregiving situation, and appraised their quality of life positively. Those parent carers whose resources and coping strategies were limited did not adapt as well (maladaptation). It is envisaged that with adequate support from professionals, parent carers can adapt to their situation by negotiating the difficulties of caregiving successfully and enhance their quality of life.

The findings of the current study fit well with the Double ABCX model and therefore mirror the experiences of the families in McCubbin and Patterson's (1983) study. They also provide a fuller understanding of the complexities of caregiving and quality of life by highlighting that, through prolonged caregiving, families develop expertise and a sense of mastery which can be used successfully as coping strategies to reduce the stresses and strains associated with caregiving. Therefore, the Double ABCX model of adjustment and adaptation assists in identifying how parent carers cope in later life with the stresses of caregiving, and provides an understanding of how they adapt successfully to this challenging role, and appraise their quality of life positively.

## **6.5 Summary of discussion**

The study examined the caregiving experiences and conceptualisations of quality of life of older parents providing long-term care for their adult children. The findings and interpretations, which were explored in Chapter 4 on older parents' caregiving experiences and in Chapter 5 on their conceptualisations of quality of life, were brought together as two overarching themes in this chapter and considered as a whole in relation to the extant literature. These two overarching

themes, around which the discussion is framed, represent older parent carers' worldviews at the time of the interviews and are the main contribution of this thesis to the existing literature on caregiving and quality of life. What has emerged is that caregiving was a transforming experience for all parent carers in positive and negative ways, and that formal and informal support for older parents was central in enhancing their quality of life. Other positive contributors to older parent carers' quality of life which were identified were: family cohesion through shared caring; reciprocity between parents and their adult children; adult children realising their potential; personal development/transformations; financial stability; having a sense of purpose; and making friends with other parent carers, which fostered a sense of belonging. The demands of caregiving were an integral part of parent carers' experiences and were seen primarily as an objective burden (socio-structural barriers). For those who relied 'heavily' on formal support due to little or no informal support, these socio-structural barriers (inadequate and unreliable services) along with multiple losses, such as loss of sleep, had a negative impact on their quality of life as they were engulfed in care.

These findings offer a deeper understanding of caregiving and quality of life in the context of long-term caregiving by older people. They also highlight the enmeshed nature of these two constructs. I have endeavoured to show how co-creating meaning with older parent carers through the constructivist approach can illuminate the subjective understandings of quality of life from the perspective of older parents who are providing care for their adult children with learning disabilities. Therefore this study's findings contribute to a more nuanced understanding of caring in later years and how it impacts on quality of life, an area that is under-explored in the current literature.

## **6.6 Critical evaluation of the research: strengths and limitations**

The following critique of the study focuses on several areas: the qualitative research paradigm, the theoretical underpinnings of the methods used, and the

overall study design. Also included is the use of reflexivity throughout the research process.

### **6.6.1 Theoretical framework**

The study adopted a qualitative constructivist approach. Qualitative work has been seen as problematic by some commentators because they are of the view that it is difficult to demonstrate rigour (Seale, 1999; Ballinger, 2006). However, regardless of the approach researchers adopt, in order to judge the quality of the work, it must be evaluated against certain criteria, and qualitative work is no exception (Meyrick, 2006). To this end, researchers have replaced the positivist criteria of internal and external validity, reliability and objectivity with the qualitative equivalent of credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985; Denzin and Lincoln, 2000b). In addition, Rodwell (1998) asserts that trustworthiness and authenticity must be demonstrated in qualitative research for it to be deemed rigorous. This critique has therefore been informed by the guidance offered from these commentators.

As previously mentioned, constructivism is premised on a relativist position and associated with multiple valid realities (Schwandt, 1994). Therefore, having taken a constructivist stance, one of the strengths of the study was its commitment to participants to embrace their multiple stories with no account privileged over another (Ballinger, 2006). This was important for the participants of the study – older parent carers, who are a marginalised group (Milne and Larkin, 2014) – and therefore, epistemologically speaking, this approach has congruence with the social work practice, as ‘central to both is an interactive context- bounded attention to dignity, individuality, empowerment and mutual respect’ (Rodwell, 1998: 4). Having worked with older parent carers, it was important for me as a researcher to uphold these values. Although other studies have used the constructivist approach in exploring the experiences of older parent carers (e.g. Cairns et al., 2012), this approach has not been used to study both caregiving and quality of life of older parent carers of adults with learning disabilities. Furthermore, with the exception of Yoong and Koritsas (2012), the

studies on caregiving and quality of life are mainly quantitative studies, which used standardised measures to assess the quality of life of participants. In contrast, in my study quality of life was defined by parent carers themselves, and therefore the findings are grounded in their subjective experiences, which Mackenzie and Greenwood (2012: 1420) argue are ‘able to highlight aspects of caregiving experiences that are not accessible in quantitative studies and offer opportunity to explore and identify meaningful positive and valued experiences for inclusion in measures used in quantitative studies’.

In addition, with the increase in life expectancy, the subjective views of older parent carers are important to inform service provision for their adult children and themselves.

### **6.6.2 Data collection, data analysis and presentation of data**

The sampling method used in this study was purposive. A concerted effort was made to recruit a diverse sample by presenting the study to parent carers in two additional boroughs where the parent carers’ population was diverse, since in the first two boroughs where I conducted the initial interviews the participants were all White. I attempted to address this bias in the study while I was still doing field work in order to achieve multiple perspectives which are characteristic of purposive sampling (Rodwell, 1998). This was achieved to some extent, in relation to ethnicity and gender (70% White and 30% Black and minority ethnic ; 63% mothers and 37% fathers). However, the limitations were that the majority of the participants were middle class and all their children were in receipt of social services. Therefore, working-class parent carers are under-represented and the voices of parents of adults who do not access social services, described as the hidden population of carers (Horne, 1989), are not represented in this study. This indicates the need for further studies which would focus on the experiences of this ‘hidden population’.

Another consideration is that the data were collected mainly from individual interviews because only one parent carer volunteered for a focus group

interview. One of the challenges I encountered during the interviews was that parents had to 'unearth' painful experiences, particularly around the birth of their children, when they learned that their children had a learning disability. Three participants became upset and were given the opportunity to withdraw from the study, but they all wanted to continue. However, they were encouraged to seek emotional support if they needed to do so. Three of the interviews with participants from minority ethnic backgrounds were difficult to keep on track because the participants were having difficulties in accessing services and this had a tendency to dominate the interview. I therefore had to use several prompts and probes, which felt like I was guiding their responses. In one particular interview, I felt that there was a researcher bias because both the participant and I are of African Caribbean heritage and this seemed to influence her responses. For example, all her responses were extremely positive and she did not identify any challenges in her caring role, even when I probed. The general tone of the interview was individualised, as the participant repeatedly used phrases like 'you know what I mean', and gave the impression that she was referring to the social norms around learning disability in the Caribbean. Although constructivism facilitated my insider (emic) perspective in the co-construction of meaning with participants, this privileged position presented challenges. For example, I needed to 'strike a balance' between drawing on my knowledge (tacit) as an insider and at the same time holding an outsider (etic) position as the researcher by ensuring that I did not raise participants' expectations of services, as my role was that of researcher. I also needed to 'immerse' myself in the participants' stories to gain an in-depth understanding of their caregiving experiences and their conceptualisations of their quality of life, so that I could question my assumptions about the participants' stories and the things that mattered to them most in their lives.

In order to keep an idiographic focus which is consistent with the constructivist approach and also to provide transparency, both convergent and divergent themes have been presented in the findings. Nevertheless, one of the strengths of the study is that the views of parent carers from minority ethnic background are represented.

### **6.6.3 Rigour, trustworthiness and authenticity in qualitative research**

Uppermost in my thoughts throughout the research process was the issue of ensuring that the study findings can stand up to scrutiny. Therefore several steps were taken to ensure rigour, as outlined in Chapter 3. These included providing an audit trail – that is, a detailed account of how the research was conducted – which included checking the accuracy of the data from the interviews and of the study findings by member checking, by returning the transcripts to participants to check their accuracy (as suggested by Rodwell (1998) and Finlay and Ballinger (2006)), and reporting the study findings at conferences, thus adding credibility and authenticity to the study. The thesis has also detailed how the data were analysed in Chapter 3, which was guided by the framework technique (Ritchie and Spencer, 1994), and provides in the appendices samples of the transcripts and the matrices which were created in the analysis of data.

### **6.6.4 Use of reflexivity**

Having adopted a qualitative constructivist approach, which was described in Chapter 3, I heeded Creswell's (2003: 182) advice that 'qualitative researchers must reflect on their impact on the study process'. Therefore, throughout my research journey, I kept a reflexive journal from which extracts were used selectively in the thesis to highlight my influence on the research process – for example, the construction of the research problem, the research setting, and research analysis and findings (Pillow, 2003) – and also to amplify key points being made by participants. However, I tried to avoid the pitfall of narcissism which has been identified by several authors (Marcus, 1994; Pillow, 2003; Finlay and Gough, 2003), where researchers become wrapped up in their presence and positioning in the research process (Patai, 1994), at the expense of overshadowing the participants' voice. I therefore endeavoured to let the 'participants and the data speak for themselves', as suggested by Pillow (2003: 179).

