Becoming Adults Together: How Having a Disabled Sibling Impacts on Young People's Transition to Adulthood

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Abstract

This thesis explores how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. Previous research has highlighted that having a disabled sibling impacts on people's lives in different ways throughout the life course. Most research has focused on children and adolescent's experiences or the experiences of older adults. There have been some studies that explore the experiences of young adults who have a disabled sibling. However, these studies mainly focused on young people's views of service provision and how having a disabled sibling impacts on their plans for the future. The experiences of young adults are underrepresented in research relating to siblings of disabled people. There is also little understanding of how having a disabled sibling impacts on young people's transition to adulthood.

Therefore, this research aimed to specifically explore the impacts that having a disabled sibling might have on young people's transition to adulthood. The research aim was approached by focusing on exploring the sibling relationship during the transition to adulthood. The ways in which the transition to adulthood for young people and their disabled sibling might impact on family life was also considered. Finally, the research explored how having a disabled sibling impacts on young people's transition to adulthood relating to four key markers of becoming an adult. These markers are moving out of the family home, leaving compulsory education, choice of occupation and relationship and family formation. The study used semi-structured qualitative interviews with 10 young people aged 18-24 who have a sibling with autism or learning disabilities to gather young people's thoughts, aspirations and experiences relating to their transition to adulthood.

One of the key findings of this study is that young people expressed that their sibling relationship changed during their life course. This study also found that young people have provided and do provide support and care to their sibling, sometimes going beyond what might be expected in a sibling relationship. Another key finding is the ways that participants viewed the transition to adulthood for themselves and their disabled sibling as having different impacts on family life. This study also found that having a sibling with autism or learning disabilities impacted on young people's thoughts, experiences and aspirations relating to moving out of the family home, their occupation choices, their family planning and their adult skill set. Young people's potential future primary caring role for their sibling impacted on their current lives and future plans.

The findings of this research suggest that young people who have a disabled sibling may experience 'disability by association' (Burke, 2010). Participants experienced stigma, stress and anxiety and a sense of being special and different because they have a disabled sibling. For young people in this study there was contention between familialism and individualism. Young people's transition to adulthood was emotionally and socially linked with their siblings' and parent's lives. This suggests that family systems theory and life course perspectives are useful when studying the experiences of people who have a disabled sibling. The findings also suggest that young people's sibling relationships are affected by other relationships in the micro, meso and exosystem (Bronfenbrenner, 1979, 1986). The research also has implications for social care practice, social services should offer families advice and support to plan for the potential support role of siblings in the future. Young people should also be involved in the transition planning for their disabled sibling, providing the disabled person and their sibling want this. More funding and research attention is required to further explore

siblings' experiences throughout the life course and to identify the support that families may need.

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Chapter 1: Introduction

Aim of the Research Study

- To explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood.

Research Objectives

1. To explore young people's experiences, thoughts and feelings relating to the relationship that they have with their sibling with autism or learning disabilities.
2. To explore young people's thoughts and experiences relating to how their transition to adulthood and their disabled sibling's transition to adulthood might impact on family life.
3. To explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to key markers of the transition to adulthood, such as: 1. Moving out of the family home; 2. Leaving compulsory education; 3. Choice of occupation; 4. Relationship and family formation.

Ten semi-structured, in-depth interviews were conducted with young people aged 18-24 who have a sibling with autism or learning disabilities. This introductory chapter will provide an overview of the overall structure of the thesis.

Rationale for Research Focus

This section will outline the rationale for the research focus mentioned above. I approached this topic after having worked as a support worker with adults with learning disabilities and autism and their families. The experiences and roles of the siblings of disabled people always interested me when I was working in social care, particularly how they planned to be

involved in their sibling's care as their parents grew older. From my background reading of literature relating to siblings of disabled people, the lack of published research that focuses on young adults became clear. Many studies have considered the experiences of siblings in childhood and adolescence (Petalas et al, 2009; Granat et al, 2012; Burke, 2010; Burke and Montgomery, 2001; Pollard et al, 2013; Moyson and Roeyers, 2012; Graff et al, 2012). The research that has been carried out with adult siblings has mainly been conducted with adults aged around 25 and above (Orsmond and Seltzer, 2007; Burbidge and Minnes, 2014; Doody et al, 2010), with some studies focusing on middle age or later life (Knox and Bigby, 2007; Bigby et al, 2015; Benderix and Sivberg, 2007). The literature on adult siblings has highlighted changes in experiences throughout adulthood. However, very few studies have identified the experiences of siblings as they transition to adulthood. I was only able identify three studies that specifically considered the experiences of siblings in young adulthood (Jacobs and MacMahon, 2016; Tozer et al, 2013; Rawson, 2010). These studies all touched on the experiences of siblings as they transitioned to adulthood. However, the studies mainly focused on service provision and future planning. They did not specifically explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, aspirations and experiences relating to their own transition to adulthood.

Within my study the transition to adulthood is understood in broad terms as related to how young people move towards adult independence (a situation that is itself variable in its meaning, varying over time and by cultural and socio-economic context). The transition to adulthood can be classified using five markers of adult independence: leaving compulsory education, getting a job, leaving the family home, getting married, entering a civil partnership or cohabiting and having children (Furlong et al, 2011; Ulrich Mayer, 2004). However, other markers of adult independence may be important to young people and relevant to

understandings of what signifies adulthood. Examples may be entering romantic relationships, starting university, becoming responsible for someone else or travelling to another country independently from family. This study focused on exploring young people's experiences, thoughts and aspirations relating to leaving the family home, leaving compulsory education, their choice of occupation or future career and relationship and family formation. This allowed me to explore experiences and aspirations relating to a range of potential markers of transitioning to adulthood, especially as occupation (considered widely) could include working, travelling, not working or caring. It was also important to find out what young people's relationships are like with their siblings as this provided context to young people's thoughts, aspirations and experiences relating to their transition to adulthood when they have a sibling with learning disabilities or autism. I also wanted some insight into how the transition to adulthood for participants and their sibling might impact on family life. A more detailed exploration of the three research objectives can be found in chapters 4 and 8 of this thesis.

Previous research provided evidence that my research focus was worth exploring. Informal conversations I had with adults who have a disabled sibling, staff from the charity Sibs (which supports siblings of disabled children and adults), and staff from a young carers project indicated that my research focus was significant to them. Adults I know personally who have a disabled sibling stated that they thought having a disabled sibling did impact on their experiences of growing up and becoming an adult. Charity staff outlined that, in their experience, young people's lives are impacted by having a sibling with autism or learning disabilities. For example, some young people they had worked with had not moved far away from their family so they could provide support to them in young adulthood. Other young people had talked to them about worrying that their own children might have disabilities. Tozer et al (2013) carried out interviews with adult siblings of people with autism plus learning

disabilities. They found that people who have a disabled sibling may feel guilty about moving away from the family home. I wanted to further explore experiences and aspirations relating to moving out of the family home with young people who have a sibling with learning disabilities or autism. I also wanted to analyse the experiences of young people who have a sibling with learning disabilities or autism who still live with their family in young adulthood. Some studies have also identified that siblings of disabled people may choose to enter 'humanitarian' careers because of the skills and knowledge they have acquired through growing up with a disabled sibling (Tozer et al, 2014; Marks et al, 2005). Rawson (2010) found when interviewing young people aged 17-23 who have a sibling with learning disabilities that some young people wanted to move abroad in the future. The young people were concerned about how they might advocate for their sibling with learning disabilities whilst living in another country. I wanted to further explore how having a sibling with learning disabilities might impact on young people's occupational choices and aspirations.

Atkin and Tozer (2011) outline in a research summary paper of their study involving adult siblings that for nearly all participants, their partner's reaction to their disabled sibling had been a big issue and had led to relationships ending in some cases. Many participants talked about worries of the genetic risks of their own children having autism plus learning disabilities, some participants had teenage children who were concerned about genetics too. I wanted to expand on the limited previous research and explore young people's experiences, thoughts and aspirations relating to relationship and family formation. I chose to focus on autism and learning disabilities because I had worked with people with autism and learning disabilities in the past. Also, many people have learning disabilities and autism, this will be discussed in detail in the next section. Overall, conversations with charity staff and siblings of disabled people and previous research highlighted that having a sibling with

learning disabilities or autism impacts on young people's experiences, choices and aspirations relating to their occupation, leaving the family home and relationship and family formation. This suggested that the research focus of my study was worth exploring.

Definitions of Disability, Autism and Learning Disabilities

This thesis is influenced by a social approach to understanding disability. The social model definition of disability was proposed by British academic and disability rights activist, Michael Oliver. Oliver has criticised individual explanations of disability that see disability as a personal tragedy. Oliver argues that:

> 'human beings give meanings to objects in their social world and subsequently orientate their behaviour towards these objects in terms of the meanings given to them. ... As far as disability is concerned, if it is seen as a tragedy, then disabled people will be treated as if they are victims of some tragic happening or circumstance. This treatment will occur not just in everyday interactions but will also be translated into social policies which will attempt to compensate these victims for the tragedies that have befallen them' (Oliver, 1990: 2).

The social model of disability emerged in the 1960s and grew in opposition to the individual model of disability, which focused on individual impairment needing to be fixed in order for the person to 'fit into' society. The social model of disability argues that it is exclusion, social barriers and negative attitudes that cause disability rather than impairment. The model suggests that disability is created by social factors and that difference is a subjective concept. The social model distinguishes between impairment and disability. Barnes (1991) defines impairment as:

> ‘the functional limitation within the individual caused by physical, mental or sensory impairment’

Disability is defined as:

> ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Barnes, 1991: 2).

Barnes (1991) adapted this definition from the 1982 Disabled People's International (DPI) definition which used the terms disability and handicap instead of impairment and disability (DPI, 1982). The social model suggests that the inequalities, stigma and difficulties that disabled people face are due to society failing to adapt to people’s differences. It is only impairment which is real and disability is a social construct. Impairment is associated with people being othered as disabled. Individual definitions of disability suggest that people should be cured of their impairment or accept their disability and negotiate their social roles which are less valued; the onus is on the individual to make changes. Social explanations of disability emphasise that the problem is social and caused by social processes (Priestley, 2003). However, the social model of disability has been criticised for simplifying disability and undermining the individual experiences of impairment (Handley, 2003). Gabel and Peters (2004) argue that the social model of disability should be considered alongside other theories of disability that recognise the material reality of impairment. Priestley (2003) argues that there are four main approaches to disability: biology, psychology (individual models), structure and culture (social models). Priestley illustrates that there is overlap between these different approaches to disability. For example, biology helps us to understand the workings of the body but culture and structure is also important, the body is understood through social processes such as patterns of employment, food and drink culture and religious practices.

Individual experiences of disability may affect people psychologically but these personal experiences are located in the social.

Shakespeare (2014) criticises separating impairment and disability and argues that the social and biological are intertwined. Shakespeare argues individuals experience the effects of biological impairment and social disablement at the same time. Shakespeare highlights that disabled people's accounts suggest that they may experience the pain or limitations relating to impairment and the social barriers relating to this impairment. Shakespeare also criticises the social model for focusing too much on social barriers creating disability. Shakespeare points out that disabled people may face barriers that are not social, for instance some natural landscapes may be inaccessible to wheel chair users (Shakespeare, 2014: 36). Shakespeare writes that disability is a 'complex interaction of biological, psychological, cultural and socio-political factors, which cannot be extricated without imprecision' (Shakespeare, 2014: 26). This thesis views individual (biological, psychological) and social definitions of disability (cultural, structural) as intertwined. The social model definition of disability influenced my research and writing, recognising the barriers that disabled people face and how disability is socially understood is vital. However, social definitions alone did not inform my understanding of disability. Individual explanations were also considered, this allowed me to recognise the biological and psychological effects relating to disability. For example, some young people in my study talked about the social barriers their family faced and the individual psychological and practical difficulties they experienced relating to providing care. Overall, this thesis adopts a social approach to understanding disability which overlaps with individual understandings of disability. This thesis agrees with Shakespeare's (2014) view that impairment and disability are intertwined rather than separate (Shakespeare, 2014). The terms 'disabled sibling', 'disabled person' and 'young disabled person' will be used throughout this thesis to refer to people who have autism or learning disabilities.

The focus of my MPhil research is on young people who have a sibling with autism and/or learning disabilities. The rest of this section will explore definitions of autism and learning disability. Both autism and learning disabilities can be considered as impairments that are linked to socially constructed concepts of disability. The diagnoses, definition and identification of autism and learning disability are highly complex and vary widely and are contingent on specific assumptions of development associated with the education and employment arrangements specific to modern economies. It is important to recognise that medical diagnoses of autism and learning disability occur within this context and provide people with access to support from services. At the same time, modern societies provide forms of 'associative sociability' where those diagnosed and their families can identify with other people who have been diagnosed with autism or learning disabilities.

The Department of Health (DoH) defines a learning disability as a 'significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development' (DoH, 2001: 14). Some people with a learning disability advocate the descriptor 'learning difficulty', this term is also utilised in educational settings in the UK, sometimes referring to people with specific difficulties in learning, for example dyslexia, dyspraxia and attention deficit disorder. 'Intellectual disability' and 'developmental disability' have been used as other descriptive terms internationally but less so in the UK. Learning disability has also been labelled with degrees of severity from mild, moderate, severe to profound and multiple. Often the severity of learning disability is determined through IQ scoring by health professionals. Usually a person with an IQ of around 50-70 is diagnosed with a mild learning disability, an IQ of 35-50 a moderate learning disability, an IQ of 20-35 a severe learning

disability and an IQ of below 20 categorises someone as having a profound learning disability. Using IQ scoring as a method of diagnosis undermines a social approach to understanding disability, as it focuses on a medical based testing system and not on social interpretations of ability. Using IQ scoring alone to diagnose learning disability has been heavily criticised and adaptive and social functioning assessments are often used alongside these by health professionals (Holland, 2011: 3-4). This paragraph has outlined different definitions of learning disability, the next paragraph will explain which definition of learning disability was adopted in my study.

The various definitions and measurements of learning disability emphasises that people with learning disabilities do not fit into a distinct category. The capabilities of people vary widely, which may contribute to why there are so many different labels and terms. This emphasises the usefulness of adopting a social approach to disability which recognises that disability is complex and socially constructed and reproduced in a variety of different ways. The term 'learning disability' will be used within this thesis because it is commonly used in UK research and policy. When discussing and analysing empirical studies, I will utilise the terms that the authors have used. The British Institute of Learning Disabilities (BILD) defines learning disability as 'a general term that refers to individuals who find it harder to learn, understand and communicate. Other terms that are used to describe an individual's situation include complex needs or high support needs' (Holland, 2011: 2). I used this definition of learning disability within my study because it recognises that people with learning disabilities are individuals like anyone else. The definition also emphasises that people with learning disabilities may have support needs. I initially used the definition provided by the DoH (mentioned above) on my recruitment poster/emails. Several people who have a sibling with specific learning difficulties such as dyslexia and dyspraxia came forward. I therefore used the BILD definition instead as I hoped to attract more

people who have a sibling with learning disabilities and higher support needs.

Like learning disability, definitions of autism are complex and having autism may not always be associated with having a disability. The National Health Service (NHS) outlines that "autism spectrum disorder (ASD) is the name for a range of similar conditions, including Asperger syndrome, that affect a person's social interaction, communication, interests and behaviour' (NHS, 2016). There are five disorders that have been medically classified under the umbrella of autism spectrum disorders. They are Asperger's syndrome, Pervasive Developmental Disorder Not Otherwise Specified, Childhood Disintegrative Disorder, Rett's Disorder and Autistic Disorder (Phetrasuwan et al, 2009). Similar to learning disability, there has been a lot of medical confusion about the boundaries and definitions of autism and these have changed in recent decades. Most of the young people in this study either specified their sibling as having autism or Asperger's syndrome. Some spoke about their sibling having severe autism, some said their sibling has higher functioning autism.

Several participants in the study have a sibling with autism and learning disabilities. Researching the prevalence of both autism and learning disabilities is highly complex. It has been estimated that the prevalence of autism in people with learning disabilities in England is between 31% and 35% (The NHS Information Centre, Community and Mental Health Team, Brugha et al, 2012). The prevalence of learning disability in people with autism in England has been estimated from 15-85% (Emerson and Baines, 2010). It is beyond the scope of this study to consider the complex methods involved in measuring the prevalence of learning disability plus autism and vice versa. The confusion and differences in findings relating to prevalence of autism and learning disability highlights that the diagnosing them together is highly complex. Also, there may be disagreement medically about whether autism or learning disability is the person's

primary diagnosis and whether autism or learning disability are the accompanying diagnosis. Overall all this complexity and confusion highlights that what we understand as autism and learning disability cannot be simply labelled with a medical diagnosis. The processes of medical diagnoses themselves are part of a complex cultural and social interactions. The confusion around medical definitions highlights that attempts to diagnose and in some cases 'cure' autism and learning disabilities have not been successful. This suggests that social understandings of learning disability and autism might be more useful, as this allows for a more holistic approach to the complexity surrounding disability and difference. It recognises that impairments are understood in complex social ways. For the purposes of this assignment, the NHS definition of autism was used as it broadly defines the different ways in which autism has been classified. Throughout the thesis I will refer to participants' siblings having disabilities, referring to both autism and learning disability. This thesis adopts the understanding that disability is a broad socially constructed concept that results from a variety of different impairments. The use of the term disability in this thesis includes people with milder support needs who have learning disabilities or autism.

Thesis Structure

Chapter 2 of this thesis consists of a literature review that explores current trends in the transition to adulthood for young people today and considers sibling relationships throughout the life course. Chapter 3 contains a literature review relating to the transition to adulthood for young disabled people and how these transitions might impact on family life. Chapter 4 outlines the methodology of the research study carried out with 10 young people who have a sibling with autism or learning disabilities. Chapter 5 contains the findings and discussion relating to the first major theme identified during the data analysis of the 10 interviews. The first major theme found was 'the impacts of transitions on family life'.

