

SIBLINGS OF ADULTS WHO  
HAVE A LEARNING DISABILITY:  
PERSONAL WISHES, REALITY  
AND PARENTAL EXPECTATIONS  
FOR FUTURE SUPPORT

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## **Abstract**

Sibling relationships are significant in the lives of people who have a learning disability. They usually form a major part of their social network and there is an expectation at government, social and family level that siblings will provide some degree of support in the event of parental decline.

A mixed methodological approach was taken, utilizing a survey in Stage one and Interpretative Phenomenological Analysis (IPA) at Stage two. In the latter, 15 face to face semi-structured interviews were conducted to support the research aim of listening to the voices of adult siblings of people who have a learning disability, regarding their personal wishes or preferences in relation to a future support role.

Three overarching themes were identified from nine superordinate themes: impact of learning disability, services, and sibling needs and recommendations. Key messages raised were that learning disability has a significant impact upon sibling lives throughout the life course; although the areas and degree of impact varies widely between individuals, most participants voiced concern about the future, particularly when older parents would no longer be able to provide care. Service issues were raised, as was the difference in role and function between families and service providers. In order to better meet sibling needs and recommendations for lifelong support, information and advice, more productive partnerships need to be established, particularly in the area of futures planning.

This research presents the clear perspective that tangible benefits may be available as a direct result of association with learning disability. It also provides a deeper insight into parental response to learning disability alongside further rationale for a lack of futures

plans and why siblings may not want to co-reside with a learning disabled person. These findings have relevance to service providers, siblings of learning disabled people, students in the field of health and social care and wider society.

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## **Chapter One: Introduction**

Having reflected upon the origin of this thesis, my feelings are that it has developed from both professional and personal interests over many years. I spent several years working as an occupational therapist within a community learning disability team, and was part of a project that focused upon futures planning with families and older parents. Whilst working with these families I became conscious of older parents' concerns about who would provide care and support for their disabled son or daughter when they could no longer do so. I also became aware of the complex nature and sensitivity of futures planning within the family context, and came to understand that, although some families were acutely worried about the future, they were unable or unwilling to make practical plans for the future of the learning disabled individual. This area became the focus of my Masters dissertation and subsequent publication on this topic (Davys and Haigh 2008). From my work at Masters Level, I became aware that the older parents I had met expected their non-disabled children to provide future support to the learning disabled person, yet at the same time did not want to place a burden upon them. These contradictory expectations and wishes of older parents led me to reflect upon the needs and wishes of adult siblings of learning disabled people. On further reflection, it is likely that my clinical experience of working with the sister of a learning disabled woman, who was a similar age to me, made me consider at a subconscious level, how much support I would be prepared to give my own sister if I was in this situation. My clinical and personal enquiry developed as I became aware that little had been written about this subject. The following thesis is the culmination of the research that grew from my reflection

### **1.1 Overall aim of the research**

To explore the perceptions of siblings of adults who have a learning disability in relation to personal wishes, family expectation, and any discrepancy between the two, concerning their role in the future support of their sibling.

Objectives:

1) To explore the personal wishes or preferences of siblings of learning disabled people, in relation to providing future support for the learning disabled person.

2) To compare personal wishes or preferences and the reality of what has actually happened or what they expect to happen, in terms of support to the learning disabled person in the future.

3) To identify how the expectations and wishes of non-disabled siblings compare to the expectations or wishes of older parents.

This research will provide a platform from which the voice of adult siblings of learning disabled people can be heard; it will inform service providers of the needs and wishes of siblings, which should then assist in the planning and provision of appropriate support and thereby enhance the quality of life for both siblings and individuals who have a learning disability.

### **1.2 Current state of research related to the adult siblings of people who have a learning disability**

Although various studies and literature reviews focus on the siblings of learning disabled children (Rossiter and Sharpe 2001; Stoneman 2005), it is acknowledged that there is little research that specifically relates to the *adult* siblings of people who have a learning disability (Hodapp et al 2005; Burke et al 2012); this was identified in the literature review that was published as part of the

research process for this thesis (Davys et al 2010). Although some studies concerned with futures planning refer to siblings (Greenberg et al 1999; Rimmerman and Raif 2001; Heller and Kramer 2009; Rawson 2009; Economic and Social Research Council (ESRC) 2011), there is more often a focus upon the needs and wishes of older parents because they are the more usual main carers of the learning disabled person until ill health or death intervenes (Griffiths and Unger 1994; Thompson 2001; Heller 2000; Alborz 2003; Davys and Haigh 2008). There is little research that specifically looks at the future care roles of adult siblings of learning disabled people (McCallion and Kolmer 2003; Hodapp and Urbano 2007) or what their needs and wishes within a support role may be (Benderix and Sivberg 2007; Heller and Kramer 2009; Arnold et al 2012).

### **1.3 Why is this subject relevant**

Large numbers of learning disabled people, many with profound and severe disabilities, live with a parent well into adulthood (Emerson and Hatton 2008). Even when learning disabled adults move out of the parental home, their parents' role as next of kin often ensures that responsibility remains within the family. The impact of this upon families and carers is acknowledged at government level, alongside a call for independent community living and a collaborative approach to service planning and provision; this includes service users and their carers, as expressed within the documents: 'Valuing people now: from progress to transformation' (Department of Health (DoH) 2008) and 'Putting People First' (DoH 2008). The government publication, 'Families Matter' (DoH 2001), states that families have a right to access support for their role in caring for learning disabled people, that they need to be supported as people in their own right, and that

services should work in partnership with families. This would suggest that the government recognises the important role family members provide in the care of learning disabled people, but despite this, there are difficulties ahead: the Commission for Social Care Inspection (CSCI) reported that many Local Authorities were failing to make plans for the future of the large number of learning disabled people presently living with older parents (CSCI 2006). This concern was more recently highlighted by Cooper and Ward (2011) in a review of 'Valuing People' (DoH 2001), and also by Mansell (2010) who found that half of those families caring for adults with profound intellectual and multiple disabilities said they received no support outside the family; the families felt that services were poorly co-ordinated and that access to and cuts in service provision created difficulty. Such reports are of concern in a climate of increased demand for learning disability services from the NHS and Local Authorities, set against budgetary constraint and huge organisational change. In essence, there is an increased pressure to provide more services with less available finance (McInnes et al 2011). At an international level, there is also concern regarding the increasing demand upon the families of learning disabled people due to increasing longevity, diminished resources and budgetary constraint (Hodapp et al 2005; Bertelli et al 2011; Burke et al 2012; Taylor and Hodapp 2012). The consequence of reduced service provision is that families are the most likely providers of support. Despite this, there is a dearth of evidence regarding the views and future plans or wishes of siblings of learning disabled adults; this is significant because when parents die, a sibling is routinely considered to be the next of kin, along with an expectation that they will provide some level of support.

Older parents of learning disabled people often worry about the future and what will happen in their absence or when they are no longer able to provide previous levels of care (Bowey et al 2005; Bowey and McGlaughlin 2007). They worry that only the family can provide the appropriate level and quality of care (Gilbert et al 2008) and therefore often have expectations that their non-disabled children will take on an active support role, whilst at the same time wishing to avoid placing a perceived burden on them (Jokinen and Brown 2005; Davys and Haigh 2008); this conflict may further accentuate stress, anxiety and difficulty with the futures planning process. Siblings are not always involved in futures planning and a change in role may be swift and difficult; this area of concern was raised in the existing literature (Rimmerman and Raif 2001; Gilbert et al 2008) and in the published results of Stage one of this research (Davys et al 2011). Several authors have drawn attention to the dearth of empirical data that specifically relates to the needs and wishes of adult siblings of people who have a learning disability, despite the expectation of a future support role from parents, family and society (McCallion and Kolmer 2003; Hodapp and Urbano 2007; Arnold et al 2012). Siblings may have a current or future care role for older parents, parents-in-law, spouse, children, grandchildren and other family members; the actual or potential additional responsibility for a learning disabled sibling may therefore be overwhelming. It is hugely important therefore to listen to the needs and wishes of siblings in this situation, as the provision of appropriate and sufficient support may be the factor that enables them to take on the carer or support role; this is of obvious benefit to service providers, as well as people who have a learning disability.



#### **1.4 Difficulties in studying this topic**

The topic of futures planning for people who have a learning disability is sensitive from a variety of aspects. For older parents, there has to be an acceptance of personal decline and ultimate death, which for many, is an uncomfortable scenario (Heller 2000; Bowey et al 2005). In addition to the contemplation of their own demise, older parents are likely to have spent many years providing care and support to a learning disabled person. They may perceive that the quality and degree of their support is superior to that of service providers, as it is borne out of familial bonds of regard, affection and a life-long history rather than the 'business' ethos of service providers (Bowey et al 2005; Gilbert et al 2008); therefore consideration of the quality of future care may be stressful. It is also understood from the literature (Jokenin and Brown 2005) and my studies at Masters level (Davys and Haigh 2008) that older parents often want the family to be involved in future care but, at the same time, do not want to place burden upon 'typically' developing children; this is because parents perceive that they have encountered some level of hardship whilst growing up, due to the presence of their learning disabled sibling. Older parents in this situation may therefore feel torn between the needs and wishes of the learning disabled person and those of the typically developing siblings; hence a double jeopardy situation is generated.

Alongside parental wishes and concern for the future are those of the non-disabled siblings. They have been raised in the presence of learning disability, which has formed part of their day to day experience; however, whilst growing up, these siblings would become aware of difference between their family situation and that where all children were typically developing (McGraw and Walker

2007; Rigney 2009). In this situation, the typically developing children would understand that the family and society perceive the learning disabled person to be in need of care and support. Research has demonstrated that even within childhood, typically developing children may worry about the future and the impact a care role may have on their own lives when their parents die (Benderix and Sivberg 2007; Hames 2008; Wilson 2011). Parental death is an uncomfortable concept for many people even in the absence of future increased care responsibilities. Additional factors that may add to worry or even generate conflict for siblings are issues such as who will provide support, the level and type of support and how long such care may be required. An additional complexity in studying the future wishes and expectations of siblings of learning disabled people is that some may have negative or ambivalent feelings towards the disabled person (Zetlin 1986; Karasik 1993; Rigney 2009; Wilson 2011). Individuals with these feelings may not wish to take part in research, or may only provide answers that they feel are socially appropriate; their views may therefore not be fully represented.

A further issue which is critical when considering futures planning and learning disability, is what learning disabled people have to say about their wishes for the future. There is little empirical research that considers future needs and wishes from their perspective; however they are hugely significant in the futures planning process, as it is their future post-parental support that is under consideration. For some learning disabled people there are issues of communication and conceptualisation as some individuals may not clearly comprehend that parents will die in the future and may not be aware of potential options that could be available to them ( Heller 2000; Bowey et al 2005 ).

Finally, it needs to be understood that each family is a unique unit made up of individuals within that unit. Although there may be commonality in the phenomena of being the adult sibling of a person who has a learning disability, there is likely to be variation in family roles, social context, values, attitudes, education, finances and life circumstances; all of these may influence and affect siblings' experience of the past and their perceived future role (Hames 2008; Rigney 2009; ESRC 2011; Wilson 2011). Due to the potential for variation in experience of the phenomena, this thesis has adopted the methodological approach of Interpretative Phenomenological Analysis (IPA) so as to focus upon the response of the individual to their situation.

### **1.5 Brief outline of the research process followed**

In order to explore the perceptions of siblings of adults who have a learning disability in relation to personal wishes, family expectation, and any discrepancy between the two in relation to their role in the future support of their sibling, a mixed methodological approach has been adopted. At the preliminary stage of the research process, a questionnaire (Stage one of this study) featuring closed questions was used to test the need for further research into this area, and to inform the questions and prompts used within the semi-structured interview, as deemed appropriate research practice by Hicks (2002). The use of a questionnaire in the preliminary stages of a study is also supported by Robson (2002), who states that a questionnaire can be used to provide both a complementary and exploratory basis for a main study. For deeper exploration in Stage two, face to face semi-structured interviews were undertaken; this allowed the researcher and participant to engage more deeply in the concept under scrutiny and to probe areas of interest, whilst providing an individual perspective of sibling needs and wishes

regarding the future care of a learning disabled brother or sister. This form of data collection is considered to be the most appropriate when undertaking an IPA study according to Smith and Osborn (2008), who are associated with the origins of this methodology. In reference to Teddlie and Tashakkori (2009), the use of a mixed methodological approach affords the advantages of triangulation, the presentation of an alternative perspective, a broader view of the issue under study and allows the strengths of two research approaches to complement each other.

### **1.6 Outline of the thesis**

As the starting point for this formal research process, a review of the literature was undertaken and is presented in Chapter two. This will be followed by the methodology section in Chapter three, the results of Stage one in Chapter four and the results of Stage two in Chapter five. A discussion of the results will be presented in Chapter six and the conclusion in Chapter seven will include a discussion of limitations as well as a summary of the findings.

### **1.7 Summary**

This chapter began with a personal reflection that shows that this research is rooted in clinical practice together with a personal motivation that has helped sustain interest throughout the research. There is a dearth of literature on the subject of adult siblings of people with learning disabilities and this thesis addresses the situation by exploring the views and experiences of adult siblings. Having outlined the rationale and the objectives of the research, the next chapter explores the literature in greater depth.

## **Chapter Two: Literature Review**

Sibling relationships are often referred to as the most enduring over the life cycle (Voorpostel and Blieszner 2008). It is through relationships with brothers and sisters that children are provided with their first experiences of companionship, rivalry, sharing and a wealth of other emotional responses. This chapter will provide an in-depth review of empirical studies that relate to adult siblings of people who have a learning disability, but will frame this within the context of typically developing siblings, child siblings in the presence of physical and learning disability, and adult siblings of people who have physical or mental health needs. The reason for framing the literature review in this way is that there may be similarities in sibling relationships whether or not disability is present. In addition to this, the topic of adult sibling relationships is under researched however a number of studies that relate to adult siblings of learning disabled people have compared and contrasted them with siblings of people who have a physical disability or mental health needs, to demonstrate areas of commonality and difference.

The review is organised into four main themes that arise from the literature: 1. The experience or impact of siblings upon an individual's life, 2. Sibling tasks, roles, relationships and factors that influence roles and relationships, 3. Sibling tasks, concerns and expectations for the future and, 4. Siblings' needs and wishes.

### **2.1 Parameters of the literature review**

The current field of research into the adult siblings of people who have a learning disability is somewhat limited; however it is aligned to a vast range of research areas which includes typically developing sibling relationships, the impact of disability upon siblings in childhood, the influence of physical disability and mental

illness upon adult siblings, the family environment and futures planning. It is recognised that the contribution of research from each of these areas is significant and in some cases extensive. For the purpose of this literature review, each of these areas will be referred to; however the body of literature that relates to adult siblings of people who have a learning disability forms the most detailed part of this review.

The articles presented in this literature review that are specific to adult siblings of people who have a learning disability include those published in peer reviewed journals and theses at Masters and PhD level between 1977 and 2013 rather than papers based on opinion. The inclusion criteria for these articles incorporated a main focus upon adults, explicit reference to learning disability and a predominant focus on the views of siblings as opposed to parents. In total, 29 published articles were reviewed alongside 5 theses at PhD level and 2 at Masters Level.

Key terms used in the literature search that solely relate to adult siblings of people who have a learning disability included *siblings, brothers and sisters, adult, learning disability, intellectual disability, developmental disability, mental retardation, mental subnormality, mental handicap and learning activity limitation*. Databases searched include Google Scholar, Psychinfo, Ovid, Medline, Cinahl, Academic Search and Social Policy and Practice. The reference sections of relevant articles were also hand searched. A table detailing the studies used to inform the literature review pertaining to adult siblings of people who have a learning disability, can be found in appendix A. The use of terminology in this field is complex and sometimes highly contested. For example the United Kingdom is one of the few countries to use the term *learning disability* as many other countries use the term *intellectual disability*. Various

researchers in the literature review have used terms that are now considered old fashioned or inappropriate however the terms of reference used within the thesis reflect those of the original authors.

## **2.2 Four key themes arising from the literature review**

### **1. The experience or impact of disability upon siblings` lives**

This theme incorporates the experience or impact of siblings within typically developing families; siblings of children who have a physical and learning disability; sibling roles and relationships during childhood and adolescence; and the impact upon adult lives of a sibling who has mental health problems, physical disability or learning disability.

### **2. Sibling tasks, roles, relationships and factors that influence roles and relationships**

Within this theme, sibling tasks, roles, relationships and influencing factors in typically developing families are reviewed, followed by consideration of these issues in the presence of mental illness, physical disability and learning disability, with reflection upon change over the life course.

### **3. Sibling tasks, concerns and expectations for the future.**

This section of the literature review presents sibling tasks, concerns and expectations of the future within typically developing families and in the presence of mental illness, physical disability and learning disability.

### **4. Sibling needs and wishes**

This small final section of the literature review presents the voice of siblings of disabled people from childhood through to adulthood with reference to their needs and wishes.

## **2.3 Key theme 1: The experience or impact of siblings upon an individual's life**

### **2.3.1 The impact of a disabled sibling in childhood**

In terms of psychological well-being, the impact of a disabled child upon the typically developing child has been the subject of empirical research over a number of years, with findings that indicate both positive and negative effects. In a literature review that considered the effect of a disabled sibling upon children's lives, Stoneman (2005) examined published empirical studies between 1990 and 2004, from countries including the USA, UK, Australia, Sweden, Greece and India; the studies featured families and siblings of children who had a learning disability, physical and sensory disabilities, and brain injury. This review identified that earlier studies presented the view that a disabled child would have a negative impact upon typically developing siblings in areas of psychological well-being such as self concept, behaviour, mental health and self-efficacy; this was a view supported by Rossiter and Sharpe (2001). Stoneman (2005) however, provided evidence of conflicting reports and concluded that overall, siblings of disabled children are not disadvantaged regarding psychological well-being when compared to children who have a typically developing sibling; however, it may be true that the experience is negative for some children. The presence of a positive influence is referred to by Moshier et al (2012) who studied siblings, aged between five and thirty-six, of individuals with Smith-Magenis syndrome and found that most siblings reported benefit from their experience, a perspective that was confirmed by their parents. A further review



by Dew et al (2011) made particular reference to the impact of physical and developmental disability upon siblings of children with cerebral palsy; the findings were that some studies demonstrated a positive psychosocial impact as a result of having a disabled sibling, others a negative impact, whilst others again demonstrated no difference in psychosocial impact when compared to a control group where no disability was present. This affirms the findings of Stoneman (2005) and Lobato (1983), who claimed that the psychological impact of a disabled child upon the typically developing sibling may be positive, negative or present as making no difference compared to families where disability is not present.

A review that reported on the social, emotional and behavioural adjustment of child siblings of people with Autism Spectrum Disorder again presented a pattern of mixed results. Some studies demonstrated a positive impact upon children's lives in terms of social, emotional and behavioural adjustment or, as a minimum, no negative impact; some studies did however, demonstrate a negative impact such as feelings of loneliness, delayed social skill acquisition, increased tendency towards internalising and externalising behaviour and lower levels of pro-social behaviour (Meadan et al 2010). The continued presence of mixed results further supports the findings of Burke (2010) and Angell et al (2012) which highlighted parents' perceptions that siblings' lives were affected in both positive and negative ways. From a positive perspective, siblings were said to gain an enhanced maturity and understanding of disability because of their family situation, and a greater degree of tolerance, patience and compassion; however, from a negative perspective, siblings were less able to take part in outings, were sometimes embarrassed or irritated by the disabled child, and sometimes experienced discrimination from the

community on account of their association with disability. Some siblings were seen to provide high levels of care to the disabled child and parents claimed they had less time to spend with the typically developing child due to increased care demands. A Belgian study by Moyson and Roeyers (2012) into quality of life for siblings of children who had a learning disability, reiterated the presence of positive aspects such as special attention and opportunities, and negative ones such as reduced parental attention, and concern about the well-being of the disabled child.

Within a longitudinal British study, Hames (2008) considered siblings' understanding of learning disability over a 12 year period. This research demonstrated that siblings' reaction to and understanding of learning disability was variable, and yet indicated some degree of impact upon behaviour, relationships, sense of self and future. Before the age of two, some siblings were seen to copy the behaviour of the disabled child, which could be interpreted as normal copying behaviour; however this was superseded by the younger typically developing child taking on a caring role. A change in the power base was also noted as siblings continued to advance their own skills and even before the age of two, some brothers and sisters would show the disabled child what to do. Between the ages of three and seven, siblings had entered the formal education system which, according to parents, made them more aware of difference; some were embarrassed and less tolerant of the disabled child. Generally they did not to give explanations of disability to friends and by six to seven years of age most siblings understood that disability was a long term condition; their play would be adapted to accommodate the disabled child and care tasks were undertaken. Between the ages of the seven and 11, siblings were seen to be cautious about what to tell friends

regarding their brother or sister, and began to describe the impact of the disabled child upon their life, which was predominantly increased care responsibilities and an awareness of future limitations. When aged between 11 and 14 years, all the siblings clearly understood the cause of disability, were still cautious about telling new friends of their brother's or sister's situation, yet overall, demonstrated protection. At this stage, siblings were aware that having a learning disabled sibling made them different in ways such as having an increased level of independence and being more caring; some talked about wanting to enter the caring professions as a future career path.

Adolescence is said to be a time when typically developing brothers and sisters are likely to experience an altered perspective of how a disabled sibling affects their life. Siblings at this stage may feel guilty about their own well-being and for having negative feelings about the disabled person (Dew et al 2008). A study into self-esteem, locus of control and career aspiration of college-age students compared those with disabled siblings to students whose siblings were typically developing (Burton and Parks 1994). The results demonstrated the presence of both positive and negative effects: positive aspects included having a higher internal locus of control than those with typically developing siblings, greater levels of responsibility, tolerance and flexibility; negative aspects were identified as embarrassment, guilt and concern about the future, findings which were similar to those of Dew et al (2011). Despite overall positive consequences however, this study also highlighted some difficulties that siblings may encounter, for example, low self esteem, adjustment issues and greater sensitivity to everyday family stresses when compared to control group families.

### **2.3.2 The impact of a disabled sibling in adulthood**

Having now considered the impact of a disabled brother or sister upon the lives of typically developing siblings in childhood and adolescence, the impact of a disabled sibling in adulthood will be considered from the perspectives of mental illness, physical disability and learning disability; the similarities and difference between these groups of siblings will be explored.

Positive and negative impacts of having a disabled sibling have been identified for siblings in childhood and in a similar way, the literature points to a mixed impact upon the lives of adult siblings of people who have a mental illness. Lukens et al (2004) noted a range of complex emotional responses in a small scale USA study involving 19 siblings of people who had schizo-affective disorder, bipolar and major depression. Sibling responses included guilt, anger, mourning for the 'lost' sibling (as mental illness often does not present until late adolescence), fear of becoming mentally ill themselves and of passing it on to their children. Survivor's guilt and frustration, which was directed towards parents, other siblings or family members, were also noted. Most participants in this study had chosen to remain childless, due to concern about an inherited genetic link to mental illness and the anticipated future support needs of their ill sibling. Positive consequences of having a mentally ill sibling however were also reported, such as compassion, increased levels of patience, a better understanding of disability and a deeper sense of personal faith and love. A study by Lively et al (1995) supports the findings of Lukens et al (2004) as it reported the presence of anger and frustration at having to cope with the demands of crisis situations and concurred with the view that siblings worried about their children developing a mental illness yet

unlike Lukens et al (2004), Lively et al (1995) found no evidence of siblings choosing to remain childless.

The presence of positive and negative impacts on the lives of adult siblings of people who have mental health needs is further presented in the literature. Dimitropoulos et al (2009) carried out a qualitative investigation from a Canadian perspective to explore the experience of siblings of women who had anorexia nervosa. All 12 participants reported negative and positive consequences to their situation. Negative aspects included the presence of anger, guilt and family conflict yet despite this, siblings referred to increased levels of understanding and compassion along with strong family ties and relationships. Leith and Stein (2012) similarly carried out an online survey with adult siblings of people who have serious mental illness in the USA. Siblings in this study reported a sense of loss that referred to their relationship with the ill siblings and the future, yet noted the ability to utilise positive coping strategies in response to their situation.

Health and finance are other areas of life found to be influenced by the presence of an adult sibling with mental illness. Some physical stress-related health issues, for example: lack of exercise, overeating and cardiac problems, were linked to the presence of a mentally ill sibling but were seen to generate less impact than factors affecting mental health (Lively et al 1995; Lukens 2004; Dimitropoulos et al 2009). There is also evidence that siblings of mentally ill people, particularly those who provide primary care tasks such as running errands, doing jobs, providing transport and crisis management, have less available money compared to those brothers and sisters who are not primary care givers (Loher et al 2007).

As in other areas of empirical research related to adult siblings and disability, there is little that directly refers to the impact of physical disability upon siblings' lives and it is therefore an area which requires further research. The body of knowledge that exists however reiterates the presence of both positive and negative consequences of having a disabled sibling. Dew et al (2008) report on 21 empirical articles published in peer reviewed journals between 1972 and 2005 to review the psychosocial impact of lifelong physical disability upon siblings; however, only four articles related to adult siblings and therefore three additional studies of siblings of people who had a learning disability were included, as the authors postulated that similar issues may be relevant to both sets of siblings. The benefits or rewards of having a disabled brother or sister, as noted by young adults, were an increased sense of responsibility, the ability to look for positive attributes in others, tolerance, a sense of humour and flexibility. Compared to typically developing siblings, young adults with a disabled sibling were seen to display a higher locus of control than a comparison group; there was no apparent difference in self-esteem or career aspirations. However, negative consequences have also been reported, such as difficulty with peer relationships and school experiences (King 2007), although this study focused on only five adult siblings aged between 35 and 58. Other young adult siblings expressed feelings of guilt and anger directed to the disabled person (due to increased responsibilities enforced by parents), in addition to life restrictions and anger towards other people because of their negative response towards the disabled person (Hartland and Cuskelly 2000, Davis and Salkin 2005). Adult siblings of people who experienced Traumatic Brain Injury (TBI) were found to demonstrate higher levels of depression compared to the general population across 18 states of the USA (Degeneffe and Lynch 2006)

although this was further linked to female gender; a previous history of depression before the sibling's TBI; higher levels of family deprivation and lower levels of available social support.

From consideration of the literature related to the adult siblings of people who have a physical disability, it is clear that this group experienced similar positive and negative consequences to those who had a mentally ill brother or sister. Research findings may therefore suggest that the experience of having a disabled sibling has the potential for both negative and positive consequences, irrespective of the origin or type of disability.

### **2.3.3 The impact of a learning disabled sibling upon adult lives**

This thesis has so far found that adult siblings of people who have a learning disability report a varied impact upon their lives in areas that include life choices, relationships, identity and future plans. Showing similarities to the literature referring to the impact of a disabled sibling in childhood, some adult siblings refer to a positive impact upon their lives, such as increased empathy and understanding of the issues around disability; others claim that their lives are comparable with other adults who do not have a learning disabled sibling, and a negative impact is reported by some. The presence of positive and negative impacts on adult siblings' lives in the presence of learning disability can be found in the empirical literature; it mirrors to some extent the impact upon adult lives of having a sibling with a physical disability or mental health.

Early studies of adult siblings in the field of learning disability, such as that by Cleveland and Miller (1977), claimed that the majority of siblings recalled positive adaptation to the experience of having a learning disabled brother or sister; they stated that they had only

missed out occasionally on activities due to the needs of the disabled person, that they had been able to bring friends home and in general, did not consider their life commitments to have been adversely affected, and were comparable with other adults where learning disability was not present. A minority of brothers and sisters however reported that life commitments had been negatively affected, a finding also supported more recently by Orsmond and Seltzer (2007). Where there was only one other typically developing child in the family, they were more likely to be orientated by the parents towards educational success; when the only other sibling was an older sister, she was likely to feel increased levels of stress due to the demand to take on care tasks, to fulfil parental desires for academic achievement, and may feel that she did not receive sufficient attention from parents (Cleveland and Miller 1977; Orsmond and Seltzer 2007). The results presented by Cleveland and Miller (1997) however, need to be considered in the context of data arising from one state of the USA, from predominantly white, middle class, well-educated participants; additionally the results are not clearly set out as terms such as 'the majority' are used.

A mixed impact of learning disability on adult siblings' lives prevails throughout the literature. Feelings of sadness on account of their disabled brother or sister, regret that they were unlikely to experience an ordinary life or to achieve independence are expressed, alongside recollections of being teased at school because of the disabled person. Feeling vulnerable due to aggression and violence is referred to by Benderix and Sivberg (2007), who aimed to describe the present and past experience of siblings who had a brother or sister with autism and moderate to profound learning disability. In contrast, a sense of life enrichment,



the development of positive attributes such as empathy, and a shaping influence on studies, serious relationships and self-identity are presented in a phenomenological self case study by Flaton (2006). This study aimed to promote the understanding of the experience of people who have a learning disabled sibling and to explore the impact on personal identity, life experience and choices. Overall, Flaton (2006) described the experience of having a brother with Down syndrome as mainly positive, yet did not make a similar claim about her relationship with a non-disabled brother.

More recent studies have again provided evidence of the mixed impact upon adult lives of a learning disabled sibling. A negative effect on mental health including anger, the need for counselling due to their experience, and feeling torn between the needs of the disabled sibling and their own lives was reported by the ESRC (2011); this work investigated adult siblings of people with autism and learning disability. Siblings also reported positive consequences such as joy at the pleasure and fun the learning disabled person brought into their lives, and attributes of patience, tolerance, empathy and a deep understanding of the needs of people who have a disability. A literature review that considered psychosocial outcomes, relationships and futures planning for adult siblings of people with developmental disabilities (Heller and Arnold 2010) also found evidence of both positive and negative impacts upon siblings' lives.

Identity development can be described as a person's extrinsic experience of self as seen through how one views the world, and subjective experience within the family and social environment. Studies in relation to this have demonstrated that typically developing siblings were aware of difference in the disabled child and their family context compared to that of their peers. Non-

disabled siblings were aware that their parents were less available to them due to the presence of the disabled person and that there was some expectation to take on a supporting role and perform well in an academic setting. The concept that siblings perceived difference, yet simultaneously were aware that their family experience was normative for them, is presented by McGraw and Walker (2007), in a small scale in-depth US study among adult sisters of learning disabled people. Linking back to the theme of positive and negative impacts, the sisters in this study reported positive attributes of patience, compassion and appreciation but also the negative impact upon family finances, relationships, parental attention and increased care tasks. Some, reported a link between their career choice and the experience of having a disabled sibling.

A range of studies have considered the impact of a learning disabled sibling upon life course outcomes including marriage, roles, personality, career choice and decision to have children. A longitudinal study by Taylor et al (2008) reviewed differential life course outcomes, by comparing 268 siblings of adults with mild intellectual deficits, 83 siblings of adults with mental illness and 791 siblings where no disability was present. Findings revealed a significant difference for siblings in the learning disability group; who were found to have a lower IQ by approximately 4 points, less education and a lower socioeconomic status than the comparison group. This survey demonstrated that having a disabled sibling has an impact upon the life course of the typically developing sibling, affecting relationships, family formation and involvement, psychological well-being and personality. However, no significant difference was found between the three groups in respect of currently being married, the number of marriages entered into by

the time of reaching their middle 60's and the number of children participants had. Siblings of learning disabled people reported visiting their relative more regularly than the comparison group, yet were found to be no different regarding psychological distress, well-being or personality. Siblings of people who had a mental illness however were found to have more episodes of depression and lower levels of well-being than the siblings of people with a learning disability and the comparison group. The findings that a learning disabled person may influence a sibling's relationships, choice of marriage partner and decision whether or not to have children, is supported by Karasik (1993), Rigney (2009), the ESCR (2011) and Wilson (2011). Burton and Parks (1994) compared career aspirations of college-age siblings of people who have a disability with those where siblings were typically developing. Although the type of disability was not clearly stated, intellectual disability was alluded to; however, no clear association between having a disabled sibling and choosing a helping profession was established. Karasik (1993) noted mixed results on the influence of a learning disabled sibling upon career choice, as did a literature review by Heller and Arnold (2010), although Wilson (2011) aligned the experience of having a learning disabled sibling with a care giving career for some siblings.

The results of Taylor et al (2008) contrast somewhat with those of Seltzer et al (1997) who also carried out a survey regarding effects upon lifestyle and psychological well-being, by comparing adult siblings of people with a learning disability to those people who had a mental illness. Seltzer et al (1997) indicated that siblings of learning disabled people believed their lives to have been more strongly affected than those who had mentally ill brothers and sisters in the areas of career choice, partner choice, decision to

have children, plans for the future and feelings about people who have a disability. The siblings in this study were drawn from two different but related longitudinal studies; possible reasons for difference in the results of these two studies could be the age and life stage of participants as their circumstances and perceptions may have changed over time. Alternative explanations include the use of different scales to measure the sibling relationship and frequency of contact.

Further evidence of mixed reports regarding the impact of a learning disabled sibling upon life course outcomes are presented in the literature. No significant difference was reported by Konstam et al (1993), between adult siblings of learning disabled people and a matched group of comparison siblings in terms of: past or current employment history; political stance; aesthetic, economic, social, religious or theoretical arenas. These results need to be interpreted in the context of this again being a small scale USA study where participants were well educated, and the majority of participants were from a Caucasian background. Marks et al (2005) however, strongly connected career choice and learning disability, although here, participants were enrolled onto a university programme for special educational needs, which may suggest significant bias.

Possible links between gender and perceived impact of a learning disabled person upon adult siblings' lives has been considered within empirical studies which compared the degree of contact and closeness they felt they had with the disabled person, perceived levels of health and well-being, and life choices related to marriage, divorce and fertility (Hodapp et al 2010). Female siblings noted more benefits from their experience than male siblings, but men reported slightly better health and lower levels of depression than female siblings; however women in the general population tend to

report higher levels of depression than men. Considering the impact of the disabled sibling upon major life events, female siblings married later, had children later and demonstrated slightly lower rates of divorce compared to the general USA female population (Hodapp et al 2010). This survey of 1,166 American adult siblings must be interpreted in the light of its limitations: the fact that it was an American web-based study could indicate that participants were well-educated and from a more affluent background, and web-based surveys can be limited in the depth of detail gained. Participants again were predominantly white, well-educated females and as this study was cross sectional, cohort effects could have influenced the results, as could the wide age range of participants.

### **Summary of key theme**

The literature demonstrates that the impact of a disabled child, be this a physical or learning disability, may be positive, negative, or appear to make no difference compared to families where no disability is present. A similarly mixed response has been found in adult lives where a sibling has a physical disability or mental health needs. Close consideration of the literature related to the impact of a learning disabled brother or sister upon adult siblings' lives shows a similarly varied response. Both positive and negative elements have been noted alongside inconclusive association with health and life choices such as career, partner choice, and decision to have children, political, economic and religious arenas. It is recognised however that many studies originate from the USA and adult participants have been predominantly well-educated females from a white ethnic background. Studies involving male participants and those from non-white ethnic backgrounds are significantly lacking.

As summarised in the thesis by Azeez (2001), who undertook a small scale study involving siblings of learning disabled people at various life stages, it may be that there is no straightforward conclusion as regards the impact of a disabled person upon siblings` lives, rather it is a unique response to a highly individualised situation and context. The impact of a learning disabled sibling upon an adult`s life is of considerable importance however, as the experience is likely to affect roles, relationships, life course and circumstance over the life course. The issue of sibling wishes and expectations for the future, a central concern of this thesis, is likely to be shaped by experience over the life course; it may also be associated with sibling tasks, roles and relationships with the learning disabled person, and this the next key theme of this literature review.

#### **2.4 Key theme 2: Sibling tasks, roles and relationships**

Sibling roles and relationships often appear to be inter-related within the literature. There are tasks or roles linked to each life stage demonstrating change over the life course and both roles and relationships are influenced by a number of variables. Within typically developing families, three key stages of the sibling relationship over the life cycle can be observed and at each stage there are typical tasks and roles. Childhood and adolescence is seen as a time when the sibling relationship is likely to be intense due to daily contact and proximity. The sibling tasks here for typically developing children are described as those of companionship and emotional support, delegated care giving and the provision of aid and direct services to each other (Goetting 1986).

#### **2.4.1 Childhood tasks, roles and relationships**

When considering the roles and relationships of children who have a disabled sibling, be this physical and/ or intellectual, the sibling relationship is seen to incorporate elements of companionship and conflict (Rossiter and Sharpe 2001), perhaps mirroring the positive and negative impact of a disabled sibling apparent within childhood. Most relationships between children where one has a disability have been described as positive, although evidence of mixed reports regarding relationships exists. Some studies report less conflict in the presence of disabled siblings than has been found in typically developing families, some report similar levels of conflict when compared with control families, and others report no difference in levels of conflict (Stoneman 2005). With regard to sibling roles, those commonly referred to include helper, entertainer, teacher and parental support (Angell et al 2012). There is however clear presence of role asymmetry where disability is present. Regardless of whether siblings are older or younger than the disabled child, they tend to take on the role of eldest child, demonstrating care and support behaviours; childhood roles may thus become increasingly asymmetrical compared to those of typically developing siblings, and it may explain the presence of asymmetrical power relationships observed in middle childhood and young adulthood (Richardson 2009). Siblings of disabled children have generally been described as being able to spend time with friends or on extra-curricular activities, although those with a major care role may be limited in these areas (Stoneman 2005). Siblings may feel dissatisfied if they perceive themselves as having more chores and care taking activities than siblings from typically developing families (Rossiter and Sharpe 2001).

Relationships between brothers and sisters can be influenced by family climate and parental relationships. Siblings are aware of differential levels of parenting; as parents need to devote more time and attention to the disabled child, typically developing offspring commonly receive less parental time and attention (Cate and Loots 2000; Stoneman 2005). Although typically developing children may understand and accept this as a practical requirement of the situation, increased levels of anxiety and depression have been noted when siblings have been dissatisfied with this situation. Family function also appears to be linked to sibling acceptance of differential parenting. In well-functioning families, siblings may feel that increased time and attention spent on the disabled child is justified; factors seen to support well-functioning families include strong marital relationships, low levels of conflict, positive sibling relationships and parental well-being, alongside effective social support for the family and the absence of behavioural problems on the part of the disabled child (Stoneman 2005). In a similar vein, those families that had regular and consistent routines were seen to demonstrate fewer adjustment difficulties than families reporting fewer routines. Families who utilized problem solving and effective communication reported better adjustment outcomes for siblings than those using less effective communication and problem solving strategies. Overall, positive family experiences have been associated with positive adjustment outcomes for siblings (Giallo and Gavidia-Payne 2006), although caution when interpreting the results of studies related the impact of childhood disability upon non-disabled siblings is advised by Rossieter and Sharpe (2001); this is because results are likely to be dependent upon the perspective of the informant, who may be the parent, non-disabled sibling or non-disabled sibling in the presence of the parent.



In addition to parental roles, family climate and function, there are a number of other variables that may influence sibling roles and relationships in the presence of a disabled child. These variables include gender (of both disabled and non-disabled child) birth order, age and age spacing, personality, temperament and life stage of each child (Stoneman 2005). The relationship could also be affected by a specific condition, as siblings of children with autism have been noted as having a more negative view of the sibling relationship than siblings of children with more generalised learning disability and those with typically developing siblings (Rossiter and Sharpe 2001). The view that relationships may be influenced by type of disability was endorsed by Nielsen et al (2012); parents reported siblings with a mean age of 11 years to be more kind and involved when in the presence of Down syndrome and autism than they were in the presence of orthopaedic conditions and diabetes. Other factors said to affect roles and relationships included local community, environment, culture, local services and support available. Meadan et al (2010) agreed that gender and age can affect sibling relationships in a family with disability, but also referred to the impact of family climate and socioeconomic background. On researching the impact of physical, intellectual, multiple disability and family size on sibling relationships, David (2008) found that overall family size did not show a consistent impact upon sibling relationships yet did demonstrate that older non-disabled children from three-child families showed more positive behaviour towards a younger disabled sibling than within two-child families. This could suggest that the presence of another typically developing sibling may support the relationship between non-disabled children and their disabled sibling.

#### **2.4.2 Sibling tasks, roles and relationships change over time**

Between typically developing siblings, the tasks of companionship, emotional support, delegated care giving and the provision of aid and direct services to each other are likely to be present in early and middle adulthood, as they are within childhood, yet they take on a different form. Companionship and emotional support is often less intense at this life stage as, although siblings may still act as confidants and friends to each other, they are commonly concerned with adult roles of partner, worker and parent. Contact between siblings is now voluntary and research suggests that there is often a reduction in sibling visiting in the adult years, but a pattern of keeping in touch exists (Goetting 1986).

In general terms, sibling support roles may be divided into instrumental or direct support (for example, financial, transport, shopping) and expressive (compassionate, sharing, listening). Siblings can be a significant source of support in times of need, especially for psychological and social activities (Van Volkom 2006); many typically developing adult siblings provide some form of support to at least one sibling over a 12 month period, and many provide and receive support on a monthly basis (Eriksen and Gerstel 2002). With regard to typically developing sibling relationships, young adults have demonstrated three key dimensions of warmth, conflict and rivalry in their relationships. Perceptions of rivalry and conflict have been shown to be minimally related to expressions of warmth, which suggests that adult siblings are able to experience both positive and negative emotions towards each other.

Gender has been raised as a factor that can influence sibling roles. Sisters are seen to provide more care to siblings than brothers overall, and are more inclined to engage with tasks such as

cleaning, child care, laundry, emotional support and family rituals. Family income and perceived levels of closeness in the sibling relationship have been linked, demonstrating higher levels of emotional closeness among those who were more prosperous (Eriksen and Gerstel 2002). Marital and parental status is also associated with sibling roles and relationships, as those individuals who are single, widowed and childless generally receive higher levels of sibling support (Goetting 1986; Connidis 1994; Eriksen and Gerstel 2002; Van Volkom 2006). Other possible influences upon sibling roles and relationships are proximity and ethnicity. Siblings are more likely to act as confidants, companions, providers of emotional and instrumental support when living close by (Connidis 1994, Campbell et al 1999). With regard to the influence of ethnicity upon sibling roles and relationship, there appears to be some difference of opinion. Erikson and Gestel (2002) noted few differences between black and white siblings when considering care provision between brothers and sisters; however Van Volkom (2006) stated that compared to non-Hispanic whites, African Americans and Hispanics were more likely to have siblings live with them or within close proximity, and cited siblings as an emergency contact.

Birth position, adjacency, family size and relative ordinal position between siblings have additionally been shown to influence the recollection of childhood and current adult sibling relationship in typically developing families. Brothers and sisters in adjacent positions have been described as more likely to form close relationships in childhood (Riggio 2006) although other research (Stocker et al 1997) has shown that siblings who are close in age may experience more rivalry along with those in larger families where there is more competition for parental attention (Stocker et

al 1997; Riggio 2006). Generally however, reports of positive or negative childhood relationships may not necessarily predict adult sibling relationships and there is a need to understand the complexities of sibling relationships over the duration of the life cycle and within the context of family and life events, although a positive correlation has been demonstrated between feelings of warmth and the amount of sibling contact. Geographical proximity has not been linked with the characteristics of the sibling relationship but in reference to psychological functioning, siblings who scored higher levels of mental health reported lower levels of sibling conflict (Stocker et al 1997).

The most significant task that siblings have to manage, and which commonly occurs in middle adulthood, is the support of elderly parents and the eventual dissolution of the parental home (Van Volkon 2006). At this point in life, the sibling bond may be re-established when siblings unite to deal with the critical responsibilities generated by older parents. Brothers and sisters at this transitional stage may see themselves as perpetuators of the family name and traditions; however, if a parent was the binding factor that kept the family together, adult siblings may drift apart after parental death. This raises the question of parental influence upon sibling relationships which is said to be complex, and supports the view that the roles and relationships of typically developing siblings change over time (Eriksen and Gerstel 2002; Voorpostel and Blieszner 2008).

In the final stage of the life cycle, sibling support in the form of companionship and emotional support, aid and direct services may continue as at previous levels during adulthood, but can be influenced by health and transport issues (Van Volkom (2006). The specific tasks for typically developing siblings in old age are said to

include shared reminiscence and perceptual validation, which are possible due to shared life events and family history. Within the sibling relationship at this stage, life events may be validated and family values and integrity upheld. Revisiting the sibling relationship in old age provides an opportunity to deal with unresolved rivalries and establish a more constructive relationship (Van Volkom 2006). As in the stages of childhood and adolescence, the nature of the sibling relationship in later life, and the roles adopted within and between siblings could depend on family structure, values, history and circumstance. As brothers and sisters continue to age, it is likely that they will provide previous levels of support to their best of their ability and where older siblings rely upon each other significantly, there can be a huge impact when one sibling dies; this death signifies the end of a relationship that has been lifelong and holds unique shared memories and experience. Sibling death can lead to reorganisation of roles within the family and increase susceptibility to physical and mental ill health, a greater sense of isolation and for some, a risk of suicide (Van Volkom 2006).

Studies that have given retrospective consideration of change in the sibling relationship over the duration of the life course have demonstrated three patterns of closeness: increased closeness (the most commonly occurring pattern), no change (the second most commonly occurring pattern) and decreased closeness (the least common pattern). Gold (1996) found that the no change and negative change groups were comprised mainly of men and the positive change groups mainly of women; this indicates the possible influence of gender upon sibling relationships, as supported by Goetting (1986), Connidis (1994), Eriksen and Gerstel (2002) and Van Volkom (2006), who all found the sister/sister

relationship to be closer than that of mixed sibling dyads or brother only relationships. The significance of marital status was again found to influence sibling roles as the unmarried and childless siblings were found to receive more support than those who were married (Van Volkom 2006)

### **2.4.3 Adult sibling roles and relationships in the presence of mental illness**

Some of the roles that siblings provide to an adult with an enduring mental illness include those of primary care giver and provider of social support, although sibling assistance to people who have a mental illness has been found to be less than that provided by a parent or spouse, yet greater than that provided by aunts, uncles, grandparents and friends (Horwitz et al 1992). Linking back to the roles of typically developing siblings and the changes that commonly occur alongside parental decline and death, there is evidence of a significant increase in sibling support to a mentally ill brother or sister after parental death (Horwitz 1993); the roles of a well sibling that may be affected by a mentally ill sibling include those of spouse, parent, worker, student and leisure participant (Horwitz et al 1992; Lively et al 1995; Loher et al 2007). The relationship found to be most affected in the presence of schizophrenia was that between the ill sibling and the well sibling, with sadness expressed by the well sibling over the loss of a brother or sister's pre-illness personality, alongside anger and frustration at having to cope with crisis situations. Disruption in some sibling relationships with parents has also been evident when the mentally ill sibling becomes the focus of family time and attention, although some brothers and sisters have reported an increased sense of closeness and compassion for parents, particularly as they aged. Relationships with other siblings in the family may be affected in a variety of ways, alternating between

increased levels of closeness and conflict (Lively et al 1995). Ignorance of mental illness and stigma from friends and acquaintances has been said to affect relationships, leading to feelings of sadness and disappointment (Lively et al 1995; Lukens 2004). Some married siblings have said that they felt torn between the demands of their spouse and the ill sibling (Lively et al 1995) although this was refuted by Lukens (2004) who noted that siblings claimed to have positive support from spouses; this further confirms the presence of conflicting results regarding the impact of a disabled sibling upon adult lives.

As previously found with sibling roles and relationships in childhood and typically developing siblings in adulthood, there are a number of factors that influence sibling roles and relationships in the presence of mental illness and many contradictory findings. Gender and family size were found not to significantly affect the quality of sibling relationships for people who had schizophrenia according to Smith and Greenberg (2008), although Horwitz et al (1992) found that more sisters than brothers were involved with a mentally ill sibling yet provided no more care than brothers, whilst Loher et al (2007) claimed that sisters were more likely to provide higher levels of care and take on a primary care role than brothers. A cohesive family environment where siblings were able to note personal gains from the experience of having an ill sibling and where the ill person was perceived as having less control over their behaviour, was linked to a better sibling relationship by Smith and Greenberg (2008); a better relationship and greater degree of emotional closeness between siblings has been associated with a primary care giving role (Horwitz et al 1992; Jewell and Stein 2002; Loher et al 2007). The mental health condition, behaviour and perceived level of need are also named as factors that contribute to

the uptake and continuance of sibling roles and relationships. Symptoms of a condition such as psychosis, verbal aggression and non-compliance with treatment are reportedly difficult issues for siblings to cope with (Friedrich et al 2008). Similarly, Smith and Greenberg (2008) claimed that siblings who grew up in an environment where the ill sibling had been violent or threatening, reported a less close relationship, although the greatest predictor of assistance was the perceived level of need of the ill sibling by the well sibling (Horwitz et al 1992; Loher et al 2007). Well siblings may have various roles and commitments in their own lives, and multiple roles could be viewed as a barrier to care giving (Horwitz et al 1992); however, Loher et al (2007) claimed that there was no evidence to suggest that well siblings' multiple roles and commitments affected their ability to be a primary care giver, or that such roles could predict future levels of instrumental support. Issues of race, gender and social network composition are not necessarily considered to be significant indicators of sibling involvement in this field, according to Horwitz et al (1992).

A further association between sibling roles and relationships within mental health, is that of parental influence. When parents have asked for more support in the care of a mentally ill person, siblings have provided more care, and when parents have been emotionally supportive to siblings, they have presented as more willing to provide care; this may indicate the presence of reciprocity between siblings and parents (Jewell and Stein 2002). Similarly, when siblings perceived parental need for assistance to be high, a strong association with intention to care has been apparent (Horwitz et al 1992; Jewell and Stein 2002; Loher et al 2007).



#### **2.4.4 Adult sibling roles and relationships in the presence of physical disability**

When reviewing the roles and relationships of young adult siblings of people who have a physical disability, parents (as in the presence of mental illness) are usually the primary carers, although some degree of obligation to provide a level of support to the disabled brother or sister is likely to be present (Harland and Cuskelly 2000). Siblings may provide some practical assistance to the disabled person, such as recreation, respite or mobility. Support with communication is also common, as is help with personal development such as teaching new skills, maintaining social contact, companionship and emotional support. The roles of protector and defender are evident, alongside an expectation to provide some form of care role in the future (Davis and Salkin 2005); this may link with the previously mentioned thoughts of providing a future care role that have sometimes been conceptualised in childhood (Cate and Loots 2000; Angell et al 2012). It has been reported, however, that social interaction between the disabled and non-disabled siblings may take place indirectly, for example, when siblings were visiting parents, which again may be normative to the age and life stage of participants (Harland and Cuskelly 2000).

Factors found to influence sibling roles and relationships in the presence of physical disability, similar to studies related to adult siblings of people who have a mental illness, are birth order and gender. Younger non-disabled siblings have described positive relationships with disabled siblings; however the only older sibling in a small scale study by King (2007) reported a poor relationship. In terms of gender, non-disabled siblings who were female were regarded as older even when chronologically younger; this links back to the concept of role asymmetry discussed within childhood

roles and relationships. The study by King (2007) however does not clarify if the perception of role asymmetry is that of the non-disabled sibling, the disabled sibling or parents.

#### **2.4.5 Adult sibling roles and relationships in the presence of learning disability**

The roles that adult siblings of a learning disabled person may assume are many and varied, including the provision of direct care, decision making regarding major life events, financial management, legal roles, mediator or monitor of services, and co-ordination of other relatives and friends to provide back up support (Bigby 1997). The role of advocate is presented strongly within the literature and across cultures (Bigby 1997; Ying Li 2006; Rigney 2009) where siblings have an important role in facilitating communication between service providers and families in order to gain better care for the disabled person. Other roles taken on by siblings are those of emotional supporter (Seltzer et al 1991; Ying Li 2006; Wilson 2011), social companion (Seltzer et al 1991; Rigney 2009; Heller and Arnold 2010) and even moderator of behaviour (Karasik 1993). The role of simply being 'a relative' was also noted by Ying Li (2006), where siblings wanted to maintain a brother or sister role to the learning disabled person. The most common instrumental tasks undertaken by siblings were those involving financial management, mediation, decision making, social interaction and companionship (Rigney 2009). Some brothers and sisters assume roles that are parental in nature, for example they may be more controlling in their interaction with the learning disabled sibling than with a typically developing sibling (Kramer 2008). Despite this, siblings reported difference in their support style to that of parents (Kramer 2008), and the level of care provided by siblings has been reported as equal or less than that provided by parents, especially where the learning disabled person has moved out from

the family home (Karasik 1993). It should not be assumed however, that all sibling roles with a learning disabled brother or sister are positive; some siblings do not have a positive presence in the life of the learning disabled person and have made decisions that were not in their best interest (Rigney 2009).