### 6.6.5 Suggestions for duplicating the research

If I had to conduct this research again, I would certainly use a qualitative approach because the subjective experiences of quality of life of older people are under-explored, as researchers have favoured the use of standardised measurements (Hendry and McVittie, 2004), such as the CarerQoL and WHOQOL-BREF, to assess older people's quality of life. These measurements are limited, do not capture what is important to people's quality of life, and are fraught with problems (Bowling, 1995; Hendry and McVittie, 2004; Gilhooly et al., 2005). However, while I would not change the decision to use a qualitative approach, there are several things I would do differently:

- I would double my efforts to recruit parent carers for focus groups, by presenting the study to parent carers' group a second time after a couple of months. There might be parent carers who were not present at the first meeting who would like to be part of a focus group.
- I would ask at the end of the individual interviews, whether participants would be willing to participate in a focus group as well. On this occasion, although it was my intention to have focus groups from each borough, I felt I gave up too early. I believe focus group data could have strengthened the research by giving parent carers who felt comfortable in a group setting the opportunity to have a 'voice'. However, I am also mindful of the potential drawbacks of using focus groups: for example, it has the potential to give a voice to the loudest in the group.
- I would give couples the option to be interviewed separately. In the current study, I took the pragmatic decision to interview couples together, as discussed in Chapter 3, as I realised that there were two people willing to participate when I arrived for the interview. On reflection, this might have curtailed what parents had to say about their experiences of caregiving, as they might not have wanted to offend their partner. I believe the option of separate interviews would enhance the research in terms of gaining a fuller account of gender perspectives.

- I would try to recruit more parents from less affluent boroughs, producing a more diverse group in terms of socioeconomic status. For the current study, the majority of the participants were from affluent boroughs, which meant that their socioeconomic status may have influenced their caregiving experiences and how they appraised their quality of life.

### **6.6.6 Final reflections on the research**

This research journey provided a lens through which I have been able to evaluate myself as a researcher. Firstly, embarking on this journey was a leap of faith, as I did not know what to expect. However, what seemed a colossal task gradually became manageable as I engaged with literature on my area of research and the diversity of methodological approaches. Over time I have become more confident in utilising the qualitative approaches.

Having chosen a constructivist approach for my research which recommends grounded theory for data analysis, and having decided to use framework as a methodological innovation instead, this ‘stepping out of line’ lingered on my mind for a while. Although I was able to justify my choice, to further strengthen the authenticity study I therefore sought external validation from experienced qualitative researchers and, after receiving assurance that framework analysis can be used successfully with constructivism, I was able to breathe easier. My confidence was further boosted when I started to analyse my data, having attended training on data analysis.

Throughout this journey I have learnt a lot about myself. My relativist worldview became part of my consciousness and this enhanced my ability to see, and embrace, multiple perspectives, which enhanced my analytical skills. The power in my research ‘battery’ was my motivation to do this research, and this kept me going in the midst of several challenges.

## 6.7 Conclusion

The study utilised a constructivist approach to examine the conceptualisations of the quality of life of older parents providing long-term care for adults with learning disabilities. Parent carers' accounts illuminated their caregiving experiences in their later years and how these impacted on their quality of life, and vice versa, thus highlighting the enmeshed nature of these two multifaceted, dynamic constructs, and the tensions that one exerts on the other.

The relevance of the theoretical models that underpinned the study was also discussed, and this was followed by a critical appraisal of the study, which included how rigour, trustworthiness and authenticity were assured. Suggestions for a future study and a final reflection were offered.

The following chapter concludes the study.

# Chapter 7 Conclusion

## 7.1 Introduction

This concluding chapter presents an overview of the study, and the findings that were derived from it. This is followed by the contribution of the research to knowledge and the implications of the findings for policy and practice, and education. Finally, this conclusion discusses the possible directions for further research.

The research used a constructivist approach to examine the caregiving experiences and the conceptualisations of quality of life of older parent carers of adults with learning disabilities. The following two research questions were addressed:

1. What are the experiences of older parents who provide long-term care for their adult children with learning disabilities?
2. How do older parents who provide long-term care for their adult children with learning disabilities conceptualise their quality of life?

## 7.2 Overview of study findings

The main findings suggest that most participants' caregiving and quality of life experiences were positive, despite the stressful challenges they had to negotiate on a daily basis. Nonetheless, for most, they were able to work through these challenges and emerged as 'survivors' who emphasised the positive aspects of their lives over the more challenging and the negative experiences. For the few participants who felt overwhelmed by the demands of having unresolved challenges, their quality of life was adversely affected. The participants who appraised their caregiving and quality of life positively reported that caring, particularly in their later life, for their adult children with learning disabilities had enhanced their quality of life as a result of several benefits/rewards, such as:

- facilitating family cohesion through shared caring;
- extending their social circles;
- adding purpose and a sense of gratification to their lives;
- receiving tangible and intangible support from their adult children;
- being able to meet their financial needs;
- gaining a sense of mastery/coherence and expertise; and

That said, the many challenges experienced by all participants originated mainly from the socio-structural barriers that they encountered in caring for their children, rather than from having a child with a learning disability. These difficulties were:

- multiple losses and constraints;
- struggling to access formal services and the challenges of personalisation;
- consequences of no formal diagnosis;
- fear about the future care of their children, particularly fear of abuse; and
- negative societal and professional attitudes.

This does not mean that having a child with a disability was not traumatic for participants, as they all described very vividly their initial sadness and grief, particularly when their child's diagnosis was confirmed. However, most participants had moved on from their initial grief to see beyond their children's disability, and focused on providing active care for their children to enhance their lives, and to help them realise their potential. This in turn added positive dimensions to parent carers' lives. Ironically, most of their difficulties related to the consequences of caring: for example, sleep deprivation, loss of career and friends, and negative professional and societal attitudes, which were exacerbated by socio-structural barriers of inadequate, unreliable and unresponsive formal services. These findings provide an in-depth understanding of what contributes to the quality of life for parents caring in later life for their adult children, and have

implications for policy, practice and education which are discussed later in this chapter.

### **7.3 Contribution to knowledge base**

The present study is one of only two UK studies that have examined the quality of life of older parent carers of adults with learning disabilities. The other, a quantitative study (Walden et al., 2000), was discussed in Chapter 2. In contrast to Walden et al.'s study, the present study used a qualitative constructivist approach to examine the quality of life of older parent carers of adults with learning disabilities, in which quality of life was defined by the participants, therefore providing a nuanced understanding of quality of life from older parent carers' perspectives.

This study confirms the findings of the existing research literature on caregiving and quality of life, and also adds to the body of knowledge by offering a counter-narrative to the dominant discourse on caregiving for people with learning disabilities. There is often an implicit 'deficit' model, focusing upon the negative and undermining positive reporting as denial and as merely a coping strategy (Green, 2007). The present study also extends the current conceptualisation of quality of life of older people, and highlights the fear of future care being abusive.

This research identified 'fear of abuse' as one of the barriers that older parent carers faced in planning future care for their adult children. This new finding possibly arose due to the heightened public awareness around the abuse of people with learning disabilities: for example, at Winterbourne View Care Home, which received wide media coverage in 2013. Although Taggart et al.'s (2012) study highlighted abuse as a concern of family carers in relation to the quality of care of their relatives, the study did not identify abuse as a barrier to planning future care. Similarly, in Bibby's (2012) review of the literature on future planning for adults with learning disabilities who live with older parent carers, fear of abuse was not identified as one of the barriers to future planning.

This was despite his acknowledgement that Prosser (1997) had identified the risk of harm as one of the areas of concern. The ‘fear’ identified amongst the barriers was centred on fear of the unknown: that is, adults with learning disabilities managing in a new environment. This seems to focus more on whether they had the knowledge and skills to cope rather than on fear of abuse.

Existing research (for example, Grant, 2010) has reported reciprocity between older parent carers and their adult children. However, the present study takes this further, suggesting that the reciprocal relationship enhances parent carers’ quality of life – and more so in their later years – and challenging the binary of carer and cared for by highlighting that caregiving is not unidirectional.

The government’s Personalisation Agenda has been seen as the main ‘vehicle’ in delivering adult social care. Previous research (Glendinning et al., 2009a; Williams et al., 2003) has suggested that parent carers’ quality of life and caregiving experiences have been enhanced by managing direct payments/individual budgets on behalf of their adult children with learning disabilities. This study contradicts this finding, since the administrative and managerial processes associated particularly with direct payments were reported by most older parent carers as a source of added stress and burden which detracted from their quality of life and caregiving experiences.

Gender has been identified as a significant influence on carer satisfaction and/or rewards. This research highlights that gender may not be as influential as previously thought; rather, the level of care provided and the quality of support received have a greater bearing on carer satisfaction and rewards. In this study, both men and women who provided greater levels of care reported less satisfaction and fewer rewards than those who were in the ‘lighter’ end of caring.