This theme displays the findings relating to participants' explanations of the impacts that the transition to adulthood for themselves and their disabled sibling have had on family life. Chapter 6 displays the findings and discussion relating to the second major theme, 'The sibling relationship'. This chapter outlines how young people described the ways in which their sibling relationship has changed throughout their life course. Chapter 7 contains the findings and discussion relating to the third and final major theme 'the impacts of having a disabled sibling on young people's transition to adulthood'. This chapter focuses on discussing participants' experiences and thoughts relating to how having a disabled sibling has impacted on their transition to adulthood. These findings are considered alongside relevant literature and theory. Finally, chapter 8 discusses the ways in which the findings link with the research objectives, explores the implications of the findings for practice, research and theory, outlines the limitations of the study and provides suggestions for future research.

Chapter 2: The Family Life Cycle, Sibling Relationships and The Transition to Adulthood

Introduction

This chapter will explore how understandings of the transition to adulthood have developed and how different life stages can be viewed as social constructs. Literature that has examined the sibling relationships across the life course will also be discussed. The transition to adulthood can be understood in the context of life development stages from infancy to childhood, to adolescence, young adulthood, middle adulthood and older age (Furstenberg et al, 2005). Entry into adulthood is also linked with family structure and 'ideal types' of family life. The first section will explore demographic changes in family structures that have led to social norms of the ideal typical family form. Current patterns of family life will then be explored, focusing particularly on gendered patterns. The chapter will then explore the social construction of childhood, adolescence and young adulthood, highlighting how life stages are culturally, socially and historically dependent. The ways in which social differences might impact on young people's transition to adulthood will also be explored. This review of literature relating to transitions is particularly relevant to the findings outlined in chapter 7 of this thesis. The analysis in this chapter will provide a broad picture of current dominant concepts of the modern family and the life course. The final section of this chapter will explore literature relating to sibling relationships across the life course. This section is directly relevant to the findings presented in chapter 6 of this thesis. Throughout this chapter the term 'family' mainly refers to a couple or single parent living with dependent or non-dependent children. However, a couple living together, a married couple or other understandings of the family may be applied.

Patterns in the Family Life Cycle 1950-1970

Hareven (1982) outlines that within the life cycle there is 'family time', 'individual time' and 'historical time'. 'Family time' refers to timing of life course events within the family, this may be a change in family roles, such as parents becoming grandparents or the marriage of the oldest child. The family moves through a life cycle and certain transitions mark changes in family relationships. 'Individual time' encompasses the points in a person's life cycle where they transition to new roles, this may be leaving the home or getting a new job. 'Historical time' impacts on individual and family time; social, economic, political, legal and cultural changes affect patterns of family and individual life (Hareven, 1982: 7). The impact that historical time has on family and individual life patterns highlights how understandings of the family are socially constructed, they are dependent on context and are not static. This section will briefly explore family and individual timing in Britain from 1950-1970, this will outline how current family patterns have emerged. Throughout this chapter the terms UK and Great Britain will be used. Great Britain or Britain refers only to England, Scotland and Wales, the UK refers to England, Scotland, Northern Ireland and Wales.

Family timing patterns can be identified as static from the 1950s to 1970s in Britain, with similar patterns in Europe and other Western nations. From 1950-1970 entry into marriage became more age specific with the age range spanning on average 8 years (Anderson, 1990: 69). The span of years in marriage in which children were born also reduced, in the 1960s and 1970s most people had children in their first 7 years of marriage. Most people could expect to live to an old age, people were marrying in their late teens and early 20s and having children in the early years of marriage. This meant that most people would live to see their grandchildren and perhaps their great grandchildren. Most teenagers left school, started a job and got married and left their family home in a

relatively short period of time (Furstenberg, 2000; George, 1993). With falling male death rates, increases in wages for male job roles and new ideals of nurturing children, the male breadwinner and female homemaker roles emerged strongly in the 20th century (Horrell and Humphries, 1997; Gente, 2001). The demographic patterns outlined above mark the emergence of the nuclear family in the 20th century. The ideals of the breadwinner and homemaker with two children become particularly dominant between 1950-1970. As we will see in the next section this dominant pattern would not last, however the nuclear family ideal has lived on.

Ideals of the Nuclear Family Live On

The previous section explored historical shifts in patterns of family life up until the 1970s in Britain. I will now outline the changing family patterns since the 1970s in the UK, this will illustrate how current family patterns have developed in recent decades. From 1950 to 1970, the general trends in family formation were increasing marriage rates, a lower age for first marriage and low divorce rates (Allan et al, 2001). Children were in households for shorter periods of time, leading to the emergence of child-free households for parents at a relatively early age (Myrdal and Klein, 1956). This time marks the intensification of the nuclear family ideal of men as breadwinners and women as homemakers caring for two to three children. From the 1970s onwards a shift can be identified from this pattern of predictable family formation to increased diversity. There has been an increase in lone parent households, step-family arrangements, non-resident fathering, single person households and cohabitation rather than marriage, changes which will be explored below. People also increasingly live with their parents in young adulthood, this will be considered in the next section of this chapter.

Growing divorce rates have affected the increasing diversity in family structures since the 1970s. Since the passing of the 1971 Divorce Reform Act, divorce rates have markedly increased. In 1971 only 5.8 couples out of every one thousand divorced, in 1986 12.7 out of every one thousand divorced (Office of Population Censuses and Surveys, 1991). Divorce rates have continued to rise, in 2012 it is estimated that 42% of married couples divorced (Office for National Statistics (ONS), 2013a: 1). Another important demographic change is the decreased number of marriages, 415,487 marriages were recorded in England and Wales in 1970, 331,150 in 1990 and 249,133 in 2011 (ONS, 2014a). There has also been an increased number of children being born outside of marriage, births outside of marriage rose from 9% in 1976 to 23% in 1995 (Haskey, 1998: 10); in 2014 47.5% of children were born outside of marriage (ONS, 2015a: 10). Increasing divorce rates meant that many children would live within a lone parent (usually a lone mother) household at some point in their childhood (Clarke, 1992). In 1991, lone parent families accounted for 19% of families with children, a large increase compared to 8% in 1972 (Office of Population Censuses and Surveys, 1993). In the UK in 2015, lone parent families represented 25% of families with child dependents, with 90% of lone parents being mothers (ONS, 2015b). In 2011, it was estimated that 11% of families in England and Wales with dependent children had at least one step child within the family (ONS, 2014b: 1).

Women have been involved in the labour market throughout British history. However, the beginning of the 20th century marked a time when women's roles as homemakers became more dominant across social classes (Alwin et al, 1992). Two major changes can be identified in contributing to the increasing participation of women in the labour market from the 1960s onward. These are the revolution in contraception control for women and equal opportunity changes in the job market (Hakim, 1999). One other change is the shift to a global market economy in the 1970s, with less of a focus on manufacturing jobs. This can be

identified as opening up ‘white collar’ or office based jobs that may be more attractive and available to women, in comparison to manufacturing or ‘blue collar’ jobs that are largely male dominated (Hakim, 2006). Economically, the breadwinner model could not support the whole family, there was a shift to a dual earner model, meaning more women needed to work (Hunter, 2016). These changes mentioned above contributed to an increase in female employment. These changes in female employment patterns impacted on family life, women whose children had left home and women who were still caring for children increasingly worked. More women delayed childbearing, or decided not to have children so they could focus on their careers (McRae, 1997; Aassve et al, 2007; Furstenberg, 2013). For example, in England and Wales, just 11% of women born in 1940 have not had children, compared to 19% of women born in 1967 (ONS, 2013b: 1).

The analysis above highlights that since the 1970s there have been changes in family patterns, with the traditional formation of a married couple with two children diminishing somewhat. Even though there has been an increase in female employment, lone parent families, step families and people opting out of having children altogether, the nuclear ideal can still be identified in the UK and beyond (with many lone parents having previously been in a dual parent household). Chambers (2000) argues that the white nuclear family is still the dominant ideal in popular Western media. Chambers defines trans-nuclear as a process by which all social relationships are transformed into familial ones. Chambers identifies that the hybrid trans-nuclear family formation is often portrayed in the media, where ideals of close, loving families are still prominent but the structures are more complex. These trans-nuclear families may be step families, lone mothers and lesbian or gay couples with children. The ideals of family life are still based on dominant nuclear family ideals of social relationships but flexibility is now socially accepted. The media may

also portray these alternative family types as dysfunctional if they do not comply with ideals of familialism (Chambers, 2000).

Some sociologists have argued that the increase in divorce rates, delayed ages of first childbirth and the fluidity in changing romantic partners and careers shows a pattern of individualisation in Western society, where the focus is now on individual self-reliance in the labour market and social life (Elias, 1991; Beck and Beck-Gernsheim, 2002). This also links with the concept of de-familisation, with individuals relying more on state intervention and the weakening of inter family economic and social dependency (Esping-Andersen, 2009). This often leads to the assumption that individualisation and familialism are at odds with one another (Scott, 1997). However, individualisation and familialism can be identified as complex and intertwining. For instance, state policy and intervention in Western societies has promoted the ideal of parental responsibility within the family, whereas some policy changes in recent decades can be seen to reduce reliance between married couples (Ganjour and Widmer, 2016). Individualisation and familialism will be explored in relation to young people's experiences of transitioning to adulthood when they have a disabled sibling in chapter 7. These sociological theories highlight that changing patterns of family life since the 1970s does not necessarily represent a break away from traditional nuclear family ideals.

The Social Construction of Life Course Stages

This section will explore how understandings of the 'transition to adulthood' have developed and how historical and cultural contexts highlight the social construction of this concept. The transition to adulthood can be understood in the context of historical and social constructs of life development stages from infancy to childhood, to adolescence, young adulthood, middle adulthood and older age (Furstenberg et al, 2005). Relevant to how we conceive the transition to

adulthood is how we separate childhood and adulthood. In modern Western societies, children are seen as dependent and in a constant state of 'becoming' and developing into their adult selves (Alanen, 1988; James et al, 1998). Aries (1962) outlines that before the development of the individualised family unit in the 19th century, the concept of childhood as a distinct time where young people should be protected from the adult world did not exist (Aries, 1962). However, MacFarlane (1978) illustrates that individualism and ideals of the small family unit can be identified before the 16th century in England (MacFarlane, 1978). This highlights that notions of childhood might have developed earlier than the 17th century. Legally, the separation from childhood to adulthood has broadly been understood in age terms as 18. However, in the UK context alone legal ages vary for different acts that may be understood as 'adult'. For example, the age of sexual consent in the UK is 16, the age of criminal responsibility is 10 and the voting age is 18. The age markers of adulthood in legal terms vary within nations and between them. The examples above highlight that what we understand as 'childhood' and 'adulthood' are socially constructed and not simply fixed by biological age.

Another life stage which has only recently become culturally defined is that of 'adolescence'. First conceived by Hall in 1904, adolescence emerged within the 20th century where paths to adulthood became more organised and structured (Hall, 1904; Furstenberg, 2000; Evans and Heinz, 1993; George, 1993). Culturally, adolescence can be seen as a distinct life stage when compulsory full-time education is the main activity for young people, rather than work. Historical and cultural shifts such as compulsory education and the increase of the welfare state created a distinct age group of 'youth' or 'adolescents', who were encouraged to explore their independence, whilst still being reliant on their parents economically and socially (Furstenberg, 2000). An important note here is that how we understand 'childhood' and 'adolescence' is dominated by Western industrialised concepts that do not necessarily fit in with other cultures

around the world, or those of ethnic minorities within the West. However, increasing globalised economic activity and technological communication has encouraged shared meanings of adolescence and youth. Adolescence emerged in the 20th century as a distinct stage and adulthood was achieved when school finished, men entered the job market and women married and left the home, most people achieving these markers in their late teens and early twenties (Mulder and Manting, 1994; Bynner, 2005; Silva, 2012). There were gender differences in these transitions, women's lack of opportunity in the job market meant they were more likely to marry at a younger age compared to men, as marrying was the main route to independence from their families (Anderson, 1985).

Studying the period from later adolescence to early adulthood has received a lot of academic attention in an attempt to understand what defines someone as an adult. Similar to constructs of 'the child' and 'adolescent' in the last century, the concepts of the 'young adult', 'youth' or 'emerging adult' have developed (Côté and Bynner, 2008). They are seen as separate to children, adolescents and adults and as a distinct category or sub group. Historical shifts in the later part of the 20th century are vital in the construction of this new group. As mentioned in the section above, within industrial societies during the 1970s the economic market changed with an increase in global competitive markets and a decrease in manufacturing jobs. Economic difficulties around this time led to high youth unemployment in the UK. The 'traditional' markers of adulthood, marrying, becoming a parent, leaving the home and entering the job market were all delayed (Furlong et al, 2011; Ulrich Mayer, 2004).

The historical and cultural trends mentioned above have resulted in academic and public speculation of when a person reaches adulthood. Arnett has proposed that the above changes have resulted in a new developmental stage called 'emerging adulthood'. Arnett suggests that young people aged 18-29 have a new period of independence where they

can explore their identities, career choices and lifestyles. These young people cannot be termed as 'young adults' in the development stage as this is better suited for people in their early 30s who are more likely to have moved out of the family home, have stable jobs and be parents. They are also not adolescents as they have freedom from their parents and from compulsory education (Arnett, 2000; Arnett, 2004). Arnett's theory has received support and criticism. Focusing on sociological criticism of this new stage, Arnett's new development stage is based on demographic analysis that applies to mostly white, privileged Western youth. Arnett does acknowledge that patterns change depending on class and culture. However, his analysis underplays class differences, studies have found that young people from poorer backgrounds may enter employment earlier, rather than going to university and taking gap years (Hayward, 2013; Jones, 2002; Bynner et al, 2002). One problem with Arnett's theory, along with other psychological theories on development stages, is that the focus relies on the white privileged pattern of life choices as the 'norm'. This underplays and sometimes ignores the importance of structural differences in young people's lives (Bynner, 2005: 367). Another problem with this approach is that the five 'traditional' markers are based on patterns that emerged for only a short time in recent history (Irwin, 1995). The current shift in the markers of adulthood have changed before and could change again in the future, therefore the claim that emerging adulthood is a new developmental stage is questionable as it could disappear (Bynner, 2005).

Sociologists have used the terms 'youth', 'transition to adulthood', 'pathways to adulthood' and 'young adulthood' to describe the shift from adolescence to adult life. These terms will be used interchangeably and holistically throughout this thesis to describe the complex ways young people achieve their own sense of adulthood and how others measure their entry to adulthood (Côté and Bynner, 2008). The approach to the sociological analysis of 'youth' has varied, some sociologists have focused

on specific cultural differences for young people, with a particular interest in 'deviance' from societal norms, human agency and how subcultures have emerged (see Clarke et al, 1976; Hebdige, 1979). Sociologists have also adopted a transitional approach to studying the life course, focusing on structural markers such as the move from education to work and how this differs between and within generations. The cultural approach has traditionally relied on small qualitative studies focusing on human agency, whereas transition studies have traditionally analysed demographic data to examine the influence of structural patterns on young people's life trajectories (Furlong et al, 2011). However, cultural and transitional studies are not necessarily only agency or structure focused and concepts such as structuration and bounded agency can be identified in both approaches (Brannen and Nilsen, 2002; Bhat, 2013; Lehmann, 2004). For example, subcultures depend on socially structured ideas about adolescence and young adulthood. Overall, recent changes in life course transitions for young people have resulted in increased academic and public interest in the topic.

Social Difference and the Transition to Adulthood

This section will examine how empirical studies have considered gender, class, ethnicity and other social differences in the transition to adulthood. Croll (2008) analysed data from the British Household Panel Survey, a large-scale survey which has interviewed a sample of British people annually from 1991. Croll analysed the survey data of 763 youths interviewed when they were 15 between 1994 and 1999, 528 of the young people were interviewed in the follow up study, aged 20-25 in 2004. Croll (2008) found that gender and class affected outcomes in education and the job market. Croll outlines that there was strong gender stereotyping in job aspirations, with more women choosing caring professions and men skilled labour jobs. Children from lower socio-economic backgrounds were found to be more

likely to have lower aspirations in comparison to more wealthy youth and they were less likely to meet their occupational aspirations.

Connolly (2006) analysed data from the Youth Cohort Study to measure the educational achievement of young people who left school in 1997, 1999 and 2001 and tracks their education and occupational achievements aged 16-19. Connolly found that girls tended to achieve more than boys in their GCSEs, however these differences were quite small and social class and ethnicity were found to have more of an effect on successful educational attainment. Yates et al (2011) found in their data analysis of the British Cohort Study that some young people were uncertain of their career aspirations and some youth's educational expectations did not align with their occupational aspirations. These young people were more likely to be not in employment, education or training (NEET) by the age of 18. Young people from lower socio-economic backgrounds were most likely to fit in with these categories. Bates et al (2009) conducted interviews with 11,000 people aged around 17, they found that for young people with 5 GCSEs grades A*-C, 70% of people who had parents who worked in professional/managerial jobs were likely to apply for university, whilst only 48% of youth whose parents worked in manual/routine jobs said they were likely to apply. Khattab (2009) analysed educational and occupations outcomes for 3% of the UK population aged 16-59 using the 2001 census. They found differences in educational and occupational outcomes for ethnic, cultural and religious groups. The most advantaged groups were White British non-religious and Jewish White-British. Christian Black Africans and Christian Black Carribeans were found to succeed in education but be disadvantaged in the job market. Sikh-Indian and Muslim Pakistanis and Bangladeshis were found to be at a disadvantage in school and work.