One role that is of particular significance in the literature is that of 'most involved sibling'. This role became apparent in early studies in this field and arises when there are multiple siblings in a family but one assumes greatest responsibility for the learning disabled person (Seltzer et al 1991; Greenberg et al 1999; Orsmond and Seltzer 2000; Heller and Arnold 2010). The profile suggested as most likely for this role is that of an older sister who lives within one hour's drive away from the family home and is likely to have at least weekly contact, either by telephone or face to face, with the disabled person (Seltzer et al 1991). Apart from the sibling who is 'most involved', other adult siblings have been shown to have generally low levels of instrumental support and face to face contact (Zetlin 1986; Seltzer et al 1991; Rawson 2009; Wilson 2011), although sibling roles may change depending upon their life stage and circumstance.

Demonstrating parity with adult siblings of people who have mental illness or physical disability, research has indicated that a variety of factors influence the care giving role; these include gender, life circumstances, level of disability, the relationship between the siblings, parental influence and the health status of the individuals involved (Heller and Arnold 2010). A key factor that influences sibling engagement in the life of a learning disabled person is that of life stage. Similar to research findings with siblings of people who have a mental illness or physical disability, siblings of learning disabled people may have few active roles with the disabled person

whilst parents are still available and able to provide a care role (Rigney 2009; Rawson 2009; Wilson 2011). Reasons cited by siblings for having lower levels of involvement include the ongoing involvement of parents, proximity, family situation and perceived nature of need. Most siblings do however expect to take on future roles such as financial advisor, supporter, and care co-ordinator, although the detail around such future roles may not be clearly understood. As parents age and become less able to care for the learning disabled person or at the point of parental death, the sibling's role is commonly seen to change and greater responsibilities are taken on. When parents are frail or elderly, siblings may need to take on supportive roles to both older parents and disabled person at the same time (Karasik 1993; Kramer 2008). Learning disabled people themselves have commented that their middle-aged siblings tend to be more reliable and able to give support than younger, less settled brothers and sisters (Zetlin 1986). Some siblings have taken on the role of primary carer when parents have no longer been able to provide support, although for most, this has not been a long term arrangement. Most siblings have however taken on long term roles such as overseer of well-being, facilitator, mediator and protector without fully assuming a parental role, possibly due to their own age, health status or demands from other family members (Bigby 1997).

Life stage and circumstance, which are often interlinked, may influence the uptake of sibling roles. Those with minor children living at home were less likely to provide instrumental support to their disabled brothers and sisters, especially when the learning disabled person lived away from the family home (Greenberg et al 1999); this links back to the issue of geographical proximity. Factors such as personal problems and choice of marriage partner

(Zetlin 1986), sibling health and that of other family members, were found to influence the uptake of roles (Jokinen 2008). Health is an important consideration in relation to care giving, as the health difficulties experienced by one family member can impact on the support arrangements to other family members. Those with multiple role demands may be more likely to experience higher levels of care-giver burden; however despite challenges that may arise, many siblings in the study by Karasik (1993) did not want to relinquish a care giving role and took pride in maintaining strong family ties.

Gender is reportedly influential in the provision of a care or support role and the evidence from empirical studies related to learning disability indicates that women are more likely to take on and be involved in a care giving role than men. Sisters are more likely to take on care giving responsibilities than brothers (Zetlin 1986; Heller and Arnold 2010); they are more likely than brothers to expect future care giving responsibility and to co-reside with the disabled adult (Greenberg et al 1999), especially when still living in the family home (Egan and Walsh 2001); sisters of females who have a learning disability are more likely to live together than any other sibling dyad (Krauss et al 1996). This predominance of female expectation to take on a future care giving role is further reinforced by Griffiths and Unger (1994) who, when researching views about futures planning, found that all those siblings suggested as future care givers by parents were daughters; where legal guardianship was already established, the majority involved daughters rather than sons, which could be aligned to the influence of parental expectation and sibling roles.

Again demonstrating similarities with the findings of studies related to adult siblings in the areas of mental illness and physical

disability, parental and family context are seen to have influence. One of the early studies related to adult siblings of people who have a learning disability demonstrated alignment between sibling care giving and parental expectation. Where parents had provided extensive support to the learning disabled person, siblings were expected to do the same; where parents had encouraged independence, siblings were expected to take on the role of overseer; and where siblings had remained uninvolved, external agencies were expected to provide the main support (Zetlin 1986). Sibling tendency to fulfil parental expectations of a support role to their disabled sibling and in some cases, to exceed parental expectations, was demonstrated by Bigby (1997), although it was clear that most cases of co-residence were temporary. The relationship between non-disabled siblings and their parents has been seen to influence care giving. In reference to Greenberg et al (1999), siblings who had a closer relationship with their mother were more likely to provide instrumental care to the learning disabled person than when the maternal relationship was distant. The motivation of a small group of adult siblings in France to take on the role of legal guardians was attributed in part to a desire to continue parental work, demonstrate loyalty and gain parental affection (Scelles 2002). An association between sibling care giving and parental health and well-being was evidenced by Krauss et al (1996), who concluded that mothers of siblings who expected to co-reside with the learning disabled person had more health problems and were considered to be more vulnerable than mothers of siblings who did not expect co-residence. Parental influence upon sibling care giving roles to learning disabled people is significant to the aims of this thesis, and is likely to have been inculcated from childhood, and therefore associated with family context and climate.

The association of family climate upon sibling care giving to learning disabled brothers and sisters, however, is again inconclusive. Family climate was found by Rimmerman and Raife (2001) to be unrelated to the frequency of sibling contact; however other studies have found that a positive family bond is important to both encourage and sustain sibling involvement (Greenberg et al 1999). Some brothers and sisters have claimed that paternal attitudes and actions have influenced their experiences, relationships and care roles in relation to the learning disabled person and there were some reports of resentment regarding these past responsibilities and parental management of the disabled person (Karasik 1993). There were also reports of conflict within families when some brothers and sisters had taken on more than their perceived fair share of responsibility for the disabled person. Certain brothers and sisters were described as more dominant than others in the decision making process, possibly linking back to the role of 'most involved'; however, in other families, siblings claimed that they worked as part of a team with support from spouses, children, nieces and nephews, although siblings-in-law have been considered a variable factor in terms of support (Jokinen 2008; Kramer 2008). Few siblings were reportedly satisfied with the distribution of care within families (Karasik 1993) and overall, the family experience appeared to be unique to each family unit. Sometimes negative attitudes towards the learning disabled person have been voiced amongst family members, including parents (Karasik 1993). The view that family reactions towards learning disability, roles and relationships were unique, was reiterated by Jokinen (2008) who found variation dependent upon the life course, values, beliefs systems, strengths and the needs of families and individuals within families.

There are different types of relationship between siblings and people who have a learning disability, which run along a continuum from very involved, with strong feelings of warmth and affection, to feelings of hostility and where there is no contact or involvement (Zetlin 1986; Karasik 1993; Rigney 2009). The most commonly reported relationship between adults and their learning disabled brothers and sisters is that of warm feelings with minimal contact which involves face to face contact approximately two or three times a year; this is according to Zetlin (1986) and it has resonance with research undertaken by Rigney (2009) and Karasik (1993). In contrast to this, Hodapp et al (2010) undertook a large scale web-based survey to compare male and female siblings aged between 18-30 of learning disabled people; data included the amount of contact and closeness they had with their disabled sibling, as well as health, well-being and major life choices. The results of this cross sectional survey identified that most siblings, and predominantly sisters, reported close relationships and regular contact with the disabled person; this was echoed in a literature review by Heller and Arnold (2010), although it is acknowledged that, as with much research in this field, respondents were predominantly white well-educated American women. A further study compared sibling relationships in adults who have siblings with and without an intellectual disability (Doody et al 2010). Few group differences were apparent in relation to contact, relationship, rivalry and critical expressed emotion between the two groups; however there was less telephone contact and more face to face contact in the learning disability group and less warmth in the sibling relationship where the learning disabled person had a more profound disability.

As observed previously when considering sibling roles and relationships, levels of intimacy appear to shift and change over the



life cycle, representing a reduction in involvement as siblings establish their own lives. Adolescence is seen to be a difficult times for siblings and one where they may typically experience feelings of guilt and embarrassment because of the learning disabled person (Rldney 2009), although again, the literature points to mixed results. Began (1989) reported more conflict in the sibling relationship for adolescents and those under 21 years compared with adults over 21, while Orsmond et al (2009) investigated differences in sibling relationships within adolescence and adulthood in relation to autistic spectrum disorder (ASD). Results showed that adolescents took part in more shared activities and reported more positive affect in their sibling relationships than the adult siblings. Differences between the results of these studies may be due to the fact that Orsmond et al (2009) specifically based his study in relation to siblings of people who have ASD rather than developmental disability, and utilized different data collection tools to Began (1989).

Moving on from adolescence, the sibling relationship in young adulthood is again seen to be varied when in the presence of learning disability. A reduction in intimacy with increasing age was noted (Zetlin 1986; Hodnapp and Urbano 2007), although Wilson (2011), when considering the experience of sisters of learning disabled women aged 22-34, found that although a range of relationships was evident, some sisters reported a bond with the disabled sibling that was considered to be 'special' or particularly close. It is likely that a change in sibling relationship is due to life stage. There is little research into sibling relationships within learning disability that extends from childhood through to old age, however one retrospective American study of siblings of learning disabled people where the average age was 64, found reduced

emotional closeness with increasing age compared to typically developing older siblings (Taylor et al 2008). This lessening of intimacy over time is in contrast to Orsmond's and Seltzer's (2007) study which identified an increased sense of positive affect towards a disabled brother or sister over time, as noted in the literature review by Heller and Arnold (2010); this further highlights ambiguity of findings in this area.

Continuing the theme of contradiction in the results of empirical research, there is disagreement about the influence of a range of variables upon the sibling relationship. Gender, age and birth order have been found in some studies to influence the sibling relationship. Sisters are described as having a closer relationship than brothers; those closer in age to the disabled person purportedly have more emotionally involved relationships in childhood and adolescence with higher levels of closeness and conflict, compared to sibling dyads that are more widely spaced. Age-related differences are said to decrease with age, however (Richardson 2009). Similarly, Orsmond and Seltzer (2000) looked specifically at the gendered nature of the sibling relationship where one person has a learning disability and found that sisters reported feeling closer to the disabled person than brothers. These results also claimed that the gender of the disabled sibling was not related to the feelings of closeness in the relationship reported by sisters; however brothers reported less positive involvement with disabled sisters than disabled brothers, and felt more worried about the future of disabled sisters than disabled brothers. Within this study, some brothers perceived a decline in positive regard for their disabled sibling when their mother's health was in decline; however the pattern of the relationship was generally re-established after maternal death. No relationship was to be found between gender,

socioeconomic status, levels of sibling contact, family satisfaction and either high or low expressed emotion (Rouse 2003); however proximity was found to be significant as siblings who scored high on expressed emotion were more likely to live close to their disabled sibling. Those brothers and sisters who scored highly on expressed emotion were also more likely to be anxious and experience higher levels of rivalry and conflict in the sibling relationship, whilst viewing differential parenting more negatively than siblings with low scores for expressed emotion. Within this sample group of siblings, parents acted as gate keepers to the participants, which may have led to bias within the results.

A further factor said to influence the sibling relationship within learning disability is the 'behavioural competency' of the disabled person. Closer sibling relationships have been associated with less severe levels of learning disability and higher levels of communication skill (Karasik 1993; Doody et al 2010), although Wilson et al (1992), who investigated the relationship between attitude towards a learning disabled sibling and behavioural competency, found no evidence of systematic difference in sibling involvement related to level of function; nor did the quality of the relationship or degree of positivity appear to be linked to functional level.

Other research related to the adult sibling relationship are comparative studies which investigated siblings of people who have a learning disability and siblings of people with a severe and enduring mental illness. Seltzer et al (1997) compared a group of siblings of adults with a learning disability to a group of siblings of people who had a severe mental illness as part of a longitudinal study. Compared to the siblings of people with a mental illness, the siblings of learning disabled people reported their experience

overall as pervasive yet positive; they described more face to face contact, sentiments of positive regard, emotional closeness and increased psychological well-being where a close relationship with their disabled person was present. Despite these findings of emotional closeness between siblings in the presence of learning disability, Taylor et al (2008) claimed that by the time siblings reach their mid 60's, there were fewer reports of emotional closeness; this links back to the concept that sibling relationships change over time.

By further contrasting one type of learning disability with another, Orsmond and Seltzer (2007) compared adult siblings of people who had Down syndrome with those who had autism. These findings identified that siblings of people with Down syndrome had more frequent contact with their disabled brothers and sisters and reported higher levels of positive affect in the sibling relationship than siblings of people with autism. Greater positive affect in the sibling relationship was demonstrated across both groups where siblings had lower levels of education, greater use of problem-focused coping, where more shared activities took place and where the disabled person had higher levels of independence. Hodnapp and Urbano (2007) also compared the sibling relationship between adult siblings of people with Down syndrome and autism, demonstrating a small to moderate difference in the overall quality of relationship in favour of siblings in the Down syndrome group compared to the autism group; this was evidenced by the number and time of contacts, perceived levels of health and depression.

### **Summary of key theme**

Sibling roles, tasks and relationships change over the life stage as siblings develop their own lives and move away from the family home. The literature suggests that most childhood relationships

where disability is present are positive; however conflict is present in some relationships and where conflict does exist, it is often due to increased care roles and reduced parental time and attention. In the presence of disability, childhood roles are seen to become asymmetrical as the typically developing child overtakes the disabled child in physical and/or cognitive skills and there is some evidence of children having an increased care role due to the presence of disability. On entering adulthood, siblings commonly provide some level of support to each other and this may be on an emotional or practical level whether or not disability is present.

When considering roles and support in the presence of learning disability, adult siblings consider their role to be different to that of their parents, although it is sometimes described as parental in type. The roles that a non-disabled sibling may hold in relation to a disabled adult however are likely to change significantly when parents are no longer able to provide previous levels of care. Non-disabled brothers and sisters commonly take on roles of advocate, financial advisor, co-ordinator of emotional or social support, and the presence of a disabled sibling is seen to impact upon the roles and relationships of the non-disabled adult. A role commonly seen in families where there is more than one typically developing child is that of 'most involved sibling'. Factors that affect sibling roles and relationships with the disabled person are said to be many and varied, including gender, birth order and spacing, family size, personality type, parental and family context however the significance of life stage and unique circumstances of the individuals involved are also critical. It is likely that past and present roles, relationships, and factors that affect these roles and relationships will influence future roles; this forms part of the aim of

this thesis and is aligned with the next theme, which is that of futures planning and concerns for the future.

## **2.5 Key theme three: Futures planning and concerns**

### **2.5.1 Typically developing families and anticipated future care**

Although typically developing families do not have to consider the future support needs of a disabled sibling, they do have to deal with the future support needs of other family members and in particular older parents, something often considered as a filial responsibility. Adult children commonly form a significant part of the support networks of older people, and studies have found that the majority of adult children expect to provide support to parents in their own homes although the issue of residential care has been raised in some families (Connidis and Kemp 2008). The distribution of care between family members may be an area of conflict; it may be viewed as inequitable if one or sometimes two people seem to be the main organisers of care and there may be little consensus about who will do what in the future (Connidis and Kemp 2008). The idea that one person is the 'most involved' and is deemed to be the probable or actual main care giver is evident in studies related to learning disability and mental illness; it is also features in research about the future needs of older parents in typically developing families. Little detailed planning or discussion about future care is likely to have taken place between typically developing adult children and their older parents until a particular event occurs and requires negotiation (Walz and Mitchell 2007; Connidis and Kemp 2008). The view that adult children and their parents are unrealistically optimistic about future care needs is described in the literature as the situation where individuals generally accept that decline and dependency occur, but tend not to accept this for themselves. This theory of unrealistic optimism

appears to be unrelated to gender, occupation, age or education, and could provide one explanation as to why older people and their families are reluctant to plan for the future and underestimate or deny likely care needs in old age (Weinstein 1980, 2003).

As demonstrated throughout this literature review, there are a number of variables that influence the uptake of support roles by siblings within their families. Changes in circumstance such as work, family responsibilities, location and relationships are factors seen to influence the ability of typically developing siblings to provide support to older parents, and in mixed gender sibling dyads, sisters have been identified as more likely to provide care than brothers. Perspectives on fairness, relationships between family members, and stage in the life cycle again affect the uptake of responsibility for parental care, and regular renegotiation is required in view of changing life events. Judgements within families regarding fairness is dependent upon how siblings feel about each other and some circumstances can be considered as legitimate excuse for not taking on a support role at various points in the life cycle. Support for older parents in typically developing families therefore is seen to be dynamic and dependent upon life events, circumstance and relationships; change in the situation of one family member is likely to impact upon their ability to provide a care role (Connidis and Kemp 2008).

### **2.5.2 Adult siblings of people with mental illness and future care**

Studies amongst adult siblings of people who have a mental illness have shown that many are willing and intend to provide some level of care to their mentally ill brother or sister in the future, although the type of support envisaged is predominantly social rather than instrumental. Examples of support siblings may expect to provide include: financial management, an overview of care in the

community, medication and assistance with household chores. The expectation is generally held that support will be periodic rather than sustained and regular (Jewell and Stein 2002; Hartfield and Lefley 2005; Smith et al 2007). As in typically developing families regarding the care and support of older parents, adult siblings of people who have a mental illness may not have a clear plan of what their future support role will entail and very few expect to live with their mentally ill sibling on a permanent basis (Hartfield and Lefley 2005). Those siblings who are married, have a strong sense of responsibility, regard the sibling relationship as reciprocal and are able to perceive gains from the relationship, are more likely to expect to provide instrumental and emotional support to a person with mental health needs. Increased levels of instrumental support may be given where behavioural problems are evident, and sisters with a high quality relationship are more likely to expect to give emotional support than brothers and those with poorer relationships (Smith et al 2007).

The literature presents the view that siblings of people who have a mental illness have concerns and anxieties about the demands and roles that may be expected of them in the future. They are seen to have particular concerns for the time when parents age and are no longer able to provide previous levels of support, and the impact this will have on their own lives (Friedrich et al 2008). Additional worries are those of other family commitments; geographical proximity; negative feelings about certain behaviours exhibited by the ill sibling; work commitments; health problems; lack of knowledge of mental illness; and opposition to involvement by a spouse or children. Brothers and sisters also raise concerns about unwillingness of the ill sibling to use service systems, non-compliance with medication, and relationships with other siblings,



although difficulty in managing the home , substance abuse and poor health are also referred to as ongoing concerns (Hartfield and Lefley 2005). Younger siblings have been found to worry about the future more than older siblings, and a trend for siblings to worry more about the future care of a sister rather than a brother with a severe mental illness has been noted. Siblings who have provided higher levels of care have demonstrated greater concern about the future, as have the siblings of people with more severe psychiatric symptoms (Greenberg et al 2010).

### **2.5.3 Adult siblings of people who have a physical disability and future care**

Similar to adult siblings of people who have a mental illness, most siblings of people who have a physical or dual physical and intellectual disability expect an ongoing care role with the disabled person and report concerns for the future. The type of support role and level of involvement anticipated again reflects that of the siblings of people who have a mental illness. These brothers and sisters anticipate that they will maintain social contact, recreational and emotional support and assistance with financial affairs. They also anticipate an advocacy and general support role in the future, although they perceive that their support role will be considerably less than that of their parents (Harland and Cuskelly 2000; Degeneffe and Onlney 2008; Dew et al 2011). Although some brothers and sisters have felt they would offer accommodation to the disabled sibling in the future, others have not; where co-residence was not expected, siblings have still wanted to ensure that accommodation is appropriate and high standards of care maintained (Harland and Cuskelly 2000).

The worries and concerns expressed by siblings of people who have a physical or dual disability has some alignment with the siblings of

people with mental health needs as they voice concerns about the future - particularly the time when parents are no longer able to provide support. They worry about having to manage behaviour deemed to be problematic, physical proximity, the quality and levels of care, not knowing enough or having enough information, and for some, the possibility of having disabled children themselves. Dew et al (2011) claimed that siblings were also concerned about a time in the future when they may not be able to oversee the care needs of the disabled person; whilst Degeneffe and Olney (2008) stated that siblings want to ensure that the disabled person is well and happy, yet allude to potential conflict that may arise if it is perceived that other brothers and sisters in the family do not provide similar levels of support.

#### **2.5.4 Adult siblings of people who have a learning disability and future care**

Futures planning is of great significance to adults who have a learning disability because if no plans are in place or if plans are inappropriate, emergency steps may be taken which are unsuitable for the individual and their family. Despite, or perhaps because of, the significance of futures planning for learning disability families there appears to be generalised worry on the part of carers about the future and what will happen to the learning disabled person (Bowey and McGaughlin 2007; Mansell and Wilson 2010; Taggart et al 2012). Carers may also have specific concerns such as the level and quality of care available from service providers outside the family (Gilbert et al 2008), and that service options outside the family are lacking compared to family support. Older parents or carers perceive the learning disabled person to be vulnerable (Bowey et al 2005) and worry about the role of siblings when parents are no longer able to provide care (Jokinen and Brown 2005; Davys and Haigh 2008; Mansell and Wilson 2010; Taggart et

al 2012). The presence of more maladaptive behaviours, a diagnosis of mental illness, fewer non-disabled children, poorer affective relationships between siblings and not being able to identify who would assume primary care responsibilities are further areas of parental concern (Prunchno et al 1996).

When making future plans for people who have a learning disability, a number of aspects need to be addressed, such as where the person will live, financial, guardianship and lifestyle issues. Four types of plan were identified in an Australian study by Bigby (1996): implicit and explicit key person plans, financial and residential. Key person plans were the most common, followed by financial and then residential plans. Within the key person plans, siblings were the people most likely to be nominated as key person, however nominations were not based on family relationship alone, but rather the nature and quality of the sibling relationship. The main reason for the implementation of plans was parental death or incapacity. According to the literature, the number of families who have made plans for the future is variable. From a USA perspective (Heller and Kramer 2009) only 32% of families had made residential plans. From a Canadian study, Jokenin (2008) reported variation in the degree of futures planning between families; whilst in the UK, just over half the number of family members were said to have some form of futures plan in place (Bowey and McGaughlin 2007; O'Grady 2007), whilst a small scale qualitative Irish study (Dillenburger and McKerr 2010) found that most older parents and carers had not made long term plans for the future. Similarly low proportions of plans were apparent in the published results of Stage one of this thesis (Davys et al 2010).

In reference to Bowey and McGaughlin (2007), around half the number of families of learning disabled people did not feel ready to

plan, which is in accordance with barriers to futures planning. Where plans did exist the depth has been seen to vary from very vague to explicit, although most have been reported as vague, even where open discussion with parents was said to occur (Bigby 1996; Taggart et al 2012); this again was evident in the publication of Stage one of this research (Davys et al 2010).

Impediments to futures planning include a lack of information on accommodation, finance and guardianship issues along with the need for case management, advocacy and support groups (Heller 2000; Bowey et al 2005; Gilbert et al 2008; Arnold et al 2012). Joint working between families and service providers can also be a significant concern, as complications may occur where there is a perceived or real lack of co-operation between family members and care providers. Inter-family conflicts can also generate complications. Some carers have experienced difficulty in 'letting go' within the futures planning process, believing that the family home is the best environment and provides the highest level of care (Bowey et al 2005). According to an Irish study by Taggart et al (2012) the most acceptable options for future care from an older carer perspective was for the learning disabled person to remain in the family home with support from the family or from paid staff or to live with a sibling. The least preferred carer options were general nursing home or non-specialist residential facilities.

Further barriers to futures planning are that some older carers prefer to ignore the issue in the belief that support will be provided as and when the need arises (Dillenburger and McKerr 2010; Taggart et al 2012). In addition to this some learning disabled people lack awareness of later life issues such as changes in health and social situation, leisure, wellness and retirement, which makes it difficult for them to make an informed choice for their future.

Some family carers claim that learning disabled people may not want to move away from the family home because they worry about how they would adapt to a new environment and new people; a further complexity is that learning disabled people may have care responsibilities for an older parent or carer and worry about how this person would manage without their support (Heller 2000). In studies where learning disabled respondents have discussed options for the future, plans have again tended to be vague, although participants have expressed a preference to stay in the local area, to be near family, friends and that which is familiar (Bowey et al 2005).

Specific parental issues have been linked to futures planning and a range of parental wishes are expressed. Some older parents who have made plans would like the learning disabled person to live with a family member (Heller 2000) and some want this to be a typically developing sibling (Knox and Bigby 2007; Taggart et al 2012). Alternatively, although some siblings have offered to take on the care of the learning disabled person in the future (Gilbert et al 2008), other parents have not wanted this, feeling that siblings had their own lives and responsibilities. Some parents have also expressed the view that the typically developing child had lost opportunity in childhood because of the disabled child and therefore do not want to place a perceived burden upon them (Todd and Shearn 1996; Dillenburger and McKerr 2012). Parents may feel a sense of being 'torn' between the needs and wishes of the disabled person and the typically developing sibling; they may accept the need for the non-disabled son or daughter to have their own lives, but equally want them to have ongoing involvement in the long-term future of the learning disabled person. This was found in the results of my Masters level work which was concerned

with the older parents of learning disabled people and preceded this thesis (Davys and Haigh 2008).

Although future plans and living arrangements may be discussed within the family, there is evidence of inter-family diversity and confusion. Krauss et al (1996) demonstrated that in 22% of families where siblings expected the learning disabled person to live with them, their parents had also put the name of the disabled adult on a waiting list for residential services. This may indicate divergence of opinion within the family or a desire on the part of parents to have a contingency plan. Similarly Griffiths and Unger (1994) found that although greater communication within families regarding futures planning was positively associated with sibling satisfaction with plans, there was some level of confusion between parents and siblings; although the majority of parents in this study said they had discussed future plans with siblings, over half of these siblings claimed they were unclear about future plans.

Factors that may influence future care giving and expectation of future care giving by adult siblings of people with intellectual and developmental disabilities, include: being female, having a close relationship with the disabled person, living close by, being the only other sibling in the family and where parents were currently able to care for the disabled person (Burke et al 2012). Further influences upon family residential plans are social, local and financial resources, personal coping styles, family culture and ethnic background. As there is such a wide array of factors that influence futures planning, it makes it a potentially difficult area to negotiate from a range of perspectives. There have been a number of futures planning initiatives across America, Canada and parts of Europe; however despite the provision of programmes and information on legal, financial, housing and community options, anecdotal

feedback suggests that such programmes have limited success in actually leading to the development of future plans (Heller 2000).

Showing parity with typically developing siblings regarding the care of older parents and siblings of mentally ill and physically disabled people, adult siblings of people who have a learning disability often expect to provide some level of care or support to the learning disabled person in the future (Heller and Arnold 2010). This expectation and sense of future responsibility has been seen in some studies to have been present in childhood and adolescence, demonstrating anticipation of a future care role and concern for the future health and well-being of the disabled child (Cate and Loots 2000; Hames 2008, Wilson 2011; Angell et al 2012). Adult siblings have reported particular concern for the time when parents are no longer available to provide previous levels of support (Griffiths and Unger 1994; Greenberg et al 1999; Benderix and Sivberg 2007; Orsmond and Seltzer 2007). There is a general feeling that family should then assume responsibility for the care of a learning disabled person, although the quality of the relationship and degree of contact between siblings where one has a learning disability varies (Zetlin 1986) and is likely to influence a care giving role.

With consideration of future expectations for co-residence between learning disabled people and their siblings, some brothers and sisters plan to co-reside whilst others do not. In a literature review related to futures planning, Heller (2000) claimed that between 25% and 50% of families had made plans for future living arrangements and that nearly half of these families wanted the learning disabled person to live with a family member. In contrast, Bigby (1996) found that only six families out of 62 planned for sibling co-residence. Despite this, there is often an expectation to provide ongoing support and to be involved even where siblings

plan to live apart. Regular face to face contact with the disabled person, ongoing discussion about future plans with parents and the intention to take on the future role of legal guardian are linked positively to expectations of future care giving (Krauss et al 1996), as is satisfaction with a care giving role and the number of shared activities between siblings and their disabled brothers and sisters. This further suggests that the relationship between siblings is significant in any plans for co-residence (Heller and Kramer 2009, Burke et al 2012).

Alongside their counterparts in the fields of mental illness and physical disability, siblings of learning disabled people are concerned about the future, and again, specifically the time when parents will no longer be available to provide previous levels of care (Egan and Walsh 2001, Orsmond and Seltzer 2007; Benderix and Sivberg 2007). Some siblings have expressed pessimism about the future for their disabled brother or sister, and concern about their ability to match parental standards of care; these concerns may have been present since teenage years and early adulthood (Benderix and Sivberg 2007), raising the possibility that siblings take on their parents' fear regarding the future for the learning disabled person, a view supported by Kramer (2008) and Karasik (1993). That siblings worry about parental death and responsibility for financial, legal and care arrangements is reinforced by Rawson (2009) and ESRC (2011), although factors that affect sibling concerns are linked to a range of variables. Orsmond and Seltzer (2007) claimed that compared to a Down syndrome sibling group, siblings of autistic people were more pessimistic about the future for the disabled person; although the reason for this pessimism was not clearly stated, the inference was that attitude was linked to the type of learning disability. This was further supported by



Greenberg (1999) who compared adult siblings of people who had a mental illness and those who had a learning disability and found that siblings in the learning disability group had a significantly higher expectation to care than those in the mental illness group.

### **Summary of key theme**

It has been demonstrated throughout this theme that adults expect to provide some level of support to family members. This may be the case in typically developing families where siblings support older parents, but also in the context of disability where siblings may support both older parents and a disabled sibling. Across all families however, whether or not disability is present, family support is often associated with circumstance, events and the life stage of family members, in addition to issues of proximity, gender and relationships. The presence of a most involved sibling is a phenomenon found in typically developing families and where disability is present. When disability is present in a family, be this physical, mental or learning disability, most adult siblings worry about the future, particularly for the time when parents are no longer able to provide previous levels of support; although a care role may be anticipated, adult brothers and sisters may not expect to provide the same levels of care that parents previously provided. Common concerns of adult siblings include the impact of a care role upon their own lives and families, not having enough information and knowledge to deal with matters arising and in particular, financial and legal issues. Proximity and health matters, for both themselves and the disabled person are also a worry.

Futures' planning within families appears to be an area of confusion with varied results. In typically developing families there is little evidence of detailed futures planning; it is rather that families respond to a situation when it arises, as is the pattern in the

presence of mental illness. With specific reference to learning disabilities, there appears to be a lack of clear future plans in place; where plans do exist, key person and financial plans are the most common types, followed by residential plans. A number of factors are seen to influence futures planning within learning disability, such as: a lack of information and advice, difficult relationships between service providers and families, inter-family conflict and learning disabled people themselves. Additionally, issues of finance, available resources, personal coping styles, gender, parental expectation and type of disability are seen to have an impact. A higher expectation of future care giving to adult siblings has been associated with gender and quality of the relationship with the disabled person; however additional factors, for example, being the only other sibling in the family and a high level of parental ability to provide support, have also been found to enhance sibling expectations of future care giving.

It is acknowledged at a national and an international level that futures' planning within the field of learning disability is a difficult and sensitive area within which to effect change. Such challenges support the aim of this thesis, which is to explore sibling wishes and preferences regarding a future care role for a learning disabled person, as it is siblings who are most likely to take on a future care role due in part to family role and expectation, but also in light of the current rationalisation of services. Only by exploring siblings' wishes and listening to their voice can services provide appropriate support that will meet the needs of families and learning disabled people themselves, which leads on to the final theme of this literature review.

## **2.6 Key theme four: Adult siblings of people who have a disability - future needs and wishes**

Overall, there is little research that considers the needs and wishes of adult siblings of people who have a disability. This is an area that requires much greater research attention, particularly as current economic and social drivers expect more support from the family and less input from formal service providers (DoH 2001; McInnes et al 2011, Burke et al 2012) . Despite the lack of empirical study, or rather because of it, this section of the literature review is of central importance as it forms the crux of the research question posed within this thesis.

In reference to adult siblings of people with a mental illness, the greatest need reported was for the ill sibling to receive appropriate support services. Open communication, emotional support and information about mental illness were rated next in importance; considered least important were stress management, counselling for self and genetic counselling (Friedrich et al 2008). Services that siblings rated most highly were those associated with long term future planning, medication issues and the availability of staff to answer questions and queries. Most siblings also wanted assistance from service providers regarding their role in longer term future planning in the wake of parental decline, and to prevent blame being placed upon families for the presence of the mental illness (Friedrich et al 2008).

Focusing upon the adult siblings of people who have a learning disability, there is again little empirical data in this area; this adds to the justification for research into this field and for the research undertaken within this study. From the research data that does exist, it is clear that some siblings need support with emotional and psychological issues such as anger and depression (ESRC 2011),

that can arise in response to having a learning disabled sibling; when siblings have undertaken therapy for these issues, they had found this to be useful (Rigney 2009). As siblings in families where learning disability is present move through the life cycle from childhood to older adulthood, consideration should be given to their needs, wishes and ability to take on a supportive role. Early intervention programmes and proactive futures planning that support the needs of individual families and their members, along with counselling services for parents and siblings (either individually or as a group), are advised. In childhood, siblings have reported the need for time apart from the disabled child, the opportunity to talk to others who understand the situation and to have access to techniques that help them to manage behaviour (Angell et al 2012); intervention groups for siblings of children who have disabilities have been shown to improve siblings' understanding and relationships in some situations (Granat et al 2012). In adulthood, siblings have voiced a wish to access peer support groups, including internet groups (Benderix and Sivberg 2007; Heller and Kramer 2009; Rawson 2009; ESRC 2011). In expressing a wish to be involved in the life of their learning disabled brother or sister, siblings highlighted the need for information on services and support with futures planning, financial issues, leisure and residential opportunities (Rawson 2009; ESRC 2011; Arnold et al 2012); this was reiterated in the published findings from Stage one of this study (Davys et al 2010).

## **2.7 Chapter summary**

From a review of the literature regarding the impact of a learning disabled brother or sister on adult lives, there is significant variation; there are reports of both positive and negative influences and inconclusive findings regarding the impact upon health and life

choices such as career, partner choice, the decision to have children, political, economic and religious beliefs. It is recognised however that many adult sibling studies in the field of learning disability originate from the USA and involve participants who are predominantly well-educated females from a white ethnic background and therefore male participants and those from non-white ethnic backgrounds are under-represented. The effect of a learning disabled sibling upon an adult's life is of considerable importance as their experience over the life course may influence not only their current roles and relationships but also their future wishes and expectations about their support role; this forms part of the research question posed in this thesis.

Sibling roles, tasks and relationships change over the life course as siblings develop their own lives and move away from the family home. The literature suggests that most childhood relationships where disability is present are positive; however conflict is present in some relationships and where it exists, this is often due to increased care roles and reduced parental time and attention. Childhood roles are seen to become asymmetrical in the presence of disability, as the typically developing child overtakes the disabled child in physical or cognitive skills. There is some evidence that children think about the future care needs of the disabled child whilst still in childhood, but in adulthood, brothers and sisters commonly take on roles of advocate, financial advisor, co-ordinator of support, and provider of emotional and social sustenance. The presence of a disabled sibling is often seen to influence the roles and relationships of a typically developing adult, and a role commonly seen in families where there is more than one typically developing child is that of 'most involved' sibling. Factors that affect sibling roles and relationships with the disabled person

are many and varied including gender, birth order and spacing, family size, personality type, parental and family context; the life stage and unique circumstances of the individuals involved are also critical.

When disability is present in a family, be this physical, mental health or learning disability related, most adult siblings worry about the future, particularly the time when parents are no longer able to provide previous levels of support. Although a care role is often anticipated, adult brothers and sisters may not expect to provide the same levels of care that parents have previously provided. Common concerns of adult siblings include the effect of a care role upon their own lives and families, not having enough information and knowledge to deal with matters arising and in particular, financial and legal issues. Proximity and health issues for both siblings and the disabled person are also a worry. With specific reference to the field of learning disability, there appears to be a dearth of clear futures plans in place; where plans do exist, key person and financial plans are the most common types, followed by residential plans. Issues said to influence the futures planning process are the availability of information and advice; relationships between service providers and families, inter-family conflict; the understanding, experience and wishes of learning disabled people themselves; finance; available resources; personal coping styles; gender; parental expectation and type of disability. It is acknowledged at both national and international levels that futures' planning in the presence of learning disability is a difficult and sensitive area. These challenges support the aim of this thesis, which is to explore sibling wishes and preference regarding a future care role for a learning disabled brother or sister, as it is siblings who are most likely to take on some degree of future responsibility,

due in part to family roles and expectation, but also in light of the current government agenda of rationalisation of services.

Existing empirical data suggests that some siblings need support with difficulties that can arise due to the presence of a disabled sibling. Early intervention programmes and proactive futures planning that support the needs of individual families and their members, along with counselling services for parents and siblings (either individually, or as a group), are advised. Siblings have also voiced a wish to access to peer support groups and the need for information on services, financial issues, leisure and residential opportunities has also been highlighted.

It is therefore clear from the review of the literature that little attention has been given to the views of siblings of people with learning disabilities in terms of the future of their relatives. Only by exploring sibling needs and wishes, and then listening and responding to the 'expert voice' of the individual who experiences this phenomenon at first hand, can more appropriate services be provided. A focus upon hearing the voice of the individual is aligned with the methodological approach of Interpretative Phenomenological Analysis (IPA), chosen as the framework for Stage two of this thesis, and which is set out in Chapter three. Furthermore, this methodological approach is congruent with the research aim of exploring the perceptions of siblings of adults who have a learning disability in relation to personal wishes, family expectation, and any discrepancy between the two in relation to their role in the future support of their sibling.

### **Chapter Three: Research Methodology**

Within the literature review, the need to listen to the voice of adult siblings of people who have a learning disability was justified by the lack of empirical study in this area; a deeper understanding is deemed necessary so that services can provide appropriate and sufficient support. The aim of this thesis is as follows and forms the starting point of the research process:

- To explore the perceptions of siblings of adults who have a learning disability in relation to personal wishes, family expectation, and any discrepancy between the two in relation to their role in the future support of their sibling.

The objectives aligned to the stated aim are:

- To explore the personal wishes or preferences of siblings of learning disabled people in relation to their role in the future support of the learning disabled person.
- To compare personal wishes or preferences with the reality of what has actually happened or they expect to happen in terms of support to the learning disabled person in the future.
- To identify how the expectations and wishes of non-disabled siblings compare with the expectations and wishes of older parents.

Having established a clear gap in the literature in Chapter two, this methodology chapter will outline and justify the philosophical stance and methodological approach of the thesis, along with the epistemological basis which led to the adoption of a constructivist approach. Following this, the use of a mixed methodology (utilizing a survey at Stage one and semi-structured interviews within an Interpretative Phenomenological Analysis (IPA) framework for Stage



two) will be discussed, along with a rationale for the choice of approach, a critique of IPA and ethical issues encountered. The process of data collection and analysis for stages one and two will then be set out, after which issues related to reflexivity, reliability and validity will be presented. As the research question deals with sensitive and potentially emotive issues, it was important to choose a methodology which would be flexible. The use of a research methodology that was not overly preoccupied with the choice and defense of a particular method, yet facilitated adult siblings of learning disabled people to express their individual perceptions and wishes on this deeply personal subject, was deemed appropriate.

### **3.1 The research question, epistemology and philosophical stance**

The research nexus is described as the web that runs between and connects epistemology, theory and method, all of which combine to inform the methodology (Hesse-Biber and Leavy 2006). The questions, beliefs and assumptions that a researcher brings to the research process form the foundations of an epistemological stance. Our epistemological basis is reflected in what and how we research. It is the belief system in relation to how humans create knowledge and what means they use to produce this knowledge (Hesse-Biber and Leavy 2006). Epistemology is closely linked with ontology, which is concerned with the structure of reality and nature of existence. An ontological perspective can be said to accompany epistemological issues and support the informing of a theoretical perspective as it is concerned with `what is`, alongside what it means to know, and therefore ontology and epistemology are considered to be intertwined (Crotty 1998). There is a range of epistemologies that include objectivism or positivism which is aligned with quantitative research. The view here is that an

objective truth or reality exists whether or not people are aware of it; reality is believed to exist externally and independently to the research process with an emphasis on objectivity and hierarchical division between researcher and object. Alternatively an epistemology of constructionism is associated with qualitative research and takes the perspective that reality or truth is socially constructed by elements such as time, place and person, and that interaction between these elements leads to the creation of social meaning (Robson 2002). From this perspective, social reality is not seen to exist externally to or independently of the research process. Within this framework therefore, the researcher is not considered to be value-free, but inherently engaged in the construction and explanation of knowledge (Hesse-Biber and Leavy2006).

### **3.2 Constructionism**

The epistemology related to this thesis is that of constructionism which is in essence interpretative. The perspective taken from this stance is that meaning does not wait to be discovered but is constructed by individuals through conscious engagement with objects in their world; this engagement is necessary in order to generate meaning. This epistemology can therefore be seen as attached to an inductive approach to research, where the underlying belief is that people construct meaning and interpret phenomena by their engagement with the world and the various contexts (social, political, historical) that also impact upon the individual. Using this perspective, truth or meaning cannot be considered as objective or subjective (Crotty 1998). Constructionism is said to bring together both objectivism and subjectivism; it asserts that one accurate or true interpretation does not exist as people will differ in their experience and

construction of the phenomena that they encounter within their world. It is more the view that individuals will generate interpretations that are illuminating or useful but the concepts of true, accurate, whole and valid in a scientific way are not appropriate (Crotty 1998, Finlay 2006b). Such a philosophical perspective is congruent with the aim of this thesis which is to explore the perceptions of individuals in relation to a given phenomena, which in this instance is learning disability. This thesis is concerned with sibling expectations, their perceptions of parental expectation, perceived difference in expectation and personal future wishes. It asserts the need to listen to sibling voices as only they are able to provide an insider perspective of this phenomenon. In other words, different individuals will experience a specific phenomenon in a unique way, dependent upon their family context, background, history, life events and personality. I also acknowledge my part as an interpreter within the research process as I listen to individual stories, wanting to provide an honest representation of individuals and their experience, yet making decisions about what I deem to be key themes and constructs arising from the data.

### **3.3 Research methodology**

A mixed methodological approach was taken. The data collection process utilized a survey in Stage one of the study and semi-structured interviews in Stage two. This links back to the philosophical stance of constructionism, described as bringing both objectivism and subjectivism together under the assertion that one accurate or true interpretation does not exist, since people differ in their experience and construction of the phenomena that they encounter (Crotty 1998). The use of a mixed methodological approach affords the advantages of triangulation, an alternative

perspective and therefore broader view of the issue under study (Robson 2002, Morse 2004), whilst also allowing the strengths of two research approaches to complement each other (Teddlie and Tashakkori 2009). It is also claimed that an IPA approach may be used to further deepen the understanding of those areas previously quantitatively studied (Howes 2005).

A survey was adopted in Stage one to provide background demographic details, to demonstrate evidence for the need to conduct a study into this area and to inform the questions used in the interviews, a process described by Robson (2002) as providing a complementary and exploratory basis for a main study. Additional justification for using a mixed methodological approach includes its ability to build up the progress and detail of a study, to enhance confidence in the results and from a pragmatic viewpoint, it allows the research question to drive the process forwards. As a typology, the mixed methodological approach employed is described by Polit and Beck (2010) as a component design, as stages one and two were carried out as two separate and discrete components of the overall study throughout data collection and analysis.

As the main aim was concerned with listening to the voice of adult siblings of people who have a learning disability regarding their personal wishes or preferences in relation to a future support role, IPA was used in the main body of the study at Stage two. For this deeper exploration, face to face semi-structured interviews were undertaken as this is considered to be the strongest tool of data collection when using an IPA approach (Smith and Osborne 2008). The use of face to face interviews allows the researcher and participant to engage in the concept under scrutiny and to probe

areas of interest; it was therefore felt to be congruent with the research aim.

### **3.3.1 Interpretative Phenomenological Analysis**

IPA is a relatively new research method and developed by Smith (1996a) and colleagues (Jarman et al 1997; Smith and Osborn 2003; Cronin-Davis 2009). It has its roots in health psychology yet is used increasingly in the fields of health and social care; it has been used to study a variety of areas such as women with learning disabilities and the menstrual cycle (Ditchfield and Burns 2004); the experience of brain injury (Howes et al 2005); wheelchair configuration (Mason et al 2010); and perceptions of challenging behavior and family impact in adults with intellectual disabilities (Hatton et al 2010).

This approach is described as qualitative because it is concerned with how people make sense of their lived experience. IPA has its foundations in phenomenology which can be explained as a philosophical approach to the study of how people understand life events and experiences, aiming to understand the lived experience of the individual (Creswell 1998). Phenomenology itself has many variations or branches, two of which are descriptive and interpretative. Descriptive phenomenology, which is associated with Husserl, asks that researchers put to one side personal knowledge and pre-understandings, to rid themselves of bias and to avoid asking specific questions, keeping as close as possible to the lived experience of the participant. Interpretative phenomenology, which is linked to Heidegger (1927/1962), modified this approach and advocated an interpretative or hermeneutic tradition; this requires the researcher to look for more than description, moving into meaning that may be gleaned from participant accounts and accepting the impact of subjective

experience upon perception of the event, along with the influence of culture, society, time and place. This interpretative approach acknowledges in a very open manner the part played by researchers in bringing their knowledge and understandings to bear upon the interpretative process (Lopez and Willis 2004). Furthermore, IPA has ideography as part of its foundation, where concern is with the individual or particular. It has an interest in smaller purposive samples which are considered in detail and a commitment to personal perspectives before advancing towards more generalized claims (Smith et al 2009).

Golsworthy and Cole (1999) described IPA as a process by which qualitative data from a range of well-being and health issues can be analyzed. This approach aims to engage the participant to gain their insider perspective on their experience. IPA is employed as a means of enriching understanding to encapsulate the subtleties and complexity of individual experience and response towards a phenomenon, in a way that pre-set categories are unable to capture (Whittington and Burns 2005). The aim of IPA is not to produce an objective presentation or representation of a phenomenon but rather to present the individual perception of the event. It aims to explore how individuals make sense of their social and personal world and accepts that within this dynamic process, the participant tries to explain or make sense of their perceptions and the researcher then aims to interpret the participants' view of their world. IPA considers the individual to be a physical, cognitive, affective and linguistic entity, presuming a connection between emotions, thoughts and what is said; the researcher's role is to interpret the mental and emotional content of what people say. IPA puts emphasis on making sense of what is said but utilises in-depth qualitative analysis (Smith and Osborn 2008).

### **3.3.2 Rationale for use of an IPA approach**

IPA is a relatively new methodology and comparatively few studies have been published that compare IPA with other methodologies (Brocki and Wearden 2006). It has been criticised for a weakness in generalisability, small participant sample groups (Cronin-Davis et al 2009) and from a negative perspective it may be claimed that the experience of a small population is not likely to be representative of older, younger or differently gendered populations. However in its defence, IPA does not claim to provide a fully exhaustive or objective view of phenomena; nor does it aim to provide a broad or representative view, although it may be the case that the findings from a small sample may or may not be representative of a larger sample (Touroni and Colye 2002; Yardley 2008). IPA is concerned with the experience of the individual from their unique perspective yet acknowledges the act of interpretation between researcher and participant throughout the process (Smith et al 2009).

Given that the stated aims and objectives of this study are concerned with the exploration and perceptions of siblings of adults who have a learning disability, the use of an approach aligned to IPA for the main study at Stage two is justified because it allows participants to describe their perceptions of the experience; with phenomenology at its core, there is an emphasis on hearing the voice and describing the lived experience of the individual who has experienced the specific phenomena - a key theoretical construct of IPA (Smith et al 2009). As a methodology therefore, IPA is congruent with the aim of the thesis. A further justification for the use of IPA is that despite, or perhaps because of, its focus upon the voice of the individual, it allows for difference and similarity of experience to be drawn out, for the presence of both convergence and divergence (Smith et al 2009). This further supports the

research aims and objectives which relate to the exploration of individual wishes and preference, rather than trying to provide an overarching theory as utilized in other approaches such as grounded theory (Glaser and Strauss (1967). Furthermore, the use of IPA at Stage two, facilitates the deeper understanding of issues raised at Stage one which was quantitative in approach.

To hear the voice of sibling participants is significant because it has been stated in the literature review that there is little empirical research related to the needs and wishes of adult siblings of people who have a learning disability regarding a future care role (McCallion and Kolmer 2003; Hodapp and Urbano 2007); this lack of literature was noted in the published results of Stage one (Davys et al 2010). A reason why research into this topic is limited could be that it is deemed emotive; subjects considered to be sensitive are difficult to study due to the potential to cause participants emotional distress (Lee and Renzetti 1993, Oriell and Dudley 2009). Because there is a lack of research in this field, it is important therefore that the voice, experience and needs of this group of people are heard. This further supports the use of IPA as a methodology because it provides a platform from which the views, opinions and needs of siblings can be heard and then be used to inform service providers of sibling needs and wishes. Hearing the voice of individuals who experience the phenomena is noteworthy, particularly in the absence of a strong body of empirical data, as services are likely to be built on the established medicalised or expert health care professional interpretations of a situation (Knight 2003). In these circumstances, services may fail to meet the needs and wishes of those siblings who are likely to take on key roles in the lives of people who have a learning disability, and there is a long history of dissatisfaction between families of people who have



a learning disability and service providers (Thompson 2001; Scelles 2002; Bhaumik et al 2011).

In the current climate of increased demand upon learning disability services and budgetary constraint (McInnis et al 2011) it is crucial that support services are appropriate and relevant to services users and their families. By using IPA as a methodology to hear the views, opinions and needs of siblings, health and social care providers will be better able to understand their needs and wishes, and provide services which are meaningful, relevant, required, and thus more cost effective. IPA has previously been used in this way to provide service providers with information upon which to build their services (Fade 2004). Associated with the climate of cuts in services and budgets, is the social and government expectation that families will become increasingly involved in the care of people who have a learning disability (DoH 2001; DoH 2008). According to the research base, many siblings expect and want some role in the future support of their learning disabled relative (Heller 2000, Thompson 2001; Dillenburger and McKerr 2010; Bigby et al 2011) and so in line with the expectation to provide care from various quarters, it is imperative that services are appropriate and meet the needs of individuals and families because it is likely that they will be called upon to provide higher levels of support in the future. Unless siblings are supported in a future care role, they may not have the skills or resources to assist the learning disabled person; this could lead to increased reliance upon services which in turn leads to increased service costs, a potentially negative impact upon family relationships and possibly a detrimental effect upon the lives of learning disabled people.

Although the ability to hear the voice of individual siblings is critical in this study, the research process outlined generates issues of

potential bias and pre-conception. The use of semi-structured interviews may give rise to 'Hawthorne', 'halo', 'stereotype' and 'prestige' effects. The Hawthorne effect is described as the principle where, by simply being present, the researcher affects the research process and therefore the results. The halo effect describes researcher bias upon the interpretation of the results; the stereotype effect is when the researcher attributes the characteristics of a group to an individual, and the prestige effect is where the respondents wish to please the interviewer and so amends their responses accordingly (Drummond 1996; Reynolds and Prior 2003). It must be reiterated however that IPA does not aim for generalisability per se, and these issues are recognised in an open manner as part of the analytical process from an IPA perspective, by accepting the presence of co-construction and interpretation between interviewee and researcher (Cronin-Davis et al 2009).

Despite the open acknowledgment of researcher interpretation when using an IPA approach, the unique world view and experience of the researcher is likely to influence understanding (Finlay 2006a); there is no call upon researchers to put aside their presumptions or pre-understandings, as required in methodologies such as grounded theory (Corbin and Strauss 2008) or Giorgi's phenomenological psychological method (1985). Some critics suggest that this can create bias, particularly where researchers are not consciously aware of their presuppositions; however in its defence, the approach is open and transparent about the influence and engagement of the researcher throughout the research process and it could be argued that any bias with respect to personal identity such as age, sex and ethnicity is not susceptible to control in the same way as other factors (Denscombe 1998). As interviewer

bias is a reality that cannot be avoided, it could be argued that the researcher should not attempt to make an interactive methodology neutral (Hammell et al 2002).

With the emphasis on individual experience and perception of particular phenomena, IPA considers the individual to be a physical, cognitive, affective and linguistic entity presuming a connection between emotions, thoughts and what is said whilst engaging in the research process (Smith et al 2009). Despite this stance at a conceptual level, not all participants are equally skilled in emotional awareness or are willing or able to translate emotion and experience into verbal communication and therefore some participants may have difficulty in expressing their thoughts and feelings for a variety of reasons (Smith and Osborne 2008). In practical terms, some individuals are more able to enter into the research process than others, which could affect the interpretative process and depth of data gathered. Some IPA studies have suggested that certain aspects of the interview process for example demographic variables, type of equipment prescribed, and psychosocial variables may be better addressed using a quantitative approach (Murray et al 2004); this further supports the use of a quantitative approach in Stage one in addition to the use of IPA at Stage two (Robson 2002; Morse 2004; Teddlie and Tashakkori 2009).