Earlier findings on caregiving and the quality of life of older parents of adults with learning disabilities have not reported quality of life from the perspective of the philosophical concepts of eudaimonia and hedonia (Walden et al., 2000; Lin et al., 2009; Leung and Li-Tsang, 2003; Chou et al., 2007; Caples and Sweeney, 2010; Yoong and Koritsas, 2012). In contrast, this research has identified the association between the concepts of eudaimonia and hedonia, which the ancient Greek philosophers Aristotle and Aristippus used to describe

quality of life ( Chung et al., 1997), and the conceptualisations of their quality of life used by older parent carers' in this study. The study has also found that most of the older parent carers' conceptualisations are consistent with eudaimonic living, thus identifying a philosophical framework that can explain older parent carers' understanding of their quality of life. This finding suggests that there is a possible link between eudaimonic lifestyle and caregiving gratification.

Past research has highlighted the barriers in accessing formal services for parent carers of adults with learning disabilities (Caples and Sweeney, 2010; Grant, 2010). However, parent carers in these studies did not report the lack of diagnosis for their children as impacting on them. In contrast, the present study found that parent carers whose children did not have a formal diagnosis were unable to access specialist services and claim entitlements. Therefore, they relentlessly sought a diagnosis by making numerous visits to the doctor. The study found that the determined pursuit of a diagnosis for most parent carers was not only in order to access services and entitlements, but also to obtain 'peace of mind'.

## **7.4 Implications for policy and practice**

The findings of this research indicate that most parent carers appraise their quality of life positively. They are providing substantial care in later life for their adult children with learning disabilities. Although current government policies, such as Valuing People (Department of Health, 2001) and Valuing People Now (Department of Health, 2009), have focused on parent carers of adults with learning disabilities in relation to social inclusion, several Acts have highlighted carers' rights to an assessment of their needs, and the support to meet the needs identified. These Acts include the Recognition and Services Act 1995, the Carers and Disabled Children Act 2000, the Carers Equal Opportunities Act 2004, and more recently the Care Act 2014. The benefits of these policy initiatives have not materialised in any significant way for older parent carers, as evidenced in the current study. One reason for this is the government's cuts to Social Services'

budgets. Therefore, in recognition of the valuable contribution that older parent carers make by providing substantial care for their adult children, at the expense of their own needs (Cairns et al., 2012) policy-makers should focus on providing adequate resources tailored specifically to alleviating the stress of older carers and focused on helping older parent carers sustain a good quality of life.

The Care Act 2014, which came into force in April 2015, emerged towards the end of the current study. However, the Act provides an opportunity for practitioners to respond to the issues raised in the study on the experiences of caregiving and quality of life of older parents who provide long term care for adults with learning disabilities.

For carers, the Care Act 2014 is a watershed moment, having repealed the previous legislative frameworks namely (The Carers Recognition and Services Act 1995; The Carers and Disabled Children Act 2000; and The Carers Equal Opportunity Act 2004) that supported informal carers. Rather than granting a power to provide services as previously was the case, this 2014 Act places a duty on local authorities to provide a service to informal carers, to address their needs identified in their carers' assessments. It broadens eligibility criteria for informal carers' assessments by removing the condition of 'regular' and 'substantial', and it also gives informal carers new rights for the first time which are at the same level as the people they care for (Carers Trust, 2016).

In relation to the findings of this study, the benefits/rewards of caregiving reported by the older parent carers need to be maintained. Therefore, health and social care practitioners involved in assessing carers, have a duty to provide appropriate services that promote and facilitate the activities which help to enhance older parent carers' quality of life. For example, a service such as respite care for the adult with learning disabilities, can allow parent carers to be part of a carers' group which gives parent carers a sense of belonging and social inclusion. This was one of the rewards parent carers reported here.

Similarly, practitioners need to provide adequate services to address the stresses experienced from the challenges and barriers encountered by older parent carers on a daily basis from providing care for their adult children. The

stresses reported by older parent carers were associated mainly with socio-structural barriers in accessing services. Therefore practitioners have a pivotal role in advocating for services on behalf of parent carers particularly in this period of austerity in order for the Care Act 2014 to be fully realised and bring about tangible benefits for informal carers. For example practitioners need to advocate strongly for culturally sensitive day services to continue (Mr Ramdeen's case) when there is a review of services for service users from Black and minority ethnic communities so that their older parents can get a break from their caring role.

In relation to practice, the findings of this research provide new insights into what enhances or reduces the quality of life of older parent carers, and inform the interventions of health and social care professionals who work with these parent carers. They also reinforce the need for practitioners working with older parent carers of adults with learning disabilities to devise interventions that take into consideration the mutuality between older parents and their adult children. A key finding was how the reciprocal relationship and interdependence between older parents and their adult children with learning disabilities enhances parents' quality of life. Therefore, parents and their adult children should be seen as a dyad or triad (when two parent carers are involved) when planning interventions, particularly alternative accommodation for the adult children. To this end, practitioners should take steps to understand that 'expert' older carers still need support to reduce the stresses of caring in later life. While stressors are mainly associated with socio-structural barriers (such as timely access to formal services), attending to the fears of older parents about the quality of care provided outside the family will enhance their quality of life. As shown by this study and supported by previous research (Redmond and Richardson, 2003), much of the carer burden experienced by parents originates from inadequate and unreliable services. Therefore, working collaboratively with parent carers in service design and delivery could be the way to enhance parent carers' quality of life.

## 7.5 Implications for education

This research has provided a nuanced understanding of the caregiving experiences and the conceptualisations of quality of life of older parents providing long-term care for adults with learning disabilities. It highlights the positive appraisals of most of the parent carers in conceptualising their quality of life. The study also identified the challenges they encountered which were not about their children's disability or their ability to care, but about the socio-structural barriers and negative professional and societal attitudes that they faced on a daily basis. These findings can inform the learning and practice of practitioners as well as students who are training in health and social professions. Therefore, practitioners and social work and other health or social care students who work with adults with learning disabilities and their families should:

- give due attention to older parent carers of adults with learning disabilities by offering them carers' assessments to ensure their needs are identified and adequately met. This should include acknowledging the interdependent relationship by seeing the adults and their parent(s) as a dyad/triad, and working holistically with families by taking into consideration both the needs of adults with learning disabilities and their older parents when conducting assessments and planning interventions, particularly when discussing future care. This way of working is integral to good practice in health and social care.

## 7.6 Dissemination of findings and implications for further research

I intend to return to the groups from which I recruited to present and discuss the findings with the parent carers. I also intend to present the findings to staff of organisations that support carers, such as Carers UK, and health and social care practitioners from Community Teams supporting adults with learning disabilities.

The study adopted a constructivist approach in which meaning was co-constructed between the participants and myself. Constructivism is premised on multiple meanings and therefore this research contributes to the understanding of quality of life from older parent carers' perspectives at a specific point in time. From an ontological perspective, this approach embraces a relativist position and therefore was well placed to accommodate the participants' multiple realities of their caregiving experiences and quality of life.

- It would be useful to conduct a further study to explore the quality of life of older parent carers along with that of their adult children with learning disabilities.
- A follow-up study with parent carers who appraised their quality of life as poor would be useful to establish whether, over time, these parent carers succeeded in garnering the necessary support and modifying their coping strategies to meet the demands of caregiving.
- It would be useful to explore further the concepts of eudaimonia and hedonia with parent carers of both children and adults with learning disabilities.

## **7.7 Summary**

In conclusion, the methods used for collecting and analysing the data were outlined and the key findings of the study were discussed in relation to the two research questions. This study revealed that there are rewards and benefits of caregiving that enhance the quality of life of older parent carers of adults with learning disabilities, despite the challenges they encounter on a daily basis. The findings both corroborate and enrich previous understandings of older parent carers' quality of life. They make a unique contribution to the existing literature in the fields of caregiving and quality of life, and have implications for policy, practice, service delivery, social work education and further research.

## Appendices

### Appendix A: Extract from my reflexive journal

19/07/13

I am doing my data analysis. I have devised a conceptual framework from the emerging themes and I am currently indexing the raw data (transcripts). I feel I am getting the hang of things, I have much data and as I read each transcript I reflect on the day I did the interview. It is so vivid. I am getting excited, the interpretation of the data seems to be coming naturally. However I need to finish the data management and then move on to the interpretation as recommended by Ritchie + Spencer who devised my framework. The next three weeks are going to be intensive.