Schoon (2010) analysed data from the British national cohort data on people born in 1958, 1970 and 1989/1990, examining their expectations regarding post-compulsory education. Schoon illustrates that teenage girl's expectations for staying on after school have risen from 37% for those born in 1958 to 93% for people born 1989/1990 and for boys from 36% to 83%. This highlights that female aspirations of attending further education have risen beyond boys' aspirations, in the UK in 2016 36.8% of young women entered higher education, compared to 27.2% of young men (UCAS, 2016). Boys may be more likely to enter manual jobs after school where a university degree is not required and wages are relatively high. Girls may only have access to low paid unqualified jobs straight after school and therefore attend university so they can access higher paid occupations. Walker and Zhu (2013) found that the private benefit of having a degree compared to not having a degree in terms of life time earnings was 53% for women and 28% for men in the UK (Walker and Zhu, 2013: 6). This suggests that women benefit more financially from attending university than men do. Recent statistics from the Annual Survey of Hours and Earnings in the UK shows that there is inequality for women in the job market, with men earning on average 9.4% more than women for full time work (ONS, 2015c). The survey reveals that 41% of women work part-time compared to 11% of men and a higher proportion of women work in jobs that are paid low wages. Interestingly, women aged 22-29 who work full time were found to earn slightly more than men, however from 30 upwards the wage gap increasingly grows. This is likely due to women taking time out from work to care for children (ONS, 2015c). This corresponds with findings that transitions to adulthood have become more similar for men and women in recent decades when considering education and employment (Gauthier and Furstenberg, 2005). However, the trend of delaying parenthood has not eradicated the trend of women becoming primarily responsible for childcare. This is further supported by a survey conducted by the UK organisation My Family Care. The survey was carried out with 1000 parents and 200 employers in the

UK. They found that less than 1% of men had used shared parental leave in the UK since its introduction in April 2015 (My Family Care, 2016).

Aassve et al (2007) found in their analysis of a sample of women aged 13-30 born between 1960 and 1968 who took part in the British Household Panel Survey that the balance of family and work life is highly complex for women. They found that some women delayed parenthood to pursue education and careers. However, 45% of women had children before they turned 25 and a more complex picture of caring for children and leaving and re-entering the job market emerged, with women adopting flexible careers around childcare. Although this data is somewhat outdated as it analyses work/family balance for women in the 1990s, it highlights that motherhood and employment are relevant in the transition to adulthood. Stone et al (2014) analysed data from the British Household Panel Survey (1991–2008) to examine how different life events might cause young people (aged 20-34) to return home to live with their parents. They found that the number of women in their early 20s returning home after university increased between 1991 and 2008, which is likely linked to the 'feminization' of the university system, with more female undergraduate students than males (Stone et al, 2014: 270; ONS, 2009; UCAS, 2016: 21). Stone et al also found that dissolution of romantic relationships is a determinant in young people returning home. They found little difference in returning home after relationships break ups for childless males and females, however for mothers, relationship dissolution had little effect on them moving back to the parental home. Fathers on the other hand were more likely to return to the parental home compared to childless men. Stone et al highlight that these patterns are likely due to compulsory housing support policy in the UK for single mothers, reducing their need to live with their parents (Stone et al, 2014: 272). The quantitative studies outlined above are useful in highlighting the changing situation for young people from different generations as they transition into adulthood and

are useful in tracking historical and cultural trends. The drawback of these large quantitative studies is that the focus is on pre-defined measurements of transitions. A deductive approach can reproduce taken for granted assumptions on what it means to transition to adulthood. Qualitative studies allow for an exploration of how structure might impact on young people's lives and the complex ways transitions are understood.

Aronson (2008) conducted 42 semi-structured interviews with young women aged 23-24 in the USA to explore meanings of transitions for women. Aronson found that the feminist movement influenced the women's lives in different ways, for women who wanted to get married and have a family, becoming financially independent before marriage was important. Marriage was also seen as optional by many, single mothers in the study illustrated that their decision processes regarding having a child were made by themselves and without the father. Uncertainty was a key aspect of young working class women's experiences of working and middle class women's experiences in further education. Brannen and Nilsen (2002) used focus groups conducted in the UK and Norway to explore how young people aged 18-30 think about their futures. They conclude from their analysis of the focus groups that most younger females in the groups deferred planning for the future, conceptualising themselves as young and not yet adult. Some young people in the groups were viewed as adaptable to their transitions to adulthood, the future was seen as laden with risks and challenges that they would need to negotiate their way through. Young British Asian men and Norwegian shipyard workers were seen as following a path of predictability. Their lives were clearly charted out for them and they did not see the transition from youth to adulthood as a major leap. These studies highlight the importance of recognising young people's agency in the study of transitions but also highlights how certain structural influences, such as gender, ethnicity and class might impact on pathways to adulthood (Gordon et al, 2005).

Gordon et al (2005) draw on a longitudinal study in the UK, the study used questionnaires, interviews and focus groups with a group of young men and women. They also reflect on a Finnish study where women were interviewed at ages 17-18, then at 20/21. Gordon et al do not outline the age of the participants in the UK study group, this would have been useful in conceptualising what comparisons they were trying to make. Their findings from both studies suggest that there are tensions between becoming an individual and becoming a 'woman', as becoming a woman is entangled with motherhood, which entails focusing on others, not just the self. They also found that women in the UK were more likely to accept full time motherhood, due to the lack of childcare support compared to Finland. This study highlights that transitions to adulthood for women are different to men, as often women are expected to be primarily responsible for childcare. The extent to which childcare conflicts with financial independence is influenced by the national policy context of maternity and childcare support. This highlights that the experiences of men and women during the transition to adulthood may be different due to the association of women as child carers.

Basit (2012) used surveys and in-depth interviews with young people in the UK who identify as Pakistani, Indian, African Caribbean, Bangladeshi or dual heritage. The participants were aged 14-24 and were either in secondary school, higher education, further education or NEET. Women from British Muslim households were particularly intent on following further education roots, a path that was encouraged by their parents. However young Muslim women highlighted that they had less freedom compared to boys, with more restrictions placed on them, especially regarding socialising outside of the family home. Some young people reported that racism and misunderstanding from others regarding their ethnicity and religion made

them feel left out from the mainstream as they transition to adulthood. This study highlights that young people's experiences of transitions to adulthood are affected by cultural and ethnic differences and that a process of 'othering' can occur.

The above analysis shows that transitions based on class, gender and ethnicity are interrelated, the transition to adulthood for particularly vulnerable youth are influenced by these and other structural inequalities. Monro (2012) used participant observation, 24 in depth interviews, 50 informal interviews and focus groups with transgender people aged 25-65 in the UK. Monro found that young transgender youth are likely to struggle in their transition to adulthood due to structural inequalities and barriers. They are particularly at risk of marginalisation within the family and within the job market, increasing the risk of homelessness, violence and exploitation as sex workers. Support from family, friends, teachers and acceptance from others helped to reduce these risks for transgender people whilst they transitioned from adolescence to adulthood. Other studies have highlighted the vulnerability and difficult experiences of transitioning to adulthood for young people who are homeless (see Napolitano, 2010) and those who have been in state and foster care (see Berzin et al, 2014). These studies emphasise the importance of recognising vulnerability for some young people as they transition to adulthood and the need for social policy and support services to consider these issues (Osgood et al, 2008). Overall this section highlights that young people's transition to adulthood may be affected by certain social characteristics. These differences may affect the timing and order of these transitions, or whether young people can achieve certain transitions at all. These differences can also impact on young people's experiences relating to their transition to adulthood. This literature review suggests that social differences do impact on transition experiences. This suggests that having a disabled sibling might impact on young people's experiences of

transitioning to adulthood. This literature review informed the third research objective of this study which focuses on exploring how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to key markers of the transition to adulthood. The findings of my research study that met this objective can be found in chapter 7 of this thesis. The ways in which young disabled people may have different transition experiences will be explore in chapter 3.

Theoretical Perspectives on Sibling Relationships Across the Life Course

The literature reviewed relating to sibling relationships in this chapter is directly relevant to the findings outlined in chapter 6 of this thesis. This section will explore the theoretical perspectives on sibling relationships that influenced my research. Sibling relationships are intertwined across the life course and can be the longest lasting relationship that individuals experience. Sroufe et al (2005) illustrate that sibling relationships are often emotionally tied within the family unit, however unlike the child-parent relationship, siblings may be of a similar age to peers. Weisner (1989) outlines that sibling relationships are unique because siblings are often the first age similar companions in a person's life and they share the same family history. Whiteman et al (2011) outline four theoretical perspectives related to sibling relationships. The first theoretical perspective is psychoanalytic-evolutionary perspectives, these perspectives emphasise sibling relationships as key to personality development and adult adjustment. One example of this perspective is attachment theory which suggests that siblings may act as an important source of security and support across the life course which contributes to the development of individuals (Samuels, 1980; Dunn, 2007; East, 2009; McHale et al, 2006). The second perspective is social psychological theories, these focus on how siblings affects and motivate each other's

behaviour. One example is social comparison theory, this theory posits that individuals compare themselves to others which motivates them in life, they particularly compare themselves to people they identify as similar to themselves (Festinger, 1954; Suls et al, 2002). Studies have found that the ways in which people compare themselves to their siblings can have positive and negative effects on their self-esteem and the quality of the sibling relationship (Connidis, 2007; Noller et al, 2008).

The third perspective identified is social learning theory, which suggests that individuals learn how to behave from observations of others. Whiteman et al (2011) outline that siblings 'shape their own relationship in the context of their social exchanges, such as by reciprocally reinforcing positive or negative behaviours and by observing and imitating one another' (Whiteman et al, 2011: 131). The fourth perspective is family and ecological systems approaches, these approaches take more of a holistic approach to studying sibling relationships, recognising the context in which sibling relationships develop. Whiteman et al (2011) use the example of Bronfenbrenner's (1979, 1986) ecological systems theory. This theory outlines that the microsystem is the smaller system of everyday life, family is included in this and sibling relationships will impact on an individual's development in the microsystem. The mesosystem refers to networks in a person's local community, siblings may need to adapt their relationship in different settings, for example at school, which may impact on their relationship. The exosystem relates to contexts that impact on individuals' lives but they are not directly engaged with these contexts. For example, a parent's working patterns may impact on sibling relationships, if a parent works long hours an older sibling may take on more caring responsibilities for younger siblings. The macrosystem encompasses the wider social context, sibling relationships may be affected by wider societal norms. For example, the two-child norm in the UK means more young people will only have one sibling compared to

other societies where they may have more or less, which will affect sibling relationship dynamics.

White (2001) summarises two theoretical perspectives in the study of sibling relationships, developmental and life course perspectives. White points out that the developmental and life course perspectives are similar in that they both focus on how sibling relationships change from childhood to old age. However, each perspective focuses on different processes that cause these changes. Developmental perspectives argue that siblings play a key part in an individual's development in childhood, the quality of the sibling relationship and interactions throughout childhood are seen to affect an individual's identity formation and their socioemotional development (Kramer, 2010; Wong et al, 2010; Sroufe et al, 2005). As siblings grow older, their impact on each other's development will decline as they spend less time with one another. Life course perspectives focus on how certain transitions, such as one sibling leaving the family home, siblings having their own children or forming a long term romantic relationship may cause the sibling relationship to change. The sibling relationship is seen as a permanent and flexible relationship throughout a person's life. One critique of adopting a developmental perspective is there may be too much emphasis on the impact that the quality of the childhood sibling relationship has on the type of relationship siblings have in adulthood. A life course perspective focuses more on how the sibling relationship changes throughout different life course events and changes. However, this perspective may over emphasise the importance of transitions and underplay the significance of how the quality of the sibling relationship might impact on contact and closeness regardless of whether either sibling is undergoing life transitions. The different theoretical perspectives outlined above informed my understanding of sibling relationships when structuring, conducting and writing up my research. Developmental and life course

perspectives particularly influenced me because these perspectives focus on how relationships change throughout childhood, adolescence and young adulthood. Life course perspectives were particularly pertinent in structuring my study because of my focus on life course transitions.

Sibling Relationships in Childhood and Adolescence

This section will review relevant literature that has explored the sibling relationship through childhood and adolescence. Sroufe et al (2005) suggest that during childhood, siblings often help to develop skills such as managing conflict in relationships and practising leadership. Kramer (2010) highlights that sibling relationships involving conflict can help children to develop skills in managing conflict and in communication. Bank and Kahn (1975) outline that during childhood, siblings provide five different functions. The first is 'mutual regulation', sibling relationships allow children to test out behaviours before presenting them to other family members and wider social groups. The second is 'defend/protect', siblings can provide care for one another and protect each other from other people or they may share secrets. The third function is 'interpret', siblings can help each other interpret the world around them, this might be interpreting behaviour from parents or peers or interpreting information through media outlets. The fifth function is 'provide direct services', siblings may provide useful daily functions to each other, such as lending each other clothes or money, providing help or providing care. The sixth function is 'teach new skills/abilities', siblings may act as a teacher, for example helping one another with school work. Yucel and Yuan (2015) outline that there are two main perspectives relating to sibling relationships in childhood, firstly dilution theory, which suggests that siblings are competitors. Siblings compete against each other for family resources, such as money and parental attention (Blake 1981, 1989; Downey 1995). The second perspective is that siblings

are resources to one another, acting as teachers and sources of support. Yucel and Yuan (2015) suggest that sibling relationships can be characterised by both competition and support. Other authors have emphasised that siblings provide important roles in each other's lives in childhood and can help develop children's social skills (Dunn et al 1991; Tucker et al, 1999). Other studies have found that if sibling relationships involve a lot of conflict, this can actually have a negative effect on children, sometimes causing depression and antisocial behaviour (Bank et al, 1996; Dunn et al, 1994; Epkins and Dedmon, 1999).

As children become older, studies have found that interaction between siblings often lessens (Dunn et al, 1999; Hetherington et al, 1999; Hetherington and Clingempeel, 1992). Research also suggests that as children become adolescents, sibling relationships may involve less conflict and controlling behaviour and involve more intimacy and friendship (Updegraff et al, 2002; Scholte et al, 2001; Cole and Kerns, 2001). However, other studies have found that affection between sibling may decrease as they become teenagers (Furman and Buhrmester, 1985; Buhrmester and Furman, 1990). Buhrmester (1992) argues that as children become adolescents, their social circles widen, which leads to less involvement and closeness with parents and siblings. However, during adolescence, siblings may still play important roles in supporting one another. Studies have found that siblings in adolescence can provide emotional support, young people may feel more comfortable talking to a sibling about sex and personal problems (Cotterell, 1996; Tucker et al, 1997; Moser et al, 1996). Tucker et al (1997) point out that during adolescence, older siblings may provide an important role as advisor for younger siblings, shaping their goals and interests. As older siblings start making important decisions regarding their education and other life choices, younger siblings can learn from the decisions that their older siblings make. Tucker et al (2001) also found that siblings can be important sources of support for adolescents relating to social,

educational and family issues. Overall, the literature suggests that sibling relationships can be supportive but can also involve conflict. As children become older, the sibling relationship may change as young people begin to become more independent from their families. Some participants in my study identified that their sibling relationship changed as they became teenagers, these findings are presented in chapter 6 of this thesis.

Sibling Relationships in Young Adulthood

This section will focus on exploring literature that has focused on how the sibling relationship changes during the transition to adulthood. Whiteman et al (2011) point out that as siblings' transition to adulthood, their relationships become more based on friendship and are often more voluntary. They suggest that an older sibling who has achieved some markers of transitioning to adulthood may act as role models to younger siblings who have not yet transitioned, they may also provide support and social capital. Older siblings who are viewed as successful in work may act as role models for younger siblings. However, there may be sibling conflict if one sibling is viewed as successful in their transition to adulthood and the other is viewed as unsuccessful. Conger and Little (2010) also highlight that when an older sibling moves out of the family home, this may result in a sense of loss for younger siblings, providing the relationship was close. For others, there may be a sense of relief if the relationship involved high levels of conflict.

Cicirelli (1995) points out that when one sibling moves out, sibling relationships may improve as siblings are freed from the conflicts of daily interaction. White (2001) conducted a panel analysis of 9000 people aged 18-83 to examine changes to the sibling relationship across the life course relating to contact, proximity and receiving/giving help and found that contact, help and social support between siblings decreased in early

adulthood. Stocker et al (1997) found in a study of young people attending university in America that siblings who lived closer to one another in young adulthood were more likely to have contact. Scharf et al (2005) used questionnaires and interviews with 116 young people, 56 were aged 14—18 and 60 aged 21-25 to examine changes in the sibling relationship during the transition to adulthood. They found that participants in young adulthood spent less time with their siblings than adolescent siblings. Young adult participants generally reported closer relationships with less conflict compared to adolescent siblings.

Milevsky and Heerwagen (2013) interviewed 52 young people at university aged 18-23 to explore various aspect of their family structure. They found that some participants reported that their sibling relationship improved when they moved away from the family home as they had more space from one another. Less time spent together meant when they did meet, this time was special and more positive. Cantor (1979) outlines that siblings are often pushed out of a person's social circle in young adulthood as they become more independent and form ties outside of the immediate family. Transitions such as moving out of the family home, forming romantic relationship and having children mean people form social circles independently from their siblings. Conger and Little (2010) argue that during the transition to adulthood a 'dynamic recentering' occurs in sibling relationships where family and sibling relationships become less central in young people's lives as young people negotiate their roles in new social contexts, such as higher education, work and romantic relationships (Conger and Little, 2010: 89).

Wider family influences may also affect sibling relationships as young people transition to adulthood. Parents may provide more financial support to one sibling than others during the transition to adulthood, producing conflict between siblings (Conger and Little, 2010; Conley, 2004; Dunn, 2007). For example, younger siblings may receive more

financial support if parents earn more money over time (Steelman and Powell, 1989). Conger and Little (2010) point out that as young people transition to adulthood, their parents may be transitioning in their lives. For example, they may retire or become grandparents. Conger and Little suggest that this may mean parents are less likely to be involved in refereeing their children's sibling relationships as they focus on their own transitions. This means that sibling and parent relationships become less connected as siblings' transition to adulthood. Stewart et al (2001) surveyed 267 people aged 17-56 to examine how people described the relationship they have with their sibling who is closest in age to themselves. They found that parental influences on the sibling relationship decreased in young adulthood and that social interaction between siblings in young adulthood is more voluntary. Scharf et al (2005) point out that as young people transition to adulthood, meeting parental expectations and receiving support from parents is important. This may impact on the relationship that young people have with their siblings. This may cause conflict if siblings compare their achievements and parental attention with one another. Or this may cause sibling relationships to be closer as siblings support one another to manage parental expectations. Sibling relationships are affected by other relationships in the family. This suggests that family systems theory is important to consider when studying sibling relationships.