In terms of data analysis, a criticism of IPA is that it lacks rules and structure, and is therefore described by some as unscientific (Giorgi 2000, 2010). This position is refuted by Smith (2011) who claimed that IPA refers researchers to detailed guidelines that may be used as a guideline. The extensive use of participant quotes is also advocated to support evidence of study findings and to demonstrate links between superordinate and subordinate themes.

The use of IPA is further justified as it offers a suggested method of data analysis which is non-prescriptive and personal rather than demanding strict adherence, and it strives to keep close to the lived experience of the individual participants, again supporting the research aim and objectives. The use of a flexible approach for data collection, analysis and presentation of results means that the individual perspective can be presented in a way that acknowledges the engagement of the researcher in the interpretative process; it also allows more freedom in the analytical process which is useful where the number of participants may vary. An IPA approach advocates the use of quality initiatives and strategies, which are discussed later under the reliability and validity section of this chapter.

A final justification for the use of IPA as a methodology at Stage two is that it acknowledges the part of the researcher in the interpretative process (Cronin-Davis et al 2009). This fits my personal philosophical and world view of the role and function of the researcher within the process. It is my understanding and belief that I will act as interpreter for the participants at some level as I listen to their stories, read and re-read the transcripts, interpret and put data into categories before deciding upon key themes which I perceive to rise from the data. I acknowledge my acts of interpretation within this process, despite my wish to remain true to the individuals' lived experiences. It is also likely that my personal world view is influenced by my professional role as an occupational therapist, as my professional code of conduct promotes a client-centred and individualistic approach to practice (College of Occupational Therapists 2010).

### **3.4 Ethics and power**

Ethical approval was granted from the ethics committee at Manchester Metropolitan University and Sibs (the UK charitable organization for people who have grown up with a disabled brother or sister) for stages one and two of this study before any data collection was undertaken.

Whilst engaged with this study, a number of ethical issues presented themselves. Issues of confidentiality and anonymity are an important aspect of the research process (Mappes and Degrazia 2006); at Stage one, data were collected by a questionnaire which was distributed via Sibs' website because the organization was not able to provide me with contact details of their members. To manage this situation in an ethical manner therefore, Sibs forwarded the questionnaire to their members on my behalf and members self-selected their participation. The questionnaire asked for no details of name or address and respondents were given the option of posting back a hard copy of the questionnaire if they did not wish to reveal their email address; however most respondents returned their questionnaire via email, which compromised anonymity to some extent, but it was the participants' active and informed choice. It is also acknowledged that the questionnaire was deemed sensitive as it asked questions related to the future care of a disabled brother or sister when parents were no longer able to provide support, and the potential impact of this upon siblings' lives. As the researcher has a responsibility for the well-being of participants who take part in a study (Beauchamp and Childress 2009) the contact details for Sibs was given at the end of the questionnaire as the organization had agreed to provide support in the event that siblings became upset by the content of the questions.

As issues of confidentiality have to be addressed at all stages (Mappes and Degrazia 2006) potential participants for Stage two were accessed via gatekeeper organizations. The lead contact in each organization was sent study information advertisement sheets (Appendix B) and study information sheets (Appendix C) which they brought to the attention of potential participants who fitted the research criteria. In two instances the lead contact invited a number of potential participants to attend an information session. In addition to this some individuals known to the research supervisors agreed for their details to be passed on to me, as my research supervisors had also distributed information sheets about the study. It could be argued that some degree of confidentiality was compromised as the lead contacts and research supervisors knew of people who had come forward as potential participants, however, to maintain confidentiality, I did not confirm to them which individuals actually took part in the interviews. Throughout the process of transcription, participants were referred to by number only, and all names and places were removed or anonymised. As I was the only person involved in transcription, this further supported the maintenance of confidentiality and anonymity; in relation to data analysis however, Polit and Beck (2010) and Smith et al (2009) argued that *anonymity* rather than confidentiality can be provided because, when signing the written consent form participants confirm that content from the transcripts may be used in an academic forum which includes presentation and publication.

A further potential issue was that of coercion. Within an ethical research process, it is imperative that participants enter into the research process freely and without any sense of pressure (Mappes and Degrazia 2006); however some participants were known to the

researcher and research supervisors, and some to the lead contact in gatekeeper organizations, even to the extent of being related to the lead contact, which could mean that some participants felt a sense of obligation or pressure to take part in the study. In order to manage issues of coercion and informed consent, these matters were discussed with each lead in the gatekeeper organization, and the purpose of the study, the right to withdraw and need for written consent were discussed with each participant before the interview took place, as deemed good research practice by Beauchamp and Childress (2009).

Research into topics that are deemed sensitive has the potential to cause emotional distress and therefore, from an ethical stance, the capacity to cause harm (Lee and Renzetti 1993). As the focus of this research related to personal wishes regarding a future care role, the conceptualization of parental death, the return to this point for those parents had already died, the impact of caring upon siblings` lives and possible conflict between personal and parental wishes, the research topic had the potential to cause emotional distress. Whilst acknowledging the sensitivity of the research area, unless such matters are raised, it is difficult to meet the needs and wishes of individuals in this situation, and so pursuit of the subject area was felt to be justified. To support the ethical call to avoid harm and do good (Beauchamp and Childress 2009), participants were asked at the end of each interview if they felt any distress and were given a handout which provided contact details of the Sibs organization who had agreed to provide emotional support and advice should participants feel the need for this. At times participants did become tearful and upset in the interviews; when this happened participants were asked if they wanted to stop the interview and the tape was switched off until they had regained

composure. The interview was only re-started when the respondents said that they were ready to continue and I used my professional judgment as a health care professional to decide whether or not I felt the participant was in a sufficiently stable condition to continue with the interview.

Having attended to issues of participant safety and comfort, researcher safety must also be addressed, particularly when researchers work alone with unknown participants in locations that are unfamiliar (Polit and Beck 2010). The process followed therefore, was that once a time and place for the interview had been agreed upon, the participant was asked for permission to leave a telephone contact number with a professional colleague for the purpose of researcher safety. Agreement was made with the professional colleague that if I had not contacted them by a pre-arranged time, they would try to contact me and if unable to do so would contact the emergency services. If the situation arose that I was in difficulty whilst at a participant's home but able to telephone, a pre-arranged code word would be used to call for support.

One situation which could span both ethical issues and the question of validity occurred when the lead person from one gate keeper organization informed me that a potential participant may present an 'official' version of her future wishes and intentions that would be acceptable to her parent, yet in reality she held different views and plans. Ethically I was obliged not to provide any information as to whether or not the individual in question had participated, although I had already interviewed this person. The question of how accurate or true this person's information would be was then raised and, according to Findley (2006b), is a contentious issue throughout qualitative research. In the spirit of IPA however, as the



participant had appeared to participate on a voluntary basis with an awareness of the aim of the research and had signed a written consent form, I adopted the stance of Smith and Osborn (2008) by considering the participant as able to link emotions and thoughts to what is said whilst engaging in the research process, and therefore accepted her account of future wishes and perspectives.

Member checking of transcripts is sometimes used within qualitative research for the purpose of checking accuracy and validity; however, although it is considered good research practice (Yardley 2008), member checking was not utilized in this study. The reasons for this were that some of the discussion and disclosure within the interviews included participants' negative feelings, attitudes and behaviour towards the person with a learning disability, along with negative views on the behaviour of parents; for some participants, the presence of the learning disabled person in their life had led to the loss of considerable hopes and wishes. To view such matters in print could lead to emotional distress, which is in conflict with the ethical principle of beneficence (Beauchamp and Childress 2006). Secondly, to see such personal issues set down on paper may lead participants to withdraw information from a research area which is already deficient. Participants were not asked to comment upon themes or interpretations which are advocated by some researchers as a quality measure as these were recognized as acts of interpretation on my part as researcher.

A final ethical consideration presented in the context of this thesis was the role of researcher versus therapist. A researcher role is considered to be one of gaining further insights and extending knowledge by the collation, analysis and presentation of findings (Polit and Beck 2010), whilst my clinical role as a therapist is more

concerned with the promotion of function, quality of life and the realization of potential for individuals who are experiencing deprivation, imbalance or alienation as an occupational being (COT 2010). When listening to some of the life histories that participants presented and their current situation, my natural inclination as a therapist would have been to give advice or problem solve the difficulties that some people were experiencing and generate an action plan. Clearly the roles of researcher and therapist are different. My role as researcher was to listen to and engage with the experience and perspectives shared by the individual within the research process, whilst supporting beneficence. I therefore used the Sibs contact details given at the end of each interview to encourage participants to access further information and advice as required and advised them to contact local service providers where appropriate.

### **3.5 Design of the study**

#### **3.5.1 Stage one**

The use of a survey in advance of in-depth semi-structured interviews can be advantageous when conducting research, to provide background demographic details, evidence of the need to conduct further study in a specified area and to inform the interview questions (Hicks 2002; Robson 2002). The combination of a survey and interview may also serve to provide a form of triangulation, the presentation of an alternative or broader perspective of the issue under study, whilst allowing the strengths of two research approaches to complement each other (Teddlie and Tashakkori 2009). For these reasons therefore it was felt that although the main focus of this thesis is based on Stage two which utilized in-depth semi-structured interviews, the use of a survey in the form of a questionnaire as a precursor in Stage one would be

beneficial, and would bring an incremental element to the process and it would support confidence in the results.

Following ethical approval by both Manchester Metropolitan University and Sibs, the UK charitable organization for people who have grown up with a disabled brother or sister, the questionnaire (Appendix D) was sent by email to the Sibs organisation who distributed it to 200 people on their database; this maintained confidentiality and ensured that participation was voluntary and without coercion - as considered to be good research practice, according to Mappes and Degrazia (2006). Any person aged 25 or over who was an adult sibling to a person with a learning disability was invited to take part. A follow up invitation was also sent out and data was collated between November 2009 and January 2010. In total, 21 respondents returned the questionnaire. To further maintain anonymity (Beauchamp and Childress 2009) respondents were not asked for names or other identifying details, and were given the option of returning the questionnaire by post if they preferred not to use email.

The questionnaire was constructed following a literature review of empirical studies related to the adult siblings of people who have a learning disability. In order to check for clarity and gain a sense of respondent reaction to the wording, layout and sequence, the questionnaire was reviewed by the Sibs organization, a professional colleague who is also an adult sibling of a person who has a learning disability and the research supervisors. As it is appropriate to modify a data collection tool in the light of feedback (Blaxter 2001), the questionnaire was then amended. The questions related to demographic details, the existence of futures plans, the degree to which futures plans were agreeable to both parents and siblings, difference between parental and sibling wishes, and whether or not

siblings were concerned about the future impact of the disabled person upon their lives. The final part was an open section where participants were invited to note any other thoughts or comment. Questionnaires can be used in social research and may include open or closed questions as both form a means of self-report in relation to a specific phenomena, and can be viewed as different tools along the continuum of self report (Polit et al 2001).

The advantages of closed questions within a survey are that they have the potential to reach a wide geographical area, are easy to administer, are less time consuming, may afford greater anonymity and avoid interpersonal bias between the researcher and respondent which may generate a greater degree of honesty in response (Polit et al 2001); however they also have the potential to be misinterpreted and are associated with a low response rate (Ruane 2005). It is also possible that participants may want to avoid aligning themselves with attributes that may be construed as less socially acceptable, and therefore some respondents may under-report certain attributes whilst over-reporting others.

The results of the questionnaires will be presented in Chapter 4 when the advantage of the methodology will be presented. It will be seen that the questionnaires helped to provide important insights into the presence of futures plans for learning disabled people, parental expectations and sibling concerns about the future. The issues around futures plans, sibling wishes and concerns from Stage one were published (Davys et al 2010) and indicated the need for further qualitative research into this area and therefore justified progression to Stage two of the research process.

### **3.5.2 Stage two**

For Stage two, ethical approval was gained from the ethics committee at Manchester Metropolitan University and Sibs to carry out face to face semi-structured interviews with up to 15 adult siblings aged 25 or over of people who have a learning disability. Setting the minimum age as 25 or over was decided upon as according to the National Statistics Office (2003) it is between the ages of 25 and 34 that people are most likely to be co-habiting or married, and therefore likely to be establishing independent lives with some awareness of potential future expectations. Face to face semi-structured interviews are supported by a theoretical perspective of phenomenology, a fundamental premise of IPA (Flowers 2008; Smith 2011), within which people are seen as individuals reacting to and interpreting their world in a unique way (Kelly and Long 2000). Semi-structured interviews are considered to be the strongest tool for data collection using an IPA approach, as this allows the researcher and individual to mutually engage in the pre-determined subject and probe areas of interest (Smith and Osbourne 2008). The interview questions (Appendix E) were based on the research aims and objectives and the literature review, and were further informed by the returned questionnaires and analysis from Stage one of this study.

Gate keeper co-operation was sought from learning disability self help organizations in the North West (Talbot House Independent Learning Disability Partnership Carers Group, the North West Families Forum and Himmat ) to gain access to adult siblings of people who have a learning disability aged 25 and over. The sampling strategy used would be described by Smith et al (2009) as purposive since it allowed access to particular groups who are able to provide a specific insight into an identified phenomenon. This

main category can be further described as a snowball or network sample (Seale 2004) as the potential respondents were gathered by those already in contact with the research supervisors or researcher as they fitted the criteria for inclusion.

The sample size stated in the ethics application was 15 adult siblings. A methodology aligned to IPA may use a sample size ranging from an individual case study to larger numbers with no set limit (Smith 2008; Smith et al 2009) and some studies have used sample sizes of 35 (Reynolds and Prior 20003; Murray 2004). The larger the number of participants, the less detailed the analysis is likely to be; however a larger sample may provide greater opportunity for consideration of convergence and divergence between and across participants (Smith et al 2009). As there is little empirical data related to the needs and wishes of adult siblings of people who have a learning disability, a larger number of cases was decided upon to allow sibling voices to be heard which supports the aim of this study. The final number interviewed and analysed was fifteen.

The gate keeper organizations that were willing to pass on information about this study were contacted and sent copies of the study advertisement sheets (Appendix B) and study information sheet (Appendix C). Verbal presentations with handouts and information sheets were given to two of the organizations that requested this and some potential participants attended these sessions. Those people who were interested in hearing more about the study or were willing to participate were asked to inform the researcher. Some people identified themselves as willing to take part at presentations, whilst others contacted the researcher by telephone or email at a later date. After individuals identified themselves as willing participants, a time and place for the

interview was agreed and further reiteration of the study aims, the interview process, consent issues and a check to ensure that participants met the research criteria were made. Some participants had heard of the study by word of mouth and volunteered to take part.

Interviews took place in participants' own homes or a setting of their choice, for example, an individual room in a community centre or place of work. Further in line with good research practice (Polgar and Thomas 2000), the researcher reiterated the purpose of the interview and the process to be followed before the start of each interview. All participants were reminded that there was no obligation to participate in the study, that they could withdraw themselves or their information at any point and that to do so would not lead to any negative impact on the services received by themselves or their family members. It was explained that the interview was expected to last between one and one and a half hours, and where the respondent agreed to proceed, written consent (Appendix F) was gained.

Each interview was recorded using a digital recorder and a non-digital recorder as a backup. The interview schedule (Appendix E) was followed as a general guide although points of interest that arose in the interview were followed up by the researcher. In order to demonstrate engagement on both sides and as a means of triangulation (Etherington 2004) some written notes were made on the interview schedules and key points were read back to the participant at the end of the interview to ensure that the interviewer has understood the essence of the respondent's experience. Each participant was thanked for their time at the end of the interview and asked if they had any questions. As sensitive questions in an interview situation have the potential to cause

distress (Lee and Renzetti 1993) participants were offered a contact sheet for the Sibs organization in case they felt distressed at any stage after the interview or wanted further advice or information (Appendix G). The data collated in the interviews will be presented in Chapter five and discussed in Chapter six.

### **3.6 Reflexivity**

As part of the reflective process, a reflective diary can be maintained and used as a form of triangulation (Butt et al 2008), and so I wrote up a reflection as soon as practicable after each interview, noting key points which served to act as a record of my personal reaction to the stories that individuals told about their lives and their future wishes and expectations. Further reflection upon my personal response to an individual's circumstance was noted at a conceptual and emotional level although not written down; for example, I would think about the individual's circumstance and consider how I would feel if I was in their situation and how I might respond.

A further reflective point was that of my relationship with the thesis over the past few years. Since its inception, I believe that I have engaged with the thesis as a therapeutic medium at times when I have encountered difficult transitions in my personal life. As an occupational therapist by profession, it is a fundamental belief that individuals need to engage with occupations that they deem meaningful and purposeful, and that meaningful engagement with such occupations is important to health and well-being (COT 2010). On a personal level, I have managed the transitions of separation and death within my own family and this has led to ongoing consideration of my sense of duty and responsibility for my family members in the present and future, which is aligned, to some



degree, with the nature of this study. Further reflection on my personal learning will be raised again in the concluding chapter.

### **3.7 Reliability and validity**

Within constructionist research, it has been alleged that concepts of reliability and validity cannot be applied as they are mainly associated with a positivist paradigm and therefore it lacks coherence to discuss reliability as something that is accurate or consistent when researching individual perspectives and perceptions (Polit and Beck 2010). In a similar way, discussion about validity as in whether or not the data collection process will accurately measure the same items when applied to the unique event of a face to face interview lacks congruence (Willig 2008). Concepts said to be more relevant to qualitative research are those of trustworthiness and credibility (Lincoln and Guba 1985; Finlay 2006a; Finlay 2006b; Polit and Beck 2010) however despite the debate, it is important that qualitative research is of high quality and that attention to the quality of a study is pursued and demonstrated (Yardley 2008).

Measures to promote quality within qualitative research have been set out in frameworks by authors such as Whitemore et al (2001) and Lincoln and Guba (1996), and are referred to in more recent texts such as those by Polit and Beck (2010) and Yardley (2008) who stated that it is not possible or practicable to include all suggestions made within these quality frameworks. It is however important to outline those steps that have been taken over the course of a research study to enhance quality and trustworthiness, and the steps taken to promote quality within this study are set out in the remainder of this section.

Yardley (2000) stated that the research process needs to be underpinned by awareness of, and reference to, relevant empirical study within the specified field which is addressed within this study by the literature review in Chapter two, and the discussion in Chapter six, which explores the links between the literature and the findings of this thesis. It is also important that there should be an appropriate choice of participants who fit the study criteria, with clear links established between the component parts of the research nexus, and therefore congruence between epistemology, ontology, research design, data collection and analysis (Yardley 2000; Ballinger 2006; Smith et al 2009). In an effort to address these demands, links between the various aspects of the research nexus, for example the appropriateness of participants and aim of the study have been referred to consistently to support congruence throughout the process.

An appropriate data collection tool is required in order to gather high quality data (Willig 2008); therefore before the questionnaire in Stage one was sent out to participants, it was read by the research supervisors, a professional colleague who was also an adult sibling of a person with a learning disability and the Sibs organization. The reason for this was to check the clarity and readability of the questions, to demonstrate sensitivity to the research context and provide an appropriate foundation upon which collect high quality data. Alterations were then made to the questionnaire following feedback. A similar process was applied to the semi-structured interview questions used at Stage two and again, amendments were made accordingly. The use of a questionnaire in Stage one and semi-structured interviews at Stage two could be described as triangulation in order to overcome the bias that may result from using a single method of data collection;

it would also provide a deeper, wider perspective of the phenomena under consideration and support the findings of data collected across the studies (Gillespie et al 2008).

Field notes can be used to record researcher reactions and engagement with the data, which, along with reflective comments, can raise awareness of personal bias, pre-understandings and experience (Polit and Beck 2010) and so I made field notes as quickly as possible after each interview. The use of reflexivity which presents personal background, experience, life events and potential bias is considered to be relevant and an act of transparency and acknowledgment of researcher engagement in the interpretative process (Watt 2007; Yardley 2008); therefore its presence in this thesis is important as a quality initiative when using a qualitative approach.

One of the most basic means used to support quality and validity was the verbatim transcription of all interviews alongside the systematic use of participant quotes to provide evidence and transparency in the presentation of superordinate and subordinate themes. The use of participant quotes also serves to provide information for readers to make their own judgments about the closeness of fit between themes and participant quotes, as well as promoting what is described by Polit and Beck (2010) as authenticity. A full and explicit description of the phenomena from the individual participants' perspective also allows for difference of experience and perception to be demonstrated between participants (Smith et al 2009); an example of key themes and supportive participant quotes can be found in Appendix H.

At Stage two, the research supervisors and research assistants were involved in the checking of super and subordinate themes

against participant quotes. This is described as investigator triangulation, when two or more researchers make decisions on data analysis to reduce bias and support the corroboration of interpretation of data (Butt et al 2008). Finally, in the spirit of coherence and transparency I have attempted, as the researcher, to acknowledge my part in the interpretation of sibling experiences throughout the thesis. Researcher credibility is anticipated when the researcher is part of the data collection and interpretation process (Yardley 200; Patton 2002) and therefore at various points I have presented my work experience and qualifications, my life experiences, and perspective of how knowledge is generated, as part of a reflexive approach to enhance transparency and confidence in the study.

### **3.8 Data analysis**

#### **3.8.1 Stage one**

Descriptive statistics in the form of percentages are presented for the closed questions and a form of content analysis based on the process outlined by Burnard (1991) was used to analyse the written comments made by 14 respondents (67%) in the final open question. The procedure used to analyse the written comments was as follows: each comment was read through and key issues arising were underlined; each respondent who completed the comment box was given a number and key sentences were written in a comment box against the respondent number e.g. Respondent 1: “problems with housing” or Respondent 3: “I feel guilty that I am able to have a normal life compared to that of my sibling”. After each comment box was reviewed and key sentences for all respondents noted, commonality of theme was sought and key themes generated, some of which were then incorporated into other broader themes arising from the interviews.

### **3.8.2 Stage two**

There is no single finite way to conduct analysis from an IPA perspective (Smith et al 2009). Smith and Osborne (2008) provided guidance but stated there was no fixed procedure to follow. The general principles suggested by Smith and Osborne (2008) were followed to provide a voice for the perceptions and experiences of a specific group in response to common phenomena. Because there were only 15 participants, wide generalisations cannot be claimed; however in reference to Smith (2007), the detailed analysis of specific cases may or may not be relevant to wider yet similar populations. A sample size of 15 is larger than the six suggested when using IPA for the first time however IPA has no fixed recommendations for sample size and claims that although a larger sample size often leads to a focus upon description rather than conceptualisation, this allows for both similarity and difference of experience to be presented (Smith et al 2009). IPA requires a group of participants who share the same experience (Smith et al 2009) and within this study all participants experienced the same phenomena, in that they were an adult sibling, aged 25 or over, of a person who had a learning disability. IPA supports data collection via semi-structured interviews, considering this to be the strongest tool because it allows the researcher and participant to engage in the concept under scrutiny and probe areas of interest (Smith and Osborne 2008). The methodology advocates the recording of interviews to ensure that all information is captured. It allows the researcher to engage fully with the method of analysis, although it is accepted that there is a process of interpretation between respondent and researcher during analysis (Smith 2011).

Within IPA, transcription of whole interviews, including questions, is advocated; for analysis, margins are traditionally left on both sides

of the script for analytical comments. A semantic level of transcription is often utilized with all words spoken, laughs, long pauses and other features of note written down (Smith et al 2009). An example of an excerpt from a transcribed interview can be found in Appendix I.

As analysis within IPA is concerned with the respondent's world view, beliefs and constructs, the aim is to understand meaning and complexity. Less attention is given to the number of times a theme is mentioned, although this may be considered when using a larger number of participants as it allows the patterning and dominance of a theme to be highlighted (Smith et al 2009). It is suggested that themes are named after phrases arising from participant quotes however there is no set criteria for the analytical process within IPA (Smith et al 2009). To analyse a transcript, the researcher has to engage with the interpretation of the transcript (Smith and Osborne 2008).

The stages of analysis utilized within this study were as follows:

Each interview was transcribed verbatim, including "emm's", pauses and colloquial language. No note of tone or body language was made unless a participant became tearful, visibly upset or laughed, and this was noted at the appropriate place in the script within brackets. Pauses were denoted by '...' and parts of the audiotape that were inaudible were indicated by empty brackets.

Each interview transcript was saved as a word document and printed. The interview was listened to repeatedly until the researcher was confident that the transcript was as accurate as possible, to remain true to the IPA philosophy of engaging with the life world of the individual respondent. Page and line numbers for each consecutive page were inserted (Appendix I). Wide margins

were applied to the left and right sides of the transcript, as advised by Smith et al (2009). Each transcript was read and re-read. Significant or interesting points were then underlined in the text and commented upon in the right hand margin of the transcript.

The transcript and notes in the right hand column were further read and emergent themes noted in the left hand column, along with how each theme may fit with another theme (Smith et al 2009). From here, superordinate or major category themes from each transcript were identified, for example 'Family' or 'Impact of Learning Disabled Person upon the Sibling'. Subordinate or smaller themes such as 'Mother' under the superordinate theme of 'Family,' or 'Role of Protector' under the superordinate theme of 'Impact of Learning Disabled person upon Sibling Life' were noted. Some subordinate themes were further broken down to sub-categories such as 'Mother finds the learning disability situation stressful' or 'Close bond between the learning disabled person and mother.'

At the bottom of each interview transcript, a list of superordinate and subordinate themes was made, as advised by Smith et al (2009). The superordinate and subordinate themes for each interview were then compared and contrasted with other interview transcripts and recorded on a chart which noted the number of times each superordinate theme arose across the interviews (Appendix J) to demonstrate the dominance of particular themes. All transcripts were compared and contrasted to note the regularity of superordinate and subordinate themes, to look for patterns of convergence and divergence, and to maintain an ideographic focus (Smith and Osborne 2008).

Nine major or superordinate themes were highlighted and defined as themes that were present in a minimum of 11 of the 15 interviews, following the advice of Smith et al (2009) who suggested that superordinate themes should be present in at least one third to a half of the transcripts in a study. Two superordinate themes which were present in two or fewer interviews were discarded from the analysis. Each transcript was then revisited. The presence of any of the nine superordinate themes was noted on the left side of the page; participant quotes, along with page and line number to support the presence of this theme, were recorded on the right side of the page. An example can be found in Appendix H.

For each interview, the major superordinate themes, subthemes and supportive participant quotes were checked by the principal researcher to confirm congruence between themes, to serve as a form of verification and audit, and to see if any amalgamations could be made. Corresponding changes and corrections were made as required. A further check of the themes, sub-themes and supporting evidence from each transcript was carried out by one of the research supervisors and a research assistant, to check that there was sufficient evidence within the transcripts to support the designated themes and sub-themes, and that all categories listed at the end were accurately represented.

Key quantitative data from each interview was also analysed on an individual interview basis, namely the respondent's relationship to any other participant; respondent age; gender; work status; ethnicity; parental status; status of the learning disabled person; respondent social context at the time of interview; number of children in the family; parental wishes regarding future care of the learning disabled person; respondent wishes regarding future care; the presence and type of futures plan; respondent concerns



about the future; respondent stated needs; and respondent advice to others. This information was then summarised across all 15 interviews and put into a single chart (Appendix K). Counting and the use of frequency can be used in IPA studies to demonstrate the frequency or importance of themes but also supports the view that IPA can be used as part of a mixed methodological process to strengthen and develop the depth and range of a study (Smith et al 2009).

### **3.9 Ways of presenting results and discussion**

There are different ways of presenting the results and discussion within IPA. The results section and discussion can be intertwined, as demonstrated in published studies by Knight et al (2003), Reynolds and Prior (2003) and Golsworthy and Cole (1999). Alternatively, they can be written up as separate sections (Smith and Osborne 2008). The results section of Stage two is written up in Chapter five, presenting superordinate and subordinate themes with examples of supportive evidence from the transcripts. This is followed by a separate discussion in Chapter six that summarises the findings and explores their links with theory and literature, as demonstrated in previous IPA studies (MacDonald et al 2003; Ditchfield 2004; Murray 2004; Howes 2005; Mason et al 2010; Hatton et al 2010).

### **Chapter summary**

This methodology chapter started with reference to the findings of the literature review in Chapter two; justification for this study was provided by the lack of empirical research concerning the wishes and future expectations of adult siblings of people who have a learning disability. The research aim, which forms the starting point of the research process, was reiterated, followed by an explanation

and justification for the research nexus utilized throughout the thesis. The epistemological stance of constructionism and its belief that people construct meaning and interpret phenomena dependent upon social, political and historical contexts was set out and aligned to the research aim. I also acknowledged my own part as researcher within the interpretative process.

The rationale for using a mixed methodological approach, combining a survey in the form of a questionnaire at Stage one, and deeper exploration of the research question in Stage two, has been presented. The survey in Stage one had several functions: it provided background demographic information and an evidence base for deeper exploration involving in-depth, semi-structured interviews at Stage two; it also informed the questions to be used in Stage two, and provided a complementary and exploratory basis which supports further confidence in the results overall. Utilization of an approach aligned to IPA was then outlined, detailing the key concepts of IPA as a research method; this involved explaining its philosophical roots in interpretative phenomenology which advocates a hermeneutic stance of looking for subjective experience in the context of time, place, society and culture rather than description alone. The part played by the researcher within the interpretative process was acknowledged. The rationale for using an IPA approach was linked to the research aim, which was to hear the voice of the individual regarding specified phenomena. The ability of IPA to accommodate a mixed methodological approach, provide a suggested rather than prescribed approach to data analysis and its use in previous studies to inform service providers of requirements from an insider perspective was further outlined. A critique of IPA was integrated within this discussion. Further consideration was given to the issues of small sample size

(which could produce results that may or may not be generalized to a wider population), the difficulty some participants may experience in communicating their experience and the complexity of researcher pre-understandings, presumptions and bias.

Ethical issues that arose during the research process were considered; of particular note were those of confidentiality and sensitivity of questions at Stage one, and anonymity, informed consent, sensitivity of questions, participant and researcher safety, coercion, validity and researcher role at Stage two. The design of the study for Stages one and two was then outlined, detailing the ethical approval process, rationale, and procedure for administration and analytical approach utilized. Finally, researcher reflexivity was considered, followed by discussion of validity and reliability within a constructionist approach which led onto strategies used to promote quality, trustworthiness and credibility throughout the thesis.

The next two chapters will present the results of the research process: Chapter four will outline the results of the survey at Stage one and Chapter five will detail the results of the in-depth semi-structured interviews at Stage two.

## **Chapter Four: Results of Stage one**

This chapter will present the findings of the research process outlined in Chapter three, starting with the results of the questionnaire from Stage one. The results of the semi-structured interviews in Stage two will be presented in Chapter five. Each stage was carried out as a separate entity, although the results of Stage one were used to inform the research methodology and interview schedule at Stage two. Discussion of the findings of Stage one is given within this chapter rather than presenting them in a separate chapter as is the case for the results of Stage two.

The Stage one questionnaire was sent out by email via the Sibs organization to 200 people on their database. Participants self-selected by choosing whether to complete and return the questionnaire. Data were collected between November 2009 and January 2010. A total of 21 respondents returned the questionnaire.

The results of the closed questions were analysed using descriptive statistics and a form of content analysis based on the process suggested by Burnard (1991) was used to examine the written comments made by 14 (67%) of the 21 respondents. The process used to analyse the written comments followed this procedure: each comment was read through and key points were underlined; a number was assigned to each respondent who had completed the comment box and key sentences, for example, “problems with housing” or, “I feel guilty that I am able to have a normal life compared to that of my sibling” were matched against the respondent’s number. Following a review of each comment box and key sentences, emergent themes were identified and some were subsumed into other broader themes.

## 4.1 Results

It is not known how many siblings viewed the questionnaire and therefore it is not possible to provide a response rate; however 21 people returned a completed questionnaire. The results presented can only be considered as an indication of adult sibling views and may differ from results generated by a larger scale study. Most participants (18; 86%) were women, 16 (76%) were under the age of 45, four (19%) were in the 45-54 age range and one (5%) did not state his/her age. As the majority of respondents were in the 25-34 years of age category (nine; 43%) and none were aged over 54, it was younger rather than older siblings who participated in the questionnaire.

The majority of participants (nine; 43%) lived in the South East of England; four (19%) came from the North West; three (14%) each came from the North East and the Midlands, whilst two (10%) came from the South West. Nine respondents (43%) lived with a partner; five (24%) lived with a partner plus children; six (28%) lived alone, and one (5%) lived with parents. No participants lived with their parents plus a learning disabled sibling. All participants reported some level of contact with their disabled brother or sister (Table 1). The most regularly stated level of contact was more than once per week (five; 24%); four participants (19%) reported contact to be couple of times a month, and three participants (14%) stated that they had contact once a week, once every three months and once every six months respectively.

### 4.1.1 Table 1 Sibling level of contact

<b>Table 1 Sibling level of contact with the disabled person</b>	
Level of contact	Number of respondents
More than once per week	5 (24%)
Once per week	3 (14%)

A couple of times per month	4 (19%)
Once per month	3 (14%)
Once every three months	3 (14%)
Once every six months	3 (14%)

Regarding future role, futures plans and parental expectation (questions 6-9 of the questionnaire charted in Table 2), 12 respondents (57%) stated that there had been full discussion with their parents on the subject of a future support role for the disabled sibling; however 12 (57%) also stated that there was no clear futures plan currently in place, which could suggest that although parents and typically developing adult children may discuss aspects of the future, it does not necessarily translate into a formalised futures plan. Where a plan did exist, seven (33%) respondents claimed it was fully agreeable to both them and their parent; one participant claimed that it was not fully agreeable and a further five respondents (24%) were unsure if the plan was fully agreeable to both parties. The most likely reason for this was that the previous question asked if there was a clear plan for future support - as 12 (57%) respondents stated that there was no clear plan it would make this question difficult to answer. When asked about any difference between their own ideal wishes regarding a future care role and that of their parents, 11 respondents (52%) claimed that there was no difference, whilst seven (33%) felt that there was a difference and 3 (14%) were unsure about any difference.

#### 4.1.2 Table 2 Responses to question 6-9

Table 2 Responses to question 6-9			
Question	Respondent answers		
	Yes	No	Unsur

			e
Has there been a full discussion between siblings and parents regarding future support role?	12 (57%)	7 (33%)	2 (10%)
Does a clear futures plan exist?	9 (43%)	12 (57%)	0
Where a plan exists is it fully agreeable to parents and siblings?	7 (33%)	1 (5%)	5 (24%)
Is there any difference between sibling wishes and those of parents regarding future role for disabled person?	7 (33%)	11 (52%)	3 (14%)

Most respondents (14; 67%) reported concern about the impact a disabled brother or sister may have upon their lives in the future. Four (19%) were not concerned about the future and two (10%) were unsure about this. One respondent marked both the yes and no boxes; the yes box was marked with the comment, “It has already affected my career” and the no box was marked with the comment, “I don’t think about it”.

The type of relationships between respondent and disabled person (question 11) were those of full brother or sister in 20 (95%) cases, and half brother or sister for one (5%) case. All respondents said that their mothers were alive: 16 (76%) reported their father was alive; two (10%) stated mother, father and step father were alive and one (5%) that mother, father and step-mother were alive. One respondent (5%) noted that a father was alive but had no contact with the disabled person. The fact that all mothers were still alive may have influenced the results as care arrangements may change after maternal death, especially if the mother is the last surviving parent.

#### **4.2 Written comments from the questionnaires**

Six main themes were generated from the open question at the end of the questionnaire: level of satisfaction with services; parental

influence or impact upon futures planning and care; siblings' worries about the future; futures planning; the impact of a learning disabled person upon siblings' lives; and siblings have needs. The process of how the themes were generated was described earlier in this chapter. An IPA study may combine the results and discussion section or write them up separately (Smith 2008, Smith et al 2009); the results and discussion section within Stage one have been combined due to the limited number of participant comments.

#### **4.2.1 Level of satisfaction with services**

This was the most commonly occurring theme and incorporates dissatisfaction with services, satisfaction with services, not wanting the learning disabled person to go into care, and the family having to take control when services are not up to standard. 15 comments that relate to these categories were made.

11 negative comments referred to services and commented upon both the lack and appropriateness of housing options available. Services were said to be of an unacceptable or inappropriate standard, service providers lacked the ability to understand the needs of learning disabled people and their families, and emergency care arrangements were described as inadequate. This theme also encompassed comments that demonstrated respondents do not want their learning disabled brothers or sisters to go into a care home and that when services break down or are inappropriate, it is the family who have to provide support, which can be interpreted in a negative light. Parental dissatisfaction with services is a common theme in the literature related to learning disabilities as supported by previous work undertaken by the researcher at Masters level (Davys and Haigh 2008); the results of Stage one demonstrate how this negative view of services now appears to be shared to some extent by siblings. Not all siblings



held a negative view of services however: three positive comments were made to the effect that the learning disabled person was now settled in a residential care setting, although it had taken some degree of trial and error in order to reach this stage.

#### **4.2.2 Parental influence on futures planning and care**

This was the second most commonly occurring theme with a total of 10 comments made. Parental influence upon futures planning and the care situation demonstrated a mixed presentation. Some siblings reported open and frank conversation with parents; for example, Respondent 7 wrote that the family openly discussed options about future care and that his/her parents wanted to avoid the person with a learning disability living with their sibling to avoid stress to both parties; this comment was reiterated by Respondent 3. Respondent 10 felt that parents had expectations of greater involvement with the learning disabled person in the future, although there was no negative comment attached to this statement. In contrast however, issues of significant distress and concern were also present: Respondent 4 stated that discussing future care with parents was a major problem, and parental distress around the topic of futures planning was upheld by Respondent 6 who wrote that his/her parents, “bury their heads in the sand,” which led to much frustration, as parental refusal to discuss the situation meant that future care for the learning disabled person remained unresolved. Despite some difficulty for certain respondents in discussing future plans with parents and increased parental expectation of future support for some participants, the view was also expressed that parents wished to avoid placing a perceived burden upon the typically developing siblings.

The view that parents want to avoid placing a perceived burden upon their typically developing children is supported by previous

research undertaken by the researcher at Masters Level (Davys and Haigh 2008), which identified that parents believed that non-disabled siblings had their own lives to lead and had already been affected by the family situation. Parents held a joint expectation that non-disabled children would develop their own independent lives yet, at the same time, parents expected them to have future involvement in the life of the disabled person. The concept of sibling involvement in care-giving to a learning disabled person, as associated with parental expectation, is supported by earlier studies (Zetlin 1986; Bigby 1997); parental stress when considering future plans for learning disabled offspring has been previously raised by Knox and Bigby (2007) who claimed that futures planning was a highly sensitive topic, whilst Gilbert et al (2008) found that parents were reluctant to make and discuss plans for the future.

#### **4.2.3 Siblings' worries about the future, futures planning and the impact of a learning disabled person upon siblings' lives**

Each of these themes gained eight comments making them the joint third most commonly occurring themes. Respondents presented various concerns about the future and their role in supporting the learning disabled person. Worries were centred on the support needs of the disabled person as siblings aged, future responsibilities and how siblings would manage the needs of the disabled person against the expectations of their own families. Respondent 9 wrote that she had recently married and hoped to have children in the future, but for her this would create, "immense pressure," as the learning disabled sibling would have to come second on the priority list. Respondent 20 made comment that he was very worried about the future when parents were no longer able to provide care as the disabled sibling already had a "massive" effect upon the respondent's life and that of his whole family. Previous empirical studies have voiced sibling concern about the

future, especially when parents could no longer provide support. Orsmond and Seltzer (2007) and Benderix and Sivberg (2007) reported that siblings were concerned about the future for their disabled brothers and sisters and the suggestion that siblings actually take on parental fear for the future and anxiety about what would happen to their disabled sibling when they were no longer able to oversee care, was noted by both Kramer (2008) and Karasik (1993).

From the results of the questionnaires, only one case (Respondent 7) said that futures' planning was openly discussed in the family. Other respondents claimed that their involvement in futures planning was limited to financial input such as holding money in trust for the disabled person. Respondent 5 claimed that futures' planning was a difficult process that impacted on both the disabled person and wider family, and that a lack of services and diminished choice inhibited the process. The results of Stage one support the findings of Heller and Kramer (2009) who found that only one third of the families had made future residential plans, that plans made often related to guardianship or financial arrangements and that only one third had identified a future care giver. A lack of appropriate services was previously highlighted by Bowey et al (2005) who referred to the emotional difficulties that some parents encountered in 'letting go' of their disabled child in addition to service issues.

When asked about the impact a learning disabled brother or sister may have upon siblings' lives, participants generally presented the opinion that extra responsibilities and the role of 'overseer' was expected by parents, to ensure that the needs of the learning disabled person would be met when parents were no longer able to provide this support. Respondent 8 provided an example of this,

having “promised” parents that s/he would, “always make sure that he is well looked after”. This theme incorporates the view that current or future partners will have to accept the learning disabled person and accommodate them; this links to some extent with previous studies where the presence of a learning disabled sibling was seen to influence siblings` lives in areas such as career choice, partner choice, the decision to have children, plans for the future, feelings about people who have a disability (Seltzer et al 1997) and the expectation to take on a role of carer or ‘overseer’ (Bigby 1997; Rigney 2009).

#### **4.2.4 Siblings have needs**

This theme stemmed from five comments in total and was therefore the least commonly occurring theme. From analysis of the questionnaire, it is clear that participants felt the need to communicate their point of view, to be informed of available options and involved in futures planning. Participants commented that better quality accommodation with a wider range of options needs to be available and that there is little support for siblings in their situation. These findings again confirm the results of previous research, such as that by Benderix and Sivberg (2007) who claimed that consideration of sibling needs, wishes and ability to take on a supportive role should be addressed as they move through the different life stages. Early intervention programmes and proactive futures planning that meets the needs of individual families and their members is called for by siblings along with counselling services, peer support groups, information on services, financial issues, leisure and residential opportunities. Support of this nature is needed to effectively support sibling involvement in the lives of their disabled brother or sister (Heller and Kramer 2009).

## **Conclusion to the results of Stage one**

Although it is recognised that Stage one constitutes a small scale study, the findings demonstrate that all respondents had contact with the learning disabled sibling at least once in a six month period. Just over half claimed that there has been full discussion with parents regarding their future care role, yet the same number reported there to be no clear formalised futures plan in place. Where a futures plan was in place, only a third of siblings claimed that the plan was fully agreeable to both them and their parents. There appears to be a lack of clarity therefore between siblings and parents regarding futures plans for people who have a learning disability. It was claimed in just over half the cases that there was no difference between siblings' personal wishes and parental wishes for a future support role; however, three quarters of the participants noted concern about the impact a learning disabled sibling may have on their future lives, which suggests that this is an area of anxiety and concern.

Analysis of the written comments from Stage one presents evidence of a range of sibling experience. Satisfaction with services is a contentious issue within learning disability services and the majority of participants in this study reported dissatisfaction, stating that services were not of an appropriate standard, and lacked understanding of the needs of families in the presence of learning disability. Some siblings, however, did note satisfaction with residential care services but claimed that it can take a long time for families to find an appropriate setting. Parental influence on the futures planning process again evoked a mixed response: some siblings noted frank and open family discussion, whilst others claimed that parents were unable to discuss the future and this was a cause of frustration and distress for some

participants. A third of the respondents raised concern about the future, futures planning and the impact the learning disabled person may have upon their lives. Worries raised were those of parents no longer being able to provide existing levels of care and how siblings would manage the support needs of the disabled person alongside responsibilities to their own families.

Sibling engagement in futures planning was generally confined to financial management. Participants whose comments informed this theme expected to take on extra care responsibilities in the future and assume the role of 'overseer' in parental absence. The last theme to emerge from the written comments was that siblings of learning disabled people want their voices to be heard and need access to support. Siblings wanted support so that they were able to assist the disabled person with futures planning and to access a better quality and range of services. The findings of Stage one demonstrated that most respondents were concerned about the impact a learning disabled sibling may have upon their lives in the future; due to the variability in the number of futures plans reported, lack of empirical study in this field and sensitivity of the research topic, it was felt that further qualitative research into this area was justified. It therefore gave credence for progression onto Stage two, in which face to face semi-structured interviews were carried out to gain a deeper exploration of the area; the results of this are outlined in the next chapter.

## **Chapter Five: Results of Stage two**

Chapter five will present the findings from Stage two of the research process, the in-depth semi-structured interviews which took place after completion of Stage one. The discussion of these results will take place in Chapter six. For Stage two, ethical approval was gained (see methodology section) to carry out face to face semi-structured interviews with up to 15 adult siblings aged 25 or over, of people who have a learning disability. Face to face semi-structured interviews are supported from a theoretical perspective of phenomenology, which can be linked to a constructivist paradigm, within which, people are seen as individuals reacting to and interpreting their world in a unique way (Kelly and Long 2000). Semi-structured interviews are also the data collection tool most favoured within IPA (Smith et al 2009). The research questions were based on the literature review, the aim and objectives of the thesis and the results from Stage one, to support alignment throughout the research nexus and to build upon the results of Stage one, as advised by Robson (2002).

The purpose of the interview and process to be followed was reiterated to each participant before starting the interview, as outlined in Chapter 3; particular attention was paid to informed consent, anonymity, beneficence and non-maleficence (Mappes and Degrazia 2006). All participants were reminded that there was no obligation to take part in the study, that they had the right to withdraw at any point and that to do so would not lead to a negative impact upon services received by themselves or their family members. Participants were further advised that the interview was likely to last for approximately one to one and a half hours, and to further support ethical research practice (Polit et al

2001) written consent (Appendix F) was gained from each participant.

All interviews were recorded using a digital and non-digital recorder as a backup, following the process outlined and justified in the methodology section of Chapter three. The interview questions (Appendix E) were followed as a general guide, although points of interest were followed up by the researcher. Written notes were made on the interview schedule and key points were read back to the participant at the end of the interview; this was to ensure that the interviewer had understood the essence of the respondent's experience, to demonstrate engagement on both sides, and as a means of triangulation as suggested by Teddlie and Tashakkori (2009). In order to conduct research in a professional and ethical manner (Beachamp and Childress 2009), all participants were thanked for their time at the end of the study and were asked if they had any questions. Each participant was offered a contact sheet for the Sibs organisation in case they felt distressed or wanted further support after the interview. As researcher, I also used my professional skills and experience as a registered health professional to make a judgement on the emotional well-being of each participant at the end of the interview. As soon as practical after each interview, field notes were made in a reflective diary on my key thoughts, queries and response to the interview as a form of reflexivity.

In total, 15 interviews were undertaken and pen portraits using pseudonyms are presented below.

## **5.1 Pen portraits of the participants**

### **Participant 1**



Andrea is 54 years old and works full time in a profession related to health and social care. She is married but has no children from choice. She is the second youngest of six children; her mother died several years ago but her father is still alive and lives with her youngest sister in the family home. She is a full sister to participant 15. Her brother Elliot contracted meningitis and measles at the age of three which was the cause of his learning disability. Elliot died at the age of 53; he lived in the family home with his father and Participant 15, (Carol) until his death.

### **Participant 2**

Claire is 50 years old and works full time in a profession related to health and social care. She is married for the second time and her husband also works in the field of health and social care. Claire has two children and step children. She is the youngest of six siblings and both her parents are now dead. Her brother Simon is 51 years old and lives nearby in a supported house. He was born prematurely which was thought to cause the learning disability.

### **Participant 3**

Helen is 30 years old and is a full time postgraduate student in a subject related to health and social care. She is single and lives alone in student accommodation a few hours away from the family home. She is the only typically developing child of the family, her brother Tony is 27 years old and has profound multiple physical and intellectual disabilities. He has shared care between his parents in the family home and a charitable organisation.

### **Participant 4**

Rachel is 49 years old and works full time in a profession related to health and social care. She has one daughter and lives with her partner. She is the only typically developing child of the family. Her mother is still alive and lives with her second husband. Her sister Amy is 48 years old; she has Down syndrome and lives in supported accommodation in the community.

### **Participant 5**

Gail is 56 years old and works part time in a profession related to health and social care. She lives with her husband and has one adult child. She was the youngest of three children in the family and is a sister to respondent 11, Rita. Both her parents are now dead and her learning disabled sister, Verity, died a couple of months before the interview took place. Verity was 67 years old when she died and her learning disability was attributed to birth trauma. Verity lived in various residential settings from adolescence onwards.

### **Participant 6**

Fran is 43 years old and work full time in a job that has no connection to health and social care. She lives with her partner and has two adult children. She is the eldest child of the family; Pete, her brother, is 41 years old and has Down syndrome. There is a younger half-sister named Gill. Pete lives with their mother who is a widow.

### **Participant 7**

Janet is 38 years old and works full time; her work sometimes brings her into contact with people who have a disability. She lives with her husband but has chosen not to have children because of having a learning disabled brother, Greg. She and her twin are the

second-youngest children in the family where there are two older half-siblings. Greg is 32 years old and has Down syndrome; he is the youngest in the family and lives with his mother. His father now lives in a nursing home.

### **Participant 8**

Maali is an Asian woman who is aged 36. She is married and has two small children but is due to emigrate soon to live with her husband. Her professional background is unrelated to health and social care but her current work role has an association with care provision. She is the second youngest of four children in the family and her parents are both still alive. Safa, her learning disabled sister, is 41 years old and is the eldest child of the family. Her learning disability was attributed to complications in pregnancy. Safa lives with her husband in the community and has a young child who also has a learning disability.

### **Participant 9**

Kath is a 64 year old retired woman with a long history of work in health and social care. She lives alone and is divorced with three adult children, grandchildren and a great grandchild. Both her parents are now dead. She is the eldest of seven children in the family. Her sister Laura is 46 and has Down syndrome. Laura moved into the community with support over the last year after living with Kath for a year following their mother's death. Kath is a sister to participant 10, Kevin.

### **Participant 10**

Kevin is a brother to Kath (Participant 9). He is aged 49 and works full time in employment that is unrelated to health and social care. He lives with his partner and has two adult step-children. His sister Laura is 46 and has Down syndrome. Laura has moved into the community with support within the last year after living with Kath for a year following their mother's death.

### **Participant 11**

Rita is an older sister to Participant five, Gail. Rita is 65 years old and is retired from employment that had no relation to health and social care. She lives with her husband and has two adult children. Both her parents are now dead and her learning disabled sister, Verity, died several months before the interview took place. Verity was 67 years old when she died and her learning disability was attributed to birth trauma. Verity lived in various residential settings from adolescence onwards.

### **Participant 12**

Steven is 34 years old and works in a job that has some connection to health and social care. He lives with his partner a few hours away from the family home and has no children at present. He is the eldest of two children; his sister Fiona is 31 years old and has a learning disability that may be associated with a virus in pregnancy. Both parents are alive and Fiona lives in the community with 24 hour support.

### **Participant 13**

James is a single man of 68. He is retired from his own business enterprise which had no connection with health and social care. He is the second eldest of five children in the family. Both parents are now dead. His sister Jayne is 58 years old and lives with him,

having done so since their parents died. Her learning disability is attributed to encephalitis in early childhood.

#### **Participant 14**

Val is aged 61 and is retired from employment which was not associated with health and social care. She has no children of her own but states this was not an active choice. She lives with her husband and brother Phil who is aged 56 and has Down syndrome. Phil has always lived with Val since their parents died.

#### **Participant 15**

Carol is 48 years old and is a sister to Participant one, Andrea. Carol has a professional background which is related to disability. She lives with her husband and they have no children but this was not an active choice. Her brother Elliot contracted meningitis and measles at the age of three which led to the learning disability. Elliot died at the age of 53; he lived in the family home with his father and Carol as main carer after their mother's death.

### **5.2 Data analysis**

There is no single, finite way to approach analysis from an IPA perspective. Smith and Osborne (2008) provided guidance but maintained that there is no fixed procedure. The general principles suggested by Smith and Osborne (2008) were followed, such as a sample size that enabled the perceptions and experience of a specific group to be presented; additionally, in keeping with the principles of IPA, all participants had experience of the same phenomena, which was that of having a learning disabled adult sibling. Because there were only 15 participants, wide generalisations cannot be claimed; however the detailed analysis of specific cases may or may not be relevant to wider yet similar

populations. The transcription of whole interviews, including questions, is advocated and for analysis, margins are traditionally left on both sides for analytical comments, an example of which can be seen in Appendix I. A semantic level of transcription is often utilized within an IPA study with all words spoken, laughs, long pauses and other features of note written down (Smith et al 2009).