## Appendix B: Moule's (2003) appraisal framework

<b>The Introduction</b>	<ul style="list-style-type: none"> <li>•Is there a clear statement about the topic being investigated?</li> <li>•Is there a clear rationale for the research?</li> <li>•Is there a clear statement about the limitations of the research?</li> </ul>
<b>The Literature Review</b>	<ul style="list-style-type: none"> <li>•Do the researchers use contemporary material about the topic being investigated?</li> <li>•Do the researchers link their work to a wider body of knowledge through the references cited?</li> <li>•Do the researchers link the topic to the questions about theory?</li> <li>•Is there a clear link between the literature and the formulation of the research question(s)?</li> <li>•Is the research question clearly stated?</li> </ul>
<b>The Methods Section</b>	<ul style="list-style-type: none"> <li>•Is the research design clearly described?</li> <li>•Are the research methods appropriate for the topic being investigated?</li> <li>•Are any advantages or disadvantages of the design acknowledged by the researchers?</li> <li>•Is there a clear statement about who participated in the research?</li> <li>•Is there a clear statement about how the participants were selected?</li> <li>•Is the selection of participants appropriate to the design?</li> <li>•Is there a clear statement about the number of people taking part in the research?</li> </ul>
<b>Data Collection and Analysis</b>	<ul style="list-style-type: none"> <li>•Is there a clear description about how the data was collected?</li> <li>•Was the data collected by appropriate people?</li> <li>•Is the approach to data analysis appropriate to the type of data collected?</li> </ul>
<b>Quantitative</b>	<ul style="list-style-type: none"> <li>•Is there any explanation of sample size used?</li> <li>•Is the level of significance of the tests (alpha) used indicated, or implied to be the customary 5%?</li> <li>•If Pearson correlation coefficients are being calculated, is there any evidence of a check for a linear relationship?</li> <li>•If t-tests or analysis of variance (ANOVA) are to be performed, is there any evidence of check(s) to demonstrate that the data follows a normal distribution, or of assumptions made?</li> <li>•Are reasons/assumptions re the level of measurement of the data given? (This affects the appropriateness of the descriptive statistics given and the tests used.)</li> <li>•Is there a clear statement describing how valid</li> </ul>

	<p>and reliable the measures are?</p> <ul style="list-style-type: none"> <li>•Are the type of statistical tests used appropriate for the sorts of data collected?</li> <li>•Is the use of any statistical analysis package, such as SPSS discussed?</li> <li>•Is there evidence of a statistician's input to the analysis?</li> </ul>
Qualitative	<ul style="list-style-type: none"> <li>•Is there a clear reflexive statement about the researcher's role in the analysis?</li> <li>•Is the approach taken to data analysis clear?</li> <li>•Is the use of any electronic analysis package discussed?</li> <li>•Is there a clear statement about how the researcher validated interpretations?</li> </ul>
Ethics	<ul style="list-style-type: none"> <li>•Is there a clear statement about ethical committee approval?</li> <li>•Is there a clear description about gaining consent, maintaining anonymity and or confidentiality?</li> </ul>
The Results/ Findings	<ul style="list-style-type: none"> <li>•Are the results related back to the literature review?</li> <li>•Are the weaknesses in research design acknowledged?</li> </ul>
Quantitative	<ul style="list-style-type: none"> <li>•Is the presentation of results clear and unambiguous?</li> <li>•Are all the results presented?</li> <li>•Do the tables and charts used give a clear picture of the sample data and results?</li> <li>•Are the charts used appropriate?</li> <li>•Are the tables easy to use?</li> <li>•If percentages are recorded, are actual numbers also clearly shown?</li> <li>•Are results of tests interpreted rightly?</li> </ul>
Qualitative	<ul style="list-style-type: none"> <li>•Does the research present evidence of the data collected?</li> <li>•Does the data presented as part of a theme support the analysis suggested?</li> <li>•Is there a clear audit trail?</li> </ul>
The Conclusions	<ul style="list-style-type: none"> <li>•Are the implications for further research acknowledged?</li> <li>•Are areas for further research identified?</li> <li>•Are further recommendations made for practice that come from the results/discussion?</li> </ul>

© Moule, P. Pontin, D. Gilchrist. M. Ingram, R. (2003)

Critical appraisal framework.

# Appendix C: Ethical approval

**Brunel**  
UNIVERSITY  
WEST LONDON

School of Health Sciences and  
Social Care

## Research Ethics Committee

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17<sup>th</sup> July 2008

**Proposer:** Carol-Ann Howson  
**Title:** Caring in old age for an adult child with a learning disability: An exploration of the meaning of the expression Quality of Life  
**Ref:** 08/05/PHD/03

### Letter of Approval

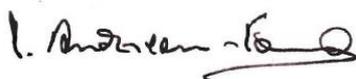
The School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

NB:

- Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.



David Anderson-Ford  
School Research Ethics Officer

School of Health Sciences and  
Social Care

**Research Ethics Committee**

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4 November 2009

Approval of Amendment to Protocol

**Proposer:** Carol-Ann Howson  
**Title:** Caring in old age for an adult child with a learning disability: An exploration of the meaning of the expression Quality of Life  
**Ref:** 08/05/PHD/03

The School Research Ethics Committee has considered the amendment to protocol recently submitted by you in relation to the above study. Acting under delegated authority, the Chair is satisfied that there is no objection on ethical grounds to the amendment. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**NB:**

- Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.



David Anderson-Ford  
School Research Ethics Officer  
School of Health Sciences and Social Care

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Social Care

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1 December 2009

Approval of Amendment to Protocol

**Proposer:** Carol-Ann Howson

**Title:** Caring in old age for an adult child with a learning disability: An exploration of the meaning of the expression Quality of Life

**Ref:** 08/05/PHD/03

The School Research Ethics Committee has considered the amendment to protocol submitted by you on 30<sup>th</sup> November in relation to using voluntary agencies, rather than Local Authorities within the above study. Acting under delegated authority, the Chair is satisfied that there is no objection on ethical grounds to the amendment. Approval is given on the understanding that the conditions of approval set out below are followed:

- *The Committee will expect to receive copies of written permissions from relevant voluntary agencies and carers' groups before recruiting parent carers.*
- *The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.*

**NB:**

- Research participant information sheets and (where relevant) flyers, posters and consent forms, should include a clear statement that research ethics approval has been obtained from the School of Health Sciences and Social Care Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.



David Anderson-Ford  
School Research Ethics Officer  
School of Health Sciences and Social Care

# Appendix D: Participant consent form



## CONSENT FORM

	<i>Please tick the appropriate box</i>	
	YES	NO
Have you read the Research Participant Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you received satisfactory answers to all your questions?	<input type="checkbox"/>	<input type="checkbox"/>
Who have you spoken to? .....		
Do you understand that you will not be referred to by name in any report concerning the study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you give permission to include anything you say as a quotation without referring to you by name?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study:		
- at any time	<input type="checkbox"/>	<input type="checkbox"/>
- without having to give a reason for withdrawing?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that the interview will be recorded on audiotape?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Research Participant:		
Date:		
Name in capitals:		
<b>Witness statement</b>		
I am satisfied that the above-named has given informed consent.		
Witness name & signature :		

# Appendix E: Approach to Carers Development Managers

LETTER TO CARERS DEVELOPMENT MANAGERS.....

Dear .....

## Research on Older Parent Carers

I am a lecturer at Brunel University with an interest in the Quality of Life of older parent carers of adults with learning disabilities. I am currently conducting research for a PhD in this area and therefore wish to recruit suitable participants.

I would to attend your carers' forum to give a twenty minute presentation about my research to the carers. I am seeking to recruit older carers who satisfy the criteria for the study, on a voluntary basis.

I have to seek approval from the University Ethics committee and a key concern in granting approval is that they are assured that carers' services are not affected by their consent or refusal to participate in the study.

I am sure that you will be in agreement with this and would take this into account in assisting me with recruiting older parent carers.

Your kind assistance will be greatly appreciated.

Yours sincerely

Carol-Ann Howson

17<sup>th</sup> December 2009

Ms Carol-Ann Howson  
Brunel University  
Mary Seacole Building  
Uxbridge  
Middx UB8 3PH

Dear Carol-Ann

**Research on Older Parent Carers**

It was good to meet you earlier today to find out about your research. Thank you for your letter dated 17<sup>th</sup> December asking if you can attend our next Carers' group meeting to give a presentation about your research.

I would be very happy for you to attend. As you know, this will take place on January 18<sup>th</sup>, 6-8pm at [REDACTED]. I would like to reassure you that carers' services from [REDACTED] will not be affected by their consent or refusal to participate in the study.