Overall, this section has highlighted that sibling relationships change during the transition to adulthood. Sibling relationships often become more distant and conflict lessens. As young people become more independent, siblings may play a less of a role in their lives. However, siblings may still play an important role in people's lives and act as sources of support and guidance during the transition to adulthood. Wider family dynamics may impact on the sibling relationship during the transition to adulthood. The ways in which the literature explored in this section compare with the findings of my research are presented in chapter 6. The

next section will briefly review literature that has examined the sibling relationship in middle to late adulthood.

Sibling Relationships in Middle to Late Adulthood

As the previous section outlines, research suggests that sibling relationships in adulthood involve less contact and are more voluntary. Research suggests that the relationship between siblings throughout adulthood may be affected by changes to other family and life commitments (Doherty and Feeney, 2004; Connidis, 2001; Crenner et al, 2002). As mentioned above, White (2001) conducted a panel analysis of 9000 people aged 18-83 to examine changes to the sibling relationship across the life course and found that sibling support decreased during young adulthood. However, White found that support increased again in middle adulthood and after the age of 70 rose further. White highlights that one reason for this is when adults become parents later in adulthood, they may commit to interacting with their siblings so their children have close relationships with their aunts, uncles and cousins. Some research suggests that adults getting divorced or not having children may mean siblings play a more significant support role in each other's lives (Connidis, 1989a; Connidis and Davies, 1990; Heinemann, 1985; Johnson and Catalano, 1981). Death of a spouse or romantic partner may also lead to siblings playing a larger role in an adult's life (Atchley et al, 1979; McCallum, 1986).

Gold (1989) used interviews with 60 people over the age of 65 who have at least one living sibling and identified five different sibling relationship types in adulthood. The intimate adult relationship involves closeness and intimacy, with frequent contact and support and possibly some minor resentments. The congenial relationship is based on friendship but lacks empathy, contact is relatively frequent but assistance and support is only

provided when needed. The loyal relationship describes sibling relationships when kin responsibility is felt by siblings but the relationship is not close. Support is only provided when there is a crisis and contact is infrequent. The apathetic sibling relationship is where siblings are not close and feel little connection with one another. The hostile relationship is where siblings feel a strong sense of resentment and hostility towards one another, there is little or no contact and siblings do not support one another. These relationship types highlight that sibling relationships are varied and complex.

Some research has focused on sibling relationship and caring for parents. Siblings will likely need to negotiate their roles in caring for ageing parents with their siblings, meaning they may need to regularly communicate with their siblings (Connidis, 2007). Negotiating care for parents may cause sibling conflict in adulthood, particularly if one sibling provides the majority of support to parents (Ingersoll-Dayton et al, 2003; Suitor and Pillemer, 1996; Strawbridge and Wallhagen, 1991). However, the negotiation of care may cause sibling to become closer as they lean on each other for support (Blasinsky, 1998). Some research suggests that female siblings are more likely to provide support to parents than male siblings (Hequembourg and Brallier, 2005; Cicirelli 1984, 1992; Spitze and Logan, 1990).

In adulthood, siblings may be important sources of support, particularly in times of crisis (Moyer, 1992; Troll, 1975). In later adulthood, as people's children become independent and have their own families, siblings may become a dominant source support (Cicirelli, 1991; Hoyt and Babchuk, 1983). White (2001) also points out that sibling relationships may become more important in old age, as people seek to interact with people they have shared their life history with. Goetting (1986) highlights that in old age, people may want to spend more time with their siblings to resolve any issues or conflict. Connidis (1989b) emphasises that the

relationship in earlier life will affect how close adult siblings are in later life. Moyer (1992) illustrates that parental death may encourage siblings to reconcile if they have not had a good relationship in adulthood and older age may encourage people to resolve previous conflicts with siblings. Research also highlights that in old age, where possible, many siblings provide support and help to one another as their care needs grow (Allan, 1977; Hoyt and Babchuk, 1983; Moyer, 1992). Overall, this section highlights that changes throughout adulthood may affect the level of support that siblings provide for one another and the closeness of the sibling relationship. My study found that having a disabled sibling might mean individuals are more likely to commit to provide care and support for that sibling in older adulthood because of their support needs, this is discussed in chapter 7.

Summary

This chapter began by outlining changes to historical, family and individual timing in the UK. Changes to household composition between 1950 and 1970 were displayed. Changing family patterns in the UK since 1970 were then explored. The next section outlined how childhood, adolescence and young adulthood are not completely fixed, understandings of these life stages are historically and culturally specific, this suggests that life stages are socially constructed. The new developmental stage 'emerging adulthood', particularly popular in psychology, was outlined as a new stage in life where young people are exploring their choices and identities but not yet young adults. This term was criticised for its underplaying of class differences, an over reliance on white norms and the problem with labelling trends that may only be temporary as a new developmental stage. A sociological approach to studying pathways to adulthood, with a more holistic definition of the transition to adulthood was presented. The next subsection explored social differences in the transition to adulthood. This literature review helped inform my exploration of young people's

experiences and thoughts relating to their transition to adulthood when they have a disabled sibling. Considering each marker of transitioning to adulthood and its relevance to participants was useful in structuring my study. Finally, theoretical perspectives on sibling relationships were discussed and literature that has considered how sibling relationships change throughout the life course was examined. Reviewing this literature and theory motivated me to explore participants' views about the relationship that they have with their disabled sibling and how this relationship has changed and might change throughout their life course. This also meant I could also consider how having a disabled sibling might impact on the sibling relationship throughout the life course. The findings relating to this are located in chapter 6 of this thesis. Literature relating to how having a disabled sibling might impact on the sibling relationship throughout the life course is also discussed in chapter 6.

Chapter 3: Disability and the Transition to Adulthood

Introduction

The focus of my MPhil research is on young people who have a sibling with learning disabilities or autism. The literature analysed in this chapter is therefore largely focused on research relating to autism or learning disability. However, some studies that involve young people with physical disabilities are discussed as they provide useful insights into how different categories of disability affect young people's experiences of transitioning to adulthood. The chapter will begin by summarising a human rights approach to disability. The chapter will then outline current social policy and legislation that is relevant to the transition to adulthood for young disabled people. The third section will review literature that has explored the transition to adulthood for young disabled people. The final section will review literature that has considered how family members are involved with the transition to adulthood for young disabled people.

Human Rights of Disabled People

The human rights of disabled people are linked to social approaches to disability. From the early 1960s onwards, political lobbying and action from advocacy and disabled people groups grew, they pushed for the human rights of disabled people to be recognised (Albrecht et al, 2001). This political lobbying and action can be identified as the disability rights movement. As mentioned in chapter 1, a social approach to understanding disability emphasises that social processes disable people. This approach to understanding disability underpins a disabled rights perspective, as it emphasises that society must change to recognise how it disables peoples. Therefore, ensuring that disabled people have the same rights as everyone else is paramount. The increased influence of the disabled rights movement and a human rights agenda around the globe influenced many countries to advocate for a convention regarding the human rights of disabled people. Initiatives from Sweden, Italy, Mexico

and other countries encouraged the United Nations to form a committee that would draft a human rights treaty named the 'Convention on the Rights of Persons with Disabilities' (Schulze, 2009). This treaty was drafted in 2006, signed by nations around the world in 2007 and came into force in 2008. The eight principles of the Convention are: 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; Non-discrimination; Full and effective participation and inclusion in society; Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; Equality of opportunity; Accessibility; Equality between men and women; Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities' (United Nations, 2006: art. 3). As mentioned above, the emphasis of a human rights perspective is that disabled people should be entitled to the same rights as anyone else. This perspective underpins the social approach to disability adopted in this thesis. This human rights discourse emphasises that young disabled people should have the same rights during the transition to adulthood as anyone else. Therefore, if young disabled people are in a disadvantaged position during the transition to adulthood, this results from society discriminating against disabled people.

Transition Services in England

In the first half of the 21st century in Western societies, people with learning disabilities and autism with support needs were generally institutionalised in separate 'colonies' or long stay hospitals (Wolfensberger, 1975; Ryan and Thomas, 1987). Changes in UK legislation from 1959 encouraged the move to care being provided in the community, however it took several decades from this date to move people out of these institutions (Race, 2002). This policy process can be termed 'deinstitutionalisation' and was popular in many Western nations

in the last half of the 20th century. 'Normalisation' also became dominant in policy discourse in the last half of the 20th century, 'normalisation' means disabled people are seen as independent citizens like everyone else and should not be segregated (Bradley, 1996). However, this discourse has been criticised for suggesting that disabled people are abnormal and should become normal (Oliver, 2009). Although a process of deinstitutionalisation has occurred, Wright argues that there are now micro institutions in the community where disabled people live, they are still segregated from 'normal' citizens in the community (Wright, 2013). Alongside discourses of deinstitutionalisation and normalisation, 'personalisation' has become popular in policy, meaning that disabled people should have power and choice over the care and support that they receive, care should be 'person-centred' (Lymbery, 2012). These recent changes highlight that UK social policy has attempted to promote disabled people's rights. Part of this policy discourse has emphasised the need for young disabled people to be supported to achieve a successful transition to adulthood.

This section will briefly outline current social policy and legislation that is relevant to the transition to adulthood for young people with learning disabilities and autism in England. Empirical studies that have examined the effectiveness of services will also be analysed. Supporting a successful transition to adulthood for young people with learning disabilities and autism is underpinned by a vast number of policy documents and law. Policy and service provision often focuses on young people gaining the same adult independence as their non-disabled peers. Although this aim has good intentions and may be achievable for some young disabled people, others may reach adult independence in other ways. A holistic view of adult independence that takes into account what young disabled people want from their adult lives should be considered alongside common understandings of adulthood. As mentioned in chapter 1, adult independence can be classified using five markers of adulthood: leaving

compulsory education, getting a job, leaving the family home, getting married, entering a civil partnership or cohabiting and having children (Furlong et al, 2011; Ulrich Mayer, 2004). However, other markers of adulthood may be important and signify independence. For example, other markers of adult independence could be going on holiday without family, taking on more responsibilities for household tasks in the family home or volunteering in the community.

The policy document 'Pathways to getting a life: Transition planning for full lives' highlighted that transition planning for disabled children needs to start early, children and adult services need to work together and that young people and their families should take the lead in planning (DoH, 2011). This policy document conceptualises the transition to adulthood as successful when young people enter work, move into independent housing and have a social life in the community. The Children and Families Act 2014 states that the Local Authority must exercise its functions to identify all children with Special Educational Needs and Disabilities (SEND) and all children in its area who have a disability (Children and Families Act 2014, pt. 3, s. 22). The 'Special educational needs and disability code of practice: 0 to 25 years' policy guidance provides a comprehensive outline of the requirements of different agencies supporting SEND children in their transition to adulthood (Department for Education (DfE), 2015). Education, Health and Care (EHC) plans were introduced in 2014 and are gradually replacing Special Educational Needs (SEN) statements for young people with complex support needs, by 2018 all young people with SEN statements should have EHC plans. EHC plans include a single assessment process and these plans cover support from ages 0-25 for young people that are eligible. A request for an EHC plan assessment can be made by parents, disabled young people themselves aged 16-25 or anyone else involved in the disabled young person's life who think they are entitled to an assessment, the local authority decides whether an assessment is required (DfE, 2015: 144). Not all young people with learning disabilities

and autism will necessarily be eligible for an EHC plan. This might impact on young people and their siblings, parents and other family members. If the thresholds for receiving support from education, health and social care services are high then family members may end up providing more support because they are not receiving sufficient services. Young people whose siblings are not receiving high levels of support from services in my study seemed to express more uncertainty about their future caring role. Further discussion of this can be found in chapter 7 of this thesis.

The SEND code of practice states that transitioning to adulthood means preparing for independent living, participating in society, being as healthy as possible and being involved in employment and/or higher education (DfE, 2015: 122). This focus on supporting transitions for disabled children aims for them to achieve the key markers of transitioning to adulthood. This is a good ideal to aim towards but needs to be considered critically. Disabled young people's aims for adulthood should be considered in transition planning and it should not be assumed that disabled young people will follow a specific path. Like their non-disabled peers, disabled young people should be able to make choices during their transition to adulthood. Young people with EHC plans must be supported up until the age of 25 and transition planning should begin when the young person is in year 9 at school (aged 13-14). Local authorities must involve and support children and their parents in transition planning and have regard to their feelings, wishes and views (DfE, 2015: 123).

Transition from children to adult services has been reported as a particularly difficult time for families, with support services dwindling or ceasing when young disabled people turn 18 (Kirk, 2008; Clarke et al, 2011). The Care Act 2014 states that if a young carer, young person, or adult carer for a young person is likely to have needs when the young person turns 18, then the local authority must provide an assessment. Children services involved with a young person's support must be involved

in this assessment (Care Act 2014, ss. 58-64). These new legislative changes were introduced in 2015, they mark an increased focus on transition support and support for carers. These changes were encouraged by research and campaigning from carers groups which reported that their roles and wellbeing have been undervalued by support services and authorities. Carers have reported high levels of stress, exhaustion and financial difficulties (Emerson, 2003; Cummins, 2001; Hubert, 2011). Research and campaigning from charities and disabled people groups also highlighted inadequacies in transition planning, particularly around involving disabled people themselves in decision making about their lives (Clarke et al, 2011; Beresford, 2004). My study found that young people reported that their families struggled with the transition from child to adult services for their disabled sibling, this finding is discussed in chapter 5 of this thesis.

In England, children with SEND are encouraged to attend mainstream schools and only in exceptional circumstances are SEND children without an EHC plan (or SEN statement) to attend special educational needs schools (DfE, 2015: 26). The formal transition process and service provision for people aged 18 and above does not apply to young people who do not have an EHC plan. Although support is still available in sixth form colleges for SEND pupils, local authorities are not responsible for funding education or occupational support after the age of 18 (DfE, 2015: 135). Young disabled people who are assessed as not having the complex needs required for an EHC plan will receive less support. As mentioned above, this might put more pressure on family members to provide support and make families feel less secure.

Martin et al (2011) conducted a survey across six local authorities regarding transition support for young people without SEN statements who have SEN, learning difficulties or learning disabilities, some interviewees stated that support for people without statements was likely

to be lacking. Although this study was conducted before the introduction of EHC plans, it highlights that young disabled people that do not meet the eligibility of EHC plans may not be eligible for the service provision that they need. Martin et al (2011) also found that foundation learning and entry level programmes was the default path for the young people with SEN, learning difficulties or learning disabilities. Several local authorities in the study said they had set up working support programmes but that only small numbers of young people could attend them. The SEND code of practice has encouraged schools, colleges and support services to focus more on employment planning, it is unclear how much support young people without an EHC plan will be entitled to. Only recent policy documents and laws relevant to England have been explored in this section, other policies and law are also relevant to transition planning in England, Scotland and Wales (see Conlon, 2014 for comprehensive summary). Overall, it appears that in England some young people with learning disabilities and autism are supported by health, social and education services in planning a successful transition to adulthood. However, people with less complex needs that are not eligible for an EHC plan may lack comprehensive support during the transition from children to adult services. Some people may not meet the criteria to receive any support at all.

Empirical research that has examined the effectiveness of transition services will now be analysed. Although there are numerous examples of good practice, common challenges in successful transition support are lack of multi-agency cooperation, poor engagement with young people and family members in transition planning and low service provision at the point of transition from child to adult services (Dewson et al, 2004; Heslop et al, 2002; Kirk, 2008; Cope, 2003; Bhaumik et al, 2011). Kaehne and Beyer (2014) explored the use of person centred planning in transition support for young people with intellectual disabilities, focusing on the quality of the plans from secondary school and families' views of

transition provisions. They conducted documentary analysis of 44 transition plans and completed phone interviews with families; they do not clearly state which family members they interviewed, but mention that respondents were asked about their sons and daughters, so one can assume that parents were questioned. They found that the person-centred planning framework encouraged attendance of young people and families at transition planning meetings. Education pathways post-school were the main focus of discussion and encouraged by educational and work placement professionals. The focus on further education in transition planning, rather than considering the importance of life skills and employment pathways has been highlighted by other studies (Kaehne and Beyer, 2008; Bouck, 2010; Hudson, 2006). Kaehne and Beyer conclude that if relevant stakeholders are not involved in transition meetings and neglect to accept their responsibilities, then person centred planning is less likely to be successful (Kaehne and Beyer, 2014).

Clarke et al (2011) conducted interviews with 130 managers from five transition services in England and administered a postal survey to disabled young people with complex needs (diagnoses included young people with autism, cerebral palsy, epilepsy and Down's syndrome) and their parents to measure their opinions regarding the level of support received for finances, housing, careers, further education and training, independent living skills, sexuality, adult relationship and leisure and social life. Surveys were administered to young people and parents who were involved in transition planning in children services (pre-transition) and also to young people and parents who had been receiving adult services for two years (post-transition). One problem with the research methods used in this the study was that the authors could not calculate a response rate of young disabled people, as they were unable to assess who would be capable to complete the surveys. This highlights that some research methods exclude people with disabilities. Clarke et al could have considered using other research methods such as face to face to interviews or focus groups with

disabled young people to ensure they gathered their views about transition services. Clarke et al found that young people and families pre-transition had more information and support compared to post-transition. Unmet needs were particularly strong in support for independent living skills, lack of services for support with housing, employment and leisure/social skills were also highlighted. The use of a specific transition workers that supported families and young people was found to be a successful example of practice. Clarke et al recommend improvement of multi-agency commissioning of services and more evaluation of unmet needs and how to address these (Clarke et al, 2011).