### **Analytical process followed at Stage two:**

Each interview was transcribed verbatim and included colloquial language, 'emm's, 'er's and pauses. No note was made of tone or body language in general, but where a participant became tearful, visibly upset or laughed, this was noted at the appropriate place in the script within brackets. Dots `...` were used to denote pauses and sections of text that were removed because they were not essential to the key essence of the featured quote. Parts of the interview that were inaudible were denoted by empty brackets ( ).

The transcript of each interview was printed and read a number of times whilst listening to the audio tape; corrections were made until the transcript was as accurate as possible. Page and line numbers for each consecutive page were inserted and wide margins applied to both sides of the transcript. All transcripts were then read and re-read. Significant or interesting points were underlined in the text and handwritten notes made in the right hand margin.

The transcript and researcher notes in the right hand column were re-read; emergent themes were then handwritten in the left hand column, along with notes on how each theme may fit with another theme. From here, superordinate or key themes that drew together a number of related components were identified, for example, 'Family' or 'Impact of learning disabled person upon the sibling'. Subordinate themes that formed a subsidiary component

of the main or superordinate theme (such as 'Parents' under the superordinate theme of 'Family') were noted. Some subordinate themes were further broken down to sub-categories such as 'Mum' or 'Dad'.

From each interview, a list of superordinate themes, subordinate themes and sub-categories was then created. Supportive evidence in the form of participant quotes, with the corresponding page and line number were placed next to each superordinate or subordinate theme. The superordinate and subordinate themes were listed on the left side of the paper and the supportive participant quote, page and line number on the right hand side to create a theme and evidence chart, an example of which can be seen in Appendix H. At the end of each theme and evidence chart, a note of superordinate, subordinate and sub-categories for that particular interview was listed.

For each interview, the theme and evidence chart was re-read to check for congruence between theme and evidence, and to see if any amalgamation of themes could be made. Corresponding changes and corrections were made as required. The research supervisors and a research assistant further checked the theme and evidence chart for each interview to verify that there was sufficient evidence in the transcripts to support the themes and sub-themes, and that all categories listed at the end were correctly represented.

The frequency of superordinate themes was analysed across all interviews (Appendix J) and those superordinate themes that were present in a minimum of 11 interviews out of 15 are referred to in this chapter.

Key quantitative data from the interviews was analysed on an individual interview basis, namely respondent relationship to any other participant; age; gender; work status; ethnicity; parental status; status of the learning disabled person; respondent's social context at the time of interview; number of children in the family; parental wishes regarding future care of the learning disabled person; respondent's wishes regarding future care; the presence and type of futures plan in place; respondent concerns about the future and respondent needs; and advice to others. This information was then summarised across all 15 interviews and put into a single chart (Appendix K).

### **5.3 Data presentation**

There are different ways of presenting the results and discussion sections in an IPA study with no fixed doctrine. It is suggested that these sections can be considered jointly or as separate entities (Smith 2008). Certain studies have combined both sections (Golsworthy and Cole 1999; Knight et al 2003; Reynolds and Prior 2003); however the results section of Stage two this thesis is written up as a separate section to the discussion because of the volume of data and a personal preference to make links to theory and literature in a distinctly discrete section. Other IPA studies have similarly followed this separate format (Ditchfield 2004; Murray 2004; MacDonald 2005; Howes 2005; Mason 2010; Hatton et al 2010).

The superordinate themes presented within this chapter were present in at least 11 of the 15 interviews. Table 3 details the superordinate and subordinate themes to be presented.



**5.3.1 Table 3 Superordinate and subordinate themes**

<b>Superordinate themes</b>	<b>Subordinate themes</b>
<b>Impact of the learning disabled person upon sibling life</b>	Growing up with learning disability Negative impact of learning disability Positive impact of learning disability Mixed sentiments Impact of learning disability upon career Impact of learning disability upon partner choice Sibling roles
<b>Family</b>	Family culture Family support the person with a learning disability The person with a learning disability is a source of stress/conflict Parents Non-disabled siblings Family and finance
<b>How learning disability affects the disabled person</b>	Origins of the learning disability Health impact of the learning disability Negative impact of the learning disability Positive attributes of the learning disabled person/benefits of learning disability Impact of learning disability upon relationships
<b>Social response to learning disability</b>	Negative social response to learning disability Positive social response to learning disability
<b>Transitions</b>	Transition and life stage in general Transition and the person who has a learning disability Sibling life stage Death as a transition Parental ageing Transition to/from a major care role for the disabled person
<b>Services</b>	Negative comments about services Positive comments about services Services provide a role that differs from the family
<b>The future</b>	Futures planning Future expectations / wishes Wishes of the learning disabled person Concerns about the future
<b>Advice to siblings combined with siblings have needs</b>	Siblings need support Siblings need to look after their own needs Siblings need support in childhood Advice around planning

	Siblings should be involved with the learning disabled person if they want to Support the learning disabled person to have a normal life
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#### **5.4 Superordinate theme: Impact of the learning disabled person upon sibling life**

This superordinate theme is present in all 15 interviews and is the biggest theme in terms of the amount of dedicated text within the transcripts. The theme incorporates the subordinate themes of growing up with learning disability; negative impact of learning disability; positive impact of learning disability; mixed sentiments; the impact of learning disability upon career; the impact of learning disability upon partner choice and sibling roles.

##### **5.4.1. Subordinate theme growing up with learning disability**

The experience of growing up as a child in a family where someone has a learning disability was referred to by seven respondents (interviews 2,3,7,14,2,4,10) as normative and part of their lived day to day experience. For some respondents, such as Maali and Carol, increasing age led to a dawning awareness of difference.

That respondents became aware of difference was apparent throughout the interviews, when respondents talked about their role with the learning disabled person and how the disability affected their brother's or sister's life; however explicit reference to awareness of difference was made in seven of the 15 interviews (4,5,6,7,8,11,12). Awareness of difference in childhood came about by different means such as professionals coming into the home for Janet (interview 7 P3 line 21), difference in intellectual skills for Rita (interview 11 P6 line 31) and comparison with friends (interviews 6,8,11,12) as discussed by Fran:

*"..some of my friends who had brothers would help them with their bikes and ...chains and tyres and things, and Pete couldn't do that ... in the house I couldn't play proper games with him... I couldn't play Monopoly, could only do bits and bobs cos he obviously wasn't able." Fran P 3 line 9*

As Andrea, Rachel and Gail entered their teenage years, they became acutely aware of difference, and for Rachel, this was a negative realisation:

*"In my adolescent years it was horrific, emm, absolutely horrific, cos in the adolescent years, the last thing you want is anybody being different and she (learning disabled person) was very different." Rachel P3 line 20*

Five of the 15 respondents (interviews 2,4,9,13,15) stated that the person with a learning disability had affected their whole life including career, family, own children and even their social life. Claire stated that the learning disabled person was the reason for her own birth and that he had influenced every aspect of her life:

*"...one of the quotes they (parents) said is that the doctor recommended her (mum) having another child that would bring Simon on... I don't really know at what age I knew, err, that I was born because he had the needs he had; but it's gone that everything I've done, he's been a part of; he's influenced not just me but lots of other people, my family, my children, my career, I think. What would our lives have been like if he hadn't been part of our life?" Claire P1 line 19*

#### **5.4.2 Subordinate theme negative impact of learning disability upon sibling life**

A negative impact of the learning disabled person upon siblings' lives was noted in all transcripts, and in 10 interviews there was a

bias of negative comments compared to positive comments. Worry or fear was the most commonly occurring negative impact, appearing in nine of the 15 interviews (3,4,8,9,11,12,13,14,15). Three main types of fear were highlighted: those associated with death, with health and well-being, and with more generalised support needs. Concerns around death included the death of the learning disabled person and for Helen and Kevin; this was a fear that stemmed from childhood:

*"...she (learning disabled person) used to have fits...everybody was scared she was going to die; I used to go in her bedroom when I was younger and check she was breathing... I wasn't sure when I was younger whether she was going to live or whether she would just die - die in her sleep cos she was handicapped." Kevin P 3 line 20*

Concern was also linked to parental death in childhood for Helen; and for Kath, fear was linked to how her own death could negatively affect her learning disabled sister. Worry associated with health and well-being was present in five interviews and referred to the health and wellbeing of the learning disabled person in most instances, but also involved concern about the learning disabled person being vulnerable in society for Kevin (interview 10 P 9 line 1). The quote from Kath below is an example of concerns about respondents' own health and well-being, and this is linked to concern about the needs of the disabled person:

*"The only thing I do worry about is my health: I mean I'm diabetic, I suffer from high cholesterol, high blood pressure; I've got arthritis, sciatica; and I just worry that I can carry on, or at least until somebody can take over." Kath P 25 line 9*

Other worries included a generalised concern about the future, which forms a separate superordinate theme. Financial concerns were raised in terms of budget cuts for Helen and financial abuse from family members for Maali. Overall, worry about the person with a learning disability can be generalised and pervasive, as seen in this extract from the interview with Maali:

*(DD question) "What are your feelings towards her (learning disabled person)?*

*(Maali) "I worry and concern all the time". Interview 8 P 24 line 6*

### **Demanding or difficult behaviour**

The learning disabled person is clearly portrayed as demanding or draining in six interviews (1,4,7,9,10,13); both Andrea and Kath refer to providing support to the learning disabled person as a 24 hour commitment:

*"...that can be very draining when you have to be there 24 hours a day, seven days a week. No matter how hard or how easy the input is to that person, you still have to be there – your life is curtailed, is put on hold a little bit." Andrea P10 line 23*

Of the 15 respondents, six discussed the presence of difficult behaviour on the part of the learning disabled person. For some this was present in childhood, sometimes only in adulthood; and for others, it was throughout the life course. Rachel, Rita, Steven and James referred to difficult behaviour in their childhood or teenage years, such as the disabled person screaming, hitting other children and sometimes hurting the respondent themselves. An example of difficult behaviour and some of its consequences was given by Rita:

*“ (If) she (learning disabled person) didn’t understand what we were doing, again, she would throw a tantrum and may well lash out at these children, so we always had mothers coming to the door complaining that Verity had hit.” Rita P 5 line 22*

James recalled how he endured physical pain inflicted by his learning disabled sister:

*“...she’d (learning disabled person) bring tears to your eyes when she was a teenager and she sunk her teeth in - I mean it really hurt. Poking you in the eye and kicking you in the ankle, yeah, the biting, if she bit you on your chest there and sunk her teeth, it would bring tears to your eyes.” James P 32 line 21*

Some respondents still had to deal with difficult behaviour in their adult lives. Steven described physical pain from biting (P 14 line 10); James was concerned with the prevention of aggressive acts to members of the public (P 16 line 23) and managing obsessive behaviour that may lead to outbursts of temper (P 14 line 21); whilst Gail commented upon disruptive behaviour in a social situation:

*“She (learning disabled person) was trying to self harm every five minutes and in the end it was making everybody ill; and Rita (other sibling) just said, ‘I’m taking her back, I’m taking her back to W (residential care setting). I’m not having this, she’s not ruining the (Christmas) day’.” Gail P 17 line 6*

## **Relationship issues**

Specific tension or difficulties within relationships on account of the learning disabled person were noted in nine interviews; and for

Helen, Rachel and James, these difficulties were apparent in childhood and the teenage years. Helen explained that she did not know how to relate to her peers and seemed to associate this with her experience of being brought up with learning disability:

*“The first school disco that I went to at high school was very strange cos I didn’t know how to dance with other kids ...How do I dance to music without a wheelchair cos I just hadn’t done it since I was about five ...everybody else knows what to do, and I just don’t know how to deal with this situation cos it was alien to me... I knew how to deal with adults at parties, I knew how to deal with Tony at parties, I didn’t really know how to deal with other people my own age.” Helen P4 line 35*

Moving on from relationship issues in the formative years to adulthood, conflict was seen to exist between other siblings in the family, husbands or partners and other extended family members. Kath talked of, “resentment” towards other siblings regarding a perceived lack of support in the care of the disabled person, a sentiment that was echoed by James (interview 13 P 22 line 33).

Conflict between spouses or partners was sometimes said to make the respondent feel as though they were “in the middle” of two different camps and gave them a sense of having split loyalties; for example, Steven talked about feeling caught between the needs of his partner and family, whilst Val referred to the different needs of her husband and learning disabled brother. For James, his learning disabled sister was said to have vetoed all personal relationships:

*“I just live with Jayne - no wife - just Jayne and me, cos Jayne wouldn’t tolerate a wife ...There’s only one person in that house that counts and that’s Jayne, cos she’s so demanding; she wouldn’t tolerate another woman in the house... It is*

*difficult when you meet somebody you like and you don't go any further with it...The last, two or three years ago... well, it is very upsetting; it unsettled me for quite a few months afterwards ... I'll try to keep away from attractive ladies, that's the answer."* James P 1 line 4

### **Negative emotional responses**

Guilt was evident in eight of the 15 interviews and takes different guises: some respondents felt that they had not spent enough time with the learning disabled person or done enough for them, which generated feelings of guilt and selfishness. Fran felt guilty and selfish because she did not accommodate her disabled brother and mother into her life as much as she felt she ought to (P 4 line 1) and Rita, Steven and Val felt guilty because their sibling had a learning disability and therefore did not have access to the same life opportunities:

*"...in later years, when I got married and had children, I had a terrible guilt feelings because I had a lovely life and I had children; and by that time, Verity was away in residential care, so I had a terrible, terrible guilt."* Rita P 7 line 23

Sometimes guilt was expressed in relation to past behaviour in childhood when the sibling had excluded the disabled person in play, as discussed by Maali (interview 8 P 4 line 34). For others, guilt related to the future: although Fran felt that it would be best for Pete to remain in the care of the family when their mother was no longer able to provide support, she did not want to live with him on a full time basis (interview 6 P 12 line 23). Guilt was also expressed as an emotion that affected respondent sibling behaviour, ranging from smaller events, such as leaving the disabled person at home to go on holiday (as described by Val in



interview 14 P 18 line 24), through to more major issues, such as a decision about residential care:

*“Objectively I can see ... and people have said, ‘Well you’d have a better life without her (learning disabled person)’, but then I’d ... and I say, ‘Well, if I put her in a home then I’d be racked with guilt’ - that’s my answer to it ... I could have done it when my mother died ... I could have gone and had a proper life, cos I’m quite wealthy and I don’t have the life of somebody who’s as wealthy as me ... If I had done that I would feel very guilty - I’m sure I would.” James P 36 line 10*

## **Anger**

Anger was manifested in six interviews and described how siblings had felt anger directly towards the learning disabled person and towards others on behalf of the disabled person. An example of anger felt directly towards the disabled person in childhood was presented by Helen as her brother had often been ill on her birthdays:

*“He (learning disabled person) had this wonderful habit of, really wonderful habit, he was always in hospital on my birthday every..single...year... It was hard not to get cross at him about that sort of thing, but you know, you knew it wasn’t his fault; but you know, you were a child and it was your birthday (laughs) surely it’s your day?” Helen P 3 line 18*

Anger was also expressed towards the learning disabled person in adulthood, for example by Rachel and Kath, sometimes to extreme levels:

*“...I could never have her (learning disabled person) living with me...it would just destroy every relationship I’ve got and*

*actually, I'd probably hurt her, because she can, you know, really, really, really, wind you up to the point of no return"*  
*Rachel P21 line 15*

Anger or upset was also directed towards others on behalf of the disabled sibling: Steven would get angry when other people made derogatory comments about learning disabled people (interview 12 P 4 line 22) and Rita vocalised anger towards service providers who she felt were not doing their job properly (interview 11 P 12 line 16). Anger with other family members is apparent as illustrated within the following quote from Kath, in relation to her mother's lack of planning for the future:

*"...I mean, I've been very, very angry - very angry; I had to have some counselling myself ...I was very angry at the fact she (mother) hadn't left us any instructions (about future care of learning disabled person) that she'd never talked to us about what she really wanted."* Kath P 23 line 7

In the examples above, anger was generally referred to as an emotion on its own although Helen combined guilt and anger in a cyclical way as seen below:

*"I went through times when I was very angry with him (learning disabled person) and then I'd feel guilty for feeling angry with him (laughs); then you feel angry at him for making me feel angry at him when it's not my fault... you'd have this horrible cycle."* Helen P 4 line 25

### **Sense of Loss or grief**

A sense of having lost a 'typical' sibling in youth was commented upon by Rachel and reiterated by Fran when she talked of her frustration at her perceived 'loss' of a sibling in adulthood. The first

quote is from Rachel in reference to loss of a typical sibling in youth:

*"...and one of the things that ...really did piss me off as a teenager, was that there was 11 months between us: I should have been talking about lipstick and boys and discos and shagging, and I couldn't - it was dolls ... because that was Amy; so I'd got this somebody who was so close to me in age and we should have been like that (crosses fingers) but we couldn't be cos we were poles apart." Rachel P 25 line 9*

For Fran, the sense of loss of a sibling continued into adult life in terms of losing someone to share hobbies and interests with, but also a loss of extended family:

*"I feel I've sort of missed out on the family unit of my (learning disabled) brother having a wife and children ...friends go off and meet sister-in laws or go and meet their brothers and the children, and I can't, ...so I feel like I've missed out on that ... I feel quite sad in one way, cos he's sort of like, he's Down Syndrome." Fran P 5 line 12*

## **Embarrassment**

This emotion was referred to in four interviews and was associated with self image in teenage years by Andrea; friends having to be advised of medication issues before coming to play in childhood, by Helen; and the behaviour of the learning disabled person in public, by Rachel and Rita. Rachel clearly expressed the embarrassment and distress she felt because of the learning disabled person in her teenage years:

*"...there's lots of things you don't say, particularly as a teenage; there's lots of feelings that you feel that are bad*

*feelings - like you know you don't want to be with your (learning disabled) sister; you don't want your sister to be with you; you don't want your sister to go to the disco; you don't want to have your friends round for dinner cos your sister eats with her mouth open; you don't want to invite your friends round for dinner cos she'll sit on their lap and slobber all over them and tell them that she kisses them." Rachel P 5 line 26*

### **Reduced parental attention**

Siblings noted less parental attention due to the presence of the learning disabled person, in four of the interviews. Gail said that when her learning disabled sister came home from residential care in the holidays, her parents had to watch over her for safety reasons, which meant there was less time and attention for the typically developing children. Rita and Steven described how, as non-disabled children, they had to learn patience and tolerance because the needs of the learning disabled child came first; similarly, Kevin explained that the learning disabled person was the focal point of the whole family from birth onwards, although this did not appear to be associated with any sense of resentment.

Other generalised negative impacts upon siblings' lives involved hospital and clinics visits in childhood (Helen and Rita), less leisure time (Claire and Val), a negative impact upon mental health (Helen and Kath), reduced educational opportunities in childhood (James) and the decision not to have children (Janet).

### **5.4.3 Subordinate theme: positive impact of learning disability upon sibling life**

In the same way that all respondents made negative comments about the presence of the person with a learning disability upon

their life, all made reference to positive comments. Andrea, Kevin and Carol made more positive than negative comments but overall, more negative than positive comments were made both in range of comments and the amount of text dedicated to them. Despite this, positive comments appear in all 15 interviews and the disabled person was viewed with pride by seven respondents and described as having brought a sense of joy, pleasure and enrichment to the siblings' lives.

A sense of pride in the learning disabled person was stated as a positive impact without further clarification by Kath, but Claire, Janet and Maali attached pride to the achievements of the disabled person. For Gail, Fran and Kevin, pride was associated with characteristics of the learning disabled person, such as their ability to cope with adversity, as discussed by Gail; their intelligence, as commented upon by Fran; and for being a 'nice person', by Kevin. Also noted in seven of the 15 interviews was the positive impact of pleasure, love and enrichment due to the presence of the disabled person. Even in the interview with James where there were significantly more negative than positive impacts, there was still an expressed sense of love despite having been prevented from developing lasting personal relationships.

### **Special bond between the learning disabled person and respondent**

A special bond between the respondent and the learning disabled brother or sister was remarked upon by Claire, Janet, Kevin, Rita, Steven and Carol. Claire likened the relationship with her learning disabled brother to one that may exist between twins, present from childhood into the present day:

*“...and it was very much like a twin relationship, and he (learning disabled person) still does it - he knows instinctively when there are things on me mind, and he must ring me; if he’s got something bothering him, he must check things out with me...” Claire P 9 line 3*

Although Kevin was not the most involved sibling, he described his sentiments towards his learning disabled sister in a way that suggested a very close and loving relationship:

*“...she’s (learning disabled person) the most important person in the world to me... I just couldn’t dream ... I don’t even want to contemplate what I might happen if she... that’s the worst thought that I could imagine” Kevin P 14 line 19*

Mostly within the interviews it was the respondent providing their view of the relationship with the learning disabled person; however Rita and Carol reported the words of the learning disabled person to provide evidence of the close bond, for example Rita said that when she went to visit Verity, she would say to Rita, *“Oh, I love you and you’re the best sister ever.”*

### **The person with a learning disability as a source of humour or fun**

That the learning disabled person brings humour or fun to siblings’ lives was noted by five respondents, and this appeared to be an asset according to Andrea:

*“He... brought an awful lot to our lives; he was very engaging, you know.. Most people who got to know Elliot loved him cos he had a fantastic sense of humour - always wanted to make us smile.” Andrea P 3 line 6*

### **Benefits on account of learning disability**

Andrea, Steven, Val and Carol all felt that they had gained new or alternative perspectives and understanding as a result of being brought up with a learning disabled person:

*“I just think it makes you a better person ... like, I’d look at somebody else (person with a learning disability) now and think, I wouldn’t be wrong, I wouldn’t stare at them, I’d be more polite with them and talk to them - whereas if you haven’t grown up with them, you are generally frightened of them and ... whereas I’m not, so I think that’s an advantage for some children.” Val P 5 line 17*

For Janet and Rita, however, direct benefits which they would not have experienced in other circumstances were clearly associated with the presence of the learning disabled person. Rita talked about the enhanced childhood experience of regular beach trips because her sister lived in residential accommodation close to the sea, and Janet referred to the significant and ongoing benefits of having a brother with Down syndrome. She described the use of what she termed, “the Down syndrome card” in order to access things she valued, such as holidays, social events, meeting celebrities, and getting extra drinks and food on an aeroplane:

*“I’ve been all round the world on holiday with him (learning disabled person) and that’s a great experience. We go together and we are like partners in crime... I use it to my advantage sometimes; we call it the ‘DS card’ - the Down syndrome card - no one’s going to say ‘no’ to a Down syndrome...” Janet P 6 line 6*

## **Learning opportunities**

Associated with new or increased opportunities were learning opportunities for Helen, Kath, Rita and James, which may not otherwise have been experienced. Helen claimed that regular visits to the hospital in childhood and hearing medical terminology have been beneficial to her work life:

*“... I learned a lot of things by osmosis; so like, now I’m working a lot with clinicians, with doctors, with ..., and I can speak their language cos I learned their language half in a hospital, so I just understand medical terminology naturally”*  
*Helen P 5 line 19*

Kath referred to attending courses associated with caring; Rita used her existing skills and developed them further to support the disabled person in a mentorship role; and although James talked about having to miss school in order to take on shared care of his learning disabled sister alongside parents in childhood, he valued being able to spend a long time reading whilst sitting at the bedside.

### **Development of positive attributes**

Some respondents claimed to have developed positive qualities or attributes that they associated with the experience of having been brought up with a disabled person. James for example made reference to the development of independence, an increased sense of determination and will power. Patience was referred to by Steven, confidence by Rita, whilst Fran included a sense of gratitude for her own health and well-being.

#### **5.4.4 Subordinate theme mixed sentiments**

Both Claire and Janet were evenly matched in the number of positive and negative comments made throughout their interviews; although for some participants (for example Val), positive and



negative comments were made about the learning disabled person within in the same sentence which may suggest conflicting sentiments. For Rachel and Janet however, the degree and range of expressed emotion within the same sentence may suggest a significant amount of ambivalence and support the view that sibling relationships are complex and multi-faceted:

*“I love her (learning disabled person) to bits; there’s nobody in this world that can make me as angry as she can ... - even today, with all the training and all the stuff that I know, she can be at my house for half an hour and I can want to throw her through a window because she can really wind you...”*  
Rachel P 14 line 16

And equally from Janet, concerning the idea of her learning disabled brother coming to live with her in the future:

*“...It is a bit of a burden to think ....but it’s a real honour...cos I absolutely think he’s a fantastic person... I’m sure in the past I really have seen it as a big responsibility, but I don’t see it as a big responsibility now, ... although I’m sure that when the time comes, it will be. But that will be something that comes, that will be second place to Greg’s needs and Greg’s thoughts at the time.”* Janet P 8 line 1

#### **5.4.5 Subordinate theme: impact of learning disability upon sibling career**

Of the sample, nine respondents had some degree of engagement with health and social care services as their full time job, in a voluntary capacity, or both. Strong connections with a health and social care work history are evident in six interviews, as can be seen in the quote from Carol:

*“I used to teach special needs at TWH (residential care) ... special needs, disabilities, learning disabilities, people like ... some of them were actually starting with Alzheimer’s.” Carol P 2 line 3*

Somewhat less direct career links with health and social care are found in three interviews as seen in the interview with Helen:

*“I didn’t want to be a doctor or a nurse, because it was too close to home, err ... emotionally I couldn’t have done it... But, I was always fascinated by it (medicine) err, and so I kind of did the next best thing and became a scientist ...but the thing that drew me back to do my research was that it was health care based ... “ Helen P5 line 28*

All those respondents with some link to health and social care in either their paid or voluntary work made a very strong link between their work or voluntary activities and their experience of learning disability, as illustrated by Carol:

*“I wanted to give back of what he’d (learning disabled person) given, and I wanted to be able to help people like him... then I fell more into adult education, and I was then offered the chance to teach and work with special needs. Only for Elliot having experienced that would I have done it , so I have to thank him for that.” Carol P 7 line 2*

In other interviews however, the link is more tentative:

*“...getting involved in local services cos the family was using them: I suppose that made me aware of positive roles that those organizations could play, so I think that probably did influence me a little bit in terms of career choice; I didn’t*

*want to be a business man or something like that.” Steven P  
8 line 25*

Five respondents: Fran, Kevin, Rita, James and Val had no links between their employment and health or social care services and gave no indication of being involved in voluntary work.

#### **5.4.6 Subordinate theme: impact of learning disability upon partner choice**

The impact of learning disability upon life partner choice was variable but significant at times and was clearly evident for Steven, James, Val and Carol. At one end of the range James stated that he did not have a wife or life partner because his learning disabled sister would not allow it. Alternatively, Steven claimed that within any serious relationship, his partner had to be able to understand, fit in with and get on with his learning disabled sister. He accepted that this may take a period of adjustment, but stated that that ability of a partner to cope with his family situation was significant to the continuation of the relationship.

Val and Carol reported an unstated expectation between themselves and their husbands that the person with a learning disability would live in the marital home and be an accepted part of their married life. If this had not been so, the marriage would have been unlikely to take place:

*“I think (husband) knew that Elliot was my responsibility; he knew that I’d lost my mum, he knew that Elliot had special needs ... (husband) just took it as read that if we got married Elliot would be with us and that would be fine... If he couldn’t accept me the way I was and my love for my brother, then he wasn’t the man I thought he was. So thankfully, he just loved*

*Elliot the same - he just accepted Elliot for the way he was.”  
Carol P 12 line 31*

#### **5.4.7 Subordinate theme: sibling roles**

Siblings provided supportive roles to the disabled person such as carer, advocate and mentor, as seen in 11 of the 15 interviews. Kath, James, Val and Carol had taken on a main carer role, providing support with personal, domestic and social activities. Other respondents had taken more of a mentor or advocate role rather than personal care; for others, for example Rachel, their support role was in a more advisory or prompting capacity.

The sibling role of defender or protector occurred in eight of the 15 interviews and Claire commented that it was her ‘mission’ in life to protect her learning disabled brother:

*“...always protecting him - you know that message: you’re there to look after Simon ... I knew what my mission was (laughs)... Claire P5 line 23*

Sometimes the comment was simply made that siblings felt protective towards the disabled person (Steven and James) although at times this protectiveness was described in more detail. Andrea, Kath, Kevin and Carol said that they wanted to protect the disabled person from the negative comments of others:

*“There was confrontation between me and someone I knew ... they called her a spaz or a mong or those sort of things... There was instances where I had to stand up and say you don’t, absolutely.” Kevin P 7 line 4*

#### **Role of responsibility or duty**

The role of having responsibility or duty may be associated with the role of protector or defender, although duty and responsibility

convey a sense of obligation which appeared at times to be different from a role motivated by choice or desire, as noted by Gail:

*"...everything that was done for our Verity was done out of duty rather than perhaps out of love." Gail P 23 line 30*

Maali commented on how she had been brought up by her parents with the clear understanding that responsibility for the care of the learning disabled person was a lifelong expectation and that they expected her to assume deferred responsibility from them. For Steven, responsibility appeared to be attached to life stage as he talked about leaving youth behind and taking on greater responsibility for his sister with age:

*"I'm going to start having to get more involved here cos this isn't just about being young anymore: this is about Fiona having a quality of life and having somebody to support her life, and me making sure that Fiona is part of my life now... I feel like I'm in a position to take a bit more responsibility."*  
*Steven P 18 line 10*

### **Sibling role of just being a sibling**

Of the 15 participants, eight said that they viewed the learning disabled person as they would any other brother or sister; however Claire and Kath made an explicit comment that they wanted to maintain a sibling role rather than that of carer, as they considered these to be conflicting roles:

*"...this is one of the reasons why I didn't want her to live with me long term, because what I felt was: I was losing the relationship that I had as a sister and to be able to go out and do sister things... I was shouting at her and getting her to do*

*things and different things that... I'd lost...it was gone (sister role), I was being her carer and it wasn't... I didn't like it."*  
Kath P 14 line 8

### **Sibling role to provide fun, leisure or social visits**

A sibling providing a visiting or social contact role was expressed in eight interviews. There were general comments about visiting the person with a learning disability when the sibling lived apart from them, but Janet, Kevin, Rita and Steven mentioned activities such as taking the disabled sibling out to lunch, shopping or bowling. Rita would take treats and gifts when visiting and the provision of holidays for the learning disabled sibling was noted by James and Carol.

### **Role of supporter to mother**

Having a support role to their mother was raised in seven interviews. Part of this role for Rachel was to make sure that supporting the disabled person was not "too much for mum". For Janet, there was a need to provide her mother with a sense of increased security regarding future care, to the extent of moving to live next door to her and her learning disabled brother. Some siblings however, provided minimal support, such as having the person with a disability stay overnight once a year (Fran); yet for others respondents such as Carol, supporting her mother had been part of daily life for a considerable time.

### **Parental role**

Six participants noted a parental role between themselves and the learning disabled sibling. Claire, Maali and Val described

themselves as being a mother figure whilst other participants claimed that they treated the learning disabled person as their own child:

*“I suppose he’s (learning disabled person) like my child, in a sense... he’s my brother and I love him, although he’s like a child... like my child as well” Val P 10 line 12*

Alternatively in some instances, the learning disabled person appeared to view the respondent as having a maternal role:

*“...he (learning disabled person) treats me like another mother, so to speak; I mean ok, so I don’t ... I’m obviously never going to replace my mum, but when she’s not there, I’m the next one.” Janet P 6 line 12*

Steven suggested that his parents would like him to assume a parental type role, in his comment below:

*“My mum and dad, I know they would want me to be able to come into Fiona’s life and help her run her affairs like they do for her ... They’d just want that peace of mind, that I was there to do it so that they could just step back and know that it was going to be alright.” Steven P 22 line 21*

### **Role of most involved**

A specific reference to their role as the sibling most involved with the disabled person was made by Claire, Kath, James, Val and Carol. All five commented on an apparent understanding within the family that this was their role and Kath highlighted that there was only one person in a family who takes on a role of overall responsibility:

*“...it doesn't matter how many times you discuss things in a family, there's only ever one person who takes the lead if you like - and it was always me ...It wasn't just me because I was retired, it wasn't just me that was thinking 'I'll have to do it' - I knew that they (other siblings) expected me to do it as well, the rest of them.” Kath P 23 line 11*

James supported the view that whilst all family members were clear about who holds the role of most involved sibling in the family, the situation was a topic of open discussion between family members. Carol suggested that she had been raised with the expectation of being the most involved sibling from childhood, whilst Val and Carol attributed their stage in the lifecycle and family situation to their role as most involved: both were the youngest in the family, were still at home when their mother died and other siblings were married or working. Although both these participants were female and the youngest in the family, this does not necessarily mean that the sibling with these characteristics will always become the most involved: James, in contrast, was male and the second eldest child of four children.

### **Roles of teacher and financial organiser**

Each of these roles was commented upon by Maali, Rita and James. Maali tried to think of new ways to teach her sister activities of daily living and Rita took the role of explainer, which included providing a rationale for the learning disability and residential accommodation. James looked up words and their meanings for his sister, as well as trying to teach her appropriate social responses:

*“I had to say, 'Well, your mum's very ill and you should be kind'; I said, 'You can't (go on holiday), you'll have to wait cos*



*your mum's too ill. You have to wait till she gets better, and she's very, very poorly and you should look after her'."*  
*James P 35 line 5*

The role of financial organiser was apparent in three interviews. Gail took on this role, as agreed with parents before their death, to ensure her sister had appropriate clothing, benefits and that other needs were met. Maali gave support with budgeting skills and James had set up a trust fund to meet the future needs of the disabled person after his death.

Overall, roles were multiple and varied for most respondents although role confusion was evident for Steven:

*"...and I don't quite know what my role is...I'd suddenly feel, 'Is that appropriate? Should I be getting involved cos I'm not really involved day to day?' But obviously maybe there is a role for me there...that's what I'm not sure, clear about."* Steven P 17 line 19

## **5.5 Superordinate theme: family**

This superordinate theme was manifest across all interviews and incorporates the subordinate themes of family culture; family supports the person with a learning disability; the learning disabled person is a source of stress within the family; parents; non-disabled siblings; family and finance; and Asian family culture.

### **5.5.1 Subordinate theme: family culture**

Reference to family culture appeared in 10 of the 15 interviews in various forms, with participants making various comments such as being brought up with a 'spare the rod, spoil the child' approach, as noted by Kath. Gail commented that only the nuclear family were involved in supporting the learning disabled person, and Fran

referred to her parents enjoying a culture of drinking and socialising in their leisure time. Comments that demonstrate the concept that families care for and support each other have been grouped together and specific comment that relates to Asian family culture has been addressed separately.

That family culture was one of care and support to each other was commented upon by five respondents and described by Andrea as an attitude that had been inculcated since childhood:

*“...we are very family orientated ... emm ... I suppose that’s been indoctrinated into both of us, you know, so coincidentally I suppose we are both very family orientated”  
Andrea P 1 line*

A family sense of love, support and concern for its members where it is apparent that they will support each other including the learning disabled person forms another cluster of comments made by Claire, Gail, Maali, Kath, Steven and Carol:

*“We all have this feeling of family and duty, you know ... mum and dad didn’t leave a lot of money but they gave us this incredible legacy of love for each other.”  
Claire P 17 line 10*

Gail explained how this sense of care extended to other family members as well as the person with a learning disability:

*“Our family had a very strong sense of duty to each other: if one of us was in trouble, everybody rallied round ... and I think it was always acknowledged that Verity wasn’t like the rest of us and not as lucky, and therefore... that it was our duty to see her and to check that she was ok... you rally round your family. It was the same when mum was ill - we all*

*rallied round; it was the same when dad was ill - we all rallied round.” Gail P 15 line 21*

Kath and Steven claimed that the overall family attitude towards the person with a learning disability was positive and that this was likely to have influenced their own attitudes:

*“...you knew you were loved, you knew that you were cared for - there was that as well. So it probably rubbed off on us and that’s probably why we nurtured Laura the way we did, all of us.” Kath P 5 line 13*

### **5.5.2 Subordinate theme: family supports the learning disabled person**

That family provide care and protect the learning disabled person was noted in five interviews, including those with Kath and Carol. Examples of support may involve making allowances for difficult behaviour as described by Gail; James talked about taking the disabled person on holiday; Maali listened to worries; and Andrea, Rita and Steven provided social contact. For Gail and Kevin, the disabled person was the focal point of the family:

*“She (learning disabled person) had most of the attention of us, as well as me mum and dad; she was the focal point of everything from when she was born, from then.” Kevin P 3 line 5*

Five respondents referred to support for the learning disabled person from the extended family apart from parents and siblings. The wider family such as grandparents, aunts, uncles and cousins were seen in a number of instances to support the nuclear family; James had involved his nieces in future financial arrangements, whilst Fran and Kath noted the involvement of their own children in a paid care capacity.

In addition to supporting the disabled person, siblings also supported other family members including an older parent, which demonstrates duality of care roles. Such family support was evident in nine interviews. Andrea gave examples of siblings caring both for their mother, the learning disabled person and the most involved sibling:

*“... we (the family) tried to support her (mum) in that ... tried to make things better for her I suppose, you know - like taking her out, like doing things together, and making sure she knew that we were there for her whenever she needed... The family used to take him (person with a learning disability)... we used to take him for weekends, you know... my older sister used to go - she didn't live too far away - so she would go round so it would give her a break. Carol (most involved and main carer after mum died) would go away on holiday and we'd look after him.” Andrea P 8 line 11.*

A commitment to the support and care of family members other than the learning disabled person was evident in other instances, for example Kath explained that her granddaughter came to live with her for a while and needed care and support; Val lived with her learning disabled brother but also visited her brother who was in residential care up to three times each week following a stroke; and Gail provided support to an elderly aunt who had no other close relatives living nearby.

### **5.5.3 Subordinate theme: the learning disabled person as a source of stress or conflict in the family**

The learning disabled person was presented as a source of stress for mothers, fathers, both parents together and siblings. In some instances, for example, the interview with Claire, the learning disabled person was cited as a cause of stress between the

parents. The marital situation was variable across the interviews: in some marriages parents took joint responsibility for the support of the disabled person (interviews 12 and 8); in other marriages there had been a difficult relationship but parents had stayed together (interviews 2, 9 and 13); and in others again, there had been a number of marriages (interviews 6 and 7), although this did not necessarily mean that there had been a poor relationship between the learning disabled person and step parents, as made clear by Fran:

*“...there’s Pete and myself with the same mum and dad, and then there’s Gill with the same mum - different dad. Then mum divorced from different dad R, and married A, my stepdad; I think they’d been together for about 25 years or something, and then he passed away last December... if you just go back to the parents as well, it’s A as my stepdad (that) Pete, my brother, would think of as being his dad” Fran  
P 1 line 26*

Apart from the learning disabled person being a potential source of conflict between parents, s/he could sometimes be a cause of stress between parents and siblings; siblings and siblings; and siblings and wider family members. In two instances, the learning disabled person was a cause of tension between the respondent sibling and parent. Claire referred to her parents restricting access to her learning disabled brother as a form of punishment because they did not approve of her first marriage, whilst Fran felt that her mother regarded her offers of support less favourably than those of another daughter in a similar situation.

Sometimes difficulties arose between siblings in a family because there was a difference of opinion on how to manage the needs of the disabled person, as presented by Val:

*“I do love my sisters; they do think I’m soft and I give in to him (learning disabled person), but they don’t know what he’s like really...Everybody thinks, ‘Oh Phil’s no trouble’ - which he isn’t half the time but a lot of the time he is - but they don’t see that side of it; so they just think that you’re just giving in to him all the time, when I know that I’m not giving in to him all the time ...” Val P 13 line 30*

Friction around the disabled person was generated from wider family members on occasion. James stated that his sisters-in-law were the reason for a lack of support from his brothers. Claire, Steven and Carol claimed that money and finances were sources of stress (discussed later under ‘family and finance’); a further stressor upon the family was poor mental health, due to being part of a learning disabled family, as outlined by Helen:

*“...me, my mum and my dad, we all got diagnosed (with depression) probably within six months of each other when I was about 18.” Helen P 5 line 13*

#### **5.5.4 Subordinate theme: parents**

Parents are mentioned jointly in the same sentence in eight of the 15 interviews. In addition to the stress parents may experience from having a disabled child, the impact of caring for a learning disabled person was conveyed by Rita as a significantly demanding role that takes time, energy and endurance. Parents were described as protective of the disabled person and the parental care role was described by Helen and Maali as ongoing, intensive

and enduring even into old age where parents had fewer physical and psychological resources to cope.

### **Mothers**

Mothers were specifically referred to in all interviews. Different mothers had different attributes: some were presented as strong, determined and matriarchal, as in the interview with Kevin:

*“Me mum always ran the house - whatever she said went, especially anything to do with Laura ...Me mum was the hard side ...she was matriarch of the family...she talked a lot, she was very outspoken... she was quite adamant in what she wanted.” Kevin P 18 line 17*

The mother of Andrea and Carol, who were sisters, was presented as loving and caring:

*“My mum was God’s gift to any child; she was the most perfect mum that anyone could ever ask for. So in that way he (person with a learning disability) was blessed with the family and the mother that he had with me mum. You could feel the waves of love coming off my mum, and I can still feel it now even though she’s not with me.” Carol P 6 line 28*

Alternatively, Rita described her mother as resilient and able to cope with the demands of life. These different attributes of mothers were presented along with the perspective that mothers have both positive and negative attributes, and may sometimes be ambivalent in their attitude towards the learning disabled person. An example of this emerged from the interview with Rita: her mother reportedly felt guilty and to some degree, embarrassed about having a learning disabled child; later in the interview she is described as “not disappointed” in her attitude towards the

disabled person, demonstrating perhaps a contradictory but more holistic view of a mother whose attitude to the learning disabled person varies. Only in the interview with James was a mother presented in a wholly negative light and unable to deal with the presence of the learning disabled person:

*“My mother’s (attitude towards the learning disabled person) was entirely different (to father’s attitude): ‘Why should it happen to me?’ ...it was always, ‘Why has it happened to me?’... I think she was clinically depressed; I don’t know that’s... she was never diagnosed as that, but she always used to go to bed every weekend. When me dad came home she’d be in bed... headaches, migraine, stress, I would say that is ... couldn’t cope basically.” James P 29 line 33*

In five interviews the mother was cited as the main carer for the learning disabled people, and in seven interviews she was described as protective, sometimes over-protective, worried or anxious about the disabled person. Seven of the respondents noted a particularly close or “special bond” between their mother and the disabled person, as illustrated in the interviews with Andrea and Fran:

*“He (learning disabled person) was still, like, attached to me mum’s umbilical cord I think, cos wherever me mum was, he wanted to be” Andrea P 7 line 31*

*“My mum and Pete have got a very, very strong bond – extremely. They sort of live for each other... I know that mums and sons can have that bond, but this is really... they are almost like the same person - they’re just so close.” Fran P 10 line 7*



From the interviews with Andrea and Claire, the closeness of bond between the learning disabled person and their mother was described in terms of the continued presence of an umbilical cord, and Carol claimed that the person with a learning disability “worshipped the ground” that his mother walked on. In addition to having a close bond with the disabled person, which could be termed a positive impact for mothers, Janet and Kath described how the presence of a learning disabled child paved the way for mothers to get involved in situations that they would not otherwise have encountered; an example is the setting up of new and alternative services which could be interpreted as generating positive opportunities that may not otherwise have arisen.

Mothers were however seen to experience negative effects from having a learning disabled child (in addition to worry and the need to protect, as reported earlier). Seven interviews made reference to difficulties such as pursuing a career and having more children (as discussed by Helen) and feelings of guilt or embarrassment which were evident in interviews 5, 11, 15. The view that mothers had more washing and cleaning to contend with was commented upon by Kath, while Andrea and Carol noted that there was no time for self. Conflict was seen to occasionally arise between mother and the disabled person, according to Kath:

*“...my mum was getting very frustrated because, as I say, my mum was very ‘everything so so’, and she was getting very frustrated; so she was shouting at Laura when Laura didn’t do something properly” Kath P 21 line 14*

In at least five interviews it was claimed that supporting the disabled person was hard work and made demands on the mother’s time and attention, therefore reducing her capacity for rest.

Andrea explained how her mother also had to manage the conflicting needs of all her children and was torn between not wanting to place a perceived burden on the typically developing children yet wanted to ensure that the disabled person was cared for:

*“...she didn’t want us to feel that we were going to have to be there in some way all of the time to look after Elliot, but realised at the time that she wasn’t going to live for ever... you’ve got your own lives, but knowing that sometimes that ... well a lot of the time, she worried about where Elliot was going to be and about who was going to look after him.”*  
*Andrea P 5 line 8*

Perhaps the strongest report of negative impact upon a mother’s life was presented by Rachel whose mother said that her life had been ruined by the learning disabled person. Despite this, her mother continued to provide support and care for the disabled adult:

*“...they’re the words she (mum) used: ‘it (having a learning disabled child) has destroyed my life - it does not have to destroy yours’, and that’s my mum’s words, that’s what she says ... Sometimes she says ‘destroyed’, sometimes she says ‘ruined’ ...”* *Rachel P23 line 8*

Mothers were seen to foster a positive relationship between the disabled child and typically developing siblings for Maali, Kath and Steven. This could be linked to the mother’s concern for the time in the future when she is no longer able to support the learning disabled person; she may feel that by fostering a supportive relationship between disabled and typically developing child, she is

protecting the future well-being of the disabled person, as inferred by Steven in interview 12:

*“My mum and dad might ...they’re like, ‘Oh, you two have some time on your own, go and pick Fiona up and go out for the afternoon and if you want to bring her back afterwards, you can.” Steven P 19 line 24*

Despite some mothers trying to foster a positive relationship between the disabled and non-disabled child, Carol, Steven and Fran talked about how their mother had tried hard to meet their individual needs as well as those of the disabled child:

*“My mum particularly put a lot of energy into encouraging me to have interests and she always made time to spend time with me.” Steven P 3 line 23*

## **Fathers**

Fathers were mentioned in their own right in 12 interviews but much less frequently than mothers. One reason for this may be that mothers often take on the main carer role, although fathers can be equally loving and accepting of the learning disabled person, sharing the caring role with the mother, as in Steven’s family situation:

*“My dad always goes, ‘Well you play the hand you’re dealt, don’t you, in life?’ and that’s kind of like his attitude ...he really loves her (learning disabled person) and he’s, you know, he wouldn’t change... he says now he wouldn’t change a thing about it, but you kind of, just have to get on with it and just enjoy it, and make the best of it.” Steven P 30 line 4*

As previously noted, step-fathers may also have a positive role and close relationship with a learning disabled person, as evidenced by Fran in interview 6 P2 line 7.

However elements of negativity from fathers towards the learning disabled person were evident in five interviews and covered areas such as the father feeling the disabled person got in the way of the marriage (interview 2); fathers feeling ashamed or embarrassed about the learning disabled person (interviews 11 and 15); father working away much of the time (interview 5) or simply not involved (interview 14).

Carol talked about her father being ashamed of his learning disabled offspring:

*"I think he (Dad) was a little bit ashamed ...I mean that's a horrible thing to say of your father, I think he was actually ashamed of him (learning disabled person), but he never actually went out with him anywhere, he would never take him to the barbers to get his hair cut or anything like that, unless of course he had to cos he was with us also." Carol P 14 line 17*

Even when negativity was present, a number of these fathers still tried to provide some level of care and support. Rita talked about her father feeling embarrassed but also said that when the learning disabled person was a child, he took her abroad to get what he considered to be the best medical advice.

In two families, the father was very involved with the learning disabled person on a day to day basis and may have had the closest parental relationship with them. This was certainly the case for James, to the point where his father was considered to be

unrealistically optimistic regarding the effects and difficulties associated with the learning disability:

*“My father’s (attitude to the learning disabled person) was positive - that she’d been poorly and she would become normal eventually, right even up to the day he died, and even one of my aunties, ...she said, ‘You know your father wore rose coloured spectacles about Jayne ...he never saw her as handicapped at all, other people can see it, but he can’t’ - he just didn’t see it at all.” James P 29 line 13*

In the interview with Kath, it was her father who explained the learning disability to the other children in the family and demonstrated an attitude of love and acceptance, followed by a close relationship. This father said the following to the other children in the family after the birth of the learning disabled person:

*“...‘This is what’s wrong with her and it doesn’t mean to say, you know, that she’ll be treated any differently; she needs a lot of love and she’s going to be brought up exactly the same as you - as all of you’... Laura spent a lot of time in the home with me dad - ‘father’ she called him - not dad, ‘father’... he was a house husband.” Kath P 4 line 14*

#### **5.5.5 Subordinate theme: non-disabled siblings**

Brothers and sisters other than the learning disabled sibling were referred to in 12 of the 15 interviews. Where there were a number of brothers and sisters in family, different relationships existed between the non-disabled siblings. Some brothers and sisters had a closer relationship with the disabled person than others, an issue described in the interviews with Janet, Gail, Kath and James:

*"...when my twin used to take care of my ...she is very regimented you know, like, 'You will play like this - you will do like this', you know; whereas I am a lot more creative, you know, free spirit ...whereas my sister was like, very regimented ....Greg obviously enjoyed spending time with me." Janet P 2 line 9*

Usually where there were two or more typically developing children in a family, one would take on greater responsibility for the learning disabled person and be referred to as the most involved sibling; this was addressed in the superordinate theme: Impact of the learning disabled person upon siblings` lives and the subordinate theme of roles.

The interviews provided some rationale as to why the most involved sibling held this role. Sometimes these insights were provided by the most involved sibling themselves and sometimes by those who were not the most involved sibling. Within a family, siblings appeared to be very clear about who held the role of most involved. The reason why a sibling may take on this role included them still living in the family home at the time of maternal death (as described by Andrea, Val and Carol); sometimes it was because they had the closest relationship with the disabled person (James and Janet); because they were the eldest (as discussed by Kevin); due to family expectation or ascribed role (Janet), or because they were deemed to have a more forceful personality (Maali). Those siblings designated as most involved made major decisions on behalf of the disabled person and had a greater sense of responsibility; this was acknowledged by those who considered themselves to have this role and also by those siblings who were less involved. Other reasons for being the most involved included

proximity (interviews 8,9,10), other siblings having their own family responsibilities and family problems (interviews 10,13,14).

Between the typically developing siblings however, was a sense that some brothers and sisters could be more supportive in the care of the disabled person and this was a potential area of resentment, as noted by Maali, Kath, James and Val:

*"I used to dread asking my sister to have him (learning disabled person), even though I knew she would, but I used to think, 'Oh, I've got to ask again. Why should I have to ask again?'...I think I would have liked a bit more (support from siblings) without me having to ask; and I know they would have had him if I would have asked but I didn't like asking all the time." Val P 18 line 20*

In contrast to this, siblings in 8 families did appear to offer support to each other, although in the interviews with Maali, Kath, James and Val, negative comments appeared alongside positive comments as some siblings were felt to provide less support than others:

*"...she's (sister D) the only one, really, that does a lot with me. We're the only two who do everything for Laura, if you like, who are very involved with Laura; and Kevin (brother)... Kevin has her every other week end. Kevin will have her and he'll take her out for a meal and then they'll go and watch football and she'll stay at his house or whatever... I love all my family and I'd do anything for them but I sometimes feel that I didn't have the support that I should have had." Kath P 12 line 26*

### **5.5.6 Subordinate theme: family and finance**

Finances within the family context are mentioned briefly in five of the 15 interviews with two main subthemes: that family are involved in financial affairs and money is a cause of stress within the family.

Family involvement in financial affairs was evident in the interview with Gail; she revealed that her father expected the non-disabled siblings to make sure that the learning disabled person had her needs met from a financial perspective, and that money was a source of worry for him:

*“Dad said, ‘I’m going to split the house between you and Rita (non-disabled sibling), and you’ll get everything that we leave but that’s on the understanding that you look after Verity’, and I think he was bothered about leaving Verity money...”*

*Gail P 18 line 14*

James involved the wider family in financial affairs by arranging for nieces and a brother to administer a trust fund for the learning disabled person in the event of his death.

That money was a source of family stress in relation to the learning disabled person was clear on different levels: for Gail, Rita and Steven, stress was generated because there was concern that there may not be enough money to meet future care needs; however an additional stress was that of financial abuse of the disabled person by another family member, as raised by Maali. Here, the respondent’s sibling and parents were very concerned as they felt that the husband of the learning disabled person had taken control of her benefits, which was to her detriment:



*“...standards and levels that my parents had set in us: ...‘dress in this way, look in this way, and do up in this way’ - Safa then became dependent on her husband, so her husband took control of her finances; he didn’t want her to spend money on it... he won’t spend that money, which is a real heartache for my parents to see, and it’s a real heartache for me to know that Safa doesn’t even have the basics... Safa doesn’t have food in the home; she only has, like, a main meal.” Maali P 17 line 22*

#### **5.5.7 Subordinate theme: Asian family culture**

The interview with Maali incorporated the aspects of family culture already stated, such as the closeness of the family unit and the expectation to care for the learning disabled person as a life-long commitment; however the following points and quotes provide an Asian perspective upon learning disability.