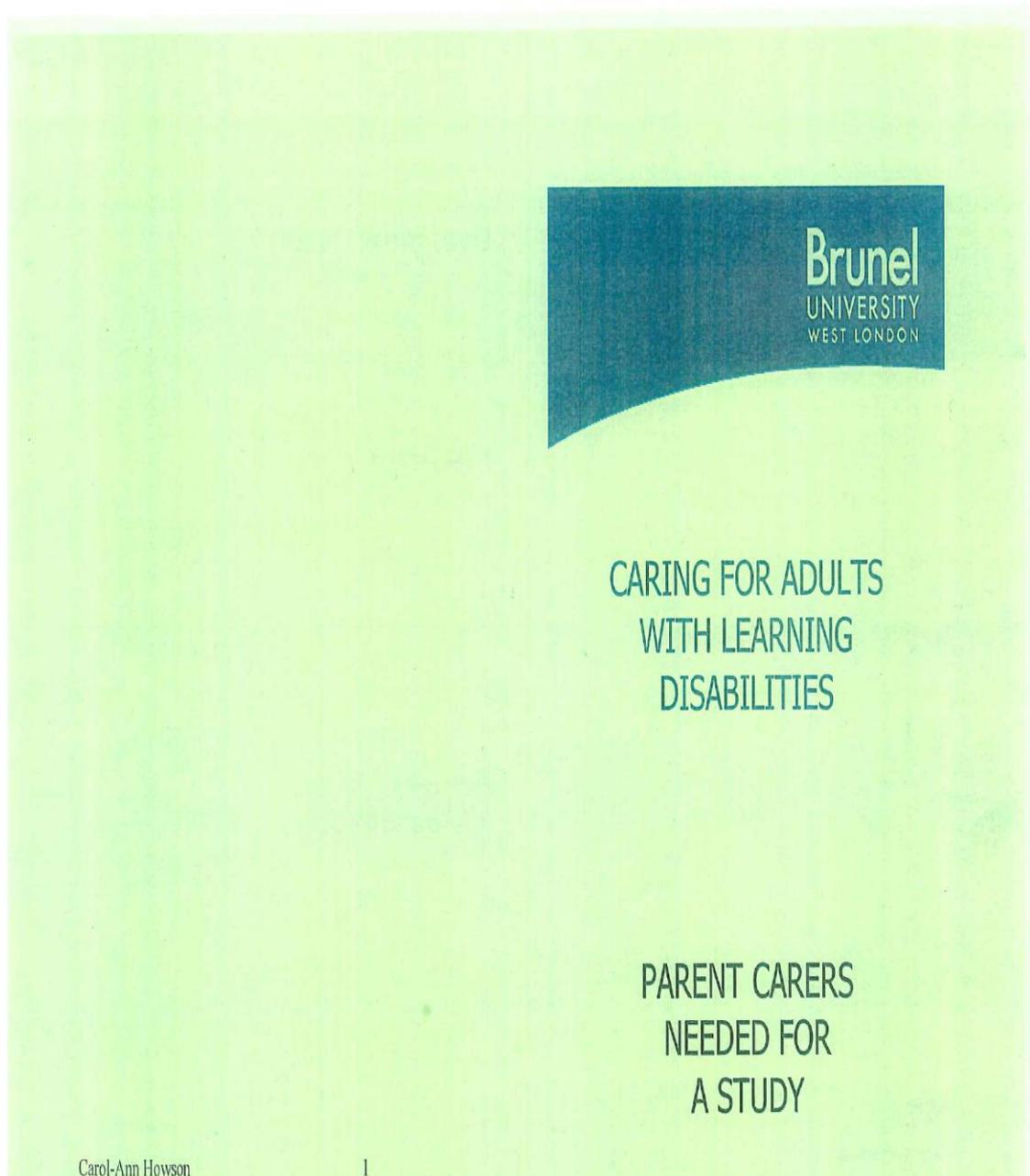
I have drawn up a list of carers who fit your criteria and will be sending details today to them to ask if they would be interested in taking part in your research. I will let you know the response early in January.

With best wishes,



Susie Rowan  
Carers' Support Worker (Learning Disability)

## Appendix F: Parent carer information pack



**Researcher:**

**CAROL-ANN HOWSON**

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Mary Seacole Building  
Uxbridge  
Middlesex  
UB8 3PH

**Telephone:** 01895 268733

**Email:**

[carol-ann.howson@brunel.ac.uk](mailto:carol-ann.howson@brunel.ac.uk)

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Dr Maggi Banning

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Dr Cathy Aymer

**Tel:** 01895 268908

**Email:** [cathy.aymer@brunel.ac.uk](mailto:cathy.aymer@brunel.ac.uk)



CARING FOR  
ADULTS WITH  
LEARNING  
DISABILITIES

*This study has been  
approved by the School of  
Health Services and Social  
Care Research Ethics  
Committee.*

PARENT CARERS  
NEEDED FOR A  
STUDY



***Who is doing the study?***

I am Carol Ann Howson, a lecturer at Brunel University, and I am conducting a study on the Quality of Life of older parent carers of adults with learning disabilities.

***What is the aim of the study?***

The aim of the study is to find out how older parent carers view their Quality of Life in relation to their caring role.

It is hoped that the information gathered will help professionals to get a better understanding of how to work with older parent carers of adults with learning disabilities.

***Why choose me?***

You are asked to take part in this study because you are a parent carer for your son/daughter who has a learning disability and you are 60 years or over.

You should be able to talk comfortably about your views and experiences in English.

***What do I have to do?***

You can volunteer for an:

- Individual (face to face) interview which will be conducted at a location of your choice and any cost incurred for traveling will be refunded. Interviews will be recorded on audiotape.

Or you can volunteer to be a member of a:

- Focus group will be conducted at a central location. Any cost incurred for traveling will be refunded. Interviews will be recorded on audiotape.

***Is the information Confidential?***

Yes. All data collected in this study will be treated as highly confidential. At no time will your name be associated with any findings. The information will be kept in a computer, but no names will be put on the computer.

***Can I change my mind?***

Yes, you can withdraw from the study at any time, giving any or no reason.

Any services you currently receive will not be affected, whether or not you participate in the study.

***What do I have to do next?***

Kindly fill in the green form and post it in the stamped self-addressed envelope.

***I would be most grateful if you would complete the green form and return it to me in the self-addressed envelope.***

Are you willing to take part in this study?

Yes

No

.....  
Contact Telephone Number :

.....  
E-mail Address:

If yes,

In a group

Individually

.....  
Please return in stamped  
self-addressed envelope.

Name :

Carol-Ann Howson

2

## Appendix G: Indexing a transcript

WS450060 ( Father sole carer)

M: I presume I'm the research participant, is that me?

Yes

M: I didn't think I was one of those!

*You are the expert of your situation*

M: It's the 9<sup>th</sup> isn't it...

*Yes it is the 9<sup>th</sup>. The year is going quickly!*

Indeed it is. In my volunteering role I have to know all about consent forms. I'm a volunteer at my local carers' centre.

Y?

Yes and to have any of our clients, to work with our clients, we've got to have consent forms and things.

*So could you tell me your daughter's name?*

It's X

**So how long have you been caring for X?**

Since we found out she had disabilities which was when she was 7 months old, so that's 20 years and 5 months, near enough.

*So she is 21*

She's going to be 21 on Sunday, yes.

**It's a big day for her. So could you tell me a little bit more about your caring role?**

Well, I think I do practically everything. Because she has autism and behaviour problems she tends to avoid doing things round the house, so I have to do things like the ironing, putting on the washing, taking the clothes upstairs, putting them away. I even have a struggle with her to just sort of pull her quilt cover up on the bed so I'm doing things like that. About the only thing she does is dresses and undresses, and puts her clothes into the laundry basket. But practically everything else round the house I have to do.

*So cooking...*

*Cooking, cleaning, messing the place up.*

*Her personal care, she does it herself?*

1

2.1

2.1

2.1

Yes, she does her bathroom and that fine. Though I do have to keep an eye on her medicines, just to make certain she's taken them. We call that distant overseeing. We formulated that because at the respite care they've asked us what X needs, so some of the things are sort of close overseeing, and some are distant.

**So she does access respite.**

Yes, we've got one weekend in four, so that's a Saturday night and Sunday night, and then every Monday night she has an overnight.

2.4

**So what's the diagnosis apart from autism? You mentioned she takes medication.**

Yes, she's got epilepsy because the first thing we noticed, when my wife was still alive, she was giving X her feed in the evening, and she said oh, X's very very floppy, and she was sort of just lying back in her arms so we immediately took her to hospital and they referred us up to the children's hospital. They did loads and loads of tests and we had MIRs and EEGs and ECGs, you name it and they said to us yes, she's got epilepsy, we hope that it'll go at 4, 5, 6, and every year they shifted it up a year, and when she got to about 8 they said no, it's not going to stop, we're going to have to reorganise the medicine and keep her on medication. We'd gone through a lot of changes on medication and ended up on Vamotragin and in the process we didn't find out she was autistic, until about 2 years again when I was having difficulty - and still am in a way - of dealing with her temper tantrums and her bad behaviour, and she gets very upset quickly if things go wrong. I had to ask our adult services group if I could speak to a clinical psychologist, and within 5 minutes of seeing X the clinical psychologist said yes, she's definitely autistic. And nobody until that time had said anything.

2.2

Struggle for change & challenge

Picked it up...

They might have picked it up, there was a few things, oh she might be on the autistic spectrum, things like that, but it was never definite. So yes, that was part of it, epilepsy and autism. And she's also got some, what doctors and social services tell me is minor sensory disabilities, which include not really being able to sense hot and cold or wet and dry. So when she's bathing she has a thermometer to check her bath, although she doesn't always use the thermometer, she tends to use me as a water tester. And drying, she's getting better as I'm watching her closer to make sure she's drying, but she sometimes forgets her toes, and just under her thighs where she has difficulty reaching under.