Bhaumik et al (2011) sent out postal questionnaires in Leicestershire to carers of young people aged 16-19 with intellectual disability, accompanied by significant physical and mental health needs, to assess satisfaction with services and unmet needs. They also conducted semi-structured interviews with 24 carers out of the 79 families who responded to the questionnaires. They found that many carers thought there were unmet needs and lack of information in transition services and that support should start earlier, last longer and be more flexible and tailored to individual need. They also illustrate that many young people had unmet needs due to the age of eligibility for certain services, young people may require a service at age 16 to support their transition to adulthood but need to be 18 to receive it. These studies emphasise the complexities of supporting a successful transition to adulthood and the need for constant critical reflection and reform. This section has briefly outlined and evaluated service provision in England for young people with autism and learning disabilities, mainly those who have higher support needs.

Are Disabled People Disadvantaged in Achieving the Markers of Adulthood?

As highlighted previously, a successful transition to adulthood is often considered to have been achieved with completion of education, entry into the job market, forming relationships, leaving the family home and having children. However, disabled people are significantly disadvantaged in achieving these markers compared to the rest of the population. It is estimated that in Great Britain in 2013/14 there were approximately 11.9 million disabled people, this includes people with longstanding illnesses, infirmity, disability and those who have a significant level of difficulty with day to day activities, 6 million of these people were working age adults (Department for Work and Pensions (DWP), 2015a: 40). In the UK in 2011, 45.6% of working age disabled people were employed, compared to 76.2% of people without a recorded disability (ONS, 2011: 1). The Youth Cohort Study and the Longitudinal Study of Young People in England suggest that for the 2009/10 academic year, 28% of disabled people aged 19 were NEET, compared with 23% of non-disabled young people (DfE, 2011: 5). This highlights that disabled people are less likely to acquire employment, often seen as a key signifier of successful adulthood. Disabled adults who may find it very difficult to get a job disrupt this ideal. Having a disability increases the likelihood of living in poverty, it was estimated that in 2011/12, 19% of families who had a disabled person living in the household lived in relative income poverty, compared with 15% without a disabled person. It was also reported that 21% of families with a disabled child were living in poverty, compared to 16% with children without a disability (DWP and Department for Disability Issues, 2014). These statistics suggest that disabled people are disadvantaged and discriminated against in their adult lives, this has led to increased academic and policy attention regarding the transition to adulthood for disabled youth.

Focusing specifically on the transition to adulthood for young people with learning disability and autism, Emerson et al (2013) used data from government departments and other publicly available data sources and estimated that 1.14 million people with learning disabilities were living in England in 2012 (Emerson et al, 2013: i). This is likely to be an underestimate as only people receiving services and benefits were used to estimate prevalence. Using data from the National Audit Social Care Intelligence Service, Emerson et al highlight that 7.1% of adults with a learning disability were employed in 2012 and 89% of working adults with learning disabilities worked part time (Emerson et al, 2013: 77). A survey with 1,142 adults with autism in the UK found that only 15% of adults were in full time employment (Bancroft et al, 2012: 26). As mentioned above in in the UK in 2011, 45.6% of working age disabled people were employed. These statistics highlight that people with autism and learning disabilities may find it more difficult to access employment compared to other disabled people. In 2014, children assessed as having SEN had poorer educational attainment than peers and were more likely to be excluded from school (DfE, 2014). In 2011, Mencap commissioned a study that analysed social services databases and conducted surveys and interviews with social care staff, disabled people and parents/carers. They estimated that 172,000 people in England and Wales with learning disabilities were known to social services, they found that 38% of people with learning disabilities were living with family or friends, 16% in supported accommodation, 22% in care homes and 12% in local authority or housing association accommodation (Mencap, 2012: 16). These statistics are by no means representative, as many people with learning disabilities will not have been in contact with social services. The survey of autistic adults mentioned above found that 38% of the adults surveyed still lived at home with their parents, 48% of this group reported that they wanted to live in their own home (Bancroft et al, 2012: 19). To draw a very rough comparison, within the general population in the UK, in 2016 39% of people aged 15-34 lived with their parents (ONS, 2016). For all age

groups, it is likely that more people with learning disabilities and autism live with their parents, however it is difficult to confirm this information from the statistics that are available. It is important to note that the trend of living with parents into adulthood seems to be the case for many young people, regardless of disability. However, the reasons for staying with parents may be different for young disabled people, especially if they require care and support from others on a daily basis. Overall, this data highlights that young people with autism and learning disabilities are more likely to struggle to achieve educationally, gain employment and move out the family home.

Disability may disrupt common assumptions of successful transitions to adulthood. Murphy et al (2011) carried out a study in England with 28 young people aged 18-19 with moderate to profound learning disabilities. Interviews, diaries, discussion groups and documentary analysis were used with young people, their carers and social services staff involved in the transition process. Parents in the study identified some anxiety about making choices for their child who lacked the capacity to make certain life decisions. The young people themselves rarely mentioned or conveyed to researchers that they were entering adulthood but carers and staff encouraged them to consider this. The staff in the study positioned the young people as having an adult status, whereas the parent carers viewed them as in a transition state between childhood and adulthood. This highlights that achieving an adult status is a constructed ideal and that some disabled young people may not conceive or even want to achieve the markers of adulthood. Young disabled people may also not have their choices properly explained to them. It is also important to note that young disabled people may have other aspirations relating to independence. The study illustrates that for social services staff and family members, concepts of pathways to adulthood were important to how they supported the young person. This study highlights the ways in which

disability might disrupt dominant ideals of successful transitions to adulthood.

Reaching all of the five main perceived markers of adulthood mentioned in the previous chapter may not be possible for some disabled youth, however for most, all or some of these markers are achievable with support. Kirkendall et al (2009) conducted an evaluation study of a programme in the USA where young people with learning disabilities aged 18-22 stayed in a college dormitory for 10 weeks over summer with a college student peer. They conducted interviews with young people and their parents to evaluate the programme, the young people reported experiences of excitement and some 'growing pains' when they moved out. Kirkendall et al point out that these experiences may be similar to any young person's when they live away from home for the first time. There was some ambivalence from parents regarding the long-term independence of their disabled children, highlighting that the transition to adulthood for disabled young people may be perceived differently by parents compared to transitions for their non-disabled children. Young people and their parents reported that the programme was useful in developing independent living skills. However, there was no ongoing support offered for young people and their families and most participants and their parents thought the young person would stay at home for the foreseeable future. This study shows that with more support, young disabled people can live independently from family. However, the study also emphasises that this support needs to be ongoing. Wedgwood (2011) conducted a single life history case with a young woman aged 20 with a severe physical impairment in Australia. The young woman found her experience in mainstream school to be generally inclusive, however she sometimes felt left out of high school cliques. She attended university and had three close friends there, during childhood her family members and mostly her mother provided high levels of physical care for her, however in adulthood she received most support from professional carers at

university. Wedgwood highlights through this life history case study that disabled identity is not all encompassing and that young people with a disability are able to reach markers of adulthood with adequate support in place. It is important to note that the type of disability will affect the ways in which transitions to adulthood are disrupted. For example, people with learning disabilities may find it more difficult to achieve educational markers compared to young people with physical disabilities.

Schuh et al (2015) conducted interviews and photo elicitation methods with six young people involved in a project in the USA that supports young people on their chosen educational or career paths after compulsory schooling. The participants were aged 18-21, two people were identified as autistic, two with a learning disability and two with no disability. Schuh et al were trying to find out about the young people's transition experiences. Forming new friendships and romantic relationships was an important aspect of all young people's transition experiences. Feeling included and accepted, being confident, speaking up for yourself, setting goals and having a life plan was important to all participants in the study. This highlights that young disabled people may have similar aspirations for their transition to adulthood as other young people. Mitchell (1999) conducted interviews with 17 families in the UK where their child was leaving a special educational needs school. Young people leaving school were interviewed, along with their parents and professionals involved in transition support. They found that many young people and their parents aspired for them to acquire jobs, however realistic employment opportunities in the future were scant. Similar to their peers without disabilities, most young people were extending their education beyond compulsory education before trying to get jobs. This study highlights that young people with learning disabilities may have a long period of transition in entering the job market and delay leaving the family home, similar to their non-disabled peers. However, disabled young people are

more likely to face barriers in achieving all the outcomes that mark the successful transition to adulthood (Caton and Kagan, 2007).

Small et al (2013) conducted a study in England using semi structured interviews and talking mats with 98 young people aged 14-22 with intellectual disabilities to explore their aspirations of transitioning to adulthood. They found that most of the young people had limited social networks and were mainly close with family members and had few friends, their number of friends seemed to decrease when leaving school. Young people wanted to be more involved in social activities that their non-disabled peers could access easily, such as swimming or going to the cinema. This study suggests that the social barriers that young disabled people face might affect the formation of adult relationships during their transition to adulthood. Overall, these studies highlight that the aspirations and difficulties during the transition to adulthood may be shared by all young people but having a disability may particularly disadvantage young people in achieving all markers of successful adulthood. These disadvantages may result from lack of appropriate support, social barriers, misconceptions about disability and discrimination.

The impact gender might have on transitions to adulthood was highlighted in the previous chapter, the ways gender and disability might intersect is also an important consideration. Perrins and Tarr (1998) used interviews and questionnaires with seven young women with learning disabilities accessing day centres in the UK to explore their experiences of transitioning to adulthood. Many of the young women in the study felt a caring role was important as part of their adult identity. Hogansen et al (2008) conducted interviews and focus groups with parents, professionals and young women with a range of different disabilities aged 15-23 in the USA. They found that some young people, parents and professionals thought that disabled women were disadvantaged in the job market,

young women were able to access vocational work in child care but faced difficulty in other occupations. Willis et al (2001) studied the experiences of transitions with young women and men with cystic fibrosis in Australia. They found that the young men in their study had higher career aspirations and were less likely to talk about their declining health and fears about the future compared to women. The young men were also less likely to identify with other disabled young people compared to the young women in the study. These studies highlight that there are gendered differences during the transition to adulthood for young disabled people and that disability intersects with other socially constructed identities.

Social attitudes towards disability may disrupt common norms around embodiment and gendered and sexual identities. People with autism and learning disabilities may be infantilised, this means they are seen as 'eternal children', which has led to moral panics regarding their sexuality (Thompson, 2011; Rogers, 2009; Milligan and Neufeldt, 2001). Parents, family members or staff may feel conflicted in how they intervene in disabled young people's sexual lives. Nichols and Blakeley-Smith (2009) conducted focus groups with parents of 13 boys and 8 girls with autism (aged 8-18). Parents were unsure of what a healthy sexuality could look like for their child, all parents wanted their children to have fulfilling relationships but were worried that they would be unsuccessful in doing this and become lonely. Parents also worried about their children being sexually exploited. Parents expressed many uncertainties and wanted more support from services. Rogers (2009) conducted an auto ethnography reflecting on her experiences of having a daughter with a learning disability and her entry into sexual adulthood. She highlights that having a boyfriend was an important status symbol for her daughter's acceptance in social circles, like any teenage girl. Rogers writes that her daughter is vulnerable in her intimate relationships and she provides more guidance and control than she would if her daughter did not have a

disability. Rogers emphasises that surveillance and control of learning disabled young people's sexuality is not appropriate, and instead young people should be encouraged to have relationships, with extra support and education.

Healy et al (2009) conducted focus groups with young people attending an intellectual disability service in the USA, one focus group included young people aged 13-17, another 18-30 and another aged 31+. They found that participants aged 18+ were generally aware of biological anatomy and sexual intercourse, however there was a particular lack of knowledge about masturbation, particularly for young women. The participants aged 13-17 said that sex was forbidden at home and in services and that it was 'inappropriate'. None of the 13-17 year olds were in a romantic relationship but aspired to be. Service users expressed frustration that their siblings enjoyed autonomy in their romantic relationships, whereas they did not. Many participants had traditional views about sex and that they should not have sex before marriage. The authors conclude that these viewpoints may suggest that carers and staff discouraged disabled young people from forming sexual relationships. The extent to which young people have capacity to consent to sexual intimacy also needs to be considered. Disabled young people's transition to sexual adulthood is viewed as more contentious compared to the transition for their non-disabled peers. Young people may aspire to have sexual independence and be restricted by staff and family through surveillance and control. Family members and staff may want to support independence but be worried about the safety of young people. There may also be fear that young people with learning disabilities and autism will have less insight into how to protect themselves from risks such as STIs, exploitation and violence compared to young people without learning disabilities or autism. Overall sexuality and the gendered identity of young disabled people should not be ignored, sexual education for disabled youth, their families and staff involved in their support should be available. This

section has explored the transition to adulthood for disabled young people. My study focused on exploring disabled young people's siblings' accounts of their own transition to adulthood. These transitions were linked with the transition to adulthood for their disabled sibling so it was important to explore literature relating to disabled young people's transition to adulthood.

Disability, the Transition to Adulthood and the Family

This section will discuss empirical research that has explored how transitions to adulthood for disabled young people need to be considered within a wider family context. The ways in which parents' gender and family composition need to be considered in research about disabled young people's transition to adulthood will be outlined. Studies that have researched the viewpoints and experiences of family members during the time of transition will be explored. The ways in which family members support young disabled people's entry into adulthood will also be analysed. It is primarily mothers that are included in studies regarding adult transitions for disabled young people. Research relating to childcare and fathers in families where one child has disabilities is generally scant. Lewis et al (2000) conducted a study with 40 families where one child has a physical or learning disability, or both. They focused their analysis on the 32 families where there were two parents living with the disabled child and conducted semi-structured interviews with mothers and fathers. They identified four types of working arrangements, 'modified single earner families' consisted of full time working fathers, whereas mothers mainly cared for the disabled child with occasional casual work. 'One and a half earner families' included families where fathers worked full time and mothers worked around 16 hours a week flexibly around their caring commitments. In 'full time dual earner families' both parents worked full time and in 'flexible dual earner families', both parents worked flexibly. Overall, they found a shared parenting approach was strongest in dual

earner families, these couples had to work hard to oppose constructs of gendered parenting when trying to make the relationship more equal (Lewis et al, 2000: 1053). This study highlights that it may be difficult for mothers who want to work and fathers who want to care for their disabled children as this opposes dominant ideologies of gender, work and care. Grant and Whittell (2000) conducted interviews with mothers and fathers of disabled children, they found that mothers had more confidence and belief in their caregiving roles, fathers had less confidence and belief in their abilities so distanced themselves from their parenting role. Overall, the gendered division of parenting and caring may mean mothers take on more responsibility in supporting successful transitions for disabled young people compared to fathers.

Family composition and the transition to adulthood for disabled youth is also an important consideration. In the UK in 2016, it was estimated that around 7% of children have a reported disability (DWP, 2017). Some studies have illustrated that there are higher rates of divorce and separation in couples who have disabled children and lower rates of re-partnering, leading to higher lone parenthood (Clarke and McKay, 2008; Risdal and Singer, 2004; Blackburn et al, 2010). Blackburn et al (2010) conducted a secondary analysis of the Family Resources Survey in the UK in 2003/4 and estimated that 34% of disabled children in the UK lived in single parent households, compared to 26% of non-disabled children. Clarke and McKay (2008) conducted secondary analysis of six national data sets in Britain and the UK. They found that in 2001, 32% of disabled children lived with lone mothers and 2% lived with lone fathers. The Families and Children Study was commissioned by the DWP, this study consisted of annual surveys from 1999-2008, conducted with a large sample of parents with dependent children in Britain. In 2008, it was estimated that 13% of lone parent families had children with SEN, compared with 10% of families headed by couples (Maplethorpe et al,

2010: 300). This data suggests that disabled children may be more likely to live in lone parent (and more often lone mother) headed households.

Another important consideration is that there may be more than one person with a disability within the household. Blackburn et al (2010) also found that almost half of disabled children lived with a disabled parent, compared with around a fifth of non-disabled children (Blackburn et al, 2010: 5). Around a quarter of disabled children had one or more siblings who also had a disability (Blackburn et al, 2010: 5). An online survey conducted by the 'Contact a Family' charity was completed by 2,312 parents of disabled people in the UK in 2012, 22% of respondents reported that they were caring for more than one disabled child, over 100 parents were caring for three or more sons or daughters with a disability (Contact a Family, 2012: 2). Families with more than one disabled child have increased vulnerability to parental unemployment and poverty (Emerson and Hatton, 2007; Lawton, 1998; Tozer, 1999; Tibble, 2005). In 2013/14 children in families with a disabled member were more likely to live in a low-income household and experience material deprivation compared to children living in families without a disabled family member (DWP, 2015b). These studies highlight the effect that disability might have on family composition which is likely to affect the transition to adulthood for disabled young people. Young disabled people are more likely to have another disabled sibling, have a disabled parent, have one parent in their household to support them and live in a lower socio-economic household. This is also likely to affect non-disabled siblings' transition to adulthood. Most participants in my study grew up with both of their parents in the household. Two participants were raised by their mother only, these participants did mention that their mothers particularly struggled to juggle caring and work.

The wellbeing of family members during the transition to adulthood for disabled people has been considered in previous research. Taylor and

Seltzer (2011) conducted interviews and administered self-completion questionnaires with 170 mothers of young people with autism in America. They found that the relationship between mothers and children became more strained when young people left high school, particularly if there was unmet service need for the young person with autism. This highlights that the stresses of transitions and lack of appropriate support might negatively impact on family relationships. Hallett and Armstrong (2013) used a phenomenological analysis of a residential project in England that aimed to help young people with autism develop skills that would assist their transition to adulthood. The young people who participated were aged 11-18, semi structured interviews were conducted with young people, parents/carers, teachers and staff at the project. One key finding of the study was that parents reported a sense of relief from caring responsibilities which meant they could give more time to their children without disabilities.