The first viewpoint to be considered is that learning disability, along with any other form of disability, is not culturally acceptable in Asian society; this is made clear in the comment below:

*“...and in Asian culture it’s a bit of a taboo... have any sort of disability, learning, physical, you know, having any defect really.” Maali P 11 line 23*

The next quote supports the view that Asian families want to maintain contact with their cultural heritage. The pressure upon parents to ensure that cultural values and traditions are upheld, especially for daughters, was evident, as was the view that western culture poses a threat to traditional Asian values:

*“...we all moved to Pakistan; my dad took retirement from the air force and we all moved to Pakistan, and that was a cultural move really I think cos they had a lot of pressure*

*that, 'Oh you've got daughters... they are growing up and they need to know about their culture and that they will get lost in the west kind of thing'..." Maali P 2 line 7*

Compared to the general population in the UK, people who have a learning disability are less likely to marry and the protectiveness of parents and families towards a learning disabled person is apparent throughout the interviews. As marriage is of strong cultural value and an expectation in Pakistan, Maali's parents agreed to the marriage of her learning disabled sister. This may have been in order to meet cultural expectations although this was a difficult decision for them to make:

*"...it was a really tough decision for them (parents)... I think in Pakistan there's also this thing that when you turn 20, you get married, so there was that too." Maali P 12 line 21*

Following marriage, Maali emphasised the extent of family involvement in the life of an individual from an Asian perspective:

*"After she (Maali's learning disabled sister) got married, ...I don't know how it is in other cultures, but traditionally husband then becomes the responsibility bearer ...in Asian cultures it's probably more difficult because you've got extended family, you've got in-laws to deal with, you got, you know, ... anybody and everybody has got a say in your life... mother-in-law would be demanding, there would be social commitments..." Maali P 9 line 21*

Having then married, the need to meet cultural expectations of hospitality to wider family members and the consequences of non-compliance was explained in the next quote. The ability to meet

such cultural standards would appear to be very challenging for a person who has a learning disability:

*“...even inviting someone to the home ...like little things like that... in our culture, these things matter right, being hospitable matters... if you’re not hospitable, you’re basically... you’re shunning yourself from the bigger family.”*  
Maali P 15 line 14

This final quote is associated with gender issues which are apparent in the results of this thesis. The following comment refers to a belief in Asian culture that mothers are accountable for the presence of any form of deficit:

*“...in Asian culture, your mother teaches you everything, and if... if anything defect, anything is left or fall short of, it’s always the mother’s fault.”* Maali P 16 line 10

## **5.6 Superordinate theme: how learning disability affects the disabled person**

This superordinate theme was evident in all interviews and encompasses the subordinate themes of origins of learning disability; health impact of learning disability; negative impact of learning disability; positive attributes of the learning disabled person and benefits of learning disability; and impact of learning disability upon relationships.

### **5.6.1 Subordinate theme: origins of learning disability**

All 15 respondents commented on how the learning disability affected their brother or sister. As three pairs of respondents (Andrea and Carol; Gail and Rita; and Kath and Kevin) were siblings to the same learning disabled person, the results of this study relate to 12 individuals who have a learning disability. The reasons given for the presence of the learning disability were Down

syndrome or related condition (five cases); birth trauma or difficulty in pregnancy (three cases); premature birth (one case); genetic (one case); meningitis and measles combined (one case) and encephalitis (one case). Those who reported meningitis, measles and encephalitis as a cause of learning disability stated that the person was typically developing at birth but experienced long term effects after the infection

### **5.6.2 Subordinate theme: health impact of learning disability**

All respondents made some reference to the physical or health impact of learning disability, although Claire and James only referred to this in early childhood and there did not seem to be any significant physical impact in adulthood. For the other respondents an associated health or physical impact upon the individual was present in adulthood but was variable in degree.

Generalised difficulty with physical co-ordination, mobility and movement was noted by six respondents, ranging from a mild physical impact such as a limp reported by Carol (interview 15 P8 line 26), to profound multiple disabilities with complex care needs as described by Helen (interview 3 P6 line 9). Five interviews mentioned fits or epilepsy, and three respondents stated that the disabled person was “big” or “overweight”. Maali and Steven referred to reduced stamina or small physical size, whilst Janet, Kath and Val stated that the disabled person had difficulty in carrying out daily living tasks such as toileting, due to shortened limbs. Other general health problems and conditions included arthritis, diabetes, anaemia, Irritable Bowel Syndrome and kidney problems. In addition to the more physically based health issues were mental health needs such as personality disorder, anxiety and behaviour that could be described as disruptive or challenging.

### **5.6.3. Subordinate theme: negative impact of learning disability**

This subordinate theme encompassed a number of components including a general need for care and supervision, support with accommodation, difficulty coping in social situations, managing behaviour, cognitive function, and personal and domestic activities of daily living.

Comments that indicated the need for care or supervision ranged from 24 hour specialist nursing care to more general references for support. The need for support with accommodation was present across the board. All respondents claimed that the disabled person needed support to live a daily life, whether this was in the family home or in a community setting with input from external services or day care.

Learning disability was seen to affect the individual's capacity to cope with social situations on a variety of levels, the first being difficulty in understanding socially accepted conventions. Claire explained that her learning disabled brother did not abide by the unwritten social norms that relate to staring at other men's girlfriends and Rachel described how her sister would flout social rules of public order and become involved with the police. There was also the issue of vulnerability in respect of financial abuse, sexual exploitation, or physical risk due to fire hazards or traffic.

Maali provided a number of examples in which she felt her sister was vulnerable:

*“...so her husband took control of her finances ...he won't spend that money ...Safa doesn't even have the basics ... Unfortunately I think, anybody who's going to marry a learning disabled person, he's got some gain out of it and for him it's a financial gain... Now Safa won't have a proper coat*

*in the winter, or she'll have a coat for three years which... you've got holes in the pocket and things like that going on; her shoes are totally worn out ... She just doesn't have appropriate clothing according to the weather; her child won't have ...they won't have decent food in the home."*  
*Maali P 17 line 24*

A further aspect of vulnerability brought to the fore by Maali, was that of social exclusion. She detailed clearly how when growing up, she and other typically developing children in the family would exclude her learning disabled sister in the presence of wider family members and community. Social exclusion may be further compounded if the disabled person lacks a general understanding of social rules which perpetuates social isolation and exclusion.

Several respondents referred to behaviour of the learning disabled person that could be described as difficult or challenging. This behaviour varied from general negative character traits such as being selfish, stubborn or lazy to behaviour that was more complex and challenging; for example in the interview with Gail, self-harming behaviours were described, and James referred to behaviour could be described as controlling, obsessive, or aggressive:

*"The last time she (sister with a learning disability) had a really bad temper tantrum, they sent her from the centre to a yoga class... a lady had to go to hospital, ...they say ... this lady, 'We're not sure if she's broken her back or not - Jayne attacked her'..."* James P 17 line 8

The cognitive skills of the disabled siblings varied across the interviews: some people were described as having profound multiple learning and physical disabilities while others were said to

have sufficient cognitive ability to read and write, but had limited social skills. There was however a generalised difficulty with cognitive function across the board related to skills such as reading, writing, coping with money and general understanding.

#### **5.6.4 Subordinate theme: positive attributes of the learning disabled person and benefits of learning disability**

Despite all respondents referring to the negative impact of learning disability, all made positive comments about their learning disabled brother or sister. Some made simplistic and basic comments that can be considered as positive, for example, Val commented upon her brother's basic personal care skills; even when participants had described behaviour that could be termed difficult or aggressive, positive comments or attributes were also said to exist, as illustrated within the interviews with Rachel, Gail, Rita, Steven and James.

Some sibling respondents described the learning disabled person as having a host of positive qualities, which included a positive outlook and disposition, as discussed by Janet; domestic abilities were noted by Kath and creative gifts were mentioned by Gail. Positive work skills were noted by at least four respondents and a good sense of humour or the ability to make people laugh was referred to in at least four instances, as outlined by Gail below:

*"...she used to laugh, and she used to joke; and she used to tell ribald jokes and she used to talk about the young lads who were the nursing ... and she'd do this nudge, nudge, wink, wink... she was so funny she just used to make me laugh ... all the time." Gail P 24 line*

Other attributes described were that the learning disabled person was sociable, accomplished at sports and held socially valued roles such as wife and mother.

One positive attribute that may be unexpected for a brother or sister who has a learning disability is that they were clever or intelligent. At least seven participants stated that their learning disabled sibling had positive intellectual or cognitive skills. One example of this can be found in the interview with James:

*“She’s (person with a learning disability) got a terrific memory ...if she wants to do, then she will learn to do it, and her memory goes right back to when she couldn’t speak ... She’s terrific on money... she’s adding up and she knows ... She can write notes: if somebody rang her on the telephone and she was in the mood where she was going to answer it, she can take a telephone message... She knows all the composers; if she was on University Challenge or anything like that about composers, she would be well away - she knows more than most people.” James P 13 line 28*

Positive community presence was also identified and Claire made particular reference to the positive contribution that people with a learning disability can make to society and the general community.

*“...Simon was always seen as a positive contributor to his community... I realised he must have been putting out up to about 20 bins cos there was lots of people coming to the door with beer cans or boxes of chocolates for him as a thank you for Christmas ... he works in a charity shop on a Saturday... I think we in society have lost that or would lose it significantly if people like Simon weren’t around” Claire P5 line 13*



An extension to the idea that learning disabled people have a positive contribution to offer society was the suggestion from some participants that learning disabled people may have some form of special gift that is of advantage to the general public at large. This can be seen in the interviews with Claire, Helen and Steven:

*"...but that's what Simon does: he connects people and he gets what he can give to other people, but what he receives from that - the pleasure - is amazing... he touches people's lives in a way that I don't see many people being able to do it". Claire P13 line3*

This same point is reiterated by Helen:

*"He brings a lot of joy ... he has a very infectious smile ... emm ... people love him. He's one of those people, you know, that once people have met him they remember him and he kind of, he kind of attracts people ... emm ... and attracts people's care... That's kind of happened the whole of his life - he just has this effect on people, that they just adore him"*  
*Helen P 8 line 6*

Four respondents made some reference to what could be termed a 'learning disability advantage'. Here, the sibling respondent represented the learning disabled person as having an advantage or able to gain more benefits than the general public might in a similar circumstance because of their learning disability. These advantages included access to celebrity events, extra opportunities at school, more meals out than most people may have and an especially supportive family. This concept was most strongly present in the interview with Janet:

*"... he gets to do all these things and go to these places and experience these things (travel, celebrity events) ... (he was invited) back stage at the end of the show ...so we got back*

*and everybody signed his book... He got exactly what he wanted; it's almost he like he knows... it's amazing... Greg was featured in a film...and it was nominated for a Royal Television Society Award - it won a regional one and it was nominated." Janet P 13 line 10*

#### **5.6.5 Subordinate theme: impact of learning disability upon relationships**

Relationships were specifically mentioned by several respondents and again covered both positive and negative elements. Andrea, Claire, Fran and Carol spoke of a particularly close bond between the learning disabled person and their mother which is detailed under the superordinate theme of Family under the section on Mothers.

Sometimes, relationships were described as difficult for the person with a learning disability in terms of understanding and responding to social cues; this is discussed in more detail within the subordinate theme, Negative impact of learning disability upon the individual. In other instances, the learning disabled person appears to lack the ability to form positive relationships with others, as outlined by Rachel:

*"...her (person with a learning disability) friends have... tend to be less able than she is, cos if they're more able or equally able (they) simply won't put up with it... She didn't really have a friend at all, not until she was in her late 40's, because she'd have a friend for five minutes and then they'd just get fed up of being told what to do, where to go, what to eat and how to do it, so they wouldn't last five minutes."*  
*Rachel P 13 line 24*

A further difficulty described in relationships for the disabled person was the initial forming of relationships and of over-involvement at other times. Relationships were also described as difficult in some instances because the disabled person was totally self-orientated, as expressed by James:

*“There’s only one person in that house that counts - and that’s Jayne, cos she’s so demanding. She wouldn’t tolerate another woman in the house, even my elder sister - she’s not been in our house in the past 20 years.” James P 9 line 22*

In contrast to these rather negative accounts of relationships, positive examples were also recounted in several instances and can be found under the section on positive attributes of the learning disabled person and benefits of having a learning disability. Although some learning disabled people were described as being able to form strong bonds and close ties with people, both in and outside the family (as described by Fran), others, such as Carol explained that her disabled brother had strong and loving relationships but only within the family network.

### **5.7 Superordinate theme: societal response to learning disability**

In the 11 interviews where societal response to learning disability was raised, evidence of both positive and negative attitudes was reported.

#### **5.7.1 Subordinate theme: negative social response to learning disability**

A negative or socially inappropriate response towards learning disability was evident in 10 of the 11 interviews. Such responses took various forms, such as the opinion that people with a learning

disability should be incarcerated and segregated from mainstream society, as voiced by Andrea:

*“(Some people held the view)...keep anybody with a disability locked up at home - and particularly people with mental health problems or learning disability - they were a danger, you know ...err... keep them locked away” Andrea P11 line 15*

James explained that the general public are sometimes afraid of people who have a learning disability, whilst Steven gave examples of negative public response such as staring, name calling and negative judgements, particularly by youths when the learning disabled person was younger. Andrea and Rita made a conceptual link between religion and learning disability where the inference was that learning disability was sent as a punishment to people (in both cases the mother) for wrongdoing.

Kevin interestingly recalled how a member of the public tried to demonstrate a positive attitude towards his learning disabled sister but in reality behaved inappropriately:

*“The landlady came over and she was new - she’d never met Laura before and she hugged her, the landlady hugged her and kept putting her arm round her...It was a little bit too claustrophobic; she didn’t ... and the fact that she didn’t know her as well.” Kevin P 14 line 6*

A generalised perspective of how society responded towards people with a learning disability approximately 80 years ago was provided by Carol, linking the concepts of protection and perpetual child. Janet however suggested that there has been an evolution over time to the place where difference is now accepted in society, not solely towards learning disability, but towards disability in general;

this leads onto the following subordinate theme that society responds positively towards learning disability:

*“I think in this culture that we’ve got now, anything goes ...once upon a time if you saw someone with Down syndrome you would stare, but nowadays, there’s that many different walks of life ...so for this day and age now, people with disabilities, it’s almost like ... to an extent ... it’s more acceptable now.” Janet P 26 line 15.*

### **5.7.2 Subordinate theme: positive social response to learning disability**

Despite Janet’s perspective that societal attitude towards learning disability has changed for the better over time, others indicated that response to learning disability has remained individualistic. James recounted how a person with a learning disability was given a valued work role in a family firm, some 20 years ago:

*“There’s one family of another (company): they had a handicapped sibling, a brother...when reps came round he’d shake hands with them, take them into the waiting room, ask them if they would like a cup of tea ...(as) if it was part of the firm - I think they accepted him.” James P 37 line 26*

Further developing the subtheme of a positive social response to learning disability is the concept of cultural response to learning disability. Carol found that a different culture may be very accepting, as evidenced within this quote:

*“My mum and Elliot and I all went on holiday to Turkey and the Turkish people were fantastic with him. There was no ostricisation; integration was being other than normal; they laughed and joked with him; and my mum appreciated that immensely. And it is the Turkish culture - it doesn’t matter*

*which way your child is: it's your child, and you accept them that way." Carol P 13 line 3*

At the opposite end of the spectrum to negativity is the view that some people have a special affection towards people who have a learning disability, due to an almost magical quality about them which links back to the superordinate theme, 'How learning disability affects the individual' under the heading of Positive / benefits attributed to people who have a learning disability. Helen described the following:

*"...there was people, a couple of people from (town), who kind of adopted him (learning disabled person) as a sort of adopted grandson ... they'd send him birthday presents and Christmas presents, and we'd take him over to meet them ...that's kind of happened the whole of his life, he just has this effect on people, that they just adore him." Helen P8 line 16*

### **5.8 Superordinate theme: transitions**

The theme of transition was present in 13 of the 15 interviews. Transition is often referred to in learning disability terms as moving into adulthood; however the concept is wider and can incorporate education, accommodation, leisure, recreation, occupational roles, relationships and responsibilities (Winn and Hay 2009). Within this superordinate theme are general comments about transition followed by subthemes of transition in the life of the learning disabled person; sibling life stage; death as transition; parental ageing; and the transition of taking on a major care role for the disabled person. A pertinent statement within this theme was made by Helen, who appeared to be referring specifically to transitional planning for her learning disabled brother in the statement below:

*“...transition is hell (laughs) and transition’s horribly stressful.” Helen P15 line 22*

The concept of transition as a continual state of change and adaptation to life circumstances is summarised by Steven in response to being asked what advice he could give to siblings in his position:

*“...I don’t know really - ask me in five years (laughs) and I’ll tell you.” Steven P 29 line 23*

#### **5.8.1 Subordinate theme: transition and life stage in general**

General comments about transition and life stage are made throughout 10 of the 13 interviews. It is interesting to start with the comment from Kath who remarked that siblings (and possibly parents) do not anticipate the future and the inevitable changes that will occur over the life course:

*“...when she (the learning disabled person) was younger I don’t think we thought about; it’s only as she gets older, as she’s getting older, we’re getting older and mum was getting older, that you start to look at things - you start to look at the future.” Kath P 26 line 31*

#### **5.8.2 Subordinate theme: transition and the person who has a learning disability**

Transitions, such as increasing levels of support from service providers or more time spent in residential care, occur as disabled people and their parents age (as described in the interview with Helen). However, change may also occur due to family context and life events. One example of this was seen in the interviews with Gail and Rita who were sisters to the same learning disabled person, Verity. They separately told how the family situation led to their learning disabled sister going into residential care because of

their father working away from the family home and his concern for mother (reported by Gail), whilst Rita said that mother having to care for her (Rita had polio in early childhood), and the arrival of a new baby (her sister Gail). The inability of the educational system to meet the needs of the learning disabled child, and behaviour that the family found difficult to manage, were further contributory factors that led to Verity going into care:

*“...with me having polio, I had to have lots of major operations as a child. I was in and out of hospital, my mum had this other baby ...and she'd Verity gone out of junior education and going into senior education, and I think they knew that she couldn't go to senior education - because obviously she couldn't.” Rita P 10 line 3*

These changes in accommodation were sometimes perceived by siblings as a positive experience: for example, Steven viewed the move away from the parental home as a step towards a more independent adult life for his learning disabled sister. Sometimes however, as was the case for Gail, changes in accommodation were perceived as a negative experience due to a combination of service decisions and the declining health status of the disabled person over time.

Some respondents made reference to age-related changes in the disabled person: for example, Val remarked that her brother prefers his own company and is less sociable as he gets older; whilst Carol noted increased physical difficulty for her brother as he aged, but also reduced reliance upon medication prescribed for anxiety, suggesting that age-related changes for the learning disabled person may bring positive or negative elements, on an individual basis.



### **5.8.3 Subordinate theme: sibling life stage**

Four respondents made reference to their youth including childhood and adolescence. Rachel made a clear differentiation between childhood and teenage years, saying that in childhood, the typically developing child may simply accept the learning disabled child as part of their normal home environment and lived experience; however the transition to teenage years may have a significant impact:

*“In our early childhood years, not a problem, I mean she (the learning disabled person) was, she’s younger, just 11 months between us, we just played. In my adolescent years it was horrific ...cos in the adolescent years, the last thing you want is anybody being different and she was very different ... I think age difference, when Amy was young you don’t notice - when you’re teenagers, you can’t do anything but notice.”*  
Rachel P 3 line 18

As respondents reached teenage years and early adulthood, there was evidence of reduced engagement with the disabled sibling and some made comment about their own selfishness or the selfishness of younger people in general terms, claiming that they have little concept of the difficulties that parents experience due to the presence of the learning disabled person:

*“I was young and out a lot. You’re very selfish when you’re young; you don’t think a lot about your parents, what they’re going through.”* Val P 15 line 3

At the stage of young adulthood, some participants talked about the desire to move away from the family home and establish an independent life, as seen in the interview with Steven:

*“...Emm, I wanted to move out and experience things, I didn’t just want to have my life in S (town) at the time. I only left S (town) when I was 21... I didn’t want to just get sucked into that S (town) world - it was quite intense and all family members getting involved and everything, and small town mentality. And I can see the appeal of it, ironically again now I’m a bit older...When you’re 21, 22 all you want to do is get away from it all and have your own life.” Steven P 17 line 6*

As the respondents have continued to move through the life stages, a number of them noted an increased awareness of the needs of the learning disabled person and the demands that this can put on family members, themselves included:

*“...my mum, bless her, she took most of the hard work on her shoulders; but I think as we all got a little bit older and we understood how difficult it was for her ...as we got older that we could look after him too.” Carol P 3 line 8*

For other respondents such as Fran however, there had been little need to get involved with the learning disabled person to date.

General references to the respondents’ life stages covered a wide range of transitions, including: work, relationships, education or training, becoming parents, setting up their own home and becoming responsible financially. One example of the multitude of life changes and transitions was presented by Claire:

*“Life became very complicated ... I’d gone from one relationship that wasn’t a good relationship, ...into changing job, qualifying as a (health and social care professional) and then finding out I was having twins ...life was manic for about five years.” Claire P8 line 19*

Maali recounted particular stress regarding her imminent move to another country which would take her away from her current role as the most involved sibling. Other respondents felt that they were currently in the process of reviewing their involvement with the learning disabled person and that change was likely in the near future:

*"...but I feel it's coming closer (the possibility of moving close to the learning disabled person), and I feel that we've started to talk about it a lot more; and I think that L (partner) wants to talk about it and at least know where we stand about things, but I'm starting to feel like it's coming quite close."*  
*Steven P 23 line 14*

#### **5.8.4 Subordinate theme: death as a transition**

Death was specifically referred to in eight of the 13 transcripts; with particular reference to parental death (nine of the 15 respondents said that both parents were dead). This was depicted as a time of difficulty due to the bereavement and the uptake of additional responsibility for the learning disabled sibling. Claire talked about her struggle in adapting to the death of her father:

*"... the hardest part was losing me dad and not having time to grieve for that; and the massive changes that had gone on in my life in the space of about five years: I'd moved house five times in one year, with twins... life became very complicated. It almost put a freeze on emotions for a while."*  
*Claire P8 line 14*

For both Claire and Kath, the learning disabled person came to live with them for a while following parental death and they reported feeling conflicting loyalties between their own families and the needs of the learning disabled sibling. In some interviews (for

example those with Claire, Kath, Kevin and Val) the most involved person was considered by themselves and other family members to have taken on the role of replacement mother to the disabled person.

#### **5.8.5 Subordinate theme: parental ageing**

For six respondents, at least one parent was still alive at the time of the interview. Seven respondents referred to parental ageing in this theme and, as previously commented upon by Kath, this change in family and parental status was not something that had necessarily been anticipated in earlier years.

Helen, Rachel, Rita and Fran said that they grew up with the understanding, imparted to them by parents in childhood, that they should not be 'burdened' with the future care of the learning disabled person. Despite this, some became aware of a change in expectation as parents aged, and had become aware of a growing expectation to increase their involvement with the disabled brother or sister. An example was provided by Rachel:

*"She (mum) always says that she'll haunt me if I do things (for learning disabled person) but she says it less and less the older she gets" Rachel P4 line 27*

The same point is reiterated by Fran:

*"I think she (mum) kind of... she kind of feels that now's the time for me to start to be in his life a little bit more." Fran P 17 line 16*

Fran, Maali and Steven voiced a growing awareness that parents found it increasingly difficult to maintain previous levels of care; this was a source of stress for parents in some instances, and for sibling respondents in others. Older parents were described as less

able to cope with care demands, in the interviews with Maali and Steven:

*".. my parents are in their 70's now and old age is kicking in ... They stress easy, and not having any outcome ... for them they just become really flustered ... Right now my parents are no longer in that situation where they can actively care for her." Maali P 30 line 6.*

#### **5.8.6 Subordinate theme: transition to taking on a major carer role for the learning disabled person**

This change in role was apparent in four of the 13 transcripts related to the superordinate theme of transition.

Close physical proximity, particularly living in the same household as the learning disabled person, can lead to the expectation that a sibling will take on full carer responsibility after parental death. This can also apply after maternal death when the father is still alive, as was the case for Val and Carol, who lived at home when their mother died and had not yet established a life away from the family home or had the responsibilities for a spouse or children:

*"I think probably we all took it for granted (that the respondent would provide support) cos I was actually there; they (other siblings) all had young families, they all had young children and they all lived at quite a bit away." Val P 12 line 13*

#### **5.9 Superordinate theme: services**

This superordinate theme occurred in all interviews and includes the subordinate themes of negative comments about services, positive comments about services and that services provide a different role to family members.

Comments about services were made by all participants; some made a significant number of comments (for example, Claire, Maali and Gail) whilst others (for example, Andrea, Fran and Carol) made brief reference. There were almost equal numbers of negative (14) and positive (13) comments made about services.

### **5.9.1 Subordinate theme negative comments about services**

Negative comments took a variety of forms. Some of the more commonly occurring included the view that services were insufficient; unsuitable in terms of quality and range; and that inappropriate services can have a negative impact on the lives of learning disabled people. Sometimes negative comments were about staff and the potential for services to be a source of conflict and frustration in siblings' lives.

The view that services were lacking and insufficient was presented by Andrea:

*"...so there was nothing there, there was no support there. Me mum got very little support with Elliot until he got a bit older... I looked around and I felt there was very, very little options." Andrea P11 line 18*

The view that services were considered inadequate, and families had to compensate for a lack of service provision to protect the needs of the disabled person, was described by Rachel:

*"...even though there's this two hours support that's supposed to go in, it's usually me or me mum have to book the opticians appointment and then get her there, and book the dentist appointment and get her there... I would like to say there are services out there that will deal with it, but in reality there aren't, so in reality I have the choice of either*

*doing it or letting my sister become bankrupt, neglect herself, not care for herself, not do her shopping or shop stupidly and have 16 million DVD's but no bread." Rachel P11 line 37*

Alongside comments that services were lacking were those associated with range and quality. Helen reflected upon the perceived need for siblings or parents to push services to meet basic needs:

*"...things don't run smoothly ... and sometimes you do need somebody to kick wheelchair services up the backside... or phone up loan stores four times a day to say, .Where the hell is the suction machine?" Helen P 10 line 18*

Poor or inappropriate services were seen to have a detrimental effect, sometimes to extreme levels, upon the lives of learning disabled people and the family, as noted by Rita:

*"...the worst thing was when I was married and I had S (child) and she (learning disabled sibling) was then in W (care setting) as a young woman...it was a locked-in place: if she misbehaved, they took privileges off her... and we went to see her once and she was in a padded cell in, like, a straight jacket... That was horrible, and that should never have happened to anybody anywhere." Rita P 8 line 5*

When considering negative comments that relate to staff within learning disability services, some staff were reported to be unhelpful (as in the interview with Rita) and some were not adequately trained; staff changes was raised by Gail as an issue that also led to dissatisfaction and discontinuity of care:

*“Every social worker that we had would stay with Verity for a while and then disappeared, and you found you were always having to tell them the story all over again.” Gail P24 line 21*

Staffs within learning disability services were also reported to be a cause of conflict, anger and frustration in the lives of some siblings, as depicted by Maali and Kath, whose mood had been affected by a lack of response from support services:

*“...her social worker has just gone on long term sick or leave or whatever, and I can't seem to get anybody. I leave messages and nobody rings me and that's getting me down at the moment...” Kath P 11 line 3*

#### **5.9.2. Subordinate theme: positive comments about services**

In contrast to negative comments, positive reviews of services were also provided:

*“The charity that does it (provides care to the disabled person) are very flexible in that way and they've been brilliant actually sorting out that sort of thing ...In terms of, like, what he gets to do and the places where he lives, those are fantastic.” Helen P 7 line 34*

Positive relationships between service providers and the learning disabled person were commented upon and valued by Claire and Helen, and where a positive view of services was held, siblings had been able to develop an attitude of trust which they found reassuring. A final aspect of positive comments related to service provision was that some respondents felt that services had been responsive and meet their needs as siblings, as distinct from the needs of the learning disabled person. This opinion was expressed



in three interviews; examples from Helen and Kath respectively are presented:

*“One thing... that was really helpful... when I was depressed, I was able to have a ... period of counselling from a counsellor who was... who specialised in families with profoundly, emm, disabled children or young people; and she specialised in counselling parents, grandparents, siblings.” Helen P 15 line 15*

Kath states:

*“...I can never ever say enough about TH (learning disability charity) they’ve saved my life many a time... I’ve gone down there when I’ve... I’ve gone down there breaking my heart... within two days I’ve had a counsellor ringing me up.” Kath P 26 line 36*

### **5.9.3 Subordinate theme: services provide a role that differs from the family**

Three participants contributed to the idea that services provide a different role and function to that of family. The first point raised was an acceptance that the level or quality of care services provide is intrinsically different to the support and care provided by family. This view was presented in the interviews with Helen and Maali who appeared to attach no blame and merely accepted that the role and relationship of family members with the learning disabled person was intrinsically different to that with a service provider:

*“...the people who do the service are fantastic but... it’s just a job.. you know, maybe a job that they invest quite a lot of emotion into, but it is just a job ... What me and my parents would do for him is a different level and that’s just the way it is.” Helen P 10 line 4*

Despite an apparent understanding or acceptance of difference in role between family and service provider, as expressed by Maali, there is an acknowledgment that on occasion, professional services are better equipped to support the learning disabled person because families do not always have the necessary tools:

*“Safa does need that professional support as well. Sometimes family support is... people just go by what they know rather than knowing the good from bad... it’s coaching Safa more - rather than just somebody coming and doing a random check...That’s the difference between family and having professional support: a family member won’t go to those lengths of providing her with the tools; they just say. ‘Oh Safa is the house clean? Do you have food? Is the baby washed, clean? Is she fed properly?’....” Maali P 31 line 9*

An alternative perspective on role difference between family members and service providers was given by Rachel. Her point was that services are bound and constrained by protocol and professional practice and might not necessarily be in the best interest of the learning disabled person. The view was expressed that a family member is able to respond to or deny demands and requests from the learning disabled person that are not deemed to be in their best interests, however this is not always possible for service providers, as illustrated by the following quotes:

*“...to some degree you’ve got to have some control - which services haven’t. So, like, because of all this money she lent the boyfriend, me mum has got her bank book; I get her some money out of the bank every week and take it over to her - a service provider couldn’t do that cos they could never have that power to take her card off her” Rachel P17 line 27*

Rachel continued in the same vein regarding the constraints of political correctness in contrast with what the family considered to be a sensible and practical approach:

*“...the social worker knew ... this is the worst possible thing that could probably happen (the learning disabled person living with her boyfriend); it is a ticket for disaster for both of them...They can't make a responsible decision because they've got to make a politically correct one which isn't always the responsible one, cos the most responsible one to that one would be, 'no way no how'.” Rachel P19 line 1*

### **5.10 Superordinate theme: the future**

This superordinate theme appeared in all interviews and incorporates the subordinate themes of futures planning; future expectations and wishes; and concerns for the future.

#### **5.10.1 Subordinate theme: futures planning**

As a subordinate theme 'futures planning' covers the elements of having futures plans in place; futures plans not being fully clear; whether or not futures plans are discussed overtly; rationale for non-discussion of futures plans and implicit family understanding about future care.

Five respondents claimed that futures plans were discussed overtly within their family, although on deeper exploration, this tended to be partial planning that predominantly covered financial issues rather than a comprehensive plan that considered all aspects of the disabled person's life. A further five interviews stated that futures plans were not an open topic for discussion. The reasons why open discussion had not taken place were varied but included fear of the future and the belief that no one other than older parents themselves could provide the right sort of care; this links to the

subordinate theme of concern for the future which is discussed later. Superstition that open discussion of the future may pre-empt parental death (Interview 1 P 6 line 23) or that discussion was likely to cause disagreement (Interview 3 P 11 line 3) or distress to older parents (Interview 8 P 27 line 4) were other reasons why open discussion did not take place.

11 participants referred to the existence of futures plans which took different forms: there was a verbal understanding of future care noted in six interviews; an end of life plan reported by Helen; a financial or advocate plan was noted by Steven and James; an unspecified written plan according to Claire; and a five year plan of an unspecified nature for Fran as outlined below:

*“...she (mum) mentioned something in passing but she doesn't go into detail ...I know she's got a plan and in the next five years, although I think she's thinking of bringing that forward, she wants him (learning disabled person) to go to some kind of shared accommodation or to go and live with another family or something ... just in her head. She's always talked about it but I never really took it on board cos I thought, 'It's not going to happen'...” Fran P12 line 18*

Rachel and Maali said that both they and their parents were clear that the demand upon services will increase over time to support the changing needs of the disabled person, rather than the parent or sibling taking on a full time care role, however there was no mention of this being a written plan:

*“I think we (mum and respondent) are both aware, that as time goes on, ... she (learning disabled person) almost relives her life backwards ...she started fully staffed and has almost got less and less support - that as time goes on, she*

*will have to have more support. But we are very clear that she will do that: she won't come to us and then try and get somewhere... as things happen, the sliding scale will have to happen."* Rachel P22 line 2

The final comment at the end of this quote could suggest that although family understanding and plans may be conceptualised at a given time and place, futures planning is likely to be a transitional process. This concept may be supported by the fact that eight respondents indicated that their family's longer term plan was not clear or may simply not have been considered. Overall, there was a lack of detail regarding futures plans.

Some respondents provided a degree of rationale as to why plans were not fully formed, citing reasons such as siblings taking a laissez-faire attitude to life and reacting to situations as they arose, rather than pre-empting them (as illustrated by Kevin); others assumed that someone within the family would provide care, or said that they did not know who to approach to take on a supportive role in their absence; Val claimed that she had only just started to think about such matters, possibly due to her current life stage. Janet, Kath and Kevin said that they had not progressed beyond the next anticipated or current stage of planning; Helen and Maali avoided future planning as this was deemed stressful for their parents, and Steven was not yet sure about his involvement in the future care of his sister.

#### **5.10.2 Subordinate theme: future expectations and wishes**

This subordinate theme incorporates the expectations and wishes of parents for the future care of the learning disabled person as perceived by participants; participants' wishes and expectations;

comparison between parental and sibling wishes; and the wishes of the learning disabled person.

### **Parental wishes and expectations**

Three of the respondents claimed that although parental wishes were not explicitly vocalised, there was a clear understanding that parents wanted the learning disabled person to remain in the care of the family:

*“The question of him going into care just was never asked, cos we’d never even considered it - that was unacceptable... we thought it was very important that Elliot stayed in the family home - very important. And as I say, I don’t think me dad or Carol (most involved sibling) would have wanted him to go anywhere else, but why would they?” Andrea P 8 line 27*

Ten participants stated that verbal discussion about the future expectations of care took place with their parents. Parental expectations were variable and the degree to which parents expected respondents to be involved was also variable. Some parents, for example in the interview with Claire, wanted the disabled person to live with a typically developing sibling after their death, whilst others had clear expectations that although the non-disabled siblings would take on certain roles and responsibilities, there was no expectation for co-residence. Although parents may expect the typically developing sibling to provide some level of support to the disabled person in the future, they also had an expectation that support for services would increase over time.

Rachel and Fran claimed that they had been given an explicit understanding in childhood that their parents (mothers) did not expect them to co-reside with the disabled person in the future. This understanding however, was perceived to change as parents aged and this contradiction in message is explicit in this quote from Rachel:

*"...she (mum) always says that she'll haunt me if I do things (for the disabled sibling) but she says it less and less, the older she gets ...She always used to say I'd say as when we were kids... I'd say, 'Oh Amy will have to come and live with me', and she said, 'Well if she did, I'd haunt you' ...."* Rachel  
P2 line 27

### **Sibling expectations and wishes**

Respondent wishes and expectations were present in 14 of the 15 interviews (the exception being Andrea whose learning disabled sibling had already died). For certain respondents (for example Kevin, James, Val and Carol) there was no expectation of change and siblings appeared to be content with their current situation, whether this involved co-residence or not. Alternatively, some siblings such as Helen and Janet expected their future level of care to increase significantly and intended to incorporate change, such as moving house to be closer to the disabled sibling, and to take on a parental role, as seen in the interview with Helen:

*"...if my parents can't do that (sort out services) then somebody's going to have to... and ...so I would do that, and if that meant moving home, working part time, so be it - that's what I would do... I don't think to be honest that he (learning disabled brother) will ever be completely full time residential, err, because he gains too much from going*

*home... and... So... yeah, I could do what they are doing now, and I would.” Helen P10 line 21*

Other anticipated support roles for the future included financial management and general responsibilities that were typically undertaken by parents, for example dropping off groceries, transport to and from appointments and acting as an advocate for service provision.

Although some siblings said that they expected to be more involved with the learning disabled person in the future, they did not expect to live with them and gave different reasons for this perspective. Rachel felt that her learning disabled sister would destroy every important relationship in her life; Kevin felt that living with his disabled sister was not possible due to her personal hygiene issues and his work commitments; whilst Fran claimed her work commitments and wish to maintain an outdoor lifestyle would prohibit cohabitation, although she also said that it should be her mother who decided the future care of the learning disabled person because she was his main carer. Maali and James wanted increased input from services in the future; whilst Kath, Rita and Val said they would like increased support from family members over time. Some participants (for example Steven) however, were unclear about the future; this may link back to the concept that futures planning and future expectations are transitional in nature.

*“...will I move back to be near Fiona one day? But it’s always been that decision that will probably be made later on, that one day we’ve made or will make itself - as I’ve never forced myself to make it yet... I’d like to see if it’s possible to see if I can stay in L (place) and do it in a way that fitted in with everything and ...it may be that we eventually*



*move up nearer and then play a role, a more active role in Fiona's life. It's hard cos I can't make my mind up which way I see it." Steven P 23 line 11*

Sometimes respondents gave a conflicting impression of family wishes and expectations of future care. Kevin said that living with the learning disabled person on a full time basis was too much for his elder sister Kath (the most involved sibling) and would also be too much for him; he later contradicted this by stating that someone in the family would provide support in the future if required, to avoid the learning disabled person going into residential care, and that if no one else was available he would provide such care. Janet equally provided a conflicting picture of the family expectation of care. She stated initially that the family understanding of future care was explicit, but later went on to say when talking about the longer terms plans:

*"...everyone's assuming that he's going to live with me...that's something we're going to have to look into..." Janet P 19 line 1*

### **Comparison between parental and sibling wishes regarding the future**

Claire and Helen noted conflict between theirs and their parents' wishes for the future, and provided some rationale for this difference. Claire described how her parents expected Simon to live with her after their death and had made this verbally clear; however Claire wanted her brother to be supported to lead an independent life in the community. When both parents eventually died, the learning disabled person did live with Claire for a number of years until an appropriate community setting was found. The

rationale given for the difference in expectation was that parents had grown up in a different era.

Helen outlined the opposite situation: her parents wanted her to have an independent life and not be disrupted by having to support her learning disabled brother, but her stated wish would be to move closer to home and take on the current parental role of providing part-time care at home in their absence:

*“I think their idea would be, well he’ll stay like that, I’d have the same level of involvement as I do now ... not changing anything in my life specifically because of him... and that’s not the way I see it (laughs)... They don’t want my life to be dictated by him; they want me to have as normal a life as possible...I respect how they’ve come to that and it’s lovely that they feel that... but if push came to shove, I couldn’t do it (laughs) - I couldn’t live with it.” Helen P10 line 10*

Her rationale for wanting to take over the parental role was that her learning disabled brother has always been part of her life and that she could not disassociate herself from this; however the final part of the quote may suggest that guilt could form part of the motivation to take on a future residential care role.

Nine other respondents reported clear alignment between their wishes and parental wishes for the future support of the disabled person. This could infer that in general, siblings take on or assume parental wishes and expectations for future care as their own.

### **Wishes of the learning disabled person regarding the future**

Janet, James and Carol made clear and particular reference to the wishes of the learning disabled person and their future care. James and Carol claimed that the person with a learning disability was

happy to continue living with them in the family home, although both said that if the learning disabled person wanted something different, they would be willing to consider this. Janet thought that her learning disabled brother would want the same as her, and which they have planned - that she will move next door to him and provide an increased level of support when their mother dies.

### **5.10.3 Subordinate theme: concerns about the future**

All participants made reference to their worries or those of their parents regarding the future in relation to the person with a learning disability. Parental concerns voiced by Steven and Carol presented a generalized fear about the future:

*"I think they have their concerns about her future ...what's it going to be like in 10 years, 20 years, they..., who knows? Nobody knows the future that will be." Steven P 21 line 2*

Kath described her mother's fear that no one else could provide the same standard of care that she had provided:

*"...it seems to me like she (mum) didn't want to commit because she was frightened that something wouldn't happen ... She didn't want to leave Laura on this earth if she wasn't here to look after her... she thought nobody could look after Laura like she could." Kath P 22 line 14*

Only one sibling (Claire) had no particular concerns about future care as she felt confident in the way that her brother's care package had been set up.

Other siblings voiced concern regarding the future, related to a range of issues such as service provision, funding and parental death. Siblings were worried about how they would personally cope in a future without their parent (mother in most cases) and

how they would deal with increased care demands for the disabled person. There was also concern from Janet about how the person with a learning disability would respond to maternal death, and how the parent would respond in the event of the disabled person dying before the parent, as outlined by Fran. Concern over dealing with finances and benefit issues was raised, as was the issue of divided loyalties between the disabled person and the respondent's own family. Health was an additional worry and was explored from two perspectives: the sibling's own health and ability to provide a care role to the disabled person (Rachel, Janet and Kath) and the health and well-being of the disabled person (Kevin and Rita). In some instances there was concern that deterioration in health of the disabled sibling could lead to unwanted changes in accommodation; whilst Val suggested that her concerns and worries about the future were caused by her own lack of planning, lack of information and available resources:

*"I've only just started thinking about that (future care for the learning disabled person) and I've not done anything about it yet but it has been on my mind... I never made a will because I don't know who would have Phil and so I tend to bury my head in the sand; I certainly wouldn't want him to go into a home ...and quite honestly, I don't know who I'd ask." Val P 16 line 9*

### **5.11 Superordinate themes: siblings have needs, and advice to siblings**

The Superordinate themes, 'siblings have needs' and 'advice to siblings' will be considered together as the answers to the two questions appeared to overlap in the interviews and were not easily separated. Both superordinate themes were relatively small in terms of the amount of text devoted to them in the transcripts; however the 'Siblings have needs' theme was evident in all 15

interviews and 'Advice to siblings' was present in 12 interviews. 'Siblings have needs' will be presented in the first instance. The subordinate themes here include siblings need support, siblings need to look after their own needs and siblings need support in childhood.

#### **5.11.1 Subordinate theme: siblings need support**

13 respondents made a general statement that as a sibling of a person who has a learning disability; they had some sort of need; as an example Fran said the following:

*"...maybe some kind of..., somebody to talk to other than your parents; some kind of support route..." Fran P 21 line 8*

Within this category, other siblings referred to more specific needs, such as those for advice, information and knowledge on what is available:

*"I mean a lot of the facilities out there aren't nationally advertised so you don't know; there are retreats that your special needs family or friend can go to give them a break and yourself... I think public awareness of what's available." Carol P 21 line 18*

Some participants identified a need for support with their emotional well-being, which was in some cases directly linked to having a learning disabled sibling. This need for emotional or psychological support was evident in the interviews with Kath (page 2 line 7) which was presented in an earlier quote under the subordinate theme "Negative impact of learning disability", and by Helen:

*"When I was depressed I was able to have ...a period of counselling from a counsellor who was..., who specialised in*

*families with profoundly, emm, disabled children or young people...” Helen P 15 line 16*

Other respondents such as Maali, recounted a need for practical assistance rather than emotional support. There was a call for support from those who were in a similar family situation: Janet perceived that they would identify with them and may be able to provide practical solutions to difficulties encountered; in contrast; Rachel and Fran voiced the need to have a separate identity from other family members and to have their own specific needs met.

Kevin and Val made reference to family support and the care of the learning disabled person. Kevin claimed that because there was a large family (7 siblings in total) there was no particular need for support from outside the family, however Val also came from a large family (10 siblings in total) yet made comment that she would have welcomed more support from family members. Disparity in the perceived level of sibling support required in a large family context supports the view that sibling perception and family response towards learning disability is variable and individualistic.

#### **5.11.2 Subordinate theme: siblings need to look after their own needs**

The perspective that siblings need to look after their own needs was present in seven of the interviews and was espoused in general terms, for example that siblings should seek advice, information or support to meet their own needs. Within this theme however, some needs were stated more specifically, such as the need to be aware that psychological health and well-being may be adversely affected by being a member of a learning disabled family; Helen felt that this would not be an unusual reaction the situation. For Rachel, ‘siblings looking after their needs’ was presented in the context that typically developing children need time for themselves away

from the learning disabled person; Gail advised seeking support from families who were in a similar situation and Carol suggested the use of appropriate services such as respite:

*“...everybody needs a little bit of a break every now and then, emm, but I think more so with the special needs cos you don’t realise how demanding they are on your time and your feelings until you get that break and that you can wind down a little bit” Carol P 21 line 1*

Related to this theme was the notion that siblings should avoid self blame or recrimination. This view was presented by Andrea, Claire and Rachel, taking a slightly varied course in each interview, but overall they advised that siblings should not blame or bring recrimination upon themselves regarding their response to the learning disabled person or their situation. Andrea explained that if a sibling was no longer able to provide care for a learning disabled person, they should not feel guilty about this:

*“I think if it comes to the point where they (the sibling) can’t care for that individual, there’s no need for self blame or recrimination cos you’ve done your ( ) best to look after that individual; and if another place offers, allows them to become more independent, and enables them to be integrated into a community, and to be offered that support - don’t feel guilty about it.” Andrea P11 line 25*

Rachel contributed to the view that siblings should avoid self blame and be tolerant of their feelings of frustration and anger in her comment below:

*“It’s OK to be angry, (laughs) it really is OK, you don’t have to go round thinking everybody thinks, ‘Oh bless, aren’t they*

*(learning disabled people) lovely'. It's ok to be really pissed off with everything ...why did this happen to me... So it's OK to be pissed off (laughs) - it really is OK."* Rachel P 25 line 6

### **5.11.3 Subordinate theme: siblings need support in childhood**

Five of the 15 interviews made direct comment about siblings' needing particular support (which took different forms) in childhood. The need for non-disabled children to meet others in a similar situation and vent feelings of anger and frustration in a safe environment was highlighted:

*"...as a child having the opportunity to meet other children in the same situation, emm ... you know, people who realised that it wasn't weird to, you know, go home from school to a children's hospice (laughs), hmmm - that it was normal to know how to change your 10 year old brother's nappy ... just being able to bitch (laughs) about how horrible it is and how they mess up your life, ... that's really good, just to realise firstly that you're not alone ...just being able to have a good moan at each other (laughs), have a good moan at somebody who can moan back (laughs)".* Helen P 15 line 35

Issues of frustration and resentment were present for Rachel who stressed the need when young, for dedicated time with her mother, away from the learning disabled person:

*"It was really important, (dedicated time with mum) and it might have been to have a screaming row or it might have been to have a game of Scrabble, or it might have been to have a giggle, or it might have been to sit outside in the garden for a glass of ... but it was really important - crucially important that I have that time, especially with no short stay*



*or respite cos there wasn't that week, there was nothing, it was those two hours." Rachel P 9 line 17*

An alternative childhood need was expressed by Maali who felt that siblings should have specific training in childhood so that they can learn to appropriately support the learning disabled child. This alternative perspective could be influenced by an Asian female cultural context.

*"I do feel that from a young age, there needs to be some sort of support or activities... some sort of training, coaching where you (brothers and sisters of learning disabled people) learn ...sometimes children need to be told, 'You know what, you've got this responsibility and I don't mean as a carer but you know she's your..., she's the weaker child you know, come on, this is how you can help her' ..."* Maali P 37 line 1

#### **5.11.4 Superordinate theme: advice to siblings**

Siblings had advice to give in 12 of the 15 interviews. The subthemes of advice around planning, siblings should be involved with the learning disabled person if they want to be and the learning disabled person should be supported to have as normal a life as possible, are presented.

#### **5.11.5 Subordinate theme: advice around planning**

Four of the five respondents who advised planning for the future suggested that it should start early in childhood to provide the most positive impact for the learning disabled person. One reason given for the recommendation of early planning was the length of time it takes for plans to come to fruition. Helen illustrates this:

*"...planning is..., it takes time, it takes a long time, ... we started planning his transition when he was 14 and*

*everybody told us we were crazy, and we only just got it - we only just got his service in place in time for him to finish school.” Helen P 16 line 22*

Steven felt that siblings should plan for the type of relationship they would like to have with the learning disabled person in the future. This may reflect the comments made by Kath who became the main carer for her disabled sister for a while following maternal death but felt that this damaged the sister role and their relationship. There is therefore a possibility that particular roles could have a negative impact upon the relationship between the typically developing sibling and the learning disabled person. Finally, within the theme of advice around planning, Rachel noted the importance of involving parents in the futures planning process, stating that their involvement is integral.

**5.11.6 Subordinate theme: siblings should be involved with the learning disabled person if they want to**

This subordinate theme includes the assertion by Helen and Rachel, that siblings have a right to be involved in the life of the learning disabled person, be this in a small or large capacity, should they wish to do so. Steven agreed that siblings should be able to be involved but did not go as far as to describe it as a right; however Helen and Steven made comment, almost after further reflection on the matter, that siblings should only be involved in the life of the learning disabled person should they choose to do so:

*“...and I think generally just being involved in the decisions (around the disabled person) and being asked ....” Helen P15 line 2*

Later in the interview Helen then said:

*“...if you don’t want to be involved, you just don’t be involved...,” Helen P16 line 17*

The need to be involved in the life of the disabled sibling with the option of withdrawal was explained further by Steven; he felt that it is was important to be involved in the life of the learning disabled person, but thought that if a sibling did not have the capacity to take this on for any reason, it was better to the avoid involvement to prevent feelings of guilt if unable to complete the task:

*“...make sure you get involved in some way, even if it’s in the smallest little bit, day to day with stuff or the odd little thing - get involved if you can... but, I think in my experience, only get involved when you really know you can give your time and energy to it... if you just do half a job you’ll feel bad about it; better just let people get on with it if you can’t do it.” Steven P 29 line 1*

Along similar lines, Rachel advised that siblings should not feel that the support of a learning disabled person was an hereditary responsibility passed down from generation to generation; James claimed that siblings should do what they feel is right rather than necessarily following the advice of service providers, and that they may need to be strong willed in order to do this.

#### **5.11.7 Subordinate theme: support the learning disabled person to have a normal life**

This theme was present in the interviews with Gail and Kath. Gail made a clear statement that she would like to see children who have a learning disability kept in main stream schools and to live as full a life as possible in the local community. This view was endorsed by Kath as her learning disabled sister had recently been supported to live in the community.

## **5.12 Summary of Stage two**

This chapter has presented the findings from Stage two of the research process. The nine main or superordinate themes that were evident in at least 11 of the 15 transcripts were set out in a chart and identified as: Impact of the learning disabled person upon sibling life; Family; How learning disability affects the disabled person; Social response to learning disability; Transitions; Services; The future and Advice to siblings and Siblings have needs (combined).

Within the superordinate theme, 'Impact of the learning disabled person upon sibling life', both positive and negative elements were recalled; however overall, more negative than positive impacts were recorded. Negative impact included: worry, having to deal with difficult behaviour for some, conflict in relationships, and reduced parental attention. Negative emotional responses including anger and a sense of loss were explored. All participants did however make positive comments about the experience of being the sibling of a learning disabled person, such as having a sense of joy or pride, a close relationship, the development of positive character traits and on occasion, positive opportunities that have only been possible because of the association with learning disability. The presence of the learning disabled sibling was seen to affect many areas of life, such as career and life partner choice for some participants but not for all. Sibling roles in relation to the learning disabled person were multiple and varied. Some siblings lived with the learning disabled person and were intensely involved in their day to day support, whilst others described roles of social contact, of "just being a brother or sister" or for some, a support to their mother. The role of most involved sibling was apparent in all

families where there was more than one typically developing sibling.