**I gather that you are the sole carer now, how long have you been the sole carer for X?**

For 5, 6 years, since 2005.

Change from main carer to sole carer.

**Probe: Would you say that the challenging behaviour she presents impacts on your caring role?**

Well yes, it just makes things harder for me, in a sense, I can give you a for instance. As I told you I volunteer at the local carers' centre. We've got an internet café as we call it with two computers. X loves computers, so when I go down to

High quality of life  
Quality of life

3.1  
3.5  
2.5  
2.2

volunteer, obviously she has to come with me, and one day we were there and one of the benefits advisors needed to get on her computer. And she just jumped out of the seat, shouted and moaned and run off down the corridor and said well they won't let me come off my computer properly, so all my stuff's lost. And she was in a real temper tantrum. I had to deal with that while everyone was standing around, thinking this was fun to see her shouting and moaning, I then had to take the time out to try and calm her down and deal with the temper tantrum. And just calming her down doesn't really finish the job because then I've got to divert her mind to something else, and it does tend to tire me out to do that. And I'm finding that I am getting more tired as the years go on. Quote

Challenge needs add stress to caring experience

**Probe: Other carers have described their feelings as being rewarding and or exhausting, could you describe your feelings?**

Oh yes, it's a lot of hard work, and sometimes it's very difficult to keep up with X's thoughts. And I know everybody says oh, autism, they like to have the day very structured and you do one thing after another. Well yes, X does have that, but if she wants to alter something, it's altering it in mid-stream if you like. We're half way through something and she says no I don't want that Dad, and it's very difficult to try and pick out what she is trying to tell me she wants. Sometimes that is very hard work, particularly if I'm driving in the car and she suddenly wants to go somewhere else and I'm going the wrong way down the motorway or something, it becomes very very difficult.

2.2

Caring seems to be tiring at all.

**Probe: Any extended family?**

I've got a brother and a sister-in-law, who are what's left of the family if I can use that phrase, there isn't any other senior members of the family, and all the other members of the family, my nieces and nephews, have got young children of their own, and it's rather dangerous with X's physical problems, I wouldn't say she can't walk, things like that, but she does walk badly, she doesn't really look where she's walking, and because of her balance she does quite often bump into things. So that in combination with young children is quite dangerous. I used to get help from my brother and sister-in-law, but since 2, 3 years ago, my sister-in-law has a brain tumour so she has difficulty looking after her grandchildren, let alone X. And my brother has got leg problems and things like that, so he finds it difficult to look after X, so in effect I am the one and only carer.

Family unable to support have their own health problems. Very little informal support.

**So what things would you say you find helpful in your caring role?**

Well I think obviously the respite care, gives me a break and a weekender sort of allows me to recharge my batteries as it were, to face the weeks. Being listened to by the social worker is very good and we've got quite a nice balance. When she comes up to visit us, if she sees things she feels aren't quite right, she tells me, rather than just sort of noting it down on the report, oh Dad's not doing this, you know, but not telling me. Because I think it's much better if I'm told things, and the social worker definitely agrees with me. So if she...one of the things is that X's a woman, I'm not, and there's lots of things that women can understand about each other that I've got no idea of. So input from the social worker and some of the carers when she's at respite care is really good, and very helpful. Same as at, she goes to a social club which is for both people with disabilities and mainstream, or 'normal' as they keep telling me, and she's very good at telling me, oh, X I think when she has

Value respite

2.4

positive experience

this long dress, she needs that type of socks, not these big thick red socks and things like that. So it's very very good to get that input which I can't have.

**Probe: Have you had a carer's assessment?**

I've had a carer's assessment, and I'm getting another one as well, yes. It's going through.

**So what things do you find unhelpful in your caring role? You have just described the input from the social worker...**

Well if they're not sort of looking after us as well, at respite care there are times when some of the carers don't follow the care package. Now X fortunately is quite outspoken, and she will tell them you're not doing this right and you're not doing that. Now some of them take that in a bad way and they go off and seemingly sulk, and they don't do the job. So I have to keep telling the manager of the unit that things aren't right. So that is hard work and when I go and pick X up, if she is angry it comes over very quickly and she shouts, and sometimes it's a bit difficult to deal with if there's lots of other carers there and I'm trying to calm X down, and they're going ah yes well she shouldn't do that, you know, she doesn't need us to check that she's dry and things like that. And as I've said to them, we've gone over it a lot of times, there have been cases where I've picked her up and noticed that her trousers have been sticking to her legs, because she wasn't dry. And I say to them well are you going to take responsibility for that so that if she has influenza or something or pneumonia, it's going to be down to you. Oh no, you're the carer, you get on with it. That sort of attitude is very unhelpful, it's better that they do try and follow the care package. If they think that X, as I say with the social worker, if they think she can do something let's discuss it and let's change the care plan. But if they accept the care plan, which is what they have done, then they should follow it. And the fact that they're not, it's very annoying, it's time consuming, there's a lot of aggro and it just affects my energy. Too much of aggro blow the day.

**So what aspects of your caring role would you say are rewarding?**

Well, this year, she's always been not the same as mainstream people and she's been behind in her education, but this year she managed to get onto a mainstream course at a college, and she's the only person with a disability to get on it, all the other people in her class have either dropped out of education or are staying on from another year or two, because they are behind. So I've been really really chuffed that she's handled the interview, the applications. There was only one occasion where I've had to help her slightly, and that was really because we were being sent round the houses and X didn't understand where to go and what to do, so she needed my input. But beyond that she did all the applications, the enrolment, and I'm really chuffed that she's done that and got through.

*I was going to ask what aspects you find difficult, you have highlighted in terms of the attitudes sometimes in not following the care plan. Is there anything else that you find difficult in your caring role?*

Well it's not sort of linked in to things like social services or other carers, but there have been occasions where I have had bad reactions from people on buses or in shops with X. Society can't seem to cope with somebody with a disability when the people themselves are not being well behaved. Like on the bus, there was three

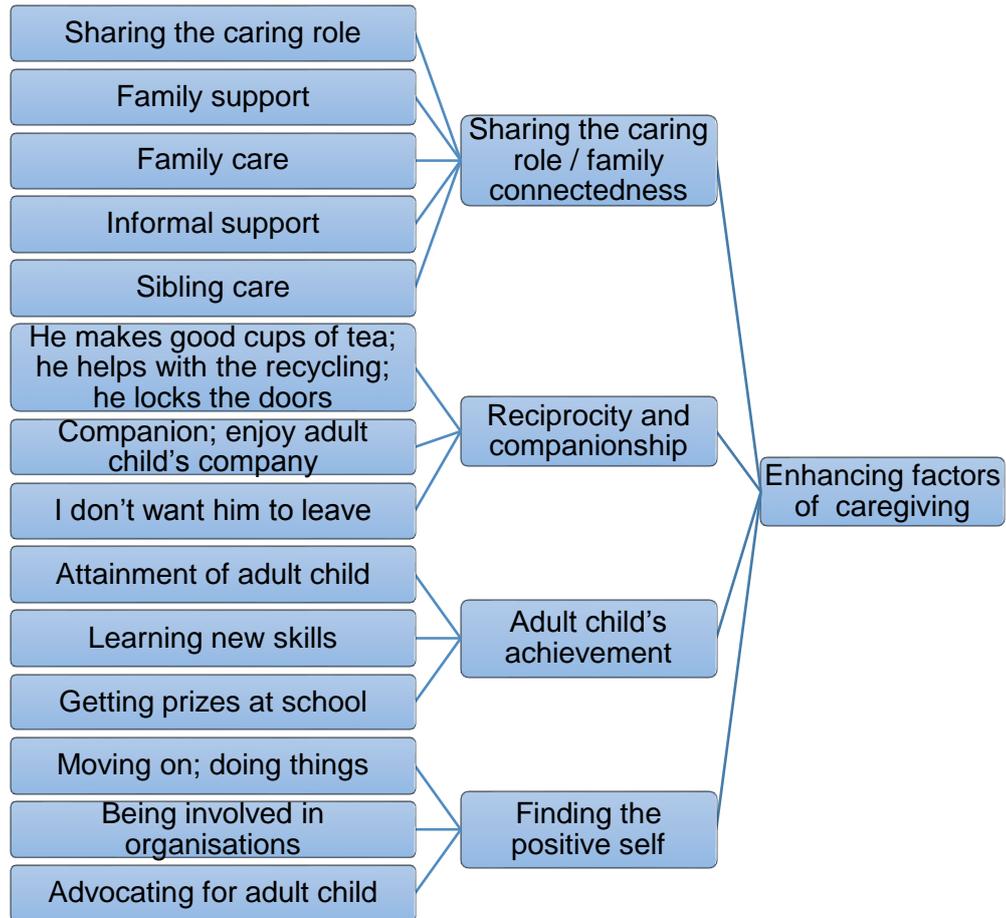
Subject of 2.5  
negative 3.5  
Challenge 2.2  
negative social attitude