Todd and Jones (2005) conducted in depth interviews with 30 mothers (aged 34-56) of young people with intellectual disabilities (aged 11-19) in Wales to consider parallels of young disabled people's transition to adolescence and young adulthood and their mothers' transition to midlife. They found that this stage of life was socially isolating for mothers. This was partly due to less support from services being available for their children as they became adults. This meant mothers needed to spend more time caring for their son or daughter and they then had less time to socialise with others. Hubert (2011) used ethnographic methods with twenty families in England where there was a son or daughter in the family aged 15-22 with a severe or profound intellectual disability. Informal interviews and participant observation techniques were used; interviews were mainly conducted with mothers as they were the main carers. Parents reported that as their children became older they worried about the risk of sexual assault when they were away from home at school or at respite services. Mothers in the study felt socially isolated and

cut off from extended family and friends. Professionals involved with families suggested that the young people should move to residential accommodation so they could gain more adult independence. Mothers disagreed and wanted young people to stay in the family home but still wanted support so they could have breaks. This study highlights that family carers, usually mothers, may be faced with new challenges when their sons or daughters transition to adulthood and that adult independence is a particularly contentious ideal when a young person requires high levels of care. The ways in which young people in my study perceived their family's wellbeing during their disabled sibling's transition to adulthood will be explored in chapter 5 of this thesis.

The importance of parental advocacy in young people's transition to adulthood has been identified as a salient factor in young people achieving the markers of adulthood, particularly advocacy from mothers (Heslop and Abbott, 2007; Neece et al, 2009). As mentioned above, mothers are usually the primary respondents in research on families and disability, however the terms 'parents' or 'carers' are often used as gender neutral terms in research. Pascall and Hendey (2004) interviewed 31 young adults in receipt of Disability Living Allowance in the UK, some had jobs and independent households, whereas others had one or neither of these. They explored what had helped those with jobs and independent living arrangements to reach these markers of adulthood. They asked about family, education, housing, benefits, employment and personal assistance. Most young people reported that support from their parents was the main factor that helped them achieve independence. Dyke et al (2013) conducted semi-structured interviews with 18 mothers of young people with either Down syndrome or Rett syndrome aged 18-33 in Australia to explore mothers' experiences of their children's transition from school to adult life. They focused particularly on employment, independent living, friendships, and day activities. They found that mothers played a key role in supporting their son's or daughter's day care

or employment access and in ensuring that they had activities throughout the week. These studies highlight the vital role that parents (particularly mothers) play in their children's transition to adulthood.

Parents' over protectiveness has been viewed as a barrier to young disabled people's independence. Mitchell (1997) organised a participatory action research project with people with learning difficulties. They conducted focus groups with six groups of people with learning difficulties about self-advocacy and their families. Many identified that they were more restricted by their parents compared to their brothers and sisters without a disability. Saaltink et al (2012) conducted interviews in Canada with four young people with intellectual disabilities and their mothers about decision making in the family, two siblings also participated. Young people with an intellectual disability were encouraged to make their own decisions and were supported with this by parents and siblings. However, parents reported that their children lacked flexibility and complex decision-making skills due to their disability, leading parents to worry about them making unsafe decisions and placing certain restrictions on them. A comparison with the decision making of non-disabled siblings was not discussed within the study. Dixon and Reddacliff (2001) conducted interviews with young people with mild intellectual disabilities in Australia, aged 19-30, regarding how family support helped in the transition from education to work. They found that parents invested a considerable amount of effort and time to support young people to gain employment opportunities. However, in other domains of independent adult life, such as forming romantic relationships, financial independence and moving out of the family home, parents were more ambivalent due to worries about their child's safety. Young people in the study expressed desires to achieve independence in the same way as their siblings. These studies highlight the contention between families promoting independence for young people with a disability and feeling the need to

protect them from harm. This contention will be discussed in relation to my study in chapter 5 of this thesis.

Isaacson et al (2014) conducted two qualitative case studies with families where one sibling has intellectual disabilities. They explored the family experience of the young person with intellectual disabilities leaving the family home to move into independent living. Both parents and the disabled young people commented that the experience of leaving the family home was a scary time but that it had helped encourage their independence. However, parents were ambivalent about whether their children had achieved adult status, as they were still dependent on others in their day to day lives. Parents still had a high level of involvement in their child's lives, more so compared to the siblings of their disabled child. Both sets of parents suggested that they played a key role in accessing services that made the move into independent living possible for their sons. Non-disabled siblings were not directly involved in the study, however one of the families commented that they did not want to place a burden of care on their other children and that their non-disabled sons chose not to be involved in their brother's transition. Within the other family, the young man with a disability had three sisters, two visited him regularly and one lived with him for a short while when he first moved out of the family home. Although the findings of this study cannot be generalised, it is interesting that within the two case studies, sisters had more involvement in their sibling's move from the family home compared to brothers. Overall, these studies illustrate that parents (especially mothers) may play a key role in supporting their disabled son or daughter to achieve independence in young adulthood. Parents may also feel hesitant to support the independence of their disabled son or daughter because they want to protect them from harm. The studies above also highlight differences between disabled and non-disabled siblings transition to adulthood within the family. These differences were explored in my study and are presented in chapter 5 of this thesis.

Summary

The first section of this chapter outlined the human rights approach to understanding disability. The next section outlined legislation and social policy that is relevant to young disabled people's transition to adulthood. Empirical studies that have examined the effectiveness of services were also analysed. The third section of this chapter reviewed literature relating to young disabled people's transition to adulthood. The final section examined research that has explored how the transition to adulthood for young disabled people needs to be considered within a wider family context. Overall the literature reviewed in this chapter emphasised the importance of adopting a family perspective when studying the transition to adulthood for young disabled people. This helped inform the second research objective of my study which was to explore young people's thoughts and experiences relating to how their transition to adulthood and their disabled sibling's transition to adulthood might impact on family life. This objective was created to explore how young people's transition to adulthood is located within a wider family context. The impacts of young disabled people's transition to adulthood on family life identified in this literature review link with the findings outlined in chapter 5 of this thesis.

Chapter 4: Methodology

Research Aim/Objectives

As mentioned in chapter 1, the research for my MPhil aims to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. The first main objective was to explore young people's experiences, thoughts and feelings relating to the relationship that they have with their sibling with autism or learning disabilities. The findings that directly relate to this research objective are presented in chapter 6 of this thesis. It was important to explore the sibling relationship to help provide context to how having a disabled sibling impacts on young people's transition to adulthood. As mentioned in chapter 2, sibling relationships are likely to be the longest lasting relationship in a person's life. Transitions in one sibling's life may impact on the other sibling's life. Sibling relationships change throughout the life course and the transition to adulthood may have a particularly significant effect on the sibling relationship. As one or both siblings become more independent the sibling relationship may become more distant. The relationship may also improve as siblings spend less time with one another. One sibling having disabilities might affect the sibling relationship dynamics throughout the life course. This will be explored in chapter 6 of this thesis. Overall, exploring how having a disabled sibling impacts on young people's experiences of transitioning to adulthood is located within the sibling relationship context. The literature review that focuses on sibling relationships was presented in chapter 2 of this thesis. This review informs the discussion of findings in chapter 6 of this thesis.

The second main objective was to explore young people's thoughts and experiences relating to how their transition to adulthood and their disabled sibling's transition to adulthood might impact on family life. This involves exploring how young people's transition to adulthood is located

within a wider family context. As mentioned in chapter 3, having a disabled person in the family impacts on other members of the family. Chapter 3 highlighted that in particular, mothers of disabled children were affected by their child's transition to adulthood. Mothers acted as advocates for their disabled children during their transition to adulthood. The transition to adulthood for their disabled child was also a stressful and worrying time for mothers. The transition to adulthood for their disabled child also provided some relief from caring responsibilities as their child became more independent. The research analysed in chapter 3 mainly focused on mother's experiences. Some fathers were included in the research studies, but most research studies mainly focus on mothers' experiences. Only a few studies included the perspectives of siblings of disabled young people as they transition to adulthood. Overall, the literature review in chapter 3 highlighted that research on the transition to adulthood for disabled young people has not considered their sibling's perspectives or how the transition to adulthood for the disabled sibling and the sibling without disabilities might impact on family life. It was important to consider this as part of my wider research aim because the transition for the sibling of the disabled young person happened, or was happening, in a family context. Most of the participants' disabled siblings were also transitioning to adulthood. The transition for both siblings impacted on one another and on other family members. To fully understand young people's experiences of how having a disabled sibling impacts on their experiences of transitioning to adulthood, I wanted to explore their experiences of how the transition to adulthood for all siblings impacted on family life. The findings that directly answer this second research objective are located in chapter 5 of this thesis.

The third main research objective was to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to key markers of the transition to

adulthood, such as: 1. Moving out of the family home; 2. Leaving compulsory education; 3. Choice of occupation; 4. Relationship and family formation. This third objective was reached via my exploration of the literature outlined in chapter 2 of this thesis. This literature revealed that the traditional markers of transitioning to adulthood have become delayed and scattered in recent years. However, these markers of adulthood are still present in everyday discourses and understandings of becoming an adult. The literature review revealed that people still frame their experiences around common understandings of adulthood. I used the markers of moving out of the family home, leaving compulsory education, choice of occupation and relationship and family formation because these cover a broad range of experiences relating to adult independence. For example, starting university can be identified within these markers, as can travelling independently, or having a boyfriend or girlfriend. The literature review in chapter 2 highlights that experiences of transitioning to adulthood are affected by difference. Gender, class and ethnic differences were discussed, along with some other characteristics that might impact on young people's experiences. Chapter 3 discussed how having a disability might impact on young people's experiences and opportunities during the transition to adulthood. This motivated my interest in understanding how having a disabled sibling might affect young people's opportunities and experiences relating to their transition to adulthood. Previous research relating to the experiences of young people who have a disabled sibling suggested that young people's experiences are impacted by having a disabled sibling, this research is discussed in depth in chapter 7 of this thesis. The findings that directly answer my third research objective can also be found in chapter 7 of this thesis.

Philosophical Underpinnings

The main interpretive approach that guides my qualitative research is derived from phenomenology. Phenomenology argues that to understand social reality, we must understand people's experiences of it. It posits that researchers should try to bracket their assumptions and preconceptions about a phenomenon so that they can try to get the fullest meaning of a phenomenon from the point of view of the participant. Phenomenology attempts to explore the cultural understandings of individuals within a study and examines the construction of their 'lifeworld' through researching lived experience (Tesch, 1994; Van Manen, 2014). Interviews are the primary method used to access lived experience within a phenomenological approach. When one is using a phenomenological approach, 'bracketing' is an important process, this means putting one's prejudices and bias aside to look at the experience or essence of the phenomenon under study. It is important that the researcher 'brackets' their assumptions of a phenomenon to try to access the experience of participants as fully as possible. The phenomenological approach assumes that there are shared meanings or essences based on experience between people whose conjoint activity constitutes a phenomenon (Merriam and Tisdell, 2016). I attempted to bracket off my previous assumptions when analysing data, however this was not fully possible. This is discussed further in the data analysis section of this chapter.

Epistemologically speaking the research adopted an interpretivist approach in that I was interested in how people interpret their social world (Mack, 2010). Ontologically speaking I would identify myself as a constructivist, I believe that we interpret reality and this is what makes it real, rather than reality existing outside of our interpretations. Therefore, interpretations of reality vary from person to person (Guba and Lincoln, 1994). I therefore focused on how individuals understand their

experiences and social world. To access these experiences, it made sense to ask them what these experiences are through interviews. Phenomenology focuses on accessing other people's experiences through interviewing. My philosophical beliefs and influences led to my chosen research method of individual interviews. Overall within the research study I was influenced by the phenomenological school of thought. However, I would not identify the research as phenomenological study because I did not want the research to be theoretically bound to one approach. Overall the research was guided by my philosophical beliefs that were influenced by phenomenology, interpretivism and constructivism.

Choice of Research Method

I chose to use in depth interviews in this study because I was interested in accessing young people's interpretations of their experiences, thoughts and aspirations relating to their transition to adulthood. I considered whether to use unstructured or semi-structured interviewing within the study. Often a clear distinction is made between an unstructured interview and a semi-structured interview. Bryman (2001) defines unstructured interviews as interviews where one question is asked and the interviewee is encouraged to speak freely, with the researcher following up certain points of discussion. Lofland et al (2006) suggest that unstructured interviews may have a guide with suggested questions relating to themes and the researcher adapts the guide in each interview. These definitions are quite different, highlighting that there is not a universal definition of unstructured interviewing. Bryman and Becker (2012) suggest that a semi-structured interview may have a guide with questions relating to relevant topics but that this guide can be adjusted during the interview. This definition closely resembles Lofland et al's definition of unstructured interviewing. For the purposes of this study, Bryman and Becker's (2012) distinction between semi-structured and

unstructured interviewing will be used. They make the distinction that semi-structured interviews are more focused on the topics and questions the interviewer wants to cover. Whereas in unstructured interviews the focus is more on letting the interviewee tell their story relating to much broader themes that emerge from the interviewee (Bryman and Becker, 2012: 292).

As my research was focused on three research objectives relating to the overall research aim, semi-structured interviews were used to ensure I asked questions directed to meeting these objectives. Bryman (2001) points out that one drawback of using a semi-structured interview format is that there may be more of an inclination to ask leading questions to guide interviewees to answer research questions. I found that this was sometimes the case, particularly if there was a theme that I wanted to pursue that had come up in previous interviews. When I wanted to ask leading questions, I carefully considered how I might re-word the question so it was more open ended.

It has been suggested that we live in an 'interview society', how we portray ourselves through talk with others is key to how we portray our public selves (Atkinson and Silverman, 1997). An important question that a researcher must ask themselves is whether participants are portraying their experiences. We can never truly access the thoughts of people and what people say does not necessarily represent the facts of what happened (Byrne, 2004). However, if the researcher is not able to observe the phenomenon sufficiently to find out what is really happening, then gaining people's accounts may be the only way to investigate. The interviews within my study were trying to gain an insight into people's experiences. Constructionists argue that the way in which experiences are expressed will be influenced by the researcher and researchers cannot therefore access another person's experiences (Silverman, 2006). There is merit to this argument, however I do not think that this means that the

experiences expressed by others do not reflect their reality in any way, perhaps just one version of participant's reality. Overall, I believe the experiences discussed in this thesis are a portrayal of people's experiences.

Gaining Access

I will now outline the ways in which I invited participants to take part in the study. I used informal networks to recruit 2 of the 10 participants. One participant was a friend of a friend and the other was recruited via a social worker I know informally. Two participants were recruited through professional contacts. I contacted a university to advertise the study amongst students who may have a sibling with learning disabilities or autism. I asked university departments to circulate an email inviting potential participants to contact me if they were interested in being part of the study, the 6 other participants in the study were recruited using this method. I also asked an autism charity I volunteer for to circulate a poster advertising my study (see appendix 1), however no participants came forward using this method. Seven of the participants are currently attending university, three have left university and are currently working. The study can be criticised for only interviewing young people who are attending or have attended university. This means vital insights from people who have different transition experiences are missing from my research. The access methods can be criticised for focusing on university recruitment and personal contacts. As a university attendee myself, I may have more university attendees in my informal networks. However, attempts were made to recruit participants through a charity where I had hoped non-university attendees might come forward, however no one did. Due to the time constraints of this study I was unable to focus my efforts on recruiting via other routes that may have led to a more diverse sample. It is also important to note that I entered my studies intending to

complete a PhD and therefore the study was advertised to potential participants as a PhD study, I later converted to an MPhil.

Sampling

Throughout my background reading of research relating to siblings of disabled people, the lack of research involving young adults became clear. A lot of research with child siblings covers the ages from 7 to 16 and sometimes to 18. The adult research has mainly focused on ages 25 and above, with few studies engaging with people aged 18-24. A life course perspective is also scant in the literature, with most studies focusing on children. I therefore chose to focus on the transition to adulthood in my research and to look at the experiences of young people who have a sibling with learning disabilities or autism during this time. Initially I planned to interview young people aged 17-24 so I could compare the experiences of young people who had left compulsory education and young people who had not left compulsory education. However, during recruitment I decided to change the age range to 18-24 so that I could focus more on other comparisons, such as gender and young people's sibling's level of support need. The third research objective of this study aimed to explore young people's experiences, choices and aspirations relating to moving out of the family home. Moving out of the family home is a societal expectation and marker of independence during young adulthood, meaning most young people aged 18-24 will have thoughts relating to leaving the family home. The third research objective of this study also aimed to explore young people's occupational choices and aspirations for the future. In England, education and employment funding and support services have traditionally been targeted towards young people aged 16-24. Young people who are classed as 'not in education or employment' (NEET) have received particular policy and media attention in recent years, NEET young people have been grouped in the age range of 16-24. New legislation came into effect in 2015 in England, raising the

compulsory education and training age from 16 to 18 (Education and Skills Act 2008). This study therefore aimed to recruit young people who have a brother or sister with learning disabilities or autism who might be classed as young adults in education and employment policy. The upper age limit was set at 24 as this age is often understood as the endpoint of young adulthood in education and employment policy. This age limit also allowed for the recruitment of young people who have recently left university. Including the perspectives of disabled siblings and their parents was considered and may have provided some useful insights into how transitions impact on family life. It was decided to focus all the time and resources on interviewing non-disabled siblings because the focus of the research was on non-disabled sibling's experiences relating to their transition to adulthood.

I initially was going to focus on the experiences of people who have a sibling with learning disabilities only. However, I had a particular interest in autism too, so hoped that some people's siblings would have autism and learning disabilities. During recruitment, I decided to broaden my sample to siblings of people with autism *or* learning disabilities for two reasons. Firstly, the first two participants had siblings with learning disabilities and autism, I noticed that participants spoke a lot about how the social impacts relating to autism affected family life. Secondly, when I circulated my email to university students regarding my study, many people who have a sibling with autism (and not necessarily an accompanying learning disability) showed interest. Although I had inclusion and exclusion criteria relating to the type of disability that young people's sibling should have, young people defined their sibling's disabilities in different ways. I interviewed two participants whose sibling have very mild support needs, Rebecca's sister has mild learning disabilities and Peter has two siblings with Asperger's syndrome, one sibling had killed himself. More details of each participant and their families can be found in the section below, pseudonyms have been used

throughout this thesis. The other eight participants have a sibling with autism and/or learning disabilities who have higher support needs, however the needs of each person vary. Some need support with practical tasks such as cooking and cleaning only and others need higher levels of support, such as help with personal care. Some participants identified their sibling as having severe autism but did not mention that they have learning disabilities. Their sibling may have learning disabilities and autism but participants may not be aware of this or they may not classify their sibling's disability in this way. The differences in the support needs of people's siblings did impact on the findings. These differences are mentioned in the chapters 5, 6 and 7 of this thesis.