'Family' was a superordinate theme that again appeared in all interviews. There was a culture of care for family members, although the learning disabled person was also presented as a source of stress in the family context. An Asian cultural perspective was seen to share all the traits outlined, above although specific issues pertinent to Asian culture were highlighted. Within the context of family, mothers were portrayed as having a range of attributes, and the impact of the learning disabled person upon their lives was again varied, with increased and unique opportunities for some and a deep sense of loss and hardship for others. Fathers were afforded much less time in the transcripts than mothers, and a picture of varied paternal response towards learning disability was apparent, as it was with mothers. Some fathers were depicted as very kind and loving while others were embarrassed or disengaged, although it was also noted that parents may demonstrate both positive and negative reactions towards the presence of learning disability at different times. In some families, there was only one typically developing sibling and in others there were several; each sibling had a unique relationship with the learning disabled person and each other. In families where there were multiple siblings, all were clear about who was the most involved with the learning disabled person and various reasons for having this role were put forward, such as: life stage, family relationships, proximity and ascribed family role. Conflict and tension between siblings was present in some families regarding the support of the disabled person but was not present in other families. The final subtheme in the superordinate theme of family was that families were involved in the financial aspects of the

learning disabled person's life and this was a further source of stress.

The scope of learning disability reported by participants ranged from mild to profound. All respondents referred to the disabled sibling having physical or health issues in childhood and for most, although not all, there was some degree of health issue in adulthood. General conditions such as arthritis and diabetes were present for some individuals, as were mental health issues and behaviour that could be described as challenging. All respondents were able to outline both positive and negative effects of learning disability upon their sibling's life. The learning disabled brothers and sisters were described as needing help to manage accommodation, social situations and to learn in general. From a positive viewpoint, they were described as having basic self care skills in some instances; positive attributes such as a good sense of humour; positive community presence; and 'learning disability advantage' was described, which can be explained as the presence of opportunities that would not otherwise be available. The impact of learning disability upon relationships was raised and was again depicted in positive and negative terms.

'Social response to learning disability' arose as a theme from 11 interviews, which highlighted positive and negative attitudes. Examples of negative social response included fear, the belief that learning disability had been sent as a form of punishment, verbal abuse towards learning disabled people and inappropriate attempts to accept learning disability. From a more positive perspective, some participants felt that society in general is accepting of disability, and that some people hold a special affection for learning disabled people.

'Transition' was evident as a superordinate theme in 13 interviews and involved participants making general comments about transitions that incorporated change in the life of the learning disabled person over time, the influence of family context, sibling life stage and personal context. Parental ageing and death were significant transitional stages leading, in many cases, to considerable change in sibling roles and extent of responsibility for the learning disabled person.

The superordinate theme of 'Services' was present in all interviews with an almost equal number of positive and negative comments made. Negative aspects of services referred to the quality, range and appropriateness of services; the need for family to fill gaps in service provision; and the detrimental effect of poor services upon the lives of the learning disabled person and their families. A positive experience of services, however, was noted by some respondents: some services were depicted as flexible, able to meet need and establish a good working relationship with service users, resulting in siblings feeling less anxious. An additional perspective about services was that in a number of cases, participants viewed the role of family and service providers to be distinctly different. Although service providers were at times criticised for a lack of knowledge of the service user and family, it was recognised that service providers may have specialist skills and knowledge that families do not; despite this, sometimes service providers are restricted by professional protocols and political correctness from using what families deem to be a 'common sense' and more appropriate approach.

The superordinate theme, 'Future', incorporates futures planning which was said to be an open topic of conversation in certain families but not in others. Where futures plans did exist, they

tended to lack depth and detail for a variety of reasons including: assumption of care by others, a laissez-faire attitude and sibling life stage. Parental expectations of siblings' future involvement with the learning disabled person were vocalised in some instances but not others. Where parental wishes remained unspoken, siblings often noted a tacit understanding of their wishes but this was not always the case. Some parents were described as wanting co-residence between disabled and typically developing siblings; others reportedly did not want this, however overall there was a parental expectation of increased levels of sibling involvement with the disabled person in the event of parental decline. Some participants noted that parental wishes and expectations seemed to change over the life course, moving from low expectation of involvement of siblings at an earlier stage of life, to greater involvement as parents aged. Siblings' wishes regarding future involvement with the learning disabled person were equally inconsistent: some were content with existing levels of involvement (whether this was co-residence or not), whilst others expected to increase their level of support in the future, particularly when parents were no longer able to provide previous levels of care. Others again were unclear about their wishes and expectations for the future. Although there was some evidence of difference between sibling and parental wishes for the future, in most cases, the two were aligned. Most siblings were concerned about the future and their worries focused particularly on service provision and finance, the demands that the learning disabled person would make on their lives after parental death and health issues.

The superordinate themes, 'Siblings have needs' and 'Advice to siblings' were presented as a combined theme as answers to these questions tended to overlap. The majority of respondents claimed



that siblings of people who have a learning disability have needs of their own, some of which were generalised calls for support, but others were more specific, such as the call for advice, information, emotional support and practical assistance. Around half the respondents felt that siblings needed to look after their own needs and to avoid self-recrimination on account of anger or frustration they may feel in response to having a learning disabled brother or sister. Particular reference was made to the needs of siblings in childhood. In terms of advice proffered by the respondents to siblings who may be in a similar situation, it was suggested that early engagement with futures planning at a practical and emotional level would be helpful, alongside the involvement of parents. Other advice was that siblings should be aware of their right to be involved in the life of the learning disabled sibling at any level, should they wish to be involved; however it was advised that they should maintain the option of withdrawal without self-recrimination. Finally, two respondents advised that the learning disabled brother or sister should be supported to have a typical lifestyle as far as possible.

### **5.13 Comparison of results from Stage one with results from Stage two**

The depth and detail of information gained at Stage two was considerably greater than that gathered at Stage one; however when comparing the results of Stage one to the results of Stage two there are a number of similarities but occasional differences. In Stage one, there were varying levels of face to face contact with the learning disabled person, ranging from multiple contacts within one week to once every six months. At Stage two there were also different levels of face to face contact, although this ranged from daily to once every two to four months. At both stages a range of

sibling experiences in relation to learning disability were reported. With regard to sibling perception of services, most siblings at Stage one noted dissatisfaction with services caused by a perceived lack of understanding of the needs of families and learning disabled people, alongside diminished range and quality of service provision which was equally found at Stage two. At both stages one and two however, some participants noted positive experience of service provision.

Respondents at both stages one and two described mixed feelings about the influence of parents upon the futures planning process. Half the respondents in Stage one claimed that there was full discussion with parents about their role in the future support of the learning disabled person, yet the same number also reported that there were no formalised futures plan in place. Where plans did exist at Stage one, there was a lack of clarity; this was a similar presentation to the findings at Stage two, where depth and clarity were lacking. In both studies, parental distress was identified as a barrier to futures planning, however a much more detailed picture of the difficulties around futures planning was provided at Stage two.

Over half the respondents in Stage one reported no difference between their wishes and parental wishes for the future; however at Stage two the majority of participants reported no difference between their wishes and parental wishes, Sibling involvement with futures planning at Stage one was predominantly financial, however siblings held the expectation that they would take on an overseeing role in the future and both these roles were present in the results at Stage two. Again at Stages one and two, sibling respondents were concerned about the future and about what would happen then their parents died, about increased levels of

support to the learning disabled person and the impact of this upon their lives. Sibling needs for support with the future planning process and an increased range and quality of service options was highlighted in both stages; however Stage two highlighted the need to support siblings in childhood and with emotional issues at all stages.

Having now set out the process of data collection, analysis and the findings from Stages one and two, the next chapter will discuss the results of Stage two in the light of existing empirical research and theory in order to draw out similarity and difference and possible conceptualisation of the results, giving attention to convergence and divergence from known theoretical perspectives alongside potentially new constructs.

## **Chapter Six: Discussion**

In Chapter four, the analysis and discussion of the findings from Stage one were presented together. This was because Stage one was a separate, small scale exploratory study and it was felt that joint presentation of the results and discussion would provide greater clarity, and avoid the risk of the results from Stage one becoming overwhelmed by the results of Stage two. Having presented the results of Stage two in Chapter five, , the results of the 15 face to face semi-structured interviews from Stage two will now be discussed in the light of empirical studies, existing theory and potentially new constructs. This discussion chapter will be structured around three overarching themes that have emerged from consideration of the superordinate themes as presented in Chapter five.

The first overarching theme is entitled 'Impact of learning disability'. This incorporates the superordinate themes: impact of the learning disabled person upon siblings` lives; how learning disability affects the disabled person; social response to learning disability; family; and the future. The second overarching theme is that of 'Services', whilst the third overarching theme is 'Sibling needs and recommendations', which assimilate the superordinate themes: siblings have needs and advice to siblings.

### **6.1 Overarching theme: Impact of learning disability**

#### **6.1.1 Impact of learning disability upon siblings` lives**

The key message to be heard in this theme is that learning disability does affect siblings` lives yet the degree and areas of impact varies between individuals. Four participants claimed that the learning disabled person had affected all aspects of their life,

including career, family, relationships, their own families and social lives. A congruent theoretical underpinning for the assertion by some participants that the learning disabled person had affected all aspects of their lives could be derived from both family systems theory and the life course perspective (Elder et al 2003) which state that the life events of one individual will impact upon other family members; however the degree of impact upon siblings' lives is influenced by a wide range of factors that will be considered later in this chapter under the influence of learning disability upon the family.

Childhood experiences of growing up with a learning disabled child were referred to in all interviews and presented from a range of perspectives, which were linked, to some extent, to life stage. Nearly half the respondents referred to the experience of growing up with a learning disabled sibling as normative and part of their identity; however participants became aware of difference between their family situation and that of their peers with age. According to Burke (2010), although children's experience of disability within the family is their norm, they are also aware of difference. Some siblings may experience a negative impact at home, school and in their relationships with peers on account of their association with disability. McGraw and Walker (2007) described this concept as awareness of normality and exceptionality. Within the interviews, participants reported both positive and negative impacts of learning disability in childhood. Negative childhood effects included the acquisition of a care role, reduced parental attention, having to attend hospital or clinic appointments, worry about the disabled child and having to assume responsibility for them. Management of complex behaviour, finding it difficult to relate to other children at a social level and sometimes missing out on social activities with

other children were also raised. A range of negative emotional responses to their situation was also apparent: for example, guilt and anger at having to miss out on opportunities such as birthday parties because of the needs of the disabled child, as described by Helen in interview 3:

*“He (learning disabled person) had this wonderful habit of, really wonderful habit - he was always in hospital on my birthday every...single...year... it was hard not to get cross at him about that sort of thing...” Helen P 3 line 18*

Despite these negative impacts during childhood, some participants referred to positive aspects of their situation. The development of positive attributes (for example, patience and tolerance) were mentioned, as were more tangible benefits such as trips to the beach, going on holiday and having access to extra treats. The varied impact of a learning disabled sibling in childhood years as presented in this thesis has resonance with previous literature reviews (Stoneman 2005; Meadan et al 2010) and studies such as that by Moyson and Roeyers (2012), who found that young siblings of learning disabled children were able to describe both positive and negative features of the disabled child; they were aware of difference in abilities and the benefits the disabled child received on account of their disability, such as increased parental attention; yet they were also aware of additional opportunities that arose due to the presence of the disabled child.

For some participants, adolescence was described as a particularly difficult time due to embarrassment at the difference between the disabled sibling compared to their typically developing peers, and embarrassment appeared to be associated with self image at this particular life stage, as expressed by Rachel:

*“In my adolescent years it was horrific, emm, absolutely horrific cos in the adolescent years, the last thing you want is anybody being different - and she (learning disabled person) was very different.” Rachel P3 line 20.*

In addition to embarrassment and concern about difference there were continued expressions of anger and a sense of loss of a typical sibling relationship, again expressed by Rachel in interview 4:

*“...and one of the things that ...really did piss me off as a teenager was that there was 11 months between us; I should have been talking about lipstick and boys and discos and shagging, and I couldn't - it was dolls ... because that was Amy. So I'd got this somebody who was so close to me in age, and we should have been like that (crosses fingers) - but we couldn't be cos we were poles apart.” Rachel P 25 line 9.*

Wilson et al (1992) and Rigney (2009) similarly reported that teenage years are the most uncomfortable or embarrassing for siblings, and Rigney (2009) introduced the experience of guilt due to association with the disabled sibling in adolescence, which is discussed further in the section on impact of the learning disabled person upon siblings' lives in adulthood.

Within adult lives, this thesis demonstrates the impact of a learning disabled sibling to be as variable, and it therefore supports existing literature (McGraw and Walker 2007; Azeez 2001; ESRC 2011). When discussing the impact of learning disability upon their brother or sister, all sibling respondents noted difficulty with cognitive function, daily living skills, social situations and other health related issues. Learning disabled people were also perceived by participants as having positive attributes and to some extent, being

afforded advantage due to their disability, such as access to experiences that would not otherwise have been available. Although all respondents made positive and negative comments about the impact of the learning disabled person upon their lives, overall more negative comments were made, in terms of the range of comments and degree of text devoted to them. Two thirds of participants had a bias of negative comments compared to positive comments, in contrast to studies such as those undertaken by Cleveland and Miller (1977); Flaton (2006) and Rigney (2009) which found that most adult siblings adapted positively to the experience of having a learning disabled brother or sister.

Negative impacts raised in the results of this study included the demands the learning disabled person was perceived to make upon respondents' leisure or social lives, although the extent of demand was again variable, reflecting disparity between respondents. Some participants referred to demands such as regular social visits or acting as advocate in relation to accommodation needs; at the opposite end of the spectrum, James described how the disabled person almost fully dictated what he could or could not do. Even where siblings had much lower levels of involvement, there was some expression of obligation to be involved in activities they would not have chosen for themselves and therefore a cost to leisure or personal time was perceived.

Additional negative impacts described in adulthood were those of having to manage difficult behaviour, conflict in family relationships including other siblings and older parents, and tensions created by a sense of split loyalty between siblings' own families and the disabled person; this is further discussed in the section on the 'Impact of learning disability upon family'. Conflict between family members was raised by Karasik (1993) and Kramer (2008) whose



work showed that adult siblings referred to dissatisfaction in the variant levels of care provided by different family members and that some siblings were seen to be more involved in the decision making process than others. The most commonly occurring negative impact of a learning disabled person upon siblings' lives from the findings of this thesis were those related to fear and worry, in relation to three main aspects; firstly, childhood fear of parents dying and the respondent becoming responsible for the learning disabled person; secondly, that the learning disabled person would die because of their condition; and thirdly, fear of the sibling's own death as this would mean that they were no longer be able to provide a support role. These fears may be understandable where siblings have grown up with the belief that family members have a role and duty to support each other, including the learning disabled person, and may link with family culture which will be discussed under impact of learning disability upon family. An additional element of worry raised in the results related to a lack of money to meet future care needs, which is associated with finance as a source of stress as discussed under the impact of learning disability upon family.

Further examples of negative emotional response towards learning disability expressed throughout the interviews incorporated guilt, anger, a sense of loss or grief, and jealousy. Feelings of guilt were noted in just over half (eight) the interviews and were sometimes attached to feelings of selfishness, or because the learning disabled person did not have the same life opportunities as the typically developing sibling. Guilt also related to both past and future behaviours such as excluding the disabled child from play in childhood or not wanting to live with them in the future. In some

instances a sibling had negated their own best interests to avoid guilt, as demonstrated by James:

*“Objectively I can see... and people have said, ‘Well you’d have a better life without her’, but then I’d... and I say, ‘Well if I put her in a home then I’d be racked with guilt’ ....”James  
P 36 line 10*

Anger in adulthood was expressed towards the learning disabled person because of their behaviour; it was also directed at people who made derogatory comments about the disabled person, poor quality services and even other family members. Some participants described the presence of an anger-guilt cycle and two explained that they had received counselling for mental health needs in adulthood due to the negative effect of the learning disabled person upon their lives. The loss of a typical sibling relationship as referred to by participants in adolescence was also experienced in adulthood: Fran raised the loss of extended family such as sister in law, nephews and nieces, and for Janet, the loss of a typical life for the disabled person was expressed as “what might have been”. The presence of such negative emotional responses have parity with the findings of the ESRC (2011) which reported that in addition to positive findings, some adult siblings felt torn between their own family’s needs and the disabled sibling; a sense of loss of typical sibling and mental health issues including depression; low self-esteem and anger.

Further following the pattern of childhood impact of learning disability, all respondents made positive comments about the learning disabled person as well as negative comments. Around half the participants (seven) claimed that the disabled sibling brought joy, pleasure and enrichment to their lives with the same

number noting pride in their brother or sister. Even where the learning disabled person created high levels of difficulty or stress in siblings' lives, (as illustrated by Rachel and James), the word 'love' was still used. Six participants referred to a special bond which, in one case, was likened to a relationship between twins.

In addition to this positive emotional connection with the disabled person, there were other benefits that included the learning disabled person being a source of fun or humour, having a greater understanding of the needs of disabled people, higher levels of patience, confidence, determination, independence and an awareness of health and well-being; these reflect positives that have been previously reported by Flaton (2006) who felt her life had been enriched by the experience of growing up with a learning disabled brother. Rigney (2009) and Hodapp et al (2010) also noted the development of positive attributes amongst adult siblings in the form of empathy, understanding, compassion, awareness of injustice and being a responsible person. Tangible benefits directly linked to the presence of the learning disabled person were referred to by some participants in adulthood as well as childhood: for example, going on holiday and gaining access to celebrity events or having extra treats by playing, what one respondent referred to as, "*the Down syndrome card.*" This is of interest, as previous studies have referred to children noting the presence of tangible benefits due the presence of the disabled child (Moyson and Roeyers 2012); however there is little reference in the existing literature to tangible benefits in adulthood.

As all respondents made both positive and negative comments about the impact of the learning disabled person upon their lives, this could be considered a typical response because most people in enduring relationships are able to voice positive and less positive

attributes of an individual. For a few respondents however, both positive and negative comments were made about the learning disabled person in the same sentence, perhaps suggesting high levels of ambivalence. An example of this can be seen in the interview with Rachel who said the following:

*“I love her (learning disabled person) to bits ...she can be at my house for half an hour and I can want to throw her through a window because she can really wind you up...”*

Rachel P 14 line 16

Existing studies have shown sibling relationships in learning disability families to be varied, ranging from warm with extensive contact to no contact at all (Zetlin 1986; Karasik 1993; Rigney 2009; Meadan et al 2010). There appear to be shifts in closeness over time with contrasting reports about whether levels of sibling intimacy in the presence of learning disability increase over time (Orsmond and Seltzer 2007) or diminish over time (Zetlin 1986; Hodapp and Urbano; Taylor et al 2008). Shift and change in sibling intimacy may be associated with change in sibling roles and relationships which will be considered shortly, and from the results of this thesis roles and relationships are seen to vary over the duration of the life course. These changes support the connecting themes of `transition` and `variation` which run throughout the thesis and connect the themes presented here, further supporting the view that the impact of a learning disabled person upon siblings` lives is complex, multi-faceted and varies between families and between individuals within families.

Having discussed positive and negative impacts of the learning disabled person upon siblings` lives, and the awareness of difference, participants also made reference to society`s response

to learning disability. Both positive and negative social attitudes are referred to. Experience of a negative social response to learning disability was present in 10 of the 11 interviews, with one respondent claiming that some individuals in mainstream society believe that people who have a learning disability should be incarcerated and segregated because they present a danger to society. Other negative responses towards learning disability that respondents had experienced at first hand included name calling, negative judgement, being considered a perpetual child, and a punishment from God for wrong doing. Conversely, an example of people trying to be friendly but inappropriately overstepping typical boundaries was recounted in Interview 10 by Kevin:

*“The landlady came over and she was new - she’d never met Laura before and she hugged her and kept putting her arm round her...it was a little bit too claustrophobic.”* Kevin P 14 line 6

From a positive perspective, respondents gave examples of positive social regard and acceptance of learning disability. Janet claimed that there is such diversity in today’s society that disability is more accepted:

*“I think in this culture that we’ve got now, anything goes... it’s almost like.., to an extent it’s more acceptable now.”* Janet P 26 line 15

Carol linked response to learning disability with culture and had experienced a high level of acceptance within Turkish culture; whilst Helen presented an almost magical image of her learning disabled brother, who was said to be “adored” by people. James gave an example from approximately 20 years ago of a learning disabled person having a valued role in the family business, which

suggests that although there may have been less public acceptance and policy that supported inclusion and equality at that time, it was still present at a local level for some individuals. From the results of this thesis therefore, siblings described a variety of positive and negative responses, towards learning disability at both a social and an individual level, which may be influenced by culture, and time and place in history. Even where the dominant culture may have a particular response towards learning disability, there may be variation in response; this further links with the recurrent theme of variability.

In reference to the impact of the learning disabled person upon sibling career, partner choice and the decision to have children, over half (nine) the number of participants had some degree of engagement with health and social care as either their full time job or in a voluntary capacity, and some respondents had both. A strong connection with employment in health and social care was present for six respondents, and seven directly associated their paid or voluntary work to their experience of learning disability; where respondents were engaged in voluntary work, this was often within learning disability services. Despite these findings, five siblings were not employed in a health or social care capacity or engaged in voluntary work and so the results would suggest that there is a clear link between career choice and learning disability for some siblings, but not in all cases.

The impact of the learning disabled person upon partner choice was variable between the interviews but was raised specifically by four participants. For three respondents, the willingness of a partner or spouse to accept the disabled sibling was central to the continuance of the relationship and sometimes meant that the learning disabled person was able to live with the respondent and

their spouse. In two interviews, the expectation that the learning disabled person would live with the sibling after marriage was an unspoken understanding between the couple, however both respondents stated that the marriage would be unlikely to have taken place had the spouse not accepted this situation. For one respondent marriage or a long term live-in relationship was not possible because the person with a learning disability would reportedly not tolerate a wife or another woman in the house. For another participant, the presence of the learning disabled person had led them to the decision to remain childless due to concerns that they may too have a disabled child, and because of the perceived future care needs of the disabled sibling.

The findings here reflect previous studies that have considered career choice, partner choice and the decision to have children, and these too demonstrate conflicting results. Seltzer et al (1997), Marks et al (2005) and Flaton (2006) all made a positive link between learning disability and career choice, although this was refuted by Karisak (1993), Konstam et al (1993) and Burton and Parks (1994). Similarly Flaton (2006), Seltzer et al (1997), Karasik (1993) and Orsmond and Seltzer (2007) all associated the experience of growing up with a learning disabled sibling with partner choice and the decision whether or not to have children. However, Taylor (2008), when comparing brothers and sisters of learning disabled people to those with typically developing siblings, found no significant difference in the number of children siblings had; this again provides evidence of disparity regarding the impact of a learning disabled person upon specific life course outcomes in adult siblings' lives.

The findings of this thesis present siblings' roles with the learning disabled person as many and varied, drawing further attention to

difference between respondents and between siblings in the same family, therefore supporting the results of earlier studies which highlighted the multiplicity of sibling roles and variation between sibling roles in different family settings (Bigby 1997; Thompson 2001; Rigney 2009; Bigby et al 2011). These studies also support the concept that sibling support roles change over the duration of the life course, especially when older parents are no longer able to provide previous levels of support. Although less than a third of respondents had taken on a major carer role such as co-residence or providing significant support with domestic, personal care and social activities, nearly half reported a significant role which was at more of an advocate or mentor level rather than direct care provision. Just over half of the respondents highlighted the role of defender or protector, giving examples from childhood through to adulthood, which may be further linked to a family culture of care and duty to support the disabled person.

A little mentioned role in the existing literature, yet referred to by six participants, was that of a support role to their mother due to the presence of the learning disabled person, and whereby siblings would aim to protect their mother from perceived burden. It was apparent that siblings were likely to hold multiple support roles in relation to: their own families, older parents because of the learning disabled person, older parents because of the ageing process, and to the person with a learning disability. Six participants felt they had a parental role with the disabled brother or sister; they sometimes suggested that the learning disabled person viewed them as a mother figure, and also that they considered the learning disabled person as their child, as expressed by Val in Interview 14:



*"I suppose he's like my child, in a sense... he's my brother and I love him although he's like a child - like my child as well."* Val P 10 line 12

This concept again has been documented in previous studies (Karasik 1993; Bigby 1997; Kramer 2008; ESRC 2011). Perhaps tying in with a parenting role is that of educator or teacher, which three participants mentioned. More than half of the participants (eight) said that they viewed the learning disabled person as they would any other brother or sister and in two instances, participants were clear they wanted to maintain a sibling role rather than become a carer, because they considered these to be conflicting roles. A financial role was noted by six participants at the time of interview (although this may rise after parental death) and was noted to be an area of concern for the future.

It is clear that adult siblings of learning disabled people have a range of roles and different degrees of involvement; however the reasons why siblings provide support needs to be considered. Using the model of adult sibling attachment based on Bowlby's life-span attachment theory (1969), the functions of the sibling relationship in adulthood are those of a symbolic representation of family history that includes internalised shared values and goals and protection of the attached figure (sibling in this case). For most people, the need to observe the bonds of attachment to members of the primary family group becomes increasingly important as time progresses.

As learning disabled people are less likely to have support from a spouse or children, siblings as kin, along with other relatives and service providers, are likely to compensate for the absence of these relationships. Within the hierarchy compensatory model (Cantor

1979) the support provided depends upon the nature of the relationship rather than the nature of the task. From this perspective, siblings as kin have the closest relationship with the learning disabled person from a socially constructed perspective and when the primary support provider (often an older parent) is not present, siblings are likely to compensate for or replace the lost support. This could explain why siblings take on more support roles when parents age and die, and why some respondents described their role with the disabled brother or sister as parental; it may also explain why the siblings' role is different to some extent to that of parents' as they are substituting for a parental relationship. This theory however would not explain why some siblings want a sibling role with the disabled person rather than that of parent or carer.

The theory of differential primary groups (Litwak 1985), however, explains that members of an informal support network cannot easily substitute for each other because they do not have the same required characteristics. From this perspective, kin are unlikely to replace care provided by parents as they do not have the same relationship, commitment, proximity, structures, characteristics and resources. Replacement, using this theoretical construct, is said to be most likely when network members have atypical characteristics, for example: that they are unmarried or live in close proximity to the person who needs support, as opposed to those who have their own life commitments or live far away. This theory could explain why some siblings in this study took on a parental role and chose to live with the learning disabled person, (they were unmarried at the time of assuming the parental role (or have remained unmarried) and lived in the family home when the main carer died); this fulfils the need for proximity and supports the acquisition of the most involved sibling role.

Where there are multiple siblings in a family but one takes on the primary responsibility for the disabled person, this role is described by the term `most involved sibling`. This role has been described in adult sibling studies within the field of learning disability from the early research until the present day (Zetlin 1986; Greenberg et al 1999; Bigby et al 2011). The findings presented here demonstrate that where there was more than one typically developing sibling in a family, all understood who held this role and were aware of the expectations and responsibilities attached to it. Kath claimed there is only one person in any family who takes overall responsibility:

*“It doesn’t matter how many times you discuss things in a family, there’s only ever one person who takes the lead, if you like, and it was always me... I knew that they (other siblings) expected me to do it, as well, the rest of them.”*

*Kath P 23 line 11*

Different reasons why people held the role of most involved were given and these included: parental expectation, stage in the lifecycle and personal circumstance, being the youngest in the family, being at home when mother died and other siblings being married or working.

Earlier studies have linked sibling care giving to: gender, life circumstances, life stage, birth order, level of disability, relationships between the siblings, parental influence, family climate and the health status of the individuals involved (Zetlin 1986; Greenberg et al 1999; Jokinen 2008, Heller and Arnold 2010). There remains, however, some conflict of opinion, especially regarding the impact of parental expectation and family culture (Karasik 1993; Rimmerman and Raife 2001). As the second eldest male child in his family, James illustrated a variation from the more

accepted norm that the most involved role is adopted by a younger sister. This further illustrates variation amongst families in the characteristics of the most involved sibling. Overall, the results presented here show sibling roles to be mixed and multiple; however role confusion was evident for Steven in Interview 12:

*"...and I don't quite know what my role is...I'd suddenly feel, 'Is that appropriate? Should I be getting involved?'- cos I'm not really involved day to day? But obviously maybe there is a role for me there...that's what I'm not sure, clear about. "*

Steven P 17 line 19

This reflection appears to further add credence to the theory that sibling roles shift and change over the life course.

The concept of the most involved sibling could be aligned to the task specificity model, developed by Litwak (1985), which comes from the theory of shared functions and emphasises the nature of the task and characteristics of the support required. In terms of support and care giving, kin are seen as appropriate providers of traditional kin-associated activities that require long term and intimate knowledge of an individual; however, due to geographical location, some tasks that require proximity are difficult for kin to undertake. Using this framework, some tasks are better completed by certain individuals rather than others: the type of task, proximity of the individuals, and relationship between the individuals will predict who is most likely to provide support. This could therefore mean that certain individuals in a family will be considered as more likely to become the most involved sibling than others.

A further perspective that may also have relevance to the concept of most involved sibling is the symbolic interactionist view of negotiation (Finch 1989; Finch and Mason 1993). Here, the actions

an individual takes are attributed to their interactions with other people, and negotiation may be explicit or implicit. Family negotiations, whether explicit or implicit, are said to evolve over time and take into account who will take on which roles for whom, and when they will take on such roles. The negotiation of roles and responsibilities is seen to be dependent upon the relationship between the individuals and is socially constructed, taking into consideration issues of gender, age, race, class and ethnicity. This perspective could provide some degree of rationale as to why some siblings are most involved, and account for the difference in how families communicate over roles, responsibilities and expectations as discussed in the next section.

#### **6.1.2 Impact of learning disability upon family**

Family may be described as two or more people brought together by ties of consent, birth or adoption, who together over time, take on responsibility for family functions (Benzies and Mychasiuk 2008). The results of this thesis demonstrate that family members support each other, including the learning disabled person, and this is concept well supported by existing literature (Mansell and Wilson 2010; Bigby et al 2011; Cooper and Ward 2011; Rillotta et al 2012). The presence of a familial bond that includes a sense of love and concern for each other's welfare, passed on as part of family culture, was commented upon by more than half the participants; notably it was described by Claire in Interview 2 as a legacy of love that had been passed on by her parents. The word 'duty' was used in some interviews and appeared to incorporate a sense of responsibility towards the person with a learning disability. For some respondents duty was linked to love, whilst for others, it was expressed as an almost moral responsibility different from love; Gail provided as illustration of this in Interview 5:

*"...everything that was done for our Verity was done out of duty rather than perhaps out of love."* Gail P 23 line 30

Even where feelings of duty, as opposed to love, were expressed, the family (or at least some family members) had provided a supportive role to the learning disabled person in a variety of ways, such as providing holidays, listening to their worries and providing social contact. The idea of a family culture of supporting a learning disabled person is present in existing literature: Benderix and Sivberg (2007) found that adult siblings of learning disabled people experienced a sense of responsibility and feelings of empathy that they felt had originated in childhood. Feelings of a family bond and the need to support family members are likely to remain with siblings as they continue throughout the life course; it is likely to be part of their family cultural values and may be associated with sibling willingness and expectancy to take on future support roles.

Alongside the view that family members support each other and the learning disabled person, the results draw attention to the interconnectedness of family systems: families were seen to support older parents, other siblings in need, children and grandchildren. In a number of instances, the wider family such as grandparents, aunts, uncles and cousins supported the nuclear family in the presence of learning disability. The perspective that family members support each other and the learning disabled person at an inter and intra-generational level, and that support within families shifts over the life course has support from earlier studies (Karasik 2006; Jokinen 2008) and suggests that siblings may often have a co-caring role; however, once again, earlier studies demonstrate variability in the degree of familial support provided, which could be viewed from a perspective of family resilience (Benzies and Mychasiuk 2008). Using this viewpoint,

families are presented as complex and diverse systems, and family resilience is defined as the ability to respond in a positive way to negative events and to increase confidence, resources and strength. Family resilience in the presence of learning disability has been related to having established rules, rituals and routines in the home; coherence; hardiness to deal with life events; ability to perceive benefits from the situation; ability to consider the learning disabled child as an individual and to view them with love and acceptance, whilst having the capacity to reflect upon the concept of family and communicate this to each other (Edd and Edd 2009).

From a theoretical stance, the reasons why families support each other can be considered from a number of different viewpoints already set out under the superordinate theme, 'Impact of a learning disabling person upon sibling life'; these include Bowlby's life-span attachment theory, family systems theory and the life course perspective, along with the hierarchy compensatory model developed by Cantor (1979). As people with a learning disability are less likely to have support from a spouse or children, siblings as kin, other relatives and service providers may compensate for the absence of these relationships; this has parity with the results presented here where families were seen to support each other as well as the learning disabled person.

A number of different theoretical frameworks and theories can be applied to families in the presence of learning disability. At a very basic level, if taking a family systems theory approach, the presence of a child with a disability will influence the whole family including other siblings (Moyson and Roeyers 2012). However, presenting a basic construct such as this becomes more complex if then overlaid with the ecological framework proposed by Bronfenbrenner (1979); this identified that wider environmental

influences such as government, educational and community systems, along with their policy and practice, are said to affect family function. Structuration theory puts emphasis on the joint recursive influence of macro and micro processes, the interaction between large social and system structures that influence everyday action including family function.

Despite many reports of love, care and support for the learning disabled person within family culture, participants referred to the learning disabled person as a source of stress or conflict, even where especially close bonds with the learning disabled person had been described. Supporting the learning disabled person was depicted as hard work and a strain on time, attention and resources; this view supports earlier research such as a UK review of carer roles in the presence of learning disability, which identified the presence of extra demand upon physical and mental health, high levels of stress, isolation, enmeshment and expressed emotion. Other stressors noted in this review were those generated when one parent (often a mother) had given up employment to provide care, which then affected family finances; high levels of marital breakdown were also noted (Yannamani et al 2009).

Further stressors of shame or embarrassment (in relation to the learning disabled person) and marital stress were raised by participant siblings. One mother and two fathers were described as ashamed or embarrassed about the learning disabled person, and marital stress was associated with the presence of learning disability in three interviews. Marital stability was inconsistent across the interviews: parents appeared to work together in a co-operative way and share responsibility for the care of the learning disabled person in some families; in others there had been a number of marriages, although a very positive relationship between



the learning disabled person and the step-parent was depicted in the interview with Fran. Stress in the family due to the presence of the disabled person was not restricted to parental stress, but included conflict between parents and typically developing siblings; siblings and siblings; and siblings and wider family members such as in-laws. One reason for conflict was difference of opinion on issues around the disabled person and their needs, and concern about the future which will be discussed under this overarching theme. A further stressor within families was poor mental health due to the presence of learning disability, as presented by Helen in interview 3:

*“Me, my mum and my dad, we all got diagnosed (with depression) probably within six months of each other when I was about 18.”* Helen P 5 line 13

Psychological difficulties and stress have been previously referred to in the literature; for example, in a UK study by Hatton et al (2010) families of learning disabled people reported reduced physical and psychological health, and lower rates of employment and finances, especially in circumstances where the disabled person was perceived as very dependent and where their needs had to be prioritised.

Mothers were referred to specifically by all participants and generally had more text assigned to them than fathers. In keeping with the theme of variance, mothers were portrayed from a range of different perspectives: some were depicted as strong, determined and matriarchal, others as loving and caring. Conflict in the relationship between mothers and the learning disabled person was also apparent and on occasion mothers were described as resentful, embarrassed and angry in relation to their learning

disabled offspring. In only one interview was the mother presented in a wholly negative light and unable to cope with the learning disabled person. Over half the interviewees described their mother as over-protective and anxious about the disabled person whilst the same number again noted a particularly close bond; in two instances this was described as *“umbilical”* and in a third interview, the expression, *“almost like the same person”* was used to describe the relationship.

Some mothers referred to in the interviews were said to have experienced particular difficulties as a direct result of having a learning disabled child: examples included career limitations, feeling unable to have more children, feeling guilty, having more household chores, having no personal time and increased difficulty with their care role as they aged. Existing empirical studies corroborate these findings in relation to maternal stress; for example, in the study by McGraw and Walker (2007) mothers were described by adult typically developing children as busy, tired and frustrated due to the presence of the learning disabled person. At an international level, mothers in Taiwan were said to experience depression, poor physical health and caregiver burden (Chou et al 2010). Other maternal stressors noted in this thesis were limited support from a spouse, time spent in meetings or advocacy, and mothers internalising their child’s disabilities as a personal failure. Perhaps the strongest report of negative impact upon a mother’s life was expressed by Rachel (Interview 4); she recalled her mother saying her life had been *“ruined”* or *“destroyed”* because of the learning disabled person. Despite her feelings however, this mother continued to provide support and care; this connects with the theme that family support the person who has a learning disability. A couple of interviews suggested that the presence of the

learning disabled person brought about new opportunities for mothers that would not have otherwise arisen, such as the setting up of voluntary services and widening social contact. The suggestion of maternal advantage linked to the presence of a learning disabled person is a novel concept in existing literature and is important to note.

In respect of the relationship between typically developing children and their mothers, three participants discussed how their mother tried hard to meet the needs of her non-disabled children. Three participants also made comment that their mother actively sought to foster a positive relationship between the learning disabled and typically developing children. One reason for this could be maternal concern for the future as a positive relationship between siblings could serve as an insurance policy for the disabled child. This again supports the view that family care for and support each other.

Compared to mothers, fathers were mentioned in their own right in 12 of the 15 interviews, but were given much less attention than mothers, possibly because mothers traditionally take on the main carer role. Fathers, like mothers, were described as having a range of attitudes towards the learning disabled person, which returns once more to the theme of variation in family response to learning disability. Some fathers were described as loving and accepting of the disabled person, as joint carer with mother and in one case as the main carer instead of mother. The stepfather in one interview was said to be the main father figure for the person with a learning disability rather than the birth father, and in two families, the father was said to have the closest relationship and spend more time with the learning disabled person than the mother. Elements of conflict or stress for fathers because of the learning disability were

expressed in five interviews and included marital stress, feeling ashamed or embarrassed, working away much of the time or simply not being involved. This presentation of fathers is apparent in the literature where fathers claimed that they too, like mothers, experienced some degree of stress because of having a disabled child in the family, however the literature also suggests that fathers generally have lower levels of stress and a more positive health status than mothers (Little 2003; Smith and Elder 2010; Quintero and McIntyre 2010). Even when negativity towards the learning disabled person was described in this thesis, a number of these fathers still tried to provide some level of care or support; this mirrors to an extent the variation in response by individual mothers towards their learning disabled child.

Other typically developing siblings in the family were referred to in 12 interviews. Different relationships existed where there was more than one typically developing sibling in the family, returning to the theme of variation in family relationships. Some siblings had a closer relationship with the disabled brother or sister than others; in families where there was more than one typically developing sibling one had the role of most involved, as discussed earlier. Conflict or stress between typically developing siblings in response to issues concerning the learning disabled person was present in some families. Four respondents suggested that other brothers and sisters in the family could be more supportive in the care of the learning disabled person. In contrast to this (again demonstrating fluctuation in response) siblings in eight families appeared to offer support to each other; however, in four of these eight families; both negative and positive comments were made as some siblings were felt to provide less support than others, which could at times cause dissatisfaction. Variation in the relationship between typically

developing siblings in learning disability families is upheld in the literature (Meadan et al 2010; Lardieri et al 2000); where the perceived impact of sibling relationships was compared between learning disabled and typically developing families there were reports of both positive and negative dynamics to the same extent in both settings. To summarise this point, some sibling relationships in both typically developing and learning disability families are supportive and warm, whilst in others there is conflict or isolation.

Conflict and stress in sibling relationships can be considered from the concept of disruptive justice which was developed in reference to typically developing families with regard to sibling support of older family members yet has relevance in the presence of learning disability. One sibling in a family may provide more care giving to a family member than others (Ingersoll-Dayton et al 2003; Suito and Pillmer 1996) and the ability of a sibling to provide a support role could be judged as dependent upon their socially constructed ability to provide care and what is deemed to be fair. The strength of emotional bond between siblings has also been shown to affect perceptions of fairness in care giving (Mathews 1987, Mathews 2002a). If siblings therefore do not consider inequality in care giving to be acceptable or reasons for inequality in care giving are not understood, this could lead to negative family relationships. This perspective is aligned with the concept of legitimate excuse (Finch 1989) which explains how certain circumstances within a family culture for example geographical proximity, work demands, ill health and other family commitments may be deemed socially acceptable reasons for not fulfilling family responsibilities.

Finance was linked to the concept of conflict and learning disability in five of the 15 interviews with two key components: firstly, that

family were involved in the financial affairs of the learning disabled person and secondly, that money was a cause of stress in the family. Both these elements have been present in previous studies (Bowey et al 2005; Rawson 2009). Parents typically manage the financial affairs of learning disabled people but when they are no longer able to do so, a sibling will often take over this role. Wider family members however, such as nieces and nephews, may also take on responsibilities; for example trust fund administration. Money as a source of stress in the family was reported on different levels: in four interviews financial stress was generated because the family was concerned that there may not be enough money to meet future care needs; one interviewee raised concern about financial abuse of the learning disabled person from another family member. Previous studies have drawn attention to finance and learning disabled families and it has been demonstrated that a stable financial situation and higher socioeconomic status is a protective factor where a child has some form of disability (Benzies and Mychasiuk 2008, Edd and Edd 2009). Within the UK, Canary (2008) claimed that families supporting learning disabled people experienced economic disadvantage compared to typically developing families.

Interview 8 included all previously stated components (the family supporting each other and the learning disabled person, the disabled person being a source of stress, and financial issues), but made specific reference to Asian family culture, the foundation being that disability is a taboo subject:

*"...in Asian culture it's a bit of a taboo... Have any sort of disability, learning, physical, you know - having any defect really". Maali P 17 line 22*

This participant stated that in Asian culture the responsibility for deficit remained with the mother:

*“... and in Asian culture, your mother teaches you everything, and if, if anything defect, anything is left or fall short of... - it's always the mother's fault”. Maali P 16 line 10*

The desire on the part of the family to retain a sense of cultural identity was clear in this interview:

*“We all moved to Pakistan ...that was a cultural move really ...you've got daughters... they are growing up and they need to know about their culture and that they will get lost in the west ...” Maali P 2 line 7*

The importance and interconnectedness of family reflected in the other interviews was strongly present, as demonstrated in the quote:

*“In Asian cultures ...you've got extended family, you've got in-laws to deal with, you got..., you know anybody and everybody has got a say in your life...” Maali P 9 line 21*

It could be argued that difference in cultural attitudes towards learning disability is another facet of variety in family response to learning disability. Cultural attitudes are likely to affect family response; however it is important to be aware that attitudes and response to learning disability vary from family to family despite cultural background, as was evident in the other interviews where respondents came from a white ethnic background.

Although limited in number, there are some published studies concerning families from an ethnic minority background and their experiences of coping with a learning disabled family member. A

review of support for families of children with disabilities undertaken by Canary (2008) found that culture may impact upon levels of family support. Latino and Chinese families were found to have more family support than other cultures where learning disability is associated with shame and discrimination, as suggested in the Asian perspective provided earlier. The few empirical studies involving ethnic minority background families and learning disability provide a generalised picture that these families may be qualitatively worse off due to poor housing, social isolation, a lack of support and information, poverty and a lack of services that are culturally appropriate (Yannamani et al 2009). This perspective is further endorsed by Samuel et al (2012) who considered the quality and quantity of service support to low income families of children with a disability in the USA who came from ethnic minority backgrounds. Results showed that over half the number of families involved felt they needed more help from services but half those who received services were satisfied; the main barriers to accessing services were said to be a lack of information, waiting lists, finance, transport, poor quality of service and communication issues. Difficulties may be further compounded by language barriers and reduced levels of assertiveness, self-advocacy, and social support (Canary 2008; Hatton et al 2010).

### **6.1.3 Impact of learning disability upon the future**

From the findings of this thesis, earlier studies (Heller 2000; Bowey and McGlaughlin 2007; Gilbert et al 2008) and the results from Stage one (Davys et al 2010) it can be seen that there is a fairly equal division between families where futures planning is openly discussed and those where it is not; this provides some contrast to the findings of Dillenburger and McKerr (2010) who found that the



majority of older parents or carers in their study had not made long-term futures plans. This draws further attention to the multiplicity of family response to learning disability. The results of this thesis show that where futures plans were openly considered, this tended to be at a verbal level rather than written level. Futures plans reported included an end of life plan, financial or advocate plans and non-specified plans. Although five respondents claimed that discussion around futures planning was not an open topic of conversation, many had a clear understanding of what parents expected of them in the future, as demonstrated by Andrea:

*"...the question of him going into care just was never asked, cos we'd never even considered it..."* Andrea P 8 line 27

Such implicit understanding may be associated with the influence of family culture and expectations, as discussed under the superordinate theme, 'Family'.

Where future plans did exist they tended to lack detail: although eight respondents gave the impression that there was a reasonably clear understanding of a futures plan at a particular stage, the longer term plan had not been considered when participants were questioned more closely. An example of an apparently clear plan lacking detail can be seen in the interview with Janet, in which she said that the plan for her to live next door to her learning disabled brother and mother was said to be an explicit understanding within the family. When asked a little later if her learning disabled brother would live with her in the longer term, her reply was that everyone assumed that he would live with her but then went on to say:

*"That`s something we're going to have to look into."* Janet P 19 line 1

The lack of detail around futures plans may provide evidence for the view that this is essentially a transitional process; this is given further credence when reviewing the rationale for a lack of futures plans.

The reasons why open discussion around futures plans had not taken place were many and varied. Participants referred to parental fear for the future and the belief that no one else apart from the older parent could provide the right sort of care for the learning disabled person, as expressed by Kath:

*"...she (mum) was frightened that something wouldn't happen... she didn't want to leave Laura on this earth if she wasn't here to look after her... she thought nobody could look after Laura like she could".* Kath P 22 line 14

Seven respondents linked parental ageing to increasing difficulty in maintaining a care role which was a source of stress to both parents and sibling participants. Distrust of the quality and level of care is associated with the idea that talking about the future is stressful for older parents; literature endorses the view that futures planning creates anxiety for older parents and carers, is complex and highly emotive (Brennan 2005, Bowey et al 2005; Bowey and McGlaughlin 2007; Taggart et al 2012).

One theoretical perspective that may shed light on the apparent unwillingness of older parents or carers to take part in futures planning is that of unrealistic optimism, as espoused by Weinstein (1980, 2003). Although this theory was originally attached to futures planning and typically developing older people rather than learning disability, it may provide an explanation as to why older parents do not wish to engage with futures planning. This theory suggests that when individuals assess the potential for needing

future support they may generally accept that decline and dependency will occur, but tend not to accept this for themselves. As such, people may be unrealistically optimistic about their health and consider themselves to be at less risk of illness. Unrealistic optimism appears to be unrelated to gender, occupation, age or education; when applied to the field of learning disability this could lead to an underestimation or denial of the carer's ability to support the disabled person, which may be further compounded by a lack of faith in the quality of service provision. Further support for the credence of this theory applied to the field of learning disability can be found within a UK learning disability study by Gilbert et al (2008) which identified that one of the reasons carers gave for not making futures plans was the feeling that they were still coping. Dillenburger and McKerr (2010) also reported an attitude of ignoring the need for futures planning by older caregivers alongside the belief that support would be provided as the need arose.

The literature also purports that specific barriers such as insufficient information (Heller 2000; Gilbert et al 2008; Taggart et al 2012) and difficulty with service providers (Bowey et al 2005; Heller 2000) are reasons for a lack of futures plans. This thesis however, raises issues of siblings having a laissez-faire attitude, as reported by Kevin, and, which is supported by a previous study by Dillenburger and McKerr (2010). Superstition was described by Andrea as a barrier to planning, as was the assumption that 'someone' in the family would provide care, as suggested by Kevin. Additional reasons for a lack of plans included sibling life stage, living in the present or next anticipated life stage, and siblings not yet being sure what they wanted for the future. This further illustrates the view that futures' planning is a transitional or developmental process that evolves over time, and that a sibling's

life stage and circumstances are likely to influence their wishes and capacity for future involvement.

Although there are difficulties in the futures planning process related to learning disability, the various parties involved may have particular wishes and expectations. The results of this study present the sibling perception of parental wishes; the wishes and expectations of the respondent sibling; and sibling perception of the wishes of the learning disabled person in a few cases. Parental wishes and expectations regarding sibling levels of involvement were varied. Some parents expected the typically developing sibling to take on the role of over viewer; others expected co-residence, whilst others again expected non-residence. The literature concerning parental expectations for the future identified that one of the main concerns of older parents is the support role that siblings will play when parents were no longer able to provide care (Jokinen and Brown 2005; Taggart et al 2012). Parents were also found to have contradictory wishes as they may want typically developing siblings to have an increased support role in the future, yet recognise likely impediments such as proximity and sibling responsibilities to their own families. Some older parents did not want to place what they perceive as a burden upon typically developing siblings, as found in the results of my studies at Masters level (Davys and Haigh 2008). Other studies have similarly demonstrated a picture of mixed results regarding parental wishes and expectations of siblings for the future care of a learning disabled person (Todd and Shearn 1996; Gilbert et al 2008; Dillenburger and McKerr 2010; Taggart et al 2012).

Some participants had noted a change in parental expectation over time. In earlier years they had understood from parents that they should not be burdened with the future care of the learning

disabled person; however with age, it was perceived that the older parent did want the sibling to provide a significant care role, which is apparent in the superordinate theme, 'The Future'. It is important to appreciate that futures planning appears to be a transitional process that evolves over time and is affected by life stage and circumstance. When parents die, siblings are faced with a significant life transition: they have to deal with the grief of losing a parent, yet may have to take on additional responsibilities towards the person who has a learning disability, as well as managing the demands of their own families. This can lead to a sense of split loyalties as commented upon by two participants and returns to the theme of conflict as discussed under the superordinate themes, 'Impact of the learning disabled person upon sibling life' and 'Families'.

The results of this thesis present a range of sibling expectations and wishes for the future. Some siblings expected no particular change and appeared to be content with the existing care arrangements, whether this meant that the learning disabled person lived in the community or with them. Other siblings expected to increase their level of support and involvement in the future, for example moving house to be nearer the learning disabled person. Many respondents expected to take on support roles such as financial over viewer, whilst those who co-habited expected this situation to continue for as long as possible; this has links with sibling roles and responsibilities as discussed under the superordinate theme, 'Impact of the learning disabled person upon sibling life'. Some siblings made a clear statement that they did not wish to co-reside with their disabled brother or sister for reasons that included life style, work, gender issues and conflict in relationships, as espoused by Rachel in Interview 4:

*"...I could never have her (learning disabled person) living with me ... it would just destroy every relationship I've got..."Rachel P 21 line 15*

Some siblings were still unclear about how much or what sort of support they were willing or able to offer in the future, which further reinforces the premise that futures planning is a transitional or developmental entity.

Earlier studies have noted that some siblings, even as children, anticipated a future care role for the learning disabled person (Hames 2008; Angell et al 2012). In adulthood, a variety of sibling wishes and expectations related to future care roles and support have been presented (Jokinen2008; Kramer 2008), linked to variables such as proximity, marital relationship, life circumstance and life stage (Zetlin 1986; Kramer 2008; Burke et al 2012). The significance of life stage and expectation to provide care has been highlighted by Burke et al (2012) who found that siblings had a greater expectation to provide future care to a learning disabled sibling at the time in their lives when parents were well able to provide support, however this expectation diminished as parental ability to provide support declined.

Reasons that may help understand why siblings of learning disabled people commonly report some level of willingness to provide a future support role can be reviewed in the light of various theories: these include Bowlby's life-span attachment theory, family systems theory and the life course perspective - as discussed within the themes, 'Impact of the learning disabled person upon siblings' lives' and 'Impact of learning disability upon family'. Further theoretical perspectives as to why siblings may provide support to a learning disabled person include the symbolic interactionist view

of negotiation (Finch 1989; Finch and Mason 1993) and the hierarchy compensatory model developed by Cantor (1979), both of which were previously referred to under consideration of the 'Impact of learning disability upon siblings` lives' and the 'Family'.

The convoy model of social support (Antonucci and Akiyama 1987) may also provide some explanation for variation in the degree of support siblings are willing or able to offer. Within this framework, networks of support are seen as constantly changing over the life course; some support members are lost and others are found and this leads to an evolutionary view of social support. The convoy of support is dynamic in nature, remaining stable in some aspects but changing in others depending upon time and circumstance; it provides a possible explanation for difference between actual and anticipated support as well as variation in levels of support over the life cycle. This theoretical framework provides further strength to the view that futures' planning is a developmental or transitional process, as the support needs of a learning disabled person and family members will change over time and therefore require review, especially when parental ability to care diminishes. Due to the variation in family culture, values, individual life stage and circumstance, it remains difficult therefore to apply one theoretical framework to the impact of learning disability upon futures planning and explain why some siblings are more involved than others.