## Appendix H: Thematic chart

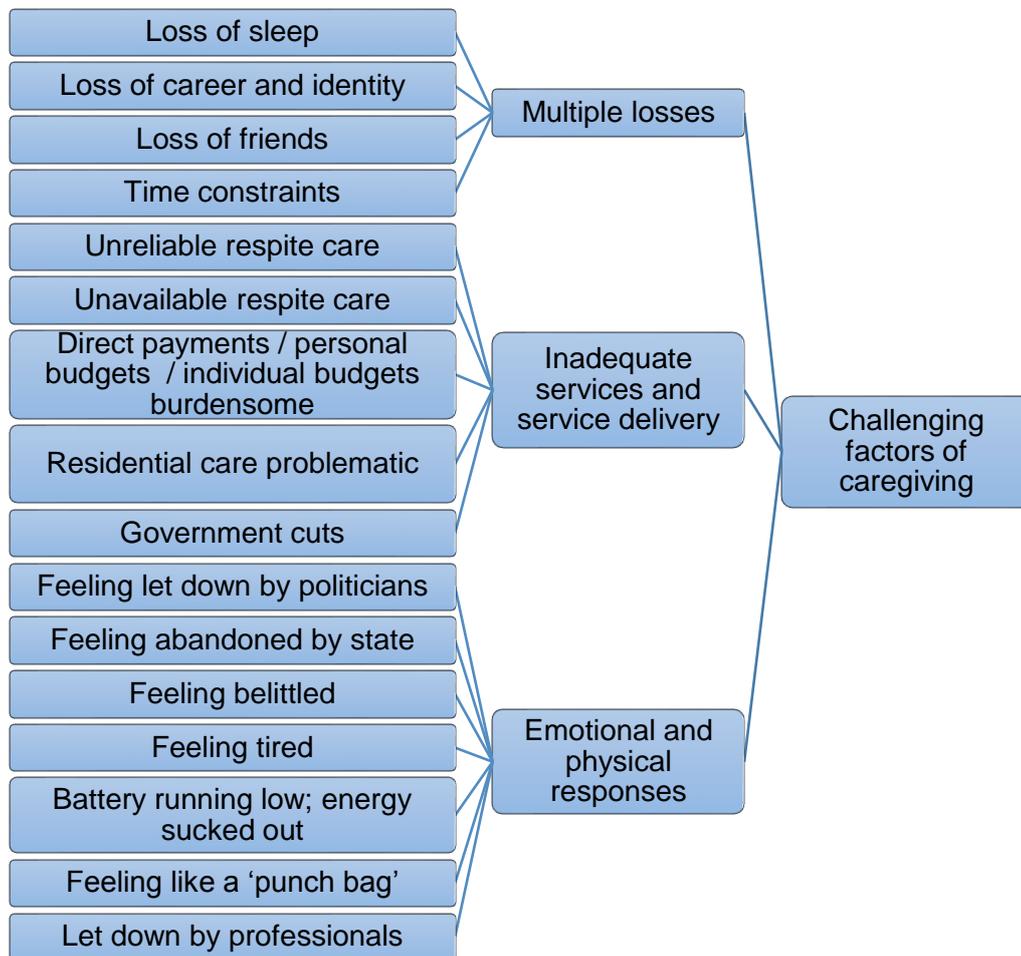
CHART 3			Quality of life						
Order	Typologies	Serial No., Gender, Age, Ethnicity etc.	3.1	3.2	3.3	3.4	3.5	3.6	3.7
			Description of quality of life	Views on quality of life	Factors contributing to Positive quality of life	Factors contributing to negative quality of life	Impact of caring on quality of life	Other	Notes and comments
		Participant 1 male, 72 years White UK, Main care after wife died. Has two disabled children	Describes his life as not bad, but you did not get a lot of time for yourself especially my wife. <b>Pg 3.</b>	We did not want for anything <b>pg4</b>	Finance, I had a job which paid over the average and I could afford the odd luxuries of life <b>pg4.</b> Friends with other disabled children <b>Pg 5 and 6</b> Sharing the care, good relationship with his wife <b>pg7.</b> Involvement with social activities for people with disabilities. improved social life, <b>Pg. 4.</b>	We went away from other people because [son] was noisy .. We found caravan holidays where we were far from other people. <b>Pg.4.</b> Stress and strain of taking son back and forth from residential <b>Pg 8 .</b>	It was a big strain on my wife far more than me but quality of life overall wasn't bad financially. <b>Pg 4</b>		Caring experience is mainly positive therefore Quality of life seemingly not affected negatively by caring responsibilities. Good engagement with social services. Quality of life enhanced by having a job good social contacts, social life. Backbone of support came from friends and family (informal support). REPORTING VERY MUCH AS THE LITERATURE ON QUALITY OF LIFE IN TERMS OF WHAT OLDER FEEL ADD QUALITY TO THEIR LIFE. THIS CASE IS VERY MUCH DIFFERENT TO THE OTHER PARTICIPANTS IN TERM OF EXPERIENCES OF SOCIAL SERVICES.
		Participant 2 male carer, 67 years White UK.	This is a difficult one. I am a positive person, so I must be positive. I am thankful for [son]. I got to say good. If I was to measure against someone else the quality of life is certainly different. <b>"Quality of life means different things to different people". Pg 2.</b>	Means different things to different people, <b>Pg. 2.</b>	Professionals having an understanding. Removing the tag of mentally handicapped, so we could see him as a person who operated slightly different to most people. It is like the <b>"volume is turned down. It is still a television set but the volume is turned down. It is not focused correctly but it is still a jolly good television set", Pg. 16.</b> Support networks: To get a good support network, you really have to work overtime, <b>Pg 18.</b>	<b>"Frustrations and struggles and hurdles to get a decent response...[for formal services]". Pg. 16.</b>	It made life complicated, to manage the complexity from being a fairly free-wheeling type. I was 23, my wife was 21 and we were both out going. We were at the parties. Always on the go. <b>"It was quite a dramatic life change", Pg 4.</b>		Caring impacted on quality of life by the young couple having to change their lifestyle dramatically. However, they embraced the caring role and father who was a participant derived personal satisfaction and expressed that he became more in touch with his human feelings.

# Appendix I: Themes and subthemes

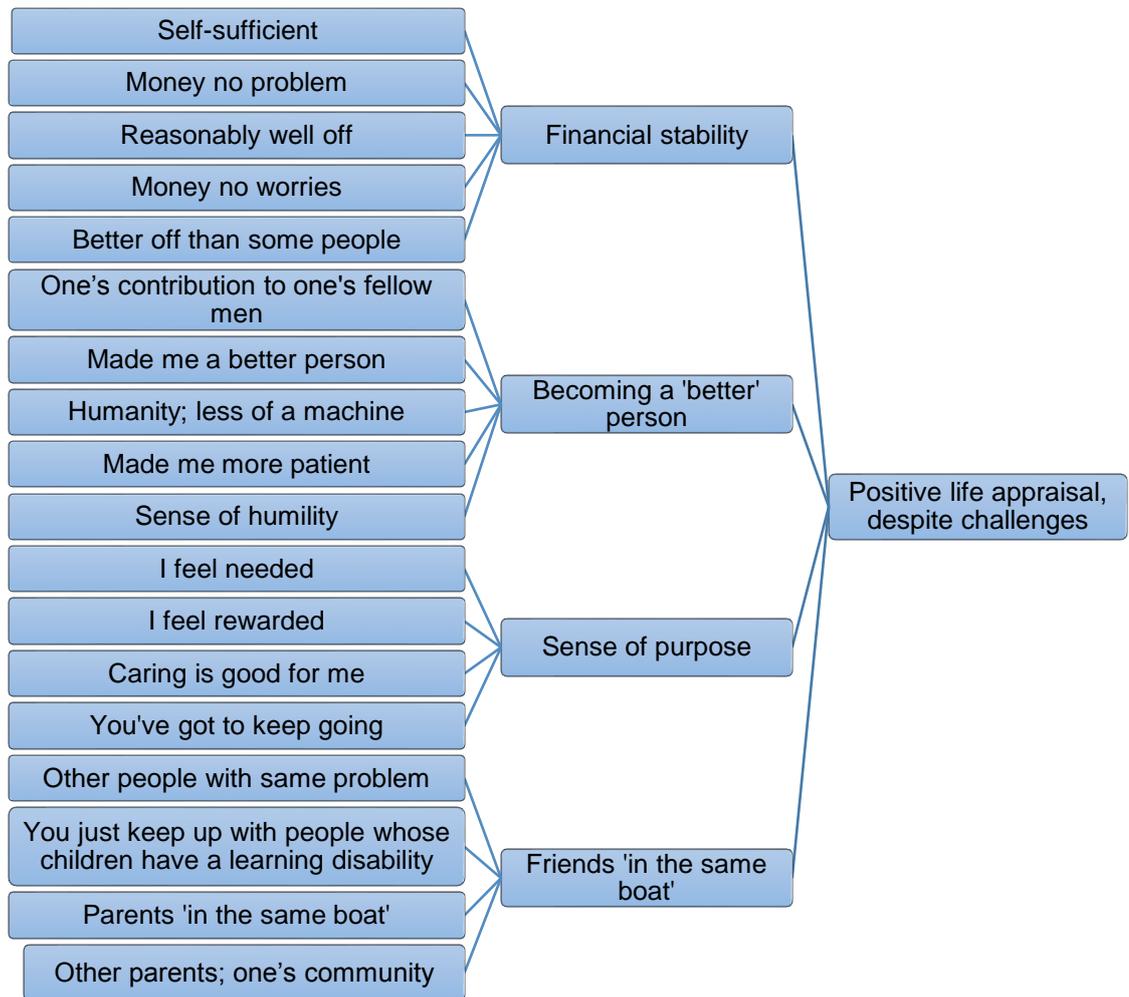
## Overarching theme 1: caregiving experiences and conceptualisations of quality of life