I interviewed seven male participants and three female participants. Most participants have a disabled brother, only two participants (Emma and Rebecca) have a disabled sister. This meant it was difficult to compare the differences in sibling relationships based on gender. It was interesting that more male participants came forward compared to female participants. The sample size is small so generalisations cannot be made but there is a possibility that more male participants came forward because they felt their caring role was unusual and they wanted to talk to someone about it. Chapter 2 of this thesis highlighted that generally women take on the primary caring role in the family. Young women may have felt that their support and care role was normal and therefore did not feel as inclined to come forward and talk to someone compared to male participants. Chapter 2 also highlighted that men and women have similar working patterns in young adulthood but when they have children women are more likely to take on the primary caring role. As the participants I spoke to were younger, perhaps young women did not feel the impact of juggling childcare and supporting their sibling so felt the impact on their life was not significant enough that they wanted to talk to someone. Overall researching gender differences was not a main objective of this

study but some discussion about potential gender differences can be found in chapter 7.

Some participants came from prosperous backgrounds and others from low income households. All participants were attending or had attended university. As mentioned in chapter 2, studies have found that young people from poorer backgrounds may enter employment earlier, rather than going to university and taking gap years (Hayward, 2013; Jones, 2002; Bynner et al, 2002). My sample only included university attendees, which means my sample may have included more people from wealthier backgrounds. The impact of coming from a poorer background on young people's experiences of growing up with a disabled sibling might have become more apparent if I interviewed some young people who have not attended university. Financial pressures related to having a sibling with disabilities might have been discussed if I had interviewed more young people who have not attended university. It would have been interesting to see if any people felt their educational attainment was affected by their sibling having a disability. Most participants in the study would be classed as white British, I did not ask participants to state their ethnic identity because the aim of the study was not to explore ethnic differences. However, considering this might have drawn out some interesting findings. Chapter 2 illustrated that young people from ethnic minorities felt that racism impacted on their transition to adulthood. Young people from ethnic minority backgrounds might feel that racism impacts on how they are treated, along with their disabled sibling and family. For example, some young people who care for a disabled sibling might feel socially isolated if they are also experiencing racism.

Overall, the aim of this study was not to be representative, so gender, ethnicity and class composition were not a great concern. However, a weakness of the study is that I did not consider differences based on

gender, class and ethnicity enough in my research design which means I struggled to draw any comparisons based on these differences later. It is important to be aware that the findings of this study do not *represent* the experiences of all young people who have a sibling with autism or learning disabilities. However, the findings may be *relatable* to the experiences of other young people who have a sibling with autism or learning disabilities.

Description of Participants and their Sibling

This section will briefly describe the age, occupation and living situation of each participants and their sibling. Pseudonyms have been used for each participant, their sibling and any other person mentioned in interviews to ensure that their identities are kept anonymous. Efforts have been made to ensure that there is no information that might identify participants and their families in this thesis.

Richard and Tom

Richard is 24 years old. He is a teacher and lives with his mum and dad, he moved out when he went to university but returned to live in the family home when he completed university. His brother Tom is 28 and has learning disabilities and autism. Tom lives in council housing in the same city as his family. Tom is not currently working. Richard and Tom also have three sisters, aged 41, 39 and 37.

Luke and James

Luke is 20 years old. He is in his final year at university and lives with other students. The city in which he studies is about a half an hour drive from his home city. Luke's brother James is 14 and has learning disabilities and autism. James attends an SEN school and lives with his mum and dad. Luke and James have a sister who is 18.

Rebecca and Lily

Rebecca is 24. She works in a supported living service for adults with learning disabilities. Rebecca lives in rented accommodation with her boyfriend in the same city as her mum and sister. Her sister Lily is 20 and has mild learning disabilities, she works in a supermarket and lives with her mum. Rebecca and Lily's parents split up when they were young and they lived mainly with their mother when they were growing up.

Megan and Ben

Megan is 18 and is currently in her first year at university. She lives with her boyfriend in rented accommodation. She lives about an hour's drive away from her mum and brother. Her brother Ben is aged 20 and has severe autism, he lives with their mother. Ben and Megan were raised by their mother, their dad left when they were young. Ben sometimes has carers in to support him, his mother could not find an appropriate day centre to meet his needs.

Samson and Joe

Samson is 21 and is currently studying at university, he is studying in his home city. He lives some of the time at his dad's house and some of the time at his mum's house. His brother Joe is aged 19 has higher functioning autism and dyspraxia. Joe also lives at his mum's house some of the time and dad's some of the time. Joe is currently studying at college. Joe and Samson have a sister (aged 25) and a brother (aged 24). They also have two step sisters.

Peter, Graham and Adrian

Peter is 22 and is currently studying at university, he lives with his girlfriend in private rented accommodation. His university city is around an hour's drive from his home county. Peter has a brother Adrian with Asperger's syndrome aged 19 who lives with their parents and works in a pub. Peter also had a brother, Graham, who had Asperger's syndrome. Graham killed himself last year, he was 20 when he died. Peter and Adrian also have two sisters, who are 16 and 24.

Lucas and Rowan

Lucas is aged 23 and is currently studying for an MA degree and works part time as a higher education teacher. He lives with his girlfriend in the city where he studies. He lives about an hour's drive from his home city. Lucas' brother Rowan is 18 and has autism and dyspraxia. Rowan is currently studying at college after attending an SEN school. Rowan lives with his parents.

Emma and Hannah

Emma is 24 and is currently studying towards a PhD, she lives with friends in rented accommodation. The university she studies at is in the same county as where her parents and sister live. Her sister Hannah is 23 and has severe autism and epilepsy. Hannah lives with her parents and attends day services.

Owen and Matt

Owen is 19 and is currently studying at university around an hour's drive from where he grew up. Owen lives in the city where he is studying. His brother Matt is 24 and has Down's syndrome. Matt lives in supported living and is involved with some services that support him to carry out

activities. Matt and Owen also have a brother who is 26. Matt, Owen and their brother grew up living with their mum and dad.

Isaac and Harry

Isaac is 24 and lives with his mum and dad, he works in a children's residential home. His brother Harry is 18 and has autism and high support needs. Harry very recently moved out of the family home into a residential home. He has recently finished at SEN school and is starting college soon.

Biographical Data of the Participants

Four tables are presented below which outline the most relevant aspects of biographical data relating to participants and their siblings.

Table 4.1 Spread of participants by gender

Gender of participant	Sample number	Percentage
Female	3	30%
Male	7	70%

Table 4.2 Gender of sibling pairs

Gender of sibling pair	Sample number	Percentage
Brother and brother	6	60%
Sister and sister	2	20%
Brother, brother and brother	1	10%
Sister and brother	1	10%

Table 4.3 Birth order of participant compared to disabled sibling/s

Birth order of participant compared to disabled sibling/s	Sample number	Percentage
Older sibling	7	70%
Younger sibling	3	30%

Table 4.4 Occupation of participants

Occupation	Sample number	Percentage
University student	6	60%
Teacher	1	10%
University student and part-time teacher	1	10%
Support worker	2	20%

Table 4.5 Type of disability that participants' sibling/s have

Type of disability	Sample number	Percentage
Autism	5	50%
Asperger's	1	10%
Learning disability	2	20%
Autism and learning disability	2	20%

Carrying out the Interviews

The 10 interviews were carried out in various locations and their duration was between 50 minutes and 2 hours. Two interviews took place in the participants' work environments. In one of the workplace interviews, we were in a private room where no one walked in. There were no distractions and the interviewee and myself seemed comfortable in our surroundings. The second workplace interview took place in a shared office of a supported living environment for adults with learning disabilities. The interview was disrupted three times with workers or tenants coming to speak to the interviewee in the office. Bassett et al (2008) highlight that interruptions can affect the flow of the interview, threaten confidentiality and cause discomfort for the interviewer/interviewee (Bassett et al, 2008). I did feel uncomfortable when the interview was interrupted and turned off the recorder when someone who had entered the office began speaking to the participant. Although I felt quite annoyed, the participant did not seem to be too affected by the interruptions and easily continued with her answers. One interview took place in the participant's home, the participant seemed

comfortable in his surroundings which made me feel comfortable. I had let one of my supervisors and mother know that I was entering an unknown person's home and texted them with the time of the interview. I also texted them when I left the participant's home. This procedure helped to manage my safety in the field. Five interviews took place in private rooms located in a university library, this was ideal for the audio recording as there were no distracting noises. However, the meeting style room sometimes made the interview feel formal. Two interviews took place in cafes. We sat far away from other people in the cafés, and I checked with participants if they were comfortable with the location where we were sat in the café. I had suggested to both participants that we could meet in more private locations, such as a private library room or their homes if they were worried about people overhearing. Both participants said they preferred the café option. I felt more relaxed in the café environments and felt it was easier to build rapport and be chatty. However, the audio was much more difficult to transcribe as there was a lot of background noise in the cafes. These experiences emphasise that no research location is ideal and that each will have their positive and negative aspects. I mainly considered the preference of the participant and my own safety when arranging interviews. On reflection, I should have also thought about which public locations may have been quieter.

Prior to interviews taking place, I had constructed my interview guide. Individual in-depth interviews were piloted with two young people aged 18-24 who have a brother or sister with learning disabilities or autism. These two pilot interviews were conducted with Richard and Luke and were included in the main data analysis of this study. Access was sought through informal family and professional networks. I asked for their feedback on the research objectives, format and delivery of questions. Once feedback was sought from the pilot interviews I edited the interview schedule (see appendix 4). Of particular use were suggestions for potential follow up questions. Kvale and Brinkman (2015) suggest starting

off with some introductory questions that elicit description, follow up questions can be used to encourage elaboration of a response. The first few questions asked participants to describe who they lived with whilst they were growing up and what their parents did for work. Demographic questions were also asked at the beginning of interviews. As the interview went on I asked more in-depth questions about participants' relationship with others. Leech (2002) recommends asking more sensitive questions in the middle or at the end of interviews so that time has been spent building rapport. Questions about relationships and relationship plans for the future were therefore placed at the end of the interview schedule. Interviews were audio recorded, I did not find that the presence of the recorder hindered the exchange much, most participants barely looked at the recorder. Most participants had been involved in studies previously or had conducted their own so perhaps they were used to voice recorders. Overall, I found the interviewing experience enjoyable, some participants spoke at length and I did not need to prompt for further explanation and others gave shorter answers and I was required to prompt more often. In a way those who gave shorter answers often were more concise and it was easier to transcribe and code the interview transcripts, whereas participants that talked at length often went off topic and there was a lot of data that I did not use from their transcript. This emphasises that there is not an 'ideal' participant, however I did find it easier to interview people who I felt I had an instant rapport with, whereas it felt more forced with others.

Data Analysis

Thematic analysis involves analysing data to find repeated patterns of meaning (Braun and Clarke, 2006). Braun and Clarke argue that thematic analysis differs from other forms of data analysis, such as discourse analysis, grounded theory or interpretive phenomenological analysis because they are bounded theoretically. As I was influenced by

phenomenology, interpretivism and constructivism, I decided to adopt a form of data analysis that was not bound to one theoretical or philosophical idea.

Braun and Clarke (2006) outline that thematic analysis is similar to content analysis, as this approach is also used to identify patterns across data. Braun and Clarke state that

> 'content analysis tends to focus at a more micro level, often provides (frequency) counts (Wilkinson, 2000), and allows for quantitative analyses of initially qualitative data (Ryan and Bernard, 2000). Thematic analysis differs from this in that themes tend not to be quantified … and the unit of analysis tends to be more than a word or phrase, which it typically is in content analysis.' (Braun and Clarke, 2006: 98)

This quote highlights that thematic analysis is similar to content analysis, however in thematic analysis codes and themes involve more descriptive units of analysis. The aim of this research was to access, display and discuss the interpretations of participants. Therefore, the findings chapters of this thesis present detailed extracts of participants' interpretations of their lives to ensure the interpretations that they expressed in their speech are presented as they were expressed and the reader can assess the validity of my claims against other possible interpretations that may be prompted by particular responses or across them. My phenomenological orientation also affected the presentation of interviews. It was important to provide both the context of the response and to allow the meaning to be developed, rather than to seek to foreshorten the interview responses according to external categories.

Braun and Clarke outline that thematic analysis can be theoretical or inductive. An inductive analysis is 'bottom up' and themes are identified

from the data itself. This approach attempts to focus on the whole data set to identify themes. A theoretical thematic analysis is driven by the researcher's theoretical interests. Themes are identified by focusing on a detailed analysis of one area of the data. My approach was mainly inductive, although there were aspects of a theoretical analysis. I attempted to find as many themes across the data set and present the thoughts and experiences of participants without imposing my theoretical ideas. The research questions also evolved throughout the coding and analysis process. However, as I approached the interviews focused on exploring transitions to adulthood, there were aspects of the data analysis that may be categorised as a theoretical thematic analysis because I had a main theory that guided my research.

Braun and Clarke also explain that a thematic analysis usually involves analysis using a semantic or latent approach. A semantic approach presents the data as what the participants said, summarises and interprets this, to 'theorise the significance of the patterns and their broader meanings and implications (Patton, 1990), often in relation to previous literature' (Braun and Clarke, 2006: 84). A thematic analysis using a latent approach 'goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualisations – and ideologies - that are theorised as shaping or informing the semantic content of the data' (Braun and Clarke, 20016: 84). My analysis mainly used a semantic approach, this meant I could present and focus on participants' interpretations and experiences without overly imposing external categories on the data (Smith et al, 2009), something that would not be warranted in a small-scale study. However, I did delve into a latent approach by considering how participant's accounts might relate to relevant theories.

I will now outline how I analysed the data collected in the interviews with the participants. Interviews with informants were audio recorded and

then transcribed. I completed transcription myself, although this was time consuming, transcribing aided me in becoming familiar with the data and can be considered as a vital stage in data analysis. Lapadat and Lindsay (1999) argue that through putting spoken word onto paper, the researcher creates meaning from the data. The main aim of the research was to understand the experiences of participants, to some extent I attempted to bracket off my own assumptions and views regarding the data. I tried to concentrate on what was said in the larger context of the interview and not create meaning from a small quote and link this to previous research or assumptions. This was challenging at times, particularly if a quote would fit perfectly with one of my pre-conceived ideas. Charmaz argues that it impossible to achieve an analysis approach that is wholly inductive and that brackets off prior theoretical knowledge (Charmaz, 2006). I did find that my prior knowledge shaped the formation of themes and this shaped what I was looking for in the data. However, I think that I could focus on the personal context of each interview and find interesting themes based on participants' experiences. Overall, the formation of themes was influenced by my previous knowledge and by what the participants said.

I used the six stages of thematic analysis outlined by Braun and Clarke (2006). They argue that thematic analysis allows researchers to identify, analyse and report patterns in data which display the rich detail of what the participants have said or done that relate to the research topic. This complies with my research aim, thematic analysis allowed me to describe and compare young people's experiences and aspirations using categories. These categories or themes were then discussed in relation to other empirical research studies and relevant sociological theory. The first stage of the thematic analysis involved familiarising myself with the data and getting an idea of the themes that might be emerging from the data. This began during data collection and continued during transcription. Braun and Clarke encourage researchers to re-listen and re-read interview

data to begin to think about meanings and patterns, I listened to my audio recordings twice. The second stage involved assigning codes to sections of the data, codes are labels that highlight data that are relevant to the research aim. Braun and Clarke encourage researchers to identify as many codes as possible that could be relevant to the study aim. The third stage consisted of grouping the codes together to search for themes. Themes were grouped into main themes and sub themes. These stages of data analysis were applied to all transcripts and themes were compared across responses. The fourth stage involved reviewing all the themes and assessing the fit of main themes and subthemes across the participants' responses. The fifth stage involved defining and naming the themes and ensuring that the themes that were identified told the story of what the participants had said regarding the research area of interest. In the sixth and final stage, I produced the findings chapters of this thesis to display the themes that were identified and how they converge or diverge with other research findings. A table outlining the thematic analysis process is presented in the appendices (appendix 7).

Ethical Considerations

This research received full ethical approval from the University of Nottingham ethics committee in February 2017. A copy of the approved ethics form is included in the appendices (appendix 6). Please note that the ethics application states that I planned to interview siblings of young people with learning disabilities. When I changed my research criteria to interviewing siblings of young people with autism or learning disability, I approached the head of the ethics committee via email to gain authorisation, this authorisation was granted via email.

I negotiated consent by preparing information sheets for participants (see appendix 2), I tried to keep the language as simple as possible to make these accessible. Nine of the participants mainly communicated with me

via email initially, I therefore was able to send them the information sheets so they had time to consider what the study would involve before they agreed to meet with me. One participant was contacted via the telephone, so I verbally explained the study and he agreed to meet with me. He read the information sheet before signing the consent form when we met for the interview. When meeting the other nine participants for the interview, I asked them to read the information sheet again before signing the consent form (see appendix 3). I ensured all participants had the opportunity to ask questions before beginning the interview. To comply with ethical considerations of confidentiality and anonymity, I made sure that I acted in accordance with Data Protection Act 1998 and stored transcripts, audio recordings and details about informants in locked storage and a secure electronic system (Alderson, 2012). I also ensured that people were not identifiable when I wrote about them in this thesis. I changed the names of all participants and I ensured all references to locations and specifics relating to their lives were changed. For instance, if a person's parent worked in a supermarket, I would just write 'supermarket' in the transcript, rather than the specific shop. I ensured that all quotes used in this thesis did not contain detail that might reveal the person's identity to someone who knows them.