When comparing and contrasting siblings wishes and expectation for the future care of the learning disabled person with those of their parents, most respondents (nine) reported close alignment, although two participants stated that their wishes were opposite to parental wishes. Close alignment of wishes could be attributed to the impact of family culture and the influence that parents have on

sibling attitudes towards the learning disabled person over the life course. This was a view endorsed within studies by Zetlin (1986); Bigby (1997); Greenberg et al (1999) and Scelles (2002). In contrast, some evidence of dissension between the wishes of siblings and older parents was found by Knox and Bigby (2007); however, the study supported the view that family values and roles needed to change and adapt over the lifecycle to meet the varying needs of different family members. This changeability and shift in sibling roles over time is mirrored within other studies, and may further indicate the transitional and developmental nature of futures planning and care giving (Zetlin 1986, Bigby 1997, Hodapp and Urbano 2007). The presence of perceived change in parental wishes and lack of clarity regarding future plans expressed by some participants in this thesis add further weight to this concept.

Only three respondents referred to the wishes of the learning disabled person regarding their future support (in two cases this was to continue co-residence with the respondent, and in the third case, for the respondent to move next door to the learning disabled person). The fact that only three participants referred to the wishes of their learning disabled brother or sister could suggest that siblings are generally not aware of what the disabled person wants, that siblings have not been involved in the futures planning process to date, or that the needs and wishes of learning disabled people tend to be overlooked. A review of the literature suggests that all three scenarios are likely. The idea that futures planning is a difficult process within families and that where plans do exist, they often lack depth and detail has already been stated (Bowey and McGlaughlin 2007; Dillenburger and McKerr 2010). Knox and Bigby (2007) reported little evidence of learning disabled people being directly involved in futures planning and Bowey and McGlaughlin



(2007) claimed that siblings are often not included in futures planning.

Having outlined wishes and expectations for the future it is clear that the majority of respondents, and in many cases their parents, were worried about the future. Siblings claimed that parental fears were associated with a lack of service ability to meet the needs of the disabled person; this was explored in the superordinate theme, 'Services'. Siblings had their own concerns about service provision which was linked to finances and benefits; this echoed earlier studies in which a general concern about the quality of services was raised (Orsmond and Seltzer 2007). Death was also acknowledged as a worry for participants, lending support to the findings of an earlier study by Rawson (2009); pertinent issues here were: sibling ability to cope with parental death, increased care demands that were likely to follow parental death, the response of the disabled person to parental death, and parental response should the learning disabled person die before them (Rawson 2009). These can be summarised as extra responsibilities and care demands, aspects which have been raised in earlier studies (Orsmond and Seltzer 2007; Benderix and Sivberg 2007) including the published results of Stage one of this thesis (Davys et al 2010).

Other participant worries concerned divided loyalties between siblings' own lives and families and the disabled person. Health was a further cause for concern, encompassing siblings' own health (and therefore ability to support the disabled person), and the health and well-being of the brother or sister with a learning disability. These worries and concerns could be interpreted as an indicator that siblings are liable to take on a parental role and therefore they inherit the worry of what would happen to the learning disabled person if they, the sibling died first. Concern

about the future and futures planning appears to be a transitional process that evolves over time and is affected by life stage and circumstances, as previously stated. In the event of parental death, siblings are faced with a significant life transition: they have to deal with the grief of losing a parent, yet may have to take on extra responsibilities for the learning disabled person. This, in combination with the needs of their own family can lead to a sense of divided loyalty for siblings; it links to the themes of 'Conflict within families' and 'Impact of a learning disabled person upon siblings` lives`.

## **6.2 Overarching theme: Services**

The theme of services was present in all interviews but had less text dedicated to it than other themes, such as the impact of learning disability upon siblings` lives and family. Some respondents made many comments about services whilst others made brief reference, yet the message arising from this theme is threefold: services are viewed from a positive perspective, a negative perspective and are seen to provide a different role to that of the family. Overall, an almost equal number of negative comments (14) and positive (13) comments were made. Negative comments related to services being insufficient, unsuitable (incorporating quality and range of services), inappropriate and having a negative impact upon the lives of people who have a learning disability. Some negative comments related to staff, and services were viewed as a cause of conflict and frustration in siblings` lives. The fact that siblings hold negative views of services may be due to a passing on of attitudes and values from parents to adult children as part of family values, culture and belief systems. The view that siblings tend to embrace familial values and beliefs as well as worries and concerns could be supported by the findings

of this thesis, as most participants agreed with parental wishes regarding the future care of the learning disabled person.

Tension between families and service providers is a longstanding issue within the field of learning disability (Thompson 2000; Mansell and Wilson 2010; Bhaumik et al 2011). Findings from my studies at Masters level (Davys and Haigh 2008) revealed that older parents may have a negative perspective of the quality of services and perceive parents and service providers to be in opposition to each other. The results of Stage one of this thesis (Davys et al 2010), which specifically focused on adult siblings of learning disabled people, found that siblings were dissatisfied with housing options and, the standard and availability of services; they were critical of, service ability to understand the needs of learning disabled people and their families, and felt that responsibility for care falls back to the family when services break down. Conversely there are studies that demonstrate how services providers hold negative opinions of families of learning disabled people, viewing them as selfish (Smith and Tobin 1993), motivated by financial gain from the disabled person (Grant 2001) and as impediments to independence of the disabled person (Scelles 2002).

The difference in role and function between family and service providers and the presence of tension could be explained by the seminal theory of shared functions (Litwak 1985) which was developed in response to typically developing older people. It purports that their support networks are commonly made up of a combination of formal organizations (government, private and voluntary services), quasi-formal organizations (storekeepers, postmen, church members, caretakers) and informal components (family, friends, neighbours, spouses), all of which are provided in the context of political, economic, legal, social and historical

contexts. Using this theory, primary groups members (kin) exchange services on the basis or motivation of affection, duty or respect, rather than economic gain, and therefore the difference in role, function and the potential for conflict can be understood. This theory also suggests that most tasks have some components best met by people with specialised skills whilst others require continual contact and every day experience. Some tasks therefore may require a combination of formal and primary group co-operation to fully meet people's needs. If applying this theoretical construct to the field of learning disability, it can be seen that the values and perspectives of families and service providers require careful consideration, co-ordination and negotiation if tension is to be avoided and harmonious working relationships established.

In contrast to the negative views of services as expressed by participant siblings, positive comments were also made; even where a respondent had devoted a large amount of text to negative comments about certain services, positive comments were sometimes made about other services, which perhaps demonstrates that siblings are able to differentiate and appreciate difference in service provision. An example of this was seen in the interview with Kath where frustration with one service was described:

*"...her social worker has just gone on long term sick or leave or whatever, and I can't seem to get anybody. I leave messages and nobody rings me..." Kath P 11 line 3*

This same respondent was later able to praise another service which was described in very positive terms:

*“...I can never say enough about TH (learning disability charity) - they’ve saved my life many a time...” Kath P 26 line 36*

Positive comments about services in the results presented here refer to both formal statutory organizations as well as voluntary services. Participant trust in service providers was evident in some instances, as demonstrated by Claire, who stated that she was aware of the systems that were in place to support her brother and that she trusted those systems. Earlier studies (Jokinen 2008) and the results of Stage one (Davys et al 2010) refer to siblings making positive comments about services, such as their appropriateness to the needs of the disabled person; however the relationship between service providers and adult siblings of people who have a learning disability is an area that requires further research.

That family and services provide a different role to each other was commented upon by three participants and could provide some rationale as to why tensions exist. Participants suggested that the difference between families and service providers is rooted in the emotional investment with the learning disabled person, the tools and skills required to support the disabled person, and the constraints of professional practice. Disparity in emotional investment due to the difference in relationship between family and service providers was raised in the interview with Helen; although she referred to staff supporting her brother as, *“fantastic”* and, *“maybe a job that they invest quite a lot of emotion into...”*, she still considered the involvement of service providers to be at an inferior level to that which she and her parents provided for the disabled person.

One respondent commented upon the difference between service providers and families, stating that although service providers lack an intimate knowledge of the service user that may inhibit individual needs being fully met, there are times when professional tools and knowledge are required in order to best support the learning disabled person. This fits with Litwak's theory of shared functions (1985) as there are said to be times when technical knowledge is required that can be applied uniformly and impartially, and formal organizations may be best placed to deliver this type of support. This idea was suggested by Maali in her comment:

*"...that's the difference between family and having professional support: a family member won't go to those lengths of providing her with the tools."Maali P 31 line 9*

The concept of differing roles and functions between families and service providers was further espoused by Rachel, who remarked that services are bound and constrained by protocol, professional codes of conduct and political correctness; this may result in responses that the family feels are not in the best interest of the learning disabled person. Rachel explained that a family member is able to take charge of a situation and either respond to or deny the demands of the learning disabled person (depending upon family assessment of the situation); she gave the example of taking control of bank books and money to avoid the learning disabled person getting into debt and being exploited by others. Taking control in this way is not always possible for service providers, which again illustrates difference in the function of services and family within a social and political context, yet further demonstrates the need for both families and service providers to

understand and appreciate each other's roles in the best interests of the disabled person.

### **6.3 Overarching theme: Sibling needs and recommendations**

That siblings have needs was mentioned in all interviews, however in most cases (13 interviews), a generalized and rather vague statement of need was made, as for example by Fran:

*"...maybe some kind of... somebody to talk to other than your parents, some kind of support route."* Fran P 21 line 8

At other points however, sibling needs were stated much more specifically, such as: the need for detailed advice and information on support that may be available; emotional support for mental health issues that may arise due to being part of a learning disabled family; help with practical solutions; and to be seen as having a separate identity. There are relatively few studies that report on the particular needs of adult siblings of learning disabled people; this is an area which requires greater research as it is these adults who are likely to take on future support roles when their parents are no longer available to provide care, and previous studies have illustrate that siblings want to be involved in the future (Rawson 2009; ESRC 2011). In previous research into sibling needs, support with emotional and psychological issues such as anger or depression has been highlighted (Benderix and Sivberg 2007; Rigney 2009; ESRC 2011; Arnold et al 2012). Other research has identified the call for peer support from those in a similar situation (Heller and Kramer 2009; Arnold et al 2012); and for help and information on futures planning, financial issues, leisure and residential opportunities and legal matters (Benderix and Sivberg 2007; Rawson 2009; ESRC 2011). Most of the needs raised in

previous studies were referred to in the findings of this study at Stages one and two.

Additional sibling requirements presented were the need for support in childhood and the need for siblings to maintain their own health and well-being. Childhood needs were apparent in one third of the interviews and incorporated the need for children to vent feelings of anger and frustration in a safe environment and for dedicated parental time away from the learning disabled person. Maali felt that children should be provided with some form of teaching or training on how best to support the learning disabled child, although this comment may have been influenced by her cultural background as an Asian woman. Support strategies (such as time apart from the disabled child, the opportunity to talk to others who understand the situation and access to behaviour management techniques) have been raised by siblings of children with autism (Angell et al 2012), and intervention groups providing information and problem solving strategies for siblings of children who have disabilities have been shown to enhance some siblings' understanding and relationships (Granat et al 2012).

The need for siblings to look after their own health and well-being was advocated in half of the interviews as respondents felt that there could be adverse effects from being part of a family where learning disability was present. Perhaps incorporated into the need to maintain health and well-being was the stated need for siblings to avoid self-blame or recrimination at times when they feel angry or frustrated with the learning disabled, as demonstrated by Helen:

*"It's OK to be angry, it really is OK: You don't have to go round thinking everybody thinks, 'Oh bless, aren't they*



*(learning disabled people) lovely?’ It’s OK to be really pissed off with everything ...” Rachel P 25 line 6*

Siblings were also advised to avoid feeling guilt or recrimination if they did not wish to provide a particular level of care. Two participants from larger families commented that they had support from siblings in the care of the disabled person and therefore felt no particular need for support outside the family network, however diversity in family support networks and perceptions of support was again variable, as another respondent who also came from a large family expressed the need for increased sibling support at times.

Advice to siblings was present in 12 interviews and centred on futures planning, levels of involvement with the learning disabled person, sibling rights and needs, and advice to support the disabled brother or sister to have as typical a life as possible. Four respondents advised that futures planning should start early in childhood due to the length of time the process takes in order to get the best service for the learning disabled person. This supports the findings of Benderix and Sivberg (2007) in which siblings voiced the need for early intervention programmes and proactive futures planning. Two respondents asserted that siblings have a right to be involved in the life of the learning disabled person should they wish to be but further advised that the level of involvement should be acceptable to the individual and limited to tasks that are within their capacity to avoid feelings of guilt, as expressed by Steven:

*“ ... I think in my experience, only get involved when you really know you can give your time and energy to it... If you just do half a job you’ll feel bad about it...” Steven P 29 line 1*

Perhaps linked to the issue of guilt is the advice was that siblings should not feel that the care of the learning disabled person is a

hereditary responsibility. Finally, siblings were advised by two participants to support the disabled person to have as typical a life as possible, such as remaining in mainstream education and living in the community.

#### **6.4 Chapter summary**

This chapter has provided a discussion of the three overarching themes: Impact of learning disability, Services, and Siblings needs and recommendations; consideration was given to key findings from the results of this thesis in the light of existing empirical study, whilst framing this against a range of theoretical perspectives. In the first overarching theme, 'Impact of learning disability', it became clear that the impact of a learning disabled person upon siblings' lives and the roles and relationships is complex, multifaceted and varies between families, individuals within families and across the life cycle. All participants were able to make positive and negative comments about the impact of the learning disabled person upon their life, and although more negative comments than positive were made, there was some evidence of tangible benefits for some siblings in both childhood and adulthood. All participants were able to describe the negative impact of learning disability upon the life of their brother or sister yet were also able to perceive positive attributes of the learning disabled person and some suggested a 'learning disability advantage'.

The response of society towards learning disability was reported to vary, and positive and negative examples were provided. Response to learning disability may be shaped by culture, time and place in history, but examples of response at an individual level were also provided. When reviewing these findings in the light of existing literature, the presentation of a mixed impact of learning

disability upon a wide range of areas of siblings' lives is upheld. Some studies reported a range of impacts; while others presented a bias of positive impacts, which is in contrast to the findings of this thesis; however concern about the future was a common finding. A number of previous studies referred to the presence of tangible benefits from association with learning disability in childhood rather than adulthood, yet affirmed the wide range of roles and relationships siblings may hold in relation to the learning disabled person, and agreed that roles and relationships change over time.

As there is such an array of variables, life events and circumstance between families and individual siblings within families, it is difficult to apply one theoretical framework or perspective to represent the impact of a learning disabled sibling upon a person's life. However, various theoretical perspectives have been used as a conceptual lens from which to view this phenomenon and may have applicability to some situation but not others. Family systems theory and the life course perspective suggest that the life events and the circumstances of one family member are likely to influence other family members and may be ongoing over the life course. If applying the model of adult sibling attachment perspective, the functions of the sibling relationship in adulthood are to preserve family history, values and goals, and to protect.

The reasons why some siblings take on particular roles and responsibilities for the learning disabled person can be viewed from a number of perspectives. The hierarchy compensatory model would indicate that siblings support the learning disabled person due to the absence of other support networks such as spouse or children, particularly when older parents are no longer able to provide support. In contrast however, the theory of differential primary groups would take the view that members of an informal

support network cannot easily substitute for each other's roles. This could therefore explain why some siblings view their roles and responsibilities as being different to those of their parents, and why they are unwilling to take on a full parenting role. The theory of shared functions places emphasis on the type of task, proximity and relationship between individuals and could offer some rationale as to why some siblings are more involved than others. The symbolic interactions perspective also claims that the actions an individual takes depends upon their interaction with others over time, and actions taken may be further influenced by factors such as age, gender, class and ethnicity.

Families were depicted as having a culture of care and support to family members including the learning disabled person; however the disabled person was also viewed as a source of stress within the family and conflict was generated between different family members. Mothers and fathers were depicted from a range of perspectives, both positive and negative, concerning their reaction to and ability to cope with learning disability. Mothers were often described as the main carer, but not in all cases. Where there was more than one typically developing sibling in a family, one would hold the role of most involved although family response to learning disability was again variable between families and family members. Existing literature supports the belief that families care for each other including the learning disabled person, and concurs with the view that this person is a source of stress upon the physical and psychological well-being of family members, in particular mothers; money is recognized as a cause of stress in such families due to reduced income and increased expenditure. As demonstrated in the results of this thesis, previous research has drawn attention to a wide range of sibling relationships which are seen to be present

in both typically developing and learning disability families, suggesting that variation in sibling relationships is a typical pattern regardless of whether or not disability is present. The few learning disability studies that have been carried with ethnic minority background families suggest that culture may have some influence on the degree of family support provided.

Various theoretical perspectives could be used to consider how and why families support each other, yet due to the numerous variables of family culture, circumstance, life stage and events, it is not possible to align the results presented here to a single framework. However, certain frameworks were considered and as noted earlier, it is reasonable to suggest that the life events and circumstance of one family member are likely to affect those of other family members, as stated in the family systems theory and the life course perspective. The ecological framework extends this concept by its assertion that family function is influenced by wider environmental factors such as government policy and community systems; whilst structuration theory claims that family function is affected by the interaction between macro and micro systems of wider society and individual family context. The presence of conflict in learning disabled families could be linked to perspectives such as disruptive justice, where siblings may be aware of inequality in care-giving between family members; yet according to the concept of legitimate excuse, stress may be alleviated if family members judge there to be acceptable reasons for not fulfilling family responsibilities. A further influencing factor within the concept of disruptive justice would include sibling perception of the relationship which could influence views upon fairness of the distribution of care.

Under the discussion of the theme, 'Future', there was a fairly equal division between families that were planners and those that were not. Reasons given for lack of discussion were varied but included parental fear and distrust of services; where plans did exist, they were seen to lack depth and detail. This lack of detailed plans supports the view that futures' planning is a transitional process. Sibling wishes and expectations of a future support role were many and varied, ranging from continuing co-residential support to rejection of this idea. Most, however, expected to increase their levels of support to the learning disabled person, particularly when parents were no longer able to provide care. There was a general parity between parental and sibling wishes for the future (although not in all cases), and some respondents noted that as their parents aged, their expectation of support from the sibling increased. The future was viewed with concern by both siblings and their parents. Sibling fears for the future concerned a lack of appropriate services, increased care demands upon their lives, health issues for themselves and the well-being of the disabled person. Existing research presents mixed results in relation to futures planning and learning disability families, however the view that futures planning is stressful for older parents and siblings is a clear message and the main barriers to planning are insufficient information and lack of confidence in service providers. A range of parental wishes for the future support of the learning disabled person is evident, along with conflict because, although they want siblings to provide support, parents do not wish to place a perceived burden on them. Some studies demonstrate alignment between sibling and parental wishes for the future, whereas others indicate dissonance; many support the view that sibling roles and responsibilities change over the life cycle. There is little in the way of empirical study that relates to what learning disabled people want for the future or of

siblings being actively involved in this process; however studies that do exist support the opinion that siblings want some degree of involvement in the care of the learning disabled person but are concerned about the future and the impact of this upon their lives.

The theory of unrealistic optimism may explain why older parents and carers have difficulty in futures planning: using this perspective, individuals may accept that decline and dependency do occur but tend not to apply this to themselves. The potentially relevant theories that could be used to explain why siblings may take on a support or care role have previously been discussed. The convoy model of social support describes how networks of support change constantly over the life course, thereby giving further credence to the view that futures' planning is a transitional process. The concept of transition has featured throughout the discussion, signifying that change is likely to arise from typically occurring life events and life stage but may also be influenced by family resilience, circumstance and contextual issues. Referring back to family systems theory, transition in the life of one family member is likely to affect other family members, although not in all cases, which further affirms the presence of variety and complexity both within and between families.

The overarching theme of 'Services' was not a dominant theme (based on the amount of text dedicated to it across the interviews), but it was present in all interviews. Positive and negative comments were made in reference to both statutory and voluntary services, and the difference in role and function between families and service providers was espoused. This view that families of learning disabled people have both positive and negative views of service providers is supported by previous research as is the longstanding presence of conflict between families and providers of

learning disability services. Difference in role and function between service providers and families can be considered in the light of the theory of shared functions, as using this concept, families are described as better placed to provide tasks that require intimate knowledge of the individual and ongoing contact, whilst formal organisation are better placed to provide technical knowledge and support.

The final overarching theme presented was that of 'Sibling needs and recommendations'. All respondents raised the issue of sibling needs which covered needs in childhood and adulthood. Siblings advised that children and adults need to be able to express feelings of anger and frustration in relation to the learning disabled person. They also need general and specific support with futures planning, housing, finance and legal matters alongside help to maintain their health and well-being. All of this is echoed in the few previous studies that relate to the adult needs of siblings in this situation. The advice that siblings gave centred on futures planning (which was highlighted in earlier research) and encouragement for siblings to be involved with the learning disabled person at a level that was right for them. Siblings were also advised to avoid self blame and support the learning disabled to have as typical a life as possible.

This discussion chapter has outlined the overarching and interlinking themes that have emerged from the results against a context of empirical study and theoretical perspectives. The final chapter will review the research question and consider the contribution of the findings of this thesis to the field of learning disabilities. Following this implications for the practice setting, a critique of the research process and areas for further study will be identified.





## **Chapter Seven: Conclusion**

The previous chapter presented a discussion of the research findings in the light of existing empirical studies and set this in the context of various theoretical positions. This chapter will provide an overall conclusion to the thesis and incorporates a reiteration of the research question, the origin of the question, the research process followed and key findings. A critique of the research process is then provided, after which, implications for practice are discussed and areas for future research identified. A final element of reflexivity considering my part in the research process and how the process has impacted upon me will then be considered.

### **7.1 Summary of the research journey to date**

#### **The research question**

The aim was to explore the perceptions of siblings of adults who have a learning disability in relation to personal wishes, family expectation, and any discrepancy between the two, in relation to their role in the future support of their sibling.

#### **How the question came about**

To return to the introduction of this thesis, the research question was generated from my clinical background as an occupational therapist in a community learning disability team working with older parents and families on futures planning. Whilst working with these families, I became aware of the sensitive nature of this topic and the fears older parents held regarding the future of their disabled son or daughter following their death. This became the focus of my Masters level dissertation from which it became clear that older parents were often in the conflicting position of wanting typically developing siblings to support the learning disabled person, yet equally, wanting to avoid placing a burden on them.

Evidence of such contradictory wishes of older parents, experience of working with an adult sibling in this situation, personal reflection about the degree of support I would be willing to offer in this scenario and lack of empirical study in this field led me to the research questions presented.

### **The research process followed**

Before any data was collected, ethical approval was sought and gained from both the Ethics Committee of Manchester Metropolitan University and the Sibs organization. A review of the literature was then carried out, as presented in Chapter two and the findings of this review published (Davys et al 2011). The literature review was organized under four main themes that arose from the review: The experience or impact of siblings upon an individual's life; Sibling tasks, roles, relationships and factors that influence roles and relationships; Sibling tasks, concerns and expectations for the future; and Sibling needs and wishes.

The alignment of the research question to an epistemological stance of constructionism was set out, presenting the view that people construct meaning and interpret phenomena at an individual level within a social, political and historical context; this was aligned with the aim of the thesis, which was to explore sibling perceptions of future care for their learning disabled brothers and sisters. This position was taken whilst acknowledging my own part as researcher within the interpretative process. The rationale for using a mixed methodological approach, combining a survey in the form of a questionnaire at Stage one and deeper exploration of the research area via face to face semi-structured interviews in Stage two, was then presented in Chapter three. The results of the survey at Stage one were outlined in Chapter four and provided

background demographic information; a complementary and exploratory foundation for the research question; demonstrated an evidence base for deeper exploration at Stage two and informed the questions utilized at this stage. The results of Stage one were published (Davys et al 2010), giving further confidence in the results overall. At Stage two, each semi-structured interview was digitally recorded, transcribed and analysed using an approach aligned to IPA; this led to the formation of superordinate or key themes, which encompassed smaller subordinate themes that were supported by participant quotes from the interviews, as detailed in Chapter five. The key or superordinate themes arising from the results were entitled: Impact of the learning disabled person upon sibling life; Family; How learning disability affects the disabled person; Social response to learning disability; Transitions; Services; The future and Advice to siblings, which was combined with Sibling needs. Chapter six presents discussion of the results in relation to existing empirical studies and relevant theory, and is structured around three overarching themes that emerged from the superordinate themes: Impact of learning disability, Services and Sibling needs and recommendations. Chapter seven concludes the thesis with an outline of the key findings and contribution to the field of learning disabilities, the relevance of the research findings to practice, a critique of the research process, suggestions for future research and a consideration of myself as researcher within this process

## **7.2 Key findings and contribution to the field of learning disabilities**

The results of this thesis confirm the findings of previous empirical study in some areas, yet provide a deeper and alternative perspective to the impact of a learning disabled person upon

siblings` lives and their concerns and wishes for the future. One key message is that a learning disabled brother or sister affects the life of a typically developing sibling over the life course, however the areas and degree of impact vary from sibling to sibling. For some, a learning disabled brother or sister affects their whole life including work, family, relationships and leisure; for others there is less impact.

The findings affirm the presence of both positive and negative effects from the experience of growing up with a disabled brother or sister in childhood, as demonstrated in earlier studies (Stoneman 2005; McGraw and Walker 2007; Meadan et al 2010; Angell et al 2012). In both the results of this study and previous research referred to above, the positive aspects of growing up with a disabled child have often been described in terms of attributes such as patience, tolerance and understanding; however participants in this thesis referred not only to the development of positive attributes in childhood but to more tangible benefits such as extra treats, outings and experiences that they were able to access as a direct result of their association with a learning disabled child. The presence of tangible benefits by association with learning disability for typically developing siblings is seldom reported within the literature, although this finding has been referred to by Moyson and Roeyers (2012). Many of the negative aspects articulated by participants such as reduced parental attention, the acquisition of additional responsibilities, the presence and management of difficult behaviour and difficulties on a social level have parity with prior studies (Rossiter and Sharpe 2001; Stoneman 2005). Some participants also referred to childhood fears that parents would die and they would therefore have to assume responsibility for the disabled child, something that was reported in earlier studies (Cate

and Loots 2000; Angell et al 2012); an additional fear expressed by participants was that the disabled child would die because of their disability. The specific life stage of adolescence was raised by the participants here and in other studies (Rigney 2009; ESRC 2011) and feelings of guilt and embarrassment were highlighted; however some respondents also referred to a sense of loss of a typical sibling, which generated feelings of sadness and anger, and was a sentiment experienced by some in adulthood as well as adolescence.

The results presented in Chapter five show the impact of a learning disabled person to be mixed in adulthood as it was in childhood, and therefore they support existing literature (McGraw and Walker 2007; Azeez 2001; ESRC 2011). All participants gave examples of both positive and negative aspects to the experience of having a learning disabled sibling, although more weight in terms of range and amount of text was given to negative comments; this is in contrast to Cleveland and Miller (1997); Flaton (2006) and Rigney (2009) who presented an overall positive experience. Further following the pattern seen in childhood, all participants made positive comments about the presence of the learning disabled person in their lives. Benefits were presented in the form of attributes such as a greater understanding of the needs of disabled people, higher levels of patience, confidence, determination, independence and awareness of health and well-being, all of which have been described in earlier studies (Flaton 2006; Rigney 2009; and Hodapp et al 2010). However this thesis draws attention to the issue of tangible benefit linked to learning disability in adulthood, for example: going on holiday, gaining access to celebrity events or having extra treats by using what was described in one instance as the '*Down syndrome card*'. Reference to such tangible benefit in

adulthood as a direct association with learning disability is a novel concept in the literature related to adult siblings of people who have a learning disability.

The most commonly reported negative impact of a learning disabled sibling was fear or worry, and for some participants this was a continuation of fear developed in childhood. In adulthood, fear was associated with the health and well-being of the disabled person, was related to siblings' own health (and therefore their ability to provide support), and was often connected to the future. Negative emotional responses were expressed towards learning disability, including anger, guilt, depression and mental health issues, demonstrating alignment with prior research (ESRC 2011). As raised in relation to adolescence, the loss of a typical sibling relationship was acknowledged by some in adulthood.

The impact of a learning disabled person over the sibling life course was again variable between participants. Some siblings claimed their experience had influenced their whole lives including career, voluntary work, partner choice and decision to have children, whereas other siblings did not claim this level of impact. This variation in impact is reflected in earlier studies; for example, a positive link between learning disability and career choice has been demonstrated by Seltzer et al (1997); Marks et al (2005) and Flaton (2006), however Karisak (1993) and Konstam et al (1993) refuted the presence of a clear link between career choice and learning disability. Mixed findings have similarly been reported regarding an association between learning disability, partner choice and the decision to have children; Flaton (2006), Seltzer et al (1997), Karasik (1993) and Orsmond and Seltzer (2007) found evidence to support such links but Taylor et al (2008) did not.

Sibling roles with the learning disabled person are portrayed in the results as many and varied, yet draw attention to difference between siblings, and between siblings in the same family. This supports earlier studies which highlight the multiplicity of sibling roles and variation between sibling roles in different family contexts, alongside a change in roles over the duration of the life course which often come to the fore when older parents are no longer able to provide previous levels of support (Bigby 1997; Thompson 2001; Rigney 2009; Bigby et al 2011). The role of most involved sibling was clearly present throughout this thesis. All participants in families where there was more than one typically developing sibling understood very clearly who in the family held this role, and this person held greater responsibility for the learning disabled person than other siblings. Some of the reasons given as to why particular siblings held this role included parental expectation, stage in the lifecycle and family situation. Being the youngest in the family, living at home when the mother died and other siblings not being available because they were married or working, were factors associated with the acquisition of this role, and ones which were also identified in preceding studies (Zetlin 1986; Greenberg et al 1999; Bigby et al 2011). Earlier research has linked care giving roles to gender, life circumstances, life stage, birth order, level of disability, relationship between the siblings, parental influence and family climate, in addition to the health status of the individuals involved (Zetlin 1986; Greenberg et al 1999; Jokinen 2008; Heller and Arnold 2010). These earlier studies support the view that a younger sister living in the family home is likely to become the most involved sibling; this was the case for some respondents of this study, but did not hold true in all cases as one respondent who identified himself as the most involved sibling was a male and the second eldest child of the



family. A little mentioned sibling role in existing literature that became apparent from the results was that of support to the mother, whereby siblings would aim to protect her from the perceived burden of caring for the learning disabled sibling.

Sibling relationships are likely to have some impact upon future care roles and, concurring with previous studies (Zetlin 1986; Karasik 1993; Rigney 2009; Meadan et al 2010), this thesis illustrates a range of sibling relationships with the learning disabled person. Some relationships were very close and involved, but others were more distant; however whilst there are contrasting reports about the levels of sibling intimacy over time, the findings of this study demonstrated variation in sibling roles and relationships which participants attributed to life stage and circumstance. There is therefore a link with the concepts of transition and variation which run throughout this thesis.

Having considered the impact of a learning disabled person upon siblings' lives, sibling wishes and expectations for the future care and support of a learning disabled person will now be summarised in the context of family. Feelings of a family bond and willingness to support family members are values that are likely to have been engendered throughout the life course and may be aligned to sibling willingness and expectancy to take on future support roles. Family was a major theme to emerge from the results in Chapter five and the findings demonstrate that family members support each other, including the learning disabled person - a concept well supported by recent literature (Mansell and Wilson 2010; Bigby et al 2011; Cooper and Ward 2011; Miller et al 2012). Family support of a learning disabled person was associated with family culture or tradition that has been passed on by parents, a perspective previously raised by Benderix and Sivberg (2007), and the origins

of this sense of responsibility and empathy were said by respondents to have originated in childhood. The interconnectedness of family systems was demonstrated by siblings in their descriptions of how the family supports older parents, other siblings, children and grandchildren, as well as the wider family; in a number of instances the wider family was seen to support the nuclear family in the presence of learning disability. The perspective that family support each other and the learning disabled person at an inter and intra-generational level, and that support within families shifts over the life course demonstrating variation in the structure of family support systems, has support within the literature (Karasik 2006; Jokinen 2008). It has also been demonstrated in previous empirical studies (Hatton et al 2010; Miller et al 2012; Rillotta et al 2012) that although the family support and care for the learning disabled person, their presence is commonly a source of family conflict with tensions arising between parents, parents and siblings, siblings and other siblings and the wider family. The results presented here however showed the degree of conflict as again variable between families and individual siblings within families.

The depiction of mothers confirms their image as presented in other studies, in which they are described as likely to experience stress, anxiety and negative psychological health (McGraw and Walker 2007; Hill and Rose 2009; Chou et al 2010); however the results provide an alternative and more detailed presentation of mothers' response to learning disability. Mothers were seen to vary in their response to the learning disabled person, as may be anticipated in any relationship between mothers and their children. They were seen to have a range of personas from strong and matriarchal at one end of the spectrum, to unable to cope with

learning disability, at the other. There was occasional reference to maternal advantage because of the learning disabled person, as some mothers were said to have encountered new opportunities that would not otherwise have arisen and could therefore be considered as a benefit associated with the learning disability. The endeavour of mothers to establish supportive bonds between typically developing children and a disabled child could be interpreted as mothers trying to ensure that the future needs of the learning disabled person are met when she is no longer able to meet these needs.

In the few studies that relate to fathers and learning disability, they have generally been presented as having lower levels of stress and a more positive health status than mothers (Little 2003; Smith and Elder 2010; Quintero and McIntyre 2010). The portrayal of fathers in this study provides a deeper insight into their response to learning disability, as was the case for mothers. Some fathers were seen to be caring and accepting of the disabled person, some acted as joint carer with mothers and in one case, was the main carer instead of the mother. Some fathers were engaged with the learning disabled person, others were distant or embarrassed, but in most cases, even when negativity was present, fathers did still try to provide some level of care or support for the learning disabled person; however more research in this area is necessary.

The range of relationships depicted between typically developing siblings in the presence of learning disability was again varied, as demonstrated in earlier studies (Meadan et al 2010; Lardieri et al 2000) where it has been claimed that in both typically developing and learning disability families, some sibling relationships are supportive and warm, whilst in others there is conflict or isolation.

Chapter five included an Asian perspective of family in the presence of learning disability, which incorporated all previously stated components of family and learning disability, such as family supporting each other and the learning disabled person, the disabled person as a source of stress in the family at parental and sibling levels, and the interconnectedness of family support. Issues that were more culture-specific included: disability being a taboo subject in Asian culture, the responsibility for deficit as incumbent upon the mother, and the desire to retain a sense of cultural identity. The few empirical studies that consider learning disabled families from ethnic minority backgrounds provide a generalised view that these families want more help from services and have concern about the quantity and quality of services received (Samuel et al 2012). These families may be at risk due to poor housing, social isolation, lack of support and information, poverty and a lack of services that are culturally appropriate (Yannamani et al 2009); such issues may be further compounded by language barriers, reduced levels of assertiveness, self-advocacy, and social support (Canary 2008; Hatton et al 2010). The area of learning disability and families from ethnic minority backgrounds is clearly a further area for research.

Cultural attitudes are likely to affect family response to learning disability, however it is important to be aware that attitudes and responses vary from family to family despite cultural background; this was evident both from other interviews where respondents came from a white ethnic background and from the comments made by participants regarding social response to learning disability. It was suggested in the interviews that whatever the time and place in history, people will and do respond to learning disability at an individual level, irrespective of the political stance or

rhetoric. Siblings described a range of responses, both positive and negative, towards learning disability at a social level and an individual level, which further links with the recurrent theme of variation.

Returning to the research question which was to explore the perceptions of siblings of adults who have a learning disability in relation to personal wishes, family expectation, and any discrepancy between the two regarding their role in the future, the matter of futures planning is raised. This study described a fairly equal split, at both Stages one and two, between families that openly discussed futures plans and those that did not; this supports the findings of previous research (Heller 2000; Bowey and McGlaughlin 2007; Gilbert et al 2008) yet provides contrast to Dillenburger and McKerr (2010) who found that the majority of older parents or carers had not made long-term futures plans, again reflecting multiplicity in family response to futures planning and learning disability. This study demonstrated that even where futures' planning was not an open topic of conversation, most respondents felt they had a clear understanding of parental wishes or expectations, although this was not the case in all instances; where no clear understanding of parental wishes was apparent, high levels of sibling distress was disclosed.

The reasons for a lack of futures planning were varied and in some instances unspoken, but were said to include parental fear, parental belief that only they could provide the right level and quality of care, and the opinion that futures planning is stressful for both parents and siblings; this all concurs with earlier empirical studies (Brennan 2005, Bowey et al 2005; Bowey and McGlaughlin 2007; Dillenburger and McKerr 2010). Participants cited other reasons for a lack of futures planning such as a lack of information

and difficulty with service providers, which has again been highlighted in previous research (Heller 2000; Bowey et al 2005; Gilbert et al 2008; Taggart et al 2012). The results presented here provide an additional perspective from siblings for the non-existence of plans, such as superstition, a laissez-faire attitude, the assumption that someone will provide support should the need arise and sibling life stage. Some of these factors, along with siblings not yet being sure what they want, may be associated with life stage, and further supports the view that planning for the future is a transitional or developmental process that evolves over time, and also that sibling life stage and circumstances are likely to influence their wishes and capacity for future involvement.

It is acknowledged that the parental wishes reported here are sibling reports rather than what parents have directly said about their wishes for the future care of the learning disabled person. Again, the findings present an assortment of parental wishes and expectations, as found in earlier studies (Todd and Shearn 1996; Gilbert et al 2008; Dillenburger and McKerr 2010; Taggart et al 2012). Some parents expected the typically developing sibling to take on the role of over viewer; others expected co-residence, whilst others again expected non-residence. This study draws attention to a change in parental expectation noticed by participants over time. In earlier years, some siblings understood from parents that they should not be burdened with the future care of the learning disabled person; however with age it was now perceived that the older parent wanted the sibling to provide a significant care role; this supports the view that futures planning is a transitional process that evolves over time and is affected by life stage and circumstance.

In line with a range of parental wishes and expectations for the future care and support of the learning disabled person, a variety of sibling expectations and wishes were found to exist, which concurs with earlier studies (Jokinen 2008; Kramer 2008). A commonly expected support role noted by siblings was in the area of finance, with many respondents expecting to take on increased care roles in the future, in alignment with previous studies. However this thesis provides further insight into the reasons why adult siblings may not want co-residence with the learning disabled person, such as disruption to existing lifestyle, anticipated conflict in relationships, and work and gender issues around personal care. At the time of the interviews, some siblings were unclear about how much or what sort of support they were willing or able to offer in the future, which yet again reinforces the premise that futures planning is a transitional or developmental entity. The significance of life stage and expectation to provide care has been highlighted by Burke (2012) who demonstrated that sibling expectation to provide future care to a learning disabled sibling was linked to life stage and as siblings got older, their expectation to provide support diminished despite parental decline.

Most participants reported close alignment between their wishes and parental wishes for the future care of the learning disabled person. This supports the view presented in some research studies that parents influence sibling wishes and expectation for future care (Zetlin 1986; Bigby 1997; Greenberg et al 1999 and Scelles 2002); however other studies provided evidence of dissention between sibling and parental wishes (Knox and Bigby 2007). Although the results demonstrated alignment between siblings wishes and parental wishes for future care in most cases,

there was some evidence of disagreement between parental and sibling wishes in a couple of instances.

Having set out sibling wishes and expectations for the future care of a learning disabled person and compared this with siblings' perception of parental wishes and expectation, it was clear that contemplation of the future was a source of concern for the majority of respondents and their parents. Parental worries related to service ability to meet the needs of the disabled person and finance were worries shared by siblings, and have been cited as concerns in earlier research (Orsmond and Seltzer 2007). A further fear concerned death and was linked to siblings having to cope with parental death, increased care demands that were likely to follow parental death, how the disabled person would cope with parental death, and how the parent or sibling would cope if the learning disabled person died, most of which have been identified previously (Orsmond and Seltzer 2007; Benderix and Sivberg 2007; Rawson 2009) including the published results of Stage one (Davys et al 2010). Worry about death may be a continuum of childhood worries, as noted by some participants, and could indicate that for some siblings, death is an ongoing concern.

Other worries concerned divided loyalties between siblings' own lives and the disabled person. Health was a cause for concern, encompassing siblings' own health (and therefore ability to support the disabled person), and the health and well-being of the learning disabled brother or sister. In the event of parental death, siblings are faced with a significant life transition; they have to deal with the grief of losing a parent yet may have to take on additional responsibilities for the learning disabled person as well as the conflicting demands of their own families, and this is clearly a key



stage for support that is aligned to issues around services and sibling needs.

Specific sibling needs for detailed advice and information, for support with emotional needs, for practical solutions and to be seen as having a separate identity were highlighted. There are relatively few studies that discuss the needs and wishes of adult siblings of learning disabled people, however the call for support with emotional and psychological issues, for help and information specific to futures planning; financial issues; leisure; residential opportunities; and legal matters has been noted (Benderix and Sivberg 2007; Rawson 2009; Rigney 2009; ESRC 2011; Arnold et al 2012). Many of these issues were also raised in the published findings from Stage one (Davys et al 2010). Two specific sibling concerns were the need for support in childhood and for siblings to maintain their own health and well-being. The childhood needs voiced by participants were the opportunity to vent feelings of anger and frustration in a safe environment, for dedicated time with parents away from the learning disabled person, and for typically developing siblings to be shown how to best support the learning disabled child, a need previously raised in a study related to siblings of children with autism (Angell et al 2012). The need to manage one's own health and well-being was advocated in half the interviews because siblings felt that there could be adverse effects from being part of a family where learning disability was present; they also advised that siblings need to avoid self-blame or recrimination if they felt angry or frustrated with the disabled person. The advice to take on a limited support role could also be interpreted as a call to manage health and well-being.

Specific advice given by participants was that futures planning should start early in childhood due to the length of time the process

takes and in order to get the best service for the learning disabled person; this is similar to the findings of Benderix and Sivberg (2007). Other advice was that siblings should be aware of their right to be involved with the learning disabled person but, to avoid feelings of guilt this should only be to a level that was compatible with their wishes and situation. This could be linked to sibling advice to avoid self-blame and recrimination, and therefore be associated with the need for siblings to manage their health and well-being. Further advice proffered was that siblings should not feel that the care of a learning disabled brother or sister was a hereditary responsibility, which could also be associated with the call to manage health and well-being. Finally, siblings were advised to support the disabled person to have as typical a life as possible.

Requests for support, advice and information all have clear links to service provision, which emerged as a superordinate theme. All participants at both Stages one and two made comment about services, and there was an almost equal split between the number of positive and negative comments. Historically (Thompson 2001; Mansell 2010; Bhaumik et al 2011) and within this study, the criticism of services was that the standard was unacceptable or inappropriate; service providers lacked an understanding of learning disabled people and their families; and when services broke down, responsibility for care fell back to the family. Despite this, respondents made positive comments about statutory and voluntary services, for example, that they were trustworthy, met service user need and the needs of sibling themselves in some instances. One further key point to arise was the difference in role and function between service providers and families of learning disabled people. This was described by some participants as difference in the degree of emotional investment with the learning

disabled person, different tools and skills available to support the disabled person, and the constraints of professional practice. A clear understanding of the different roles and constraints at the start of a relationship between service provider and service user may serve to reduce tension and establish a clearer appreciation of each other's role and function in the life of the learning disabled person. The development of positive working relationships between service providers and families is an area that requires further investigation. It is crucial to the implementation of the findings of this study at all levels because, without such a relationship, the needs of siblings, families and ultimately people who have a learning disability may not be appropriately met.

### **7.3 Implications for practice**

In consideration of existing literature and the results presented here, there are implications for statutory and voluntary service providers, and for pre and post graduate health and social care students as it is clear that siblings' lives are impacted by the presence of learning disabled brother or sister over the life course. The extent of impact and areas affected, however, will differ from family to family and sibling to sibling, dependent upon a huge number of variables.

The results of this thesis point to a number of service issues; however, one of the key points identified was the difference in role and function between services providers and families. If this difference is established when service users and providers first engage, it may avoid some of the historical tensions and misconceptions between the two parties and support a more productive partnership. In terms of service provision, adult siblings stated that in retrospect, childhood support in the form of dedicated parental time apart from the disabled child and the

opportunity to express feelings of anger and frustration in a safe environment would have been beneficial. In adulthood, some siblings reiterated the need for ongoing support with feelings of anger, frustration and psychological well-being. They also said they had additional needs for information and advice on topics such as futures planning, service provision, finance and the various roles that they may be willing to undertake.

Service support with futures planning is a significant issue and requires attention. Previous literature and the results presented here draw attention to the sensitive nature of this topic; it is apparent that some families do not openly discuss futures planning and where plans do exist, they often lack depth and detail. The future is cited as an area of worry and concern for adult siblings and their parents, regarding what will happen to the learning disabled person and who will meet their needs. Of critical importance to siblings and older parents is the life stage when parents are no longer able to provide previous levels of support to the disabled person, leading to concern about who will then meet their needs. Anxiety and concern are exacerbated when futures plans do not exist or lack depth and detail.

Advice proffered by siblings was that futures planning should start early and include siblings at a level that is appropriate for them, under the proviso that siblings should not feel guilty if they chose to take on a limited role. It is important that service providers consider and include siblings in futures planning and that more is done to ask learning disabled people themselves what their wishes are. Additionally, futures planning needs to be considered from a long term perspective with the understanding that there are likely to be many changes in sibling and family needs and circumstances over the life course; regular updating and negotiation of futures

plans is therefore required. In essence, both services and families need to consider futures planning as a developmental and transitional process which will require regular review, alongside flexibility in the type of services and support required by the family at any one time so as to accommodate change. This is of particular relevance to the current rhetoric regarding the needs and rights of learning disabled people and their families against a backdrop of budgetary constraint.

An alternative implication for practice is the need to highlight the potential benefits and advantages experienced by some adult siblings and family members of learning disabled people. There has been some reference to this in the form of positive attributes in previous studies; however this thesis draws attention to more tangible benefits and experiences reported by some participants as a direct result of having a learning disabled brother or sister.

#### **7.4 Critique of the research process and findings**

Providing a critique of the process is an essential element of any research pathway. It is acknowledged that at Stage one the sample size of 21 participants was small, raising questions of generalisability and bias. The majority (18; 85%) of participants were women who self-selected their involvement in the study, and matters of ethnicity, education or socio-economic status were not addressed. It is also accepted that the questionnaire only captured those individuals who were on the database of the Sibs organisation and had access to the internet and email systems. No respondent over the age of 54 took part in the study; most (nine, 42%) lived in the South East of England and there were no responses from Scotland, Wales or Ireland. Despite this, it is accepted that the purpose of using a survey at Stage one was to establish a rationale for the need to carry out further research into

this area, to provide background demographic details, an overall deeper exploration of the topic and triangulation for the results at Stage two. The results of Stage one also helped to inform the questions asked in the semi-structured interviews at Stage two. In defence of the small response rate, Keegan and Lucas (2005) asserted that reliance upon high response rates alone can lead to bias and that reporting data in areas known to be sensitive where a low response rate is expected is essential.

As a cross-sectional study, the semi-structured interviews at Stage two took place at one point in time and can therefore only represent the participant's current situation and perceptions at this specific life stage. The use of a longitudinal methodology which interviewed siblings of learning disabled people across the life course, from childhood through to old age would demonstrate more clearly any changes in roles, relationships, perceptions and wishes, providing greater depth and clarity of this phenomena; however the time and cost implications for such a study would be considerable and lie outside the remit of a PhD thesis. It is also acknowledged that retrospective accounts were provided regarding sibling wishes and expectations to provide a care role where parents and sometimes the learning disabled person had already died. Wishes and expectations may have been different had both parties still been alive; the tendency for wishes and expectations to change over the life course has been noted within the discussion and in recent research into siblings' expectations for the future (Burke et al 2012).

The use of semi-structured interviews with 15 adult siblings of learning disabled people at Stage two also needs to be considered from a methodological perspective. This may be described as a relatively small sample size that cannot be portrayed as

representative of the whole population of adult siblings of people who have a learning disability; before being able to suggest that findings are generalisable, many more interviews would have to take place. This point may hold some degree of credibility however: from a pragmatic standpoint the time constraints of a PhD thesis are set by external procedures; and from the methodological stance, IPA is concerned with the detailed consideration of individual perspectives and does not set out to provide an objective representation of a situation; rather, its concern is to hear the voice of the individual on a specific phenomena (Smith et al 2009) and therefore the findings of a sample this size may or may not be representative of a larger study (Yardley 2008).

Having considered sample size and issues of generalisability, sample constitution should also be addressed. It is acknowledged both within the literature and government documentation that there is insufficient research into learning disability within minority ethnic and black families (DoH 2001). Research that investigates what people who have a learning disability want for the future, and also studies involving men in learning disability families, is scarce. This thesis included only one participant from a minority ethnic background and only three of the 15 participants were male. The results presented here therefore cannot be described as representative of these minority groups within learning disability research, although as stated above, an approach aligned to IPA does not intend to provide a representative perspective.

In further consideration of the methodology applied, I have stated that the process utilized was based on and closely aligned to IPA; however I did not fully adhere to the analytical stages suggested by Smith et al (2009). Within the analytical process, I gave more attention to description than linguistic and conceptual issues such

as tone, fluency or the use of pronouns when reviewing the transcripts; I could also have provided a deeper level of interpretation (such as the temporal or micro-analysis of text which is undertaken by some IPA researchers into the realms of psychoanalysis). Smith et al (2009) also suggest that superordinate themes are named after phrases arising from participant quotes, which I have not fully adhered to, and a sample size of 15 participants is considerably larger than the six suggested for a researcher using IPA for the first time. Despite these differences, other suggestions for the stages of analysis outlined by Smith et al (2009) were followed, and there is no insistence upon strict adherence to the suggested analytical process within IPA. The focus on description rather than conceptualisation and interpretation was due in part to the sample size, and my using IPA as a methodology for the first time; however, focusing upon description can serve to avoid the pitfall of a researcher becoming overly engrossed with their own life world and conceptualisation to the extent where they do not focus sufficiently on the life world of the participant (Smith et al 2009).

Although issues of reliability and validity are discussed in Chapter three alongside the steps taken throughout the process to support quality such as alignment between the research aim, epistemology, ontology, research design, data collection and analysis, there are always more steps that could have been taken. One quality initiative that has been used in IPA and other qualitative studies is that of participant feedback (Yardley 2008), which I did not utilise. Professional colleagues who were also adult siblings of people who have a learning disability provided input into the questions asked in the survey at Stage one and the questions used in the semi-structured interviews at Stage two. The reasons for not asking



participants to provide input to the data analysis process included the sensitive nature of some of the questions; as some participants became tearful in the interviews and expressed feelings of anger and resentment towards family members, including the learning disabled person, it could have caused them further distress to read their responses in print, and may have led them to withdraw information from this under-researcher area. In addition to this, the themes generated and associated with participant quotes are recognised as acts of interpretation on my part as researcher, and which is acknowledged within the IPA process (Smith et al 2009). It is acknowledged therefore that as participants did not validate my interpretations, there is the potential for researcher bias in the presentation of themes within the findings. In an attempt to address this situation however, the superordinate themes and corresponding participant quotes were checked for congruence by a research supervisor and two research assistants.

### **7.5 Further areas of research identified**

The findings of this thesis have contributed to the field of learning disabilities and specifically the adult siblings of people who have a learning disability. However the following have been identified from the findings and a review of the literature as areas that require further empirical study:

More longitudinal studies of siblings of people who have a learning disability across the life span are required, with a particular emphasis on older adulthood, as changes in life events over the life course have been seen to impact upon sibling roles and responsibilities. A deeper appreciation of changes in care roles and responsibilities over the life course of siblings may mean that their needs and ability to provide appropriate support to a learning

disabled person are better understood, and that services are better able to support them in their roles.

It is acknowledged that there is comparatively little research that gives voice to learning disabled people themselves and when considering futures planning, a significant proportion of the existing research is devoted to family and carer perspectives rather than people who have a learning disability. This is clearly an area for significant research development, as is the whole area of futures planning. New and innovative ways in which to better engage and support families in futures planning is urgently required. Futures plans need to fully involve the learning disabled person, their parents and siblings over the duration of the life course. The evidence in Chapter five and existing literature highlight the continued difficulties in futures planning and that where plans do exist, they are wanting in depth and detail. The perspective that futures planning is a continually evolving process needs to be embraced by both service providers and families.

Fathers of people who have a learning disability are under-represented in learning disability research both when the learning disabled offspring is a child, and when they reach adulthood. Existing parental research has focused mainly upon mothers as main carers with few studies giving attention to fathers, however this study demonstrates that in some instances fathers do take on a key support role. In the current economic and social context, it is likely that fathers may increasingly take on a significant care role for the learning disabled person as there is an increased expectation for women to work and as stable employment becomes increasingly difficult to find.

Alongside fathers, research into learning disabled families from ethnic minority backgrounds is under-represented. There is little evidence of the impact of learning disability upon these families or how cultural values influence the support, care and future needs of learning disabled people from these backgrounds. This situation needs to improve because existing research outlines the difficulties these families have in gaining access to services that are culturally sensitive and appropriate to their needs.