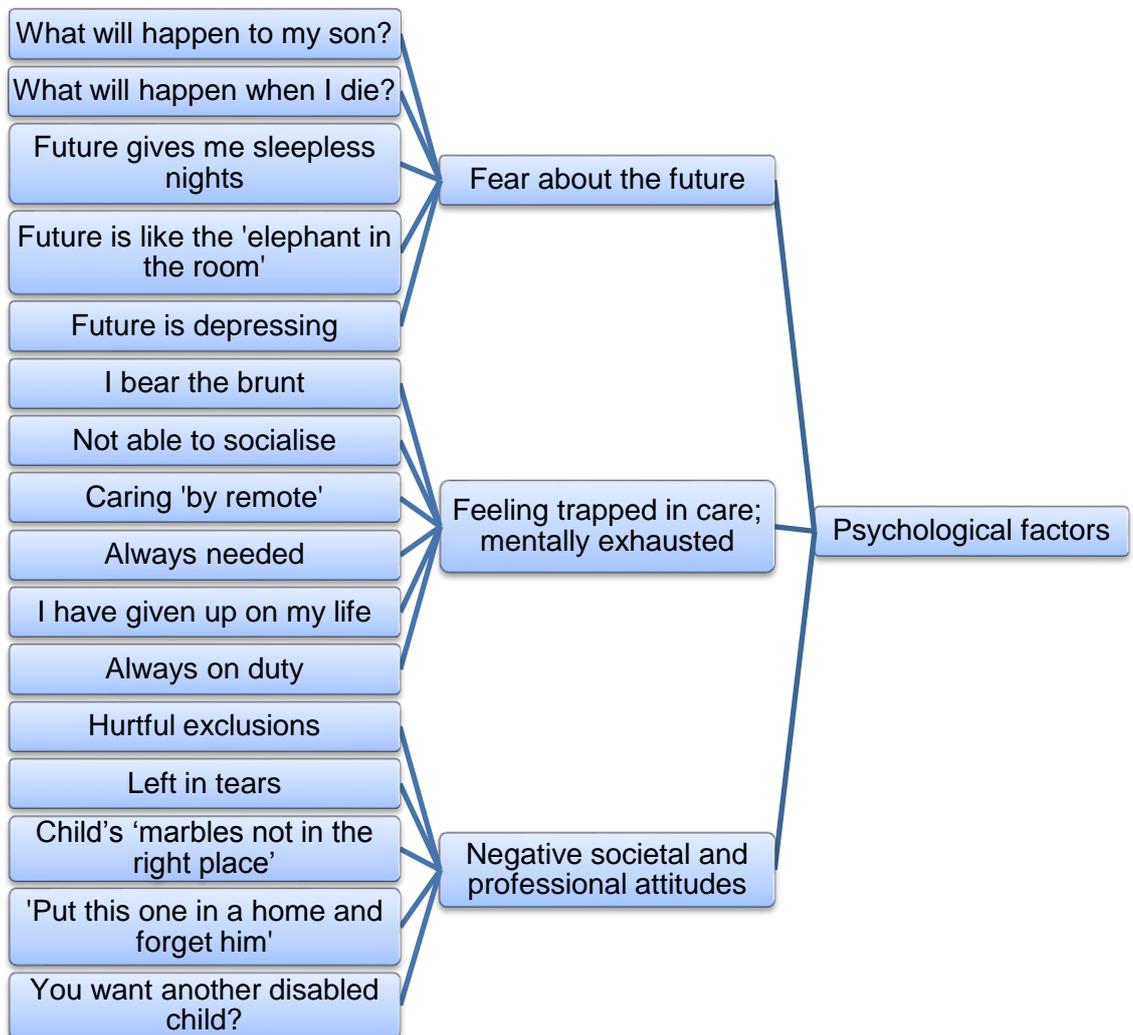
## Overarching theme 2: psychological and practical challenges



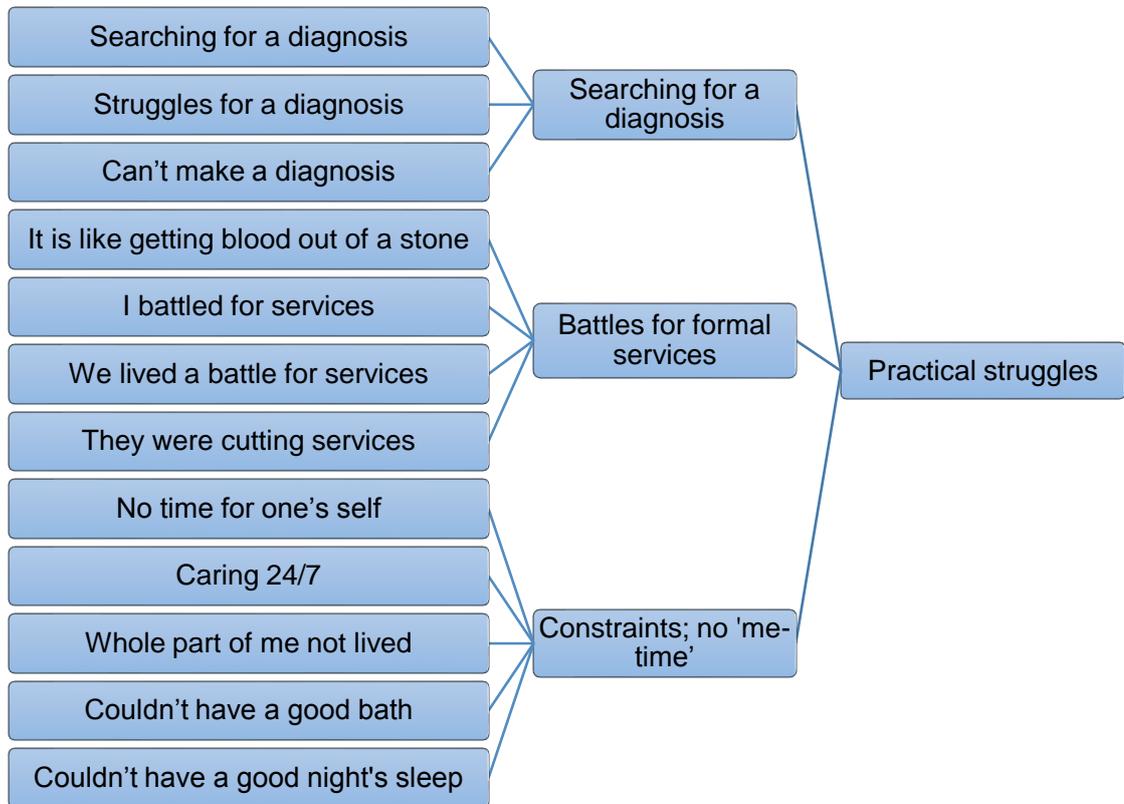
## Theme 1: quality of life



## Theme 2: psychological factors



### Theme 3: practical struggles



## **Appendix J: Conference presentations**

Howson, C. A. (2009) 'Caring in old age for an adult child with a learning disability: an exploration of the meaning of quality of life'. PhD Conference, Brunel University, Uxbridge. July.

Howson, C. A. (2014) 'Exploring the quality of life of older parent carers of adults with learning disabilities'. PhD Conference, Brunel University, Uxbridge. July.

Howson, C. A. (2015) 'Personalisation (direct payments): the impact on older parent carers of adults with learning disabilities'. Family Geographies Conference, Brunel University, Uxbridge. January.

Howson, C. A. (2015) 'Caring in later life: examining the subjective understandings of quality of life of older parent carers of adults with learning disabilities'. 6th International Carers Conference, Gothenburg, Sweden. September.

### **Other presentations**

Howson, C. A. (2012) 'My methodological journey'. Presentation to Health and Social Care staff, Brunel University. May.

Howson, C. A. (2015) 'Caring in later life: examining the subjective understandings of quality of life of older parent carers of adults with learning disabilities'. Presentation to Health and Social Care staff, Brunel University. June.

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