Due to the ongoing history of conflict and difficulty in relationships between families and services providers, new and creative ways for both parties to work together and appreciate difference in role and function is required to establish more productive and harmonious working partnerships. By recognising the gifts, skills and basis of engagement with the learning disabled person and the part that each party is willing and able to play, families, service providers and ultimately the learning disabled person should benefit in the longer term.

Further study into the support needs of siblings in the negotiation of conflict and stress around the support of a learning disabled sibling in the absence of parental support is essential. This is a time of huge transition and concern for both siblings and the learning disabled person. Some siblings feel well supported by family members but others do not, and this situation has the potential for much conflict which could have a negative impact upon all family members and the learning disabled person.

As there is, and is likely to continue to be, a growing number of re-constituted families in the presence of learning disability, further research into this area would be an advantage. This study demonstrates that learning disabled people are able to have a

positive relationship with a step-parent and factors that support this would be a worthy area of investigation, again in the light of increasing demand upon family support and budgetary constraint at a service and political level.

The concept of learning disability advantage is of interest. There tends to be an emphasis on the negative consequences of having a learning disabled person in the family and it is important that families are able to voice the difficulties and frustrations that this brings to their lives; however the concept of learning disability advantage is worthy of further study. This thesis has provided some evidence of advantage for learning disabled people themselves, for siblings and even mothers in some cases, despite other evidence of significant hardships and difficulties experienced on account of having a learning disabled person in the family. Research that is able to provide evidence of learning disability advantage may support the acquisition of more valued social roles for learning disabled people and their families within our society.

## **7.6 Conclusion**

The findings of this research add to the knowledge that a learning disabled person impacts upon siblings' lives over the life course; however the degree and range of influence is widely variable and siblings are often able to identify both positive and negative aspects. Further affirmation of sibling concern for the future is presented, particularly for the time when parents are no longer available. Siblings voiced their need for support in childhood, adulthood and in the future, however family engagement in futures planning remains an area of complexity. The results support the view that adult siblings generally wish to be involved to some extent with a learning disabled brother or sister in the future, and

further highlight the significance of life stage, circumstance and events in sibling ability to provide support.

In addition to affirmation of the current knowledge base, this research provides a unique contribution to the field of learning disability by the presentation of tangible benefits that are available to some adult siblings and their mothers because of their association with a learning disabled person. Also provided is a deeper insight into the response of mothers and fathers in the face of learning disability, a more comprehensive understanding of sibling perception of the role and function of service providers and further rationale for a lack of futures plans.

In the methodology chapter under the heading of reflexivity, I raised the issue of my relationship with the research process, how I believe that I have at times used the study as a therapeutic medium to cope with transitions of death and separation in my own life, and I now return to this consideration of my personal learning. It is my belief that I have gained immensely from the thesis in a variety of ways. Referring back to using the research process as a therapeutic medium during my own life transitions, the discipline, routine and time required to undertake this study has certainly provided a very 'meaningful and purposeful occupation' for me which has resonance with my professional background and perspective as an occupational therapist. At another level, I have learnt a great deal from the different lives and experiences, hopes, wishes and fears for the future of the sibling participants. Each participant presented their unique experience and perspective, set within a family culture and life events which has made me realise that each individual within a family has to be considered as an entity in their own right, and that life events and circumstance over the life course affect each individual in very different ways. The

words and experience of numerous sibling participants within this study have provided me with useful and wise perspectives as I now negotiate futures planning issues for both myself and members of my own family. I appreciate and value their wisdom, humour and honesty which I will hopefully use to good effect in my personal and professional future as it evolves.

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## **Appendices**

- A** Literature chart related to the adult siblings of people who have a learning disability
- B** Study advertisement sheet
- C** Study information sheet
- D** Questionnaire for stage 1
- E** Interview questions for stage 2
- F** Consent form
- G** Sibling contact sheet post interview
- H** Example of theme and evidence chart from interview 4
- I** Example of transcribed interview 12
- J** Frequency table for superordinate themes
- K** Key quantitative data from the interviews

**Appendix A: Table summary of studies included in the review related to the adult siblings of people who have a learning disability**

Author	Aim	Method	Sample	Data collection	Analysis	Results
Arnold et al. (2012)	Examine the support needs of adult siblings of people with developmental disabilities	Qualitative	139 siblings (18-62 years) of people with developmental disabilities	Survey	Content analysis of open questions	Siblings need disability related information, support for their care giving role and for their needs to be better addressed by formal support systems.
Azeez (2001) PhD thesis	Consider the impact of the learning disabled person upon sibling lives at the different life stages and their relationships	Qualitative	12 siblings of people with a learning disability, 4 children, 4 adolescents and 4 adults	Open ended interviews	Content analysis and phenomenological perspective	Common themes of guilt, anxiety, worry and ambivalence across the life stages. Response to the impact of learning disability upon sibling upon life was variable.

Author	Aim	Method	Sample	Data collection	Analysis	Results
Benderix and Sivberg (2007).	Describe past and present sibling experiences related to autism	Qualitative	14 siblings (5-29 years )of children who have autism and moderate to severe learning disability	Face to face interviews	Content analysis	Siblings experience a sense of responsibility, feelings of empathy and a negative impact upon their lives.
Begun (1989)	Explore sibling relationships involving developmental disability	Quantitative	46 sisters ( mean age 30.1) of people with moderate to profound developmental disability	Questionnaire	Statistical including sample distribution and multiple regression analyses	Relationships are affected by life stage, birth order, age spacing, degree of disability, gender and living arrangements.
Bigby (1997)	Examine the roles of siblings in the lives of older people with intellectual disability	Mixed	62 people (30 siblings aged 55 years or older) who provided support to learning disabled people.	In-depth semi-structured interviews	Descriptive statistics and thematic analysis	Nearly half of non-disabled siblings acted as primary carer after parental death on a short term basis. Sibling roles were associated with relationship quality.



Author	Aim	Method	Sample	Data collection	Analysis	Results
Brennan (2005) PhD thesis	Consider the roles and expectations of non-disabled siblings in the lives of adult learning disabled brothers and sisters	Qualitative	8 adult sibs of people who had a learning disability	Semi-structured interviews	Thematic analysis	Futures planning within learning disabilities are complex. Siblings have little involvement in futures planning but expect a future role which differs from a parental role. Factors affecting sibling roles include family context, gender and personal lives.
Burke et al. (2012)	Identify factors related to the future care giving expectations of adult siblings of individuals with intellectual and developmental disabilities	Quantitative	757 adult siblings (18 years and over) of people who had an intellectual and developmental disability and parents were still alive	Web based survey using pre-set categories	Statistical analysis including Mann-Whitney U, Spearman's rho correlations, median values and Cronbach's alpha	Higher expectation of care giving was associated with being female, having a close relationship, close and when parents were able to provide good levels of support.

Author	Aim	Method	Sample	Data collection	Analysis	Results
Cleveland and Miller (1977).	Determine the impact of a mentally retarded sibling upon life commitments	Quantitative	90 adult siblings (25 years and over) of adults diagnosed with mental retardation	Questionnaire including closed questions and space for additional comment	Statistical analysis including Chi-squared testing and content analysis	Mainly positive adaptation to experience of having a disabled sibling. Life commitment not affected. Older sisters had greater degree of contact, responsibility and more likely to experience stress when growing up.
Egan and Walsh (2001)	Explore sources of stress among siblings of Irish people with intellectual disability	Quantitative	39 adult siblings of Irish people with intellectual disability , 22 who were primary caregivers and 17 who had a strong relationship with the disabled person	Questionnaire s standardised and non-standardised related to stress, general health, perceived social support and futures planning	Statistical analysis using multiple regression scales	No difference between the groups but significant link between sibling perception of social support, level of disability and sibling stress. Few future plans in place.

Author	Aim	Method	Sample	Data collection	Analysis	Results
Flaton (2006).	Life experience of growing up with a sibling who has mental retardation	Qualitative	1 sister ( 39 years) of a man with Down syndrome	Case study	Thematic analysis	The experience of growing up with a person who has Down syndrome shaped identity, experiences and life choices.
Greenberg et al. (1999)	Identify factors associated with sibling support and future care expectations of middle aged siblings of people with mental illness or retardation	Quantitative	61 siblings of people with serious mental illness and 119 siblings of people with mental retardation	Questionnaires	Statistical analysis including alpha reliability, analyses of covariance and logistic regression	Factors affecting support provided include geographical proximity, other care responsibilities, gender and relationship with mother. Majority of siblings expect future care responsibilities.
Griffiths and Unger (1994).	Explore parental and sibling views of futures planning for adults with mental retardation	Quantitative	41 pairs of parents (Mean age 59.7) and siblings (mean age 31.3) of adults who have mental	Questionnaires, standardised and non-standardised scales related to	Statistical analysis including paired t tests	Almost half of siblings were willing to take on future care giving responsibilities but parents

Author	Aim	Method	Sample	Data collection	Analysis	Results
			retardation and live at home	demographics , family function, stress/distress , future care giving and satisfaction with futures plans		reluctant for this. Willingness to provide future support influenced by family communication, and functional demands of disabled sibling.
Heller and Kramer (2009)	Factors that contribute to sibling involvement in futures planning and care giving	Quantitative	139 adult siblings ( mean 37 years) of people with developmental disabilities	On-line survey	Statistical analysis including hierarchical multiple and logistic regressions	Few futures plans identified. Most siblings wanted support and advice on future responsibilities. Less than half expected to be primary caregivers. Expectation of future care giving associated with gender, geographical proximity and perception of care giving burden.

Author	Aim	Method	Sample	Data collection	Analysis	Results
Hodapp and Urbano (2007).	Establish if there is an advantage to siblings of people who have Down syndrome compared to siblings of people who are autistic	Mixed	284 adult siblings of people who had Down syndrome and 176 siblings of people who had autism	Web-based survey utilising closed questions and a final open section	Statistical analysis including Cronbach`s alpha, Kilk`s lambda, analyses of covariance and content analysis	Small to moderate advantage in overall quality of relationship, level of contact and sibling perception of health and depression for Down syndrome group compared to autism. Sibling relationship deteriorated with age. Better relationship associated with fewer behavioural problems.
Karasik (1993) PhD thesis	Consider the impact of a learning disabled sibling from the perspective of middle age onwards life	Qualitative	52 sibs (31-81yrs) of learning disabled adults	Open-ended interviews	Modified grounded theory	Historical context, social attitudes, current and anticipated needs influence care giving. Impact of learning

Author	Aim	Method	Sample	Data collection	Analysis	Results
						disabled person upon sibling lives was diverse, most retained some contact. Relationships were variable and felt to be parental.
Konstam et al. (1993)	Explore the influence of developmental disabilities upon sibling career, occupational interests, values and goals	Quantitative	27 adult siblings (mean age 41) of people with developmental disabilities living in a private residential programme and 27 adult siblings in a comparison group	Questionnaire including standardised and non-standardised components	Descriptive and inferential statistics	No significant difference between the sibling groups in relation to career choice, value orientation, political, aesthetic, economic or theoretical orientation.
Kramer (2008) PhD thesis	Examine the perspectives of adult siblings with and without a learning disabled sibling regarding relationships, meaning of support and the impact of social	Qualitative	8 siblings pairs where 1 sibling had a learning disability and 1 did not	Open ended interviews with the siblings pairs and then separately	Grounded theory	Converging trajectories of support were present. Sibling relationships were close but asymmetrical. Age, life course events, gender, policies and

Author	Aim	Method	Sample	Data collection	Analysis	Results
	context upon life transitions					services affected the sibling relationship.
Krauss et al. (1996).	Identify predictors of future role expectations for adult siblings of people with mental retardation	Quantitative	51 siblings of people with a learning disability who intend to co-reside with the disabled sibling in the future and 89 who intended to live apart	Questionnaire	Statistical analyses including multivariate analyses	Co-residence plans linked to gender, level of disability, maternal health and current level of shared activities. Of siblings who planned to live apart at least half had regular contact and intended to provide support in the future. Family diversity regarding future living arrangements.
McGraw and Walker (2007)	Explore how non-disabled sisters understand themselves and their developmentally disabled siblings and wider systems of power	Qualitative	10 sisters ( 21-82 years) of people who predominantly had a dual disability that included developmental disability	In-depth interviews	Grounded theory approach	Siblings experienced both normality and exceptionality on account of their experience. Positive and

Author	Aim	Method	Sample	Data collection	Analysis	Results
	of discourse					negative impacts upon lives were noted. Some expected a future care role that was different to parental role.
Marks et al. (2005)	Explore the impact of a learning disabled sibling upon career pathway in special education	Qualitative	7 adult siblings (21-49 years) of learning disabled people who were on a special education training programme	Focus group followed by face to face interviews	Thematic analysis	The positive impact of the disabled person upon sibling lives was noted as was parental influence upon career choice. Participants reported being very involved with the disabled person.
Orsmond et al. (2009)	Investigate sibling relationships and well being in adolescents and adults linked to autism	Quantitative	142 adult siblings (mean age 32 years) and 56 adolescent siblings (mean age 16 years) of people with an autism	Questionnaires and interviews that included standardised scales	Statistical analysis including univariate analyses, bivariate correlations and multiple regressions	Adolescents took part in more shared activities with the disabled person and reported more social support from parents and friends



Author	Aim	Method	Sample	Data collection	Analysis	Results
			spectrum disorder			than adults. Gender and level of behavioural problems affected adult sibling relationship.
Orsmond and Seltzer (2007)	Examine differences between adult siblings of people with Down syndrome and autism regarding the experience of growing up, relationship quality, gender differences and factors that may impact upon the relationship	Quantitative	77 adult siblings of people with Down syndrome and 77 adult siblings of people with autistic spectrum disorder	Questionnaire	Statistical analysis including matched pairs t-tests, McNear tests and Wilcoxon matched pairs rank tests	Siblings of people with Down syndrome reported more contact with the disabled person, closer relationship, more futures plans in place and more family planning than the autism group. Gender differences were present.
Orsmond and Seltzer (2000)	Examine differences/similarities in care giving between adult brothers and sisters of people with mental retardation	Quantitative	245 adult siblings (mean age 39) of people with mental retardation	Questionnaire	Statistical analyses including multivariate and univariate analyses	Contact, quality of relationship, involvement and concern about the future linked to gender. Positive affect

Author	Aim	Method	Sample	Data collection	Analysis	Results
						increased with time and not associated with gender.
Rawson (2009)	Explore the attitudes, hopes and apprehensions of teenage and young adult siblings of people who have a learning disability	Qualitative	13 siblings (17-23 years) of people who had a learning disability and attended a full time residential school	Semi-structured interview	Thematic analysis	Siblings anticipated future involvement but to varying degrees. Most were concerned about the future and stated a need for support in the future. Varying degrees of sibling relationship.
Rigney (2009) Master's thesis	Explore the long term impact of a learning disabled sibling upon identity	Qualitative	12 adult siblings (21-58 years) of people with cognitive and other disabilities	15 point questionnaire followed by semi-structured interviews	Content analysis	Siblings were aware of difference from childhood. Embarrassment was present in teenage years. Siblings had an increased sense of responsibility and common roles included

Author	Aim	Method	Sample	Data collection	Analysis	Results
						advocate, helper and care giver. Positive and negative impacts were noted as was parental expectation to provide support.
Rimmerman and Raif (2001)	Examine sibling involvement in the lives of people with mental retardation when parents are elderly or have died	Quantitative	76 siblings of adults ( aged 40 and above)with mental retardation and 69 siblings (aged 40 and above) of people who did not have mental retardation	Questionnaire s some of which were standardised	Statistical analysis including Chi-square and Chronbach alpha	Siblings of mentally retarded people had slightly more contact that those in the control group, and a significant increase on parental death. Frequency of contact and family climate not related to sibling contact. Sibling gender linked to family cohesion after parental death.
Rouse (2003) PhD thesis	Investigate the relationship between levels of	Quantitative	30 adult siblings (20-56 years) of	A variety of scales including the	A variety of statistical analyses	Proximity was associated with levels of sibling

Author	Aim	Method	Sample	Data collection	Analysis	Results
	expressed emotion and level of behavioural competency in siblings of learning disabled people		people who had a learning disability	5 minute speech sample, Vineland adaptive behaviour measure, Hospital anxiety and depression scale and Adult sibling relationship questionnaire		expressed emotion yet age, gender and socioeconomic status were not. No significance found between levels of sibling expressed emotion and behaviour of the learning disabled person.
Scelles (2002)	Consider how professionals and siblings regard the sibling role for adults with learning activity limitation	Qualitative	20 adult siblings of learning disabled people, 6 judges and 10 professional guardians	Semi-structured interview	Thematic analysis	Reasons for sibling guardianship roles included parental loyalty, personal role, status and money. Role may create family conflict. Professionals may view parents and siblings as impediments to independence.

Author	Aim	Method	Sample	Data collection	Analysis	Results
						Siblings consider financial management an appropriate role.
Seltzer et al. (1997)	Compare siblings of mentally ill and learning disabled people regarding relationships, frequency of contact and psychological well being	Mixed	61 adult siblings of people with mental illness and 329 adult siblings of people with mental retardation( mean age 40 years)	Questionnaire, some of which were standardised	Statistical analysis including Chi-squared, t-tests and multivariate analyses along with participant quotes	Siblings of people with mental retardation reported more impact upon career choice, family planning, and partner choice. Most reported their sibling life experience to be positive with higher levels of affection, more face to face contact and better psychological wellbeing than siblings of people with mental illness.
Seltzer (1991)	Describe relationships between adult	Quantitative	44 mothers (aged 55 years of over)	In-depth interview and questionnaires	Descriptive statistics and other	Most involved sibling is likely to be female,

Author	Aim	Method	Sample	Data collection	Analysis	Results
	siblings where mental retardation exists and the effect of these relationships upon maternal well-being		of adults with mental retardation	, some of which were standardised	statistical analysis including two-way analyses of variance and bivariate correlations	older than the disabled person, live within 1 hours drive from the family home and have at least weekly contact. Higher levels of family cohesion and sibling involvement linked to better maternal wellbeing.
Taylor et al. (2008)	Explore differential life course outcomes of siblings of adults with mild intellectual deficits compared to those who have mental illness	Quantitative	268 adult siblings of people with mild intellectual disability, 83 adult siblings of people with mental illness and a comparison group of 791 adult siblings	Interviews and questionnaires including standardised tools	Statistical analyses including two-way analyses of covariance	Siblings of people with intellectual deficit reported less emotional closeness and contact with siblings than comparison group. No group significance for marriage pattern, number of children ,psychological

Author	Aim	Method	Sample	Data collection	Analysis	Results
						well-being or personality scores with comparison group.
Taylor and Hodapp (2012)	Examine the predictors of inactivity of people with a learning disability and whether lack of vocational activity affects the well being of their non-disabled siblings	Quantitative	796 siblings (18-85 years) of adults who had a learning disability	Adult Sibling Survey	Statistical analysis include descriptive statistics, Chi squared and Mann Whitney U	No significant difference between activity levels of the disabled person and sibling positive wellbeing. Some link between low activity levels and lower levels of sibling wellbeing and relationship. No links found between lack of activity and time spent with disabled person.
Wilson et al. (1992)	Examine how levels of competency and life stage affects relationship and involvement between non-	Quantitative	30 adult siblings of people with mental retardation(age range 16-55)	Questionnaire and semi-structured interview	Statistical analysis including two-tailed probability and comments from interview	Higher level of interaction and relationship quality when disabled sibling had higher functional

Author	Aim	Method	Sample	Data collection	Analysis	Results
	disabled and disabled siblings				rated on a five point continuum	ability. No overall evidence of difference between functional level and involvement. Limited impact of gender. Significant expectation of future involvement. Life stage affects sibling perception of disability.
Wilson (2011) Masters dissertation	Explore the relationship between young adult women and their learning disabled sisters	Qualitative	12 sisters (22-34 years) of women who have a learning disability	Open-ended semi-structured interviews by telephone or Skype	Thematic analysis	Contact was mostly by phone or email, visits were more occasional. Sisters felt a sense of responsibility, had various roles depending upon circumstance and expected a future care role



Author	Aim	Method	Sample	Data collection	Analysis	Results
						but were unclear about the future. A range of relationships and impacts upon sisters lives were reported.
Ying Li (2006)	Present the experience of sibling advocates of people with intellectual disability	Qualitative	6 adult sibling advocates (mean age 49.8 years) of people with an intellectual disability	Semi-structured interview	Content analysis	Sibling advocates role included call for better services for disabled people and families. Siblings need support and training for support roles.

Author	Aim	Method	Sample	Data collection	Analysis	Results
Zetlin (1986)	Examine adult sibling relationship and roles where mental retardation is present	Qualitative	35 adults with mild mental retardation and their family members	Participant observation and discussion with adults with mental retardation and interviews with family members	Examination of field notes and life history interviews	Different types of relationship ranging from very warm with extensive contact to hostile and no contact. Warm feelings with minimal contact and involvement most common relationship.

## **Appendix B: Study advertisement sheet**

# **Adult Brothers and Sisters of People Who Have a Learning Disability – Understanding your Concerns for Future Support.**

I am an Occupational Therapist who has previously worked with people who have a Learning Disability and their families. As part of my doctoral studies at Manchester Metropolitan University, I am interested in the views and opinions of people who are aged over 25 and have a brother or sister who has a learning disability.

### **My research aim is:**

To explore the personal wishes, needs and family expectation of adults who have a learning disabled brother or sister in relation to future support. The information will then be brought to the attention of service providers and hopefully improve care provision.

I would like to interview approximately 15 adult brothers and sisters who are aged 25 or over and who live in the North West area.

Each interview will last approximately 1-1.5 hours and can be held in your own home or in a private room at the University of Salford. All interviews will be kept confidential and participants will not be identified.

**If you are interested or know someone who may be interested, please contact:**

**Deborah Davys on 0161 295 2869 or e-mail [D.Davys@salford.ac.uk](mailto:D.Davys@salford.ac.uk) and leave your contact details.**

**Appendix C: Study information sheet for those who have demonstrated interest in the research project-interview**

Deborah Davys

Directorate of Occupational Therapy

Frederick Road Campus

Salford University

M6 6PU

**Telephone 0161 295 2869**

**Email [D.Davys@salford.ac.uk](mailto:D.Davys@salford.ac.uk)**

**For the attention of brothers and sisters of people who have a learning disability**

I am an Occupational Therapist who has previously worked with people who have a Learning Disability and their families. As part of my doctoral studies at Manchester Metropolitan University, I am interested in the views and opinions of people who are aged over 25 and have a brother or sister who has a learning disability. My area of interest is the personal wishes and family expectation in relation to future support.

I would like to ask some face to face questions on this topic. The interview could take place in your home or in a private room at the University of Salford. I am interested in your views and opinions on questions such as:

- 1) What are your personal wishes / preferences regarding your role in the future care of your learning disabled brother / sister?
- 2) What do you think will actually happen or has already happened when parents are no longer able to provide support?
- 3) Do you think there are any differences between your own wishes and those of your parents in relation to future support?
- 4) Is there anything that would help you in supporting your brother / sister who has a learning disability?

The aim of this research project is to consider the questions above and bring the concerns and needs of siblings in this situation to the attention of service providers and hopefully improve service planning and delivery.

Each interview will take place at a time to suit you and will last approximately 1 to 1 and half hours. I would like to audio-tape the conversation so as to help my memory and to gain full use of the information you have given. Within the interview I will make brief written notes and check these back with you at the end of the interview for accuracy.

Any information you give will be kept confidential and in accordance with the Data Protection Act 1998. When the research is written up, you and your family will not be identified so as to protect your privacy. Direct quotes may be used in published work after it has been anonymised.

The information I gather from the study will be shared with services responsible for futures planning for people who have a learning disability and may also be presented in professional journals and at conference. I will provide a report and access to my final thesis to any participant on request.

You do not have to take part in this research project, however if you would like to take part or want more information, please contact me on **0161 295 2869** and ask for **Deborah Davys** or you can email me at **D.Davys@salford.ac.uk** If I am not in the office, please leave your name and contact number on my answer-phone and I will return your call as soon as possible.

Please note that whatever choice you make regarding the research project, this will make no difference to any services you or your family currently receive.

If you do decide to take part you can refuse to answer any questions and can withdraw your information at any point without this affecting any services you or your family may receive.

Please also note that if at any time in the interview you provide information that gives evidence of harm or intended harm to a third party, this information will have to be reported to the necessary services.

Thank you for taking time to read this letter.

Yours sincerely

**Deborah Davys**

**Lecturer in Occupational Therapy**

**Telephone 016 295 2869**

**Email D.Davys@salford.ac.uk**

Appendix D: Questionnaire for Adults aged 25 and over who have a brother or sister **who has a learning disability – Concerns for the future**

I am a lecturer in occupational therapy with an interest in learning disability studies. I am conducting research as part of my doctoral studies at Manchester Metropolitan University. My research aim is to explore the personal wishes and family expectations of adults who have a learning disabled brother or sister in relation to future support.

If you aged 25 or over and have a brother or sister who has a learning disability you are invited to take part in this questionnaire.

The results from the questionnaire will be used to gather background information, to form questions for face to face interviews at a later stage and inform services in the future.

There is no obligation to take part. If you do complete the questionnaire your name and personal details are not requested so that your reply will remain anonymous. If you do choose to complete the questionnaire this will be understood to indicate consent for the information to be used within the study outlined above.

Should you wish to complete and return the questionnaire, your support is much appreciated and the contact details are given at the end of the questionnaire. If you have any questions about the study you are welcome to contact me on 0161 295 2869 or via email to [D.Davys@salford.ac.uk](mailto:D.Davys@salford.ac.uk).

Deborah Davys, Lecturer at the University of Salford and part-time PhD student at Manchester Metropolitan University.

**There are twelve questions to complete and space for additional comments. Please place a cross (X) in the appropriate box and return the completed questionnaire to either the email or postal address given at the end.**

**1) How old were you on your last birthday?**

--

**2) Are you?**

Male	
Female	

**3) Where do you live?**

Scotland	
North East England	
North West England	
Wales	
Midlands of England	
South East England	
South West England	
Ireland	



**4) At the moment are you?**

Living with parents	
Living with parents and learning disabled brother or sister	
Living with partner	
Living with partner and children	
Living with children	
Living alone	

**5 )How often do you have face to face contact with your learning disabled brother or sister?**

More than once a week	
Once a week	
A couple of times each month	
Once a month	
Once every three months	
Once every 6 months	
Once every 9 months	
Once a year	
No contact	

**6) Has there been a full discussion with your parents about the support you might provide to your disabled brother / sister when they are no longer able to provide care?**

Yes	
No	
Unsure	

**7) Is there a clear plan for the future support of your learning disabled brother / sister?**

Yes	
No	
Unsure	

**8) If a plan exists, is it fully agreeable to both you and your parents?**

Yes	
No	
Unsure	

**9) Is there any difference between your ideal wishes and your parents' wishes with regard to your role in the future?**

Yes	
No	
Unsure	

**10) Do you feel concerned about how supporting your disabled brother / sister may affect your own life in the future?**

Yes	
No	
Unsure	

**11) Is your relationship with your learning disabled brother / sister that of:**

Full brother / sister	
Half brother / sister	
Step brother / sister	
Adoptive brother/sister	

**12) Are the following still alive?**

Mother	
Stepmother	
Father	
Stepfather	

**Having read through and answered this questionnaire, are there any thoughts or comments you would like to make. If so, please write them in the box below.**

**Thank you very much for your time and co-operation in completing this questionnaire.**

**\*If you feel that the questionnaire has raised any sibling issues you would like to discuss, Sibs is a UK organisation for siblings of disabled people and they can be contacted by telephone on 01535 645453, Email [info@sibs.org.uk](mailto:info@sibs.org.uk) Website [www.sibs.org.uk](http://www.sibs.org.uk)**

**Please send the completed form back by email or post to the address below [D.Davys@salford.ac.uk](mailto:D.Davys@salford.ac.uk)**

**\*Please also let me know if you would be willing to take part in face to face interviews on this topic**

**Deborah Davys,  
Directorate of Occupational Therapy,  
The University of Salford,  
Allerton Building,  
Frederick Road,  
Salford, M6 6PU.**

## **Appendix E: Interview guide for semi-structured interviews**

Issues prior to the start of the interview:

Introductory comments regarding the aims and purpose of the research.

Request for permission to tape record the interview and why.

Information related to the dissemination of results.

Go through the consent form and gain signature.

Interview Guide:

### **Can you tell me about something about yourself such as:**

Your family members and who you live with

Your work

Other commitments in your life that demand time and attention e.g. voluntary work, leisure pursuits

What it was like to grow up in a family where someone had a learning disability

Do you think having a disabled brother / sister has affected your life and if so in what way?

### **Can you now tell me about your brother / sister who has a learning disability such as:**

Where they live now

What level of support they need

How they spend their time

How their disability affects them

How do you feel about them?

### **Do you feel involved in your brother / sisters life at present?**

If you are involved, in what way are you involved and if not, is there any reason for non-involvement?

How often does contact / support / involvement take place and what sort of contact/ involvement is it?

Do you think this level of contact/ support will change in the future?

If answer yes or no –why do you think change / non change will occur?

**Have you talked about the future support needs of your brother / sister with your parents?**

If so, to what extent have discussions taken place?

If not – is there any reason why the discussion has not taken place?

**Is there any difference between your ideal wishes for the future care of your brother / sister and your parents' wishes?**

If so, what is the difference and why do you think the difference exists?

**Do you have any concerns about supporting your brother / sister in the future?**

If so what are they?

If not, is there any reason for the lack of concern?

**What do you think will actually happen in the future when your parents are no longer able to provide previous levels of care?**

Where will the person with learning disabilities live?

What sort of support will the disabled person need?

Will there be any change in role on your part and if so what will that be?

**Can you think of anything that would be helpful to brothers and sisters of people who have a learning disability when thinking about planning for the future?**

If so, what would be useful?

At what stage in thinking about the future would this be useful?

**At the end of the interview check details such as participant age and that of disabled sibling**

**At the end of each interview the participant will be thanked for their time, summary field notes taken in the session will be read back to them to check for accuracy, the participant will be left with the researchers contact details and should the participant**

**have presented as distressed in any way within the interview, Sib UK contact details will be provided.**

## **Appendix F: Consent form**

Deborah Davys  
Lecturer in Occupational Therapy  
University of Salford  
Allerton Annexe  
Frederick Road Campus  
Salford  
M6 6PU  
Tel. 0161 295 2869

### **CONSENT FORM**

#### **PARTICIPATION IN RESEARCH INTO THE VIEWS AND OPINIONS OF ADULT SIBLINGS OF LEARNING DISABLED PEOPLE IN RELATION TO PERSONAL WISHES AND FAMILY EXPECTATION FOR FUTURE SUPPORT.**

##### **I understand that:**

- The aim of this research project is to bring the concerns of siblings regarding their learning disabled brothers and sisters future care needs to the attention of services and hopefully to improve service planning and delivery.
- The research questions are related to the future support needs of my brother / sister who has a learning disability, family expectations and any needs I as a sibling may have.

- That the interview will last approximately 1-1.5 hours.
- The interview will be audio recorded.
- Key points from the interview will be read back to me at the end of the interview so that I can agree to its content.
- I can refuse to answer any questions and this will have no impact on any services received by myself or my family members.
- I can withdraw from the research at any point without this affecting services received by myself or my family members.
- My personal details and that of my family will be kept private and that all information will be kept and destroyed in accordance with the Data Protection Act 1998

I agree that:

- The information can be used as part of a Doctoral studies programme.
- The information may be published as long as it retains my privacy and anonymity.
- Direct quotes from the interview can be used as long as they have been anonymised
- The interview can be audio taped

Signed.....

.....

Date.....

.....



Full  
Name.....

## **Appendix G: Sibs contact support sheet**

Thank you very much for taking part in the interview.

If you have any concerns or worries that the interview has raised, Sibs, the UK charitable organisation for people who grow up with a disabled brother or sister is willing to provide support and information. They can be contacted on 01535 645453 or email to [www.sibs.org.uk](http://www.sibs.org.uk)

Many thanks

Deborah Davys

Appendix H: Example of theme and evidence chart **from interview**

**4**

Themes	Presence in transcript
<p><b>Demands upon time (later incorporated into Family and Impact of LD person upon sibling life)</b></p> <p>Work</p> <p>Family + work</p> <p>Partner</p> <p>LD person</p> <p>Friends + partner</p> <p>Voluntary work and friends</p> <p><b>Services</b></p> <p>Positive</p> <p>Negative</p>	<p>P 2 line 1...so we moved to A where I had another sisters post and that`s where I went into community ,</p> <p>P 2 line 4 emm then I had my own daughter, and just before I had her, I moved into nurse education, ...and I`ve been working in it ever since so in a</p> <p>P 2 line 16 I live with my partner but we`ve got emm, my friend also shares with us</p> <p>P 2 line 18 ( in response to question about demands upon time) My sister (laughs) very much time my sister, (**Put under Impact on Sib life)</p> <p>P 2 line My friend that shares the house with us has just had a very difficult time at work so trying to be a good friend is somewhat of a commitment ..and my partners had his own problems in the past so supporting him`s been a bit difficult as well,</p> <p>P3 line 4 W and B, ( Friends of LD person) who don`t have much contact from their family, I actually take them on holiday a couple of times a year ...and I have a very strong social network cos I travel quite a lot, so it`s mostly in the UK but I travel up and down to see my friends</p> <p>P18 line 21 the social worker came along and met with us and was absolutely brilliant</p> <p>P 24 line 10 ( in reference to current accommodation) she`s happy where she is</p> <p>P 11 line 29 those sort of support needs ( emotional) ... are really</p>

<p>Services provide different role to family</p>	<p>difficult and the ones that you can never access</p> <p>P11 line 37 even though there`s this 2 hours support that`s supposed to go in, it`s usually me or me mum have to book the opticians appointment and then get her there and book the dentist appointment and get her there</p> <p>P17 line 16 I would like to say there are services out there that will deal with it ( services to cover what mum currently does) but in reality there aren`t, so in reality I have the choice of either doing it or letting my sister become bankrupts, neglect herself, not care for herself, not do her shopping or shop stupidly and have 16 million DVD`s but no bread</p> <p>P 18 line 1 I`ve worked in health care for long enough to know that the poorly paid are the ones that have the most direct contact and are the ones that move on most often,</p> <p>P22 line 26 When something happens to my mum, other people have to step up to the mark, but the reality is I know they won`t,</p> <p>P17 line 27 to some degree you`ve got to have some control ...which services haven`t, so like because of all this money she lent the boyfriend, me mum has got her bank book, I get her some money out of the bank every week and take it over to her, a service provider couldn`t do that cos they could never have that power to take her card off her</p> <p>P18 line 18 somebody who`s a service provider couldn`t say that, ( tell LD person what to do) they`d</p>
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	<p>have to politically correct about it all</p> <p>P 18 line 22 you could tell that the last thing she ( the social worker) wanted to do was to put A and K`s name forward to anywhere to live together, for A`s sake, K`s sake for the neighbours sake, ...but had to say this is what she`s telling me that she wants and I have to support in doing that, even though it was a ticket to disaster ... so I can say I`m not going to put your name forward anywhere, ...if you want to do it matey, you get on the phone, ..knowing that she`ll have real difficulty doing it ...so that I`m putting barrier after barrier after barrier in a way to stop her doing what I know is a harmful thing</p> <p>P18 line 35 Providers, can`t do that, ( tell people what to do) providers have a duty</p> <p>P19 line 1 the social worker knew ... this is the worst possible thing that could probably happen,( LD person living with boyfriend) it is a ticket for disaster for both of them,..they can`t make a responsible decision because they`ve got to make a politically correct one which isn`t always the responsible one, cos the most responsible one to that one would be no way no how,</p>
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## **Appendix I: Excerpt from Interview 12**

**Interview 12**

**DD = Interviewer R = Respondent**

**DD** So I wonder if you could start perhaps by telling me a little bit about yourself, and your family members and who you live with emm I`ll just make one or two notes if that`s alright?

**R** Oh course, yeah, well I currently live in L, 34 years of age, I live with my partner, L, and my family live in S , L(county) M (area),where my mum and dad live and my sister who`s 31 , F, she lives there in S too but she currently lives in her own house now, emm that she shares with another woman, yeah, so I`m down there, and they`re up here, been to visit them this week end which I do every couple of months at least, travel up to see them and so yeah I work down in L and...

**DD** And is that permanently G?

**R** I`ve lived there for about 9 years now

**DD** So have you got any other brothers and sisters or is there just you and F?

**R** Just me and F

**DD** And F is your sister who`s got learning disabilities?

**R** Yes, F, that`s right, yeah

**DD** Sorry, and how old is F?

**R** F`s 31

**DD** 31 Right... can you tell me a little bit about your work?

**R** yeah, at the moment I`m working for a foundation, a charitable foundation that supports projects to do with arts and young people and around L 2012, it`s called X and I work to support a lot of the projects that are happening around the country and delivering whatever their project is about, whether it`s about working with young people or fundraising to support the arts festivals, different things, very varied really

**DD** So what would you say, how would you describe your role in the organisation, is it kind of like hands on with the young people or is it admin or IT?

**R** Err it`s a good question, I suppose my job title is policy and partnerships manager but I guess I`m more of a... it`s kind of like a

support to the projects, so I`m kind of support worker to the projects, emm help with fundraising, support in the delivery of their projects, things like that

**DD** Would you say you have like any day to day contact with the young people?

**R** Yeah, a little, a little, depends on the projects, I might be working on a, like this afternoon I`m going to go and be part of a focus group, the programme the NW is running about how they want to develop their festival for this year, so that they get involved in that, in terms of how they`re going to plan it and evaluate the work

**DD** OK ...and is it young people with particular needs, or any young people?

**R** Emm any really, I mean we are funding all sorts of different things, there`s youth programmes, there`s art festivals, there`s projects we`re working with, people that have left prison , volunteering in the catering industries and hopefully into employment, err but it`s varied, we funded 80 odd projects across the UK they`re all doing different things, so I work with them to help them promote what they are doing to other people and promote learning and help them work on the evaluations and stuff

**DD** Right, and is that a job that you`ve always done or have you worked in different sorts of work before that?

**R** Emm before that I worked at another large funding, the big lottery fund, but before that I was doing mainly youth and community work, before that, so I started off as a youth worker when I was about 22 and I`ve done, worked on community developments stuff in regeneration programmes, moved through to working with voluntary sector organisations locally in SL, so moved gradually through things to end up in policy side

**DD** Right, Ok, so...you said that you`ve got your work and that`s full time I guess

**R** Mmm

**DD** And you`ve got your partner, would you say you`ve got other demands in your life that perhaps take time...perhaps any leisure activities or any allegiance to voluntary organisations or anything like that?

**R** Emm outside of work I mean I do do a little bit with a couple of voluntary groups , it`s not regular, I wouldn`t say I was a regular

volunteer but I do a little bit, but little things like I`ve just bought a house , so little things like that , but a lot of time just trying to fix up the house , trying to be really sensible with money (laughs) , things like that, but that`s been quite a recent thing cos I only moved to the new job in September , the same month bought the house so it`s been a busy time really

**DD** Surely... and you don`t have any children yourself?

**R** No, no

**DD** Can I ask you then, what was it like for you to grow up in a family where somebody had a learning disability, how would you describe that?

**R** emm I think it was quite enriching in a lot of ways, I kind of, I wasn`t without its problems, emm and tensions and frustrations, but generally I think it was a really positive experience for me, there was only 2 of us, as kids I mean, my mum and dad were very supportive, they were very much kind of about F`s got her needs but we want you to make sure that you have a full, full life in lots of ways, my mum particularly put a lot of energy into encouraging me to have interests and she always made time to spend time with me and stuff but there was a lot of ,emm they were very encouraging but obviously F`s support needs were quite , were more than the average child`s I suppose so you needed to put a lot of time into her, in effect it took over their life quite a lot , so it enriched it in lots of ways, I think it...

**DD** Can I ask you, I mean I`ll ask you more about F`s needs in a minute but I mean it`s interesting that you said it was enriching, can you say in what ways it was enriching, for you?

**R** Yeah, maybe it`s hindsight, saying that, I think it`s kind of like, it taught me to be patient with F and so I think I learnt to be patient and that kind of, her needs came first a little bit



## Appendix J: Frequency of themes across the transcripts

Superordinate Theme Name	Interviews in which superordinate theme occurs
<b>Demands on time (Occurs in all 15 transcripts later subsumed into Impact of learning disability upon sibling respondent)</b>	15, 14, 13,12,11,10,9,8,7,6,5,4,3,2,1,
<b>Services (Occurs in all 15 transcripts)</b>	15,14,13,12,11,10,9,8,7,6,5,4,3,2,1,
<b>Social response to learning disability (Occurs in 11 out of 15 transcripts)</b>	15,14,13,12, (NOT 11),10,9,(NOT 8),7,6,(NOT 5),(NOT 4),3,2,1,
<b>Impact of learning disability on sibling respondent (Occurs in all 15 transcripts)</b>	15,14,13,12,11, 10,9,8, 7,6,5,4,3,2,1,
<b>Transitions (Occurs in 13 out of 15 transcripts)</b>	15,14,(NOT13),12, 11,10,9,8,7,6,5,4,3,2, (NOT 1)
<b>Family (Occurs in all 15 transcripts)</b>	15,14,13,12,11,10,9,8,7,6,5,4,3,2,1
<b>How learning disability affects the individual (Occurs in all 15 transcripts)</b>	15,14,13,12, 11, 10,9,8,7,6,5,4,3,2,1
<b>Future (Occurs in all 15 transcripts)</b>	15,14,13,12,11, 10,9,8,7,6,5,4,3,2,1
<b>Finance (Occurs in 1 out of 15 transcripts)</b>	13,
<b>Advice to siblings (Occurs in 12 out of 15 transcripts)</b>	15,(NOT14), 13,12,11, (NOT 10),9,8,7,(NOT 6),5,4,3,2,1
<b>Siblings have needs (Occurs in all 15 transcripts)</b>	15,14,13,12,11,10,9,8,7,6,5,4,3,2,1
<b>Sibling respondent is academically able (Occurs in 1 out of 15 transcripts)</b>	3,

### **Summary statement:**

From consideration of the prevalence of themes from the table above, only 2 themes, those of Finance and Sibling respondent is academically able occur in less than two thirds of all transcripts and so the decision to exclude these themes was made. Only those superordinate themes that occur in a minimum of 10 of the 15 transcripts were developed and analysed further. The superordinate theme `Demands upon time 'was incorporated into the superordinate theme `Impact of learning disabled person upon sibling respondent` at the stage of writing up the results.

**Demands on time  
(Occurs in all 15 transcripts)**

**Services  
(Occurs in all 15 transcripts)**

**Society response to learning disability  
(Occurs in 11 out of 15 transcripts)**

**Impact of learning disability on sibling respondent  
(Occurs in all 15 transcripts)**

**Transitions  
(Occurs in 13 out of 15 transcripts)**

**Family  
(Occurs in all 15 transcripts)**

**How learning disability affects the individual  
(Occurs in all 15 transcripts)**

**Future  
(Occurs in all 15 transcripts)**

**Advice to siblings  
(Occurs in 12 out of 15 transcripts)**

**Siblings have needs  
(Occurs in all 15 transcripts)**

## Appendix K: Summary of quantitative data from interviews

<b>Respondent numbers</b>	15 respondents in total including pilot interview
<b>Relationship to any other respondent?</b>	Interviewees 1 and 15 were full sisters Interviewees 9 and 10 were full sister and brother Interviewees 5 and 11 were full sisters
<b>Age of respondent</b>	Ages ranged from 30(female) to 68 (male) 4 respondents were aged between 30-40 (1 male, 3 female) 4 respondents were aged between 40-50 (1 male, 3 female) 3 respondents were aged between 50-60 (3 female) 4 respondents were aged between 60-70 ( 1 male, 3 female)
<b>Gender of respondent</b>	3 males (aged 34-68) 12 females ( aged 30-64)
<b>Respondent work status</b>	8 respondent held full time positions ( 1 currently on maternity leave) 1 was in full time study 1 worked part time 1 was not in paid employment at present 4 were retired *Of the 15 interviewees, 9 stated that they had involvement in the caring professions / services within their work or study history and 6 reported no involvement with caring services throughout their work history
<b>Ethnicity</b>	14 White British interviewees, 1 Asian interviewee
<b>Parental status</b>	9 interviewees reported both parents to be dead 3 interviewees reported both parents to be alive and living together 3 respondents reported mum to be the only parent actively involved with the LD person (1 father estranged no contact since childhood, 1 father in residential care and 1 father dead)
<b>Learning disabled person status</b>	4 respondents reported the LD person to be dead at the time of the interview however their details are recorded as when alive: 3 respondents reported LD person to currently live or did live when they were alive with the respondent ( 2 respondents currently living with LD siblings, 1 LD sibling did live with respondent but now died) 2 respondents reported the LD person currently living with mum 7 respondents reported LD person living or having lived in a community setting with support (2

	<p>respondents reported LD person now dead- same person for these respondents)</p> <p>1 respondent reported shared care between parents and charity</p> <p>1 respondent reported LD person lived with another sibling</p> <p>1 respondent reported LD person living in community with husband and child</p> <p>*NB 2 respondents reported that LD person had lived with them for a period after last parent died but have now gone to supported accommodation in the community</p>
<b>Respondent social context at the time of interview</b>	<p>6 respondents lives with partner / husband and have adult children / step children</p> <p>1 respondent lives alone and is single</p> <p>3 respondents live with a partner / husband with no children</p> <p>2 respondents report living with husband, LD person and no children ( 1 reports LD person used to live with her + husband + father until LD person died)</p> <p>1 respondent was single and lives with his LD sibling</p> <p>1 respondent was married with children but her husband lived currently in a different country</p> <p>1 respondent was single, lives alone and has adult children</p>
<b>Number of children in family including the learning disabled person</b>	<p>Ranged from between 2 and 10 children in a family including the LD person</p> <p>3 respondents reported 2 children in the family including the LD person</p> <p>3 respondents reported 3 children in the family including the LD person</p> <p>1 respondent reported 4 children in the family including the LD person</p> <p>2 respondents reported 5 children in the family including the LD person</p> <p>3 respondents reported 6 children in the family including the LD person</p> <p>2 respondents reported 7 children in the family including the LD person</p> <p>1 respondent reported 10 children in the family including the LD person</p>
<b>Parental wishes regarding future care for learning disabled person according to respondent</b>	<p>5 respondents reported that parents wanted the LD person to be looked after by siblings / within the family ( may have been spoken or unspoken understanding</p> <p>6 respondent report that parents wanted the LD person to be supported in the community with support / contact from siblings/family</p>

	<p>2 respondent report that parental wishes were unstated</p> <p>1 respondent reports that mother wants her to live next door to LD person and provide support alongside services</p> <p>1 respondent stated that mother says she wants supported accommodation in the community but actually wants the LD person to be cared for by a family member</p>
<b>Respondent wishes regarding future care</b>	<p>9 respondents stated that they were in agreement with parental wishes re the future care of the LD person</p> <p>2 respondents did not hold the same view about future care for the LD person as their parents</p> <p>4 were unclear about their agreement with parental wishes for the future ( 1 respondent was not sure about his own wishes for future care, 1 was not sure if what mum verbalises is actually what she wants, 2 respondents stated that mum did not express what she wanted for future care)</p>
<b>Presence of future plans</b>	<p>1 respondent reported the presence of a written plan ( no further details)</p> <p>5 respondents reported a verbal understanding with parents about the future</p> <p>2 respondents reported the presence of a financial and care / advocate plan</p> <p>5 respondents reported no futures plan in place (reasons for this included that it was stressful for older parents to discuss, that the respondent tends to “bury her head in the sand”, that there was not enough clarity(??) and that the person had only just moved to a new accommodation setting)</p> <p>1 respondent reported the presence of an end of life plan for the LD person</p> <p>1 respondent reported the presence of a 5 year plan but was unsure what this meant</p>
<b>Degree of respondent involvement in life of learning disabled person</b>	<p>Telephone contact, face to face contact and the type of support sibling provide:</p> <p>4 respondents report telephone contact at least daily / most days with LD person</p> <p>2 respondents report telephone contact at least 2-4 times each week with the LD person</p> <p>4 respondents reported telephone contact every few weeks</p> <p>4 respondents reported daily face to face contact with the LD person</p> <p>2 respondents reported face to face contact 2-4 times each week</p> <p>6 respondents reported face to face contact every 1-2</p>

	<p>weeks</p> <p>2 respondents reported face to face contact every 3-6 weeks</p> <p>1 respondent reported face to face contact every 2-4 months</p> <p>Types of support / reasons for contact with the LD person included the following:</p> <p>10 respondent reported support with meetings and appointments</p> <p>14 respondents provided social contact such as outings and holidays</p> <p>5 respondents noted provision of direct care/supervision / instruction</p> <p>3 respondent noted providing all support as the LD person lives ( or used to ) live with them- includes meals, laundry, shopping, personal care, transport</p>
<b>Respondent concerns regarding the future</b>	<p>1 respondent was concerned about her own health status and how this could affect the LD person</p> <p>7 respondents noted the health status / wellbeing of the LD person as a concern</p> <p>5 respondents were concerned about future accommodation needs of the LD person</p> <p>5 respondents were concerned about how the future needs of the LD person will be met such as appropriate services / funding</p> <p>5 respondents were worried about the long term future of the LD person when they were not able to care / die themselves</p> <p>2 respondents were concerned that the LD person would not be willing to accept appropriate support from services</p> <p>3 respondents were concerned about taking over the parental role in the future and how this would impact their life and that of the LD person</p> <p>2 respondents were concerned about the LD person dealing with grief on future loss of mum and / or mum coping with the loss of the LD person</p> <p>2 respondents voiced no future concerns ( i because the LD person was now dead and had lived with a family member until death, and 1 because they trusted the current support system and other family members to provide support in the future)</p> <p>2 respondents were concerned about understanding the service systems when parents are no longer providing this role</p> <p>1 respondent was concerned that the LD person would get fed up with her</p>
<b>Respondent stated needs</b>	<p>5 respondents wanted knowledge of support systems and services</p>

	<p>5 respondents wanted more / appropriate support from services</p> <p>3 respondents had no stated needs</p> <p>5 respondents wanted support for child siblings of LD people</p> <p>8 respondents wanted support / advice / counselling for siblings of LD people ( including support from other family members)</p> <p>2 respondents wanted sibling rights to be recognised</p> <p>1 respondent wanted to be involved in decisions about the LD person`s life</p>
<b>Respondent advice to others</b>	<p>2 respondents advised being tolerant / accepting of the LD person and their needs</p> <p>1 respondent advised learning to take second place in the family to the LD person</p> <p>1 respondents advised teaching own children to support LD people</p> <p>2 respondents advised being aware of sibling rights and what is available</p> <p>1 respondents advised that it is OK to be angry</p> <p>4 respondents advised stating what siblings own needs and wishes are</p> <p>4 respondents advised preparing for the future (3 of the 4 stated preparation should take place early)</p> <p>1 respondent advised supporting parents to prepare for the future of the LD person</p> <p>6 respondent advised seeking support from own needs from LD families or professionals</p> <p>4 respondents advised allowing the LD person to have as normal a life as possible</p> <p>1 respondent advised that respite should be taken</p> <p>1 respondent advised that siblings should not feel guilty</p> <p>1 respondent advised that child siblings of LD people should be supported</p> <p>1 respondent advised that siblings should be included in the life of the LD person to some extent</p>
<b>Role of most involved with LD person?</b>	<p>*NB 12 different families took part, 3 interviewees were brother / sister to another person interviewed</p> <p>3 people interviewed were the only other child in the family apart from the LD person and of the remaining interviews where there was at least 2 non-disabled children in the family, 9 stated that they were the most involved sibling.</p> <p>where 2 siblings from the same family were interviewed (3 families) the most involved was one of the people interviewed in each instance</p> <p>There were no step families included in the interviews however 3 out of the 12 families represented had half</p>

	<p>sibling relationships – all interviewees shared the same mother</p> <p>Rationale given from the most involved siblings included the following reasons:</p> <p>5 respondents noted a close bond between them and the LD person</p> <p>4 respondents noted the most involved role as due to family / family wishes or assumption</p> <p>3 respondents noted their physical proximity</p> <p>2 respondents noted issues with family relationships such as a very close bond between themselves and mum or difficult relationships with sisters-in-law</p> <p>2 respondents noted that other siblings had young children / established their own homes away from the family home</p> <p>1 respondent noted their own personality traits</p> <p>1 respondent noted that it was the reason for their birth ( to support the LD person)</p> <p>3 respondents noted that they were the eldest / most responsible child</p> <p>2 respondents noted that they were the youngest child and were at home when the parent's died</p>
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