Another important ethical consideration was that within interviews, discussions might have brought up difficult issues for participants. Family issues or difficult experiences related to stigma around disability did arise. Qualitative methods have been viewed as appropriate for sensitive research areas, as the researcher and participant can negotiate the data collection process and the research methods are often flexible (Mawn et al, 2016). Discussion of sensitive topics within interviews may be beneficial to participants as they are able to talk about their experiences to someone who is detached from the situation (Biddle et al, 2013). Several participants mentioned after the interviews that they felt relieved after the interviews or that they had enjoyed talking about their

experiences. However, talking about difficult experiences may be upsetting and bring up memories and emotions that are unexpected and difficult to deal with (Corbin and Morse, 2003; Dickson-Swift et al, 2007). One participant did become tearful in the interview, she had said before the interview that she might become upset. I reminded her that she could take a break or withdraw from the study at any time. I also highlighted that crying was nothing to be ashamed of and if she was happy to continue interview when upset then I would carry on. I also ensured I had some tissues with me when interviewing participants. I ensured that participants had my contact information if they needed to talk me after the interview. I also compiled a list of support services and gave these to participants after the interviews had taken place (see appendix 5). This way they could access support if they felt they needed to or access the services for information that might be relevant to them.

Chapter 5: The Impacts of Transitions on Family Life

Introduction

As mentioned in chapter 3, young disabled people may transition to adulthood differently when compared to other young people because of discrimination, social barriers and lack of appropriate support. Young disabled people may take longer to develop skills during the transition to adulthood and they may need ongoing support to maintain their independence. With support, many young disabled people can reach their adulthood goals. The literature review revealed that it is often families (mainly mothers) who provide the most support to disabled young people during the transition to adulthood. The literature review highlighted that it can be a difficult and stressful time for parents when their disabled child transitions to adulthood. Adult independence for the disabled person was found to have positive effects on family life, such as parents having more time to themselves. However, research suggests that families may worry about the vulnerability of their disabled relative when they enter independent adult life. Most studies have focused on the views of mothers of disabled young people during their transition to adulthood. My study focused on the views of siblings, seeking out their perspectives regarding how their own transition to adulthood, and the transition for their sibling, has impacted on family life.

This chapter will outline the first of the three major themes that were identified during the thematic analysis of the interview transcripts. The three major themes also contain subthemes and will be presented in each chapter. This chapter will present the findings relating to the impact that the transition to adulthood for siblings with and without disabilities have on family life. It is important to note that these impacts are the perceived impacts of the participants. The first subtheme discusses participants' views of transition services and how they think services affect the family. The second subtheme outlines participants' thoughts relating to how the

transition to adulthood for their disabled sibling has impacted on their own life and their family's life. The final subtheme discusses participants' thoughts relating to how their own transition to adulthood has impacted on their siblings' and parents' lives. The findings within each sub theme will be discussed in relation to relevant literature and theory. Throughout this chapter I will refer to 'supported living' and 'residential care'. Supported living refers to accommodation where a person has a tenancy agreement and receives support from social services staff. Residential care refers to accommodation where a person lives under the care of the residential home rather than having a tenancy agreement.

Family Struggles with Transition Services

The findings of this study suggest that young people perceive the transition to adulthood for themselves and their non-disabled siblings as impacting on family life in different ways. As mentioned in chapter 3, the transition to adult services can be a particularly difficult time for families, there may be less support available from adult services or support may stop altogether (Kirk, 2008; Clarke et al, 2011; Bhaumik et al, 2011). Five participants talked about the struggles their families had with the transition from child to adult services. Richard states:

> 'Richard: there's so many departments and so many different kind of social workers and uh support that is there that they passed him around a bit until they found the right one and the right budget for him'

Other participants mentioned struggles with changing social workers:

> 'Isaac: getting it sorted was the biggest pain known to man… er we had, due to the way the child sector is… we had… in the last 2 years we've had 20 social workers

Me: wow

Isaac: yeah… we used to have a good one but it tended to be mum having to do the grunt work 'cause the social workers were never around'

'Owen: you know obviously a lot of the cuts that are going on make it very difficult to work and we went through three or four different social workers within a year 'cause people had started to retire, people had started to leave, people had started to move departments, things like that'

'Emma: erm yeah we've always had like a social worker… some have been really crap

Me: mm

Emma: others have been really good… like yeah they're not always great, like my parents do spend a lot of time like fighting for things'

The lack of consistency from social work teams was reported by young people as causing stress for their families.

'Me: mm… how was that transition from children to adult services?

Isaac: terrible

Me: mmhm

Isaac: a nightmare

Me: mm

Isaac: no social worker

Me: mm

Isaac: or once they did turn up, another one turned up the next week, it got to the point of two years ago even, my mum just gave up with social workers, didn't bother, didn't know their names anymore, didn't email them, didn't do anything with them'

> ‘Emma: there wa… just like… really annoying things like… something’s always like getting cut or someone in the social services like messed up with some paperwork’

> ‘Owen: it was, it was quite a struggle and it got to the point where you know my mum was on the phone crying saying like right we need him to move somewhere, he’s been back for about a year now I can see him losing that independence that he once had’

> ‘Megan: erm so he’s been all over the place so like went to school, like he went to a specific special needs school and then like a... a day centre and he’s been to like 3,4 different day centres and they’ve all said that they can’t cope with his type of autism as well… so he keeps getting moved around to all different places erm and then erm… so I think he’s been to like 5, 6 different places since he was like 16’

Unfortunately, most young people expressed negative experiences of transition support from the local authority. Some participants did mention services that had helped their families and sibling. Emma mentioned an incident where her sister came back from day services with bruises, which she said caused great upset for her and her family and anxiety around support services. Overall, the transition from childhood to adult services caused upset, anxiety and stress for some participants and there was a sense of inadequate or missing support from social services around this time. Participants spoke about the stress and upset that the transition from children to adult services had on their parents, particularly their mothers. Some participants mentioned that the transition from children to adult services was disruptive to their sibling’s life. Seeing their families going through such difficulties was stressful and frustrating for some participants. Most participants spoke negatively about the local authority and there were mixed reviews about the actual services their siblings

receive. Jacobs and MacMahon (2016) conducted interviews with six young people aged 16-22 who have a brother or sister with learning disabilities living in a residential school. For one participant, there was a clear plan regarding their sibling's adult placement. For all other participants, they knew that adult services would take over from their sibling's residential placement but this transition was thought of in abstract terms. Participants were worried about the future support services that would be available for their sibling. Some participants spoke about a close link with their sibling's residential school. Other participants spoke about local authorities focusing on costs rather than caring about their sibling and family. Isaac emphasised in his interview that all councils look at are pound signs. Other participants in my study suggested that the local authority is too procedural.

Rawson (2010) conducted semi structured interviews with young people aged 17-23 who have a brother or sister who attend a residential school for complex needs. Participants reported concern and uncertainty about the transition from child to adult services for their sibling. They were worried about the quality of the adult service provision, if their sibling would settle into a new placement and the processes involved in finding placements. They worried about their potential future role in supporting their siblings and working with social services. Many participants in my study were uncertain about the future support provision for their sibling and this caused anxiety for some. Others spoke about their future support roles, this will be discussed in more detail in chapter 7. Mostly, young people in my study and other studies have expressed frustration and uncertainty in relation to social services support. This highlights that the transition to adulthood for disabled siblings can cause stress and anxiety for other family members because of a lack of appropriate support. As mentioned in chapter 3, most previous research has focused on the experiences of mothers as their disabled child transitions to adulthood.

More research is needed that focuses on the transition to adult services for disabled children and how this impacts on all family members.

Impacts of Disabled Sibling's Transition on Family Life

As mentioned in chapter 3, the background literature suggests that the transition to adulthood for young disabled people can cause stress, anxiety and upset for families. Some participants talked about their parents, particularly their mothers, being afraid to let go and encourage independence for their disabled child. Others mentioned how all the family worried about their disabled relative's future. However, for the most part independence for the young disabled person was reported as being positive for the whole family. Isaac's brother recently moved out of the family home into residential care, the family had struggled with some of his brother's behaviour. Isaac said he thought his brother might have to be arrested or his mother go into a secure unit for mental ill health. After his brother moved out Isaac talked about the difference it made to his family life:

> 'Isaac: you know just… you come home and… it's peaceful… the computer isn't on with my brother sat at it or there's no… it's just so much less stressful
> Me: mm
> Isaac: we still get the odd bit of paperwork to do now and then but it's more easily approached now cause it's just not worrying'

This highlights that Isaac believes that his brother's move into residential care relieved stress and worry experienced by the family. Owen talked about how his family missed his brother when he moved out. However, Owen thought his move to independence was a positive experience for the family, particularly for his mum:

> ‘Owen: so like him moving out, I think everyone’s really spotted, he’s become more and more independent and I think that’s, I think that’s really… I think that’s why my mum finds it so easy… ‘cause I think she’d struggle with like how dependent those two were, like how much they, how much interaction those two had, seeing Matt actually become more and more independent I thinks made it easier for my mum’

Some participants expressed feelings of uncertainty for the family during the transition to adulthood.

> ‘Samson: living living by himself… I mean if he can go to football matches by himself, he can go to [specifies bar] my himself, he can order food and drink er washing machines have instructions will he be able to do it? So, there’s a lot of unknowns ‘cause we’ve done so much for him
> Me: mm
> Samson: because we’ve cared but then maybe sometimes… you know we need to sort of go… we need to... see how how he can cope with himself so… I don’t know, a real great deal of uncertainty’

> ‘Lucas: erm but we’ll see, I don’t think he’s erm in a position where he’ll go into communal living, I think he’ll either live with me for a bit but I think eventually he will live by himself… his independence has grown a lot in the last few years so I think he’ll be ok
> Me: mm
> Lucas: erm but it’s difficult to say’

Overall participants expressed that the move to independence is an uncertain and worrying time for their families. Some participants felt that the move to independence for the young disabled person had improved

their family's lives, as their sibling developed new skills and the rest of their family adopted less intense support roles. Connell et al (2014) present an auto ethnography of a woman named Zoe who has grown up with a sibling with autism. Her mother cared for her and her brother alone, which put large strains on her mother's life. Zoe talks about how the relationship with her brother and mother improved when her brother lived away from home on a shared care basis. Other studies have found that family life can improve when young disabled people move out and become more independent (Hallett and Armstrong, 2013; Dyke et al, 2013; Neece et al, 2009). This highlights that support from care services can help support positive family relationships as there is less of a strain on family members to provide care. Overall the transition to adulthood for young disabled people can be positive for some families with the right support. For others, this is a time of great anxiety, stress and uncertainty.

Theoretically, young people's accounts of their family experiences of the transition to adulthood can be linked with the concept of 'disability by association' (Burke, 2010). Burke (2010) uses the concepts stigma by association and 'disability by association' when analysing two studies he carried out with siblings and parents of disabled children. Disability by association is used in his paper to describe the social, physical and attitudinal consequences that disability labels might have on people close to the disabled person. Burke argues that the consequences of disability by association may be negative and linked with stigma or be positive in that they motivate people to change their situations and identify with other people with similar experiences. Burke found in interviews and questionnaires with siblings of disabled children and their parents that having a disabled relative was not seen as exceptional, however the impact on family life socially was disadvantageous, for instance restricting the social activities that families can engage in in public (Burke, 2010). Participants in my study suggested that the social effects of disability had an impact on their lives and on their parents' lives as their sibling

transitioned to adulthood. Participants experienced the social consequences of lacking support services and reported that their parents did too. Participants and their parents experienced stress and worry about their family member transitioning to adulthood because of other people in society who might try and hurt their disabled family member. Participants outlined that their families tried very hard to make the lives of their disabled family members better and acted as advocates in some cases. The literature reviewed in chapter 3 of this thesis also identified this. Overall it should be recognised that people close to a disabled person may experience the social effects of the disability label themselves and may therefore need support.

Impacts of Non-Disabled Sibling's Transition on Family Life

Participants expressed that their own transition to adulthood had some impact on their families. Some participants spoke about how moving out of the family home impacted on their families:

> 'Megan: like I mean I guess Ben was more disturbed at first, 'cause he didn't know what was going on and obviously changes in his routine and stuff but erm I was going to end up leaving for uni anyway… so it was kind of… yeah so it wasn't that bad.'

> 'Luke: and I think I've seen how much he relied on me since then … because it's things like… just things like he won't go to bed unless me or Laura (sister) is upstairs… so like that puts a lot more pressure on Laura because obviously now I'm not there…'

> 'Richard: I guess it was difficult for them [Richard's parents] to miss me and miss me being there... not to be the barrier between them but I could distract Tom sometimes, do you know what I mean?'

These quotes highlight that participants felt that the loss of their supportive role might have been difficult for their family to adjust to. They also thought the change of routine for their sibling with autism could have provided some discomfort. Overall the transition to adulthood for young people who have a sibling with autism or learning disabilities may cause difficulties for families as a support role for the family lessens. Some participants did not suggest that their transition to adulthood had a large impact on their families. This may be due to them having a small part to play in their sibling's support or that their parents and siblings had not mentioned the difficulties to them. For the young people who still live with their family, the transition to higher education may not have had much of an impact on family life.

As mentioned in chapter 3, Isaacson et al (2014) conducted two qualitative case studies of families in Australia where one sibling in the family has intellectual disabilities. One of the families commented that they did not want to place a burden of care on their other children. Rawson (2010) also found that some young people were not that involved in their sibling's support in young adulthood because their parents did not want them to have to take on the burden of extra responsibilities. Other studies have found that parents do not want their children without disabilities to be burdened with their sibling's care (Dillenburger and Mckerr, 2011; Bowey and McGlaughlin, 2007; Isaacson et al, 2014; Davys and Haigh, 2008). Overall, most young people in my study pursued their adult independent lives and their parents encouraged them to do this. This might be difficult for parents and young disabled people as they lose contact and support from their family member. However, some participants spoke about their sibling relationship improving when they moved out and their parents being happy and proud of their achievements in young adulthood. So, young people's transition to adulthood might have some positive effects on their families. Other participants mentioned that they did not really provide much support to

their sibling and parents, therefore their transition to adulthood might not have had a large impact on their families in terms of their support role. Overall, the transition to adulthood for young disabled people and their siblings may have positive or negative impacts on family life. It is important that support services are aware of these impacts and provide families with adequate information and support.

A life course perspective of the family recognises that the life events of one person in the family will impact on the family as a whole (Elder and Kirkpatrick Johnson, 2003). As mentioned in chapter 2, Hareven (1982) outlines that within the life cycle there is 'family time' and 'individual time'. 'Family time' refers to the timing of life course events within the family. The family moves through a life cycle and certain transitions mark changes in family relationships. 'Individual time' encompasses the points in a person's life cycle where they transition to new roles. 'Individual time' and 'family time' are interrelated and integrated, people's lives are often related to the collective family life, from childhood through to old age (Hareven, 1982: 7). These concepts of individual and family time are relevant to this study. The transition to adulthood for young disabled people and their siblings impacts on family life and causes changes in family relationships. In addition, young people may contribute varying levels of support to their brother or sister with autism and/or learning disabilities throughout their lifetimes. The support that participants provided in childhood, are providing now and plan to provide in the future will be explored in the next two chapters. Individual and family time may be particularly interrelated and dependent on one another in families where one child has autism and/or learning disabilities. This is because people with autism or learning disabilities may require more support from family members than other individuals throughout their life course. Family systems theory is also relevant to the findings of this study, Bowen argues that when there is a change in the functioning or wellbeing of one family member, this impacts on the family system as a whole (Bowen, 1974). This

theory focuses more on the emotional connection between family members. In my study, some participants expressed worry and concern about how their transition to adulthood impacted on the wellbeing of their siblings and parents. This highlights that some of the participants felt that their transition to adulthood impacted on the wellbeing of others in the family system.

Summary

This chapter has summarised and discussed the findings of the first of three themes identified from 10 interviews carried out with young people aged 18-24 who have a sibling with autism or learning disabilities. The first subtheme outlined participants thoughts relating to how their family have struggled with services during their disabled sibling's transition to adulthood. The second subtheme outlined how participants thought their disabled sibling's transition to adulthood has impacted on family life. The third and final subtheme explored participants' experiences relating to the ways in which they believe their transition to adulthood has impacted on family life. The findings in this chapter aimed to answer the second research objective, exploring young people's thoughts and experiences relating to how their transition to adulthood and their disabled sibling's transition to adulthood might impact on family life. Overall, the findings in this chapter highlight that the participants' transitions to adulthood are located in a family context. The transition to adulthood for participants and their siblings impact on one another and other family members. Theoretically, this illustrates the relevance of disability by association, family systems theory and life course theory.

Chapter 6 The Sibling Relationship

Introduction

This chapter will display the findings regarding participants' thoughts and experiences relating to their sibling relationship throughout the life course. Participants' views and experiences relating to the sibling relationship was a major theme identified in the data analysis. The findings will be displayed within each subtheme that was formulated within the main theme. The first subtheme discusses the care and support role that young people reported that they had for their sibling in their childhood and teenage years. The second subtheme considers the embarrassment and distance that young people said they felt towards their disabled sibling in their teenage years. The final subtheme outlines the ways in which young people talked about the ways in which the sibling relationship changed when they entered young adulthood. The findings displayed in each subtheme will also be discussed in relation to relevant literature and theory.

Support Role in Childhood and Teenage Years

Young people spoke about the support role that they had for their sibling whilst they were growing up:

> 'Luke: Yeah… I think it was really really good… I yeah I definitely… I feel like I was the sibling that like as the oldest I felt like I had some degree of responsibility, so we didn't have to do… I suppose major amounts stuff for him in the sense of like my mum was there but it was just always expected that we would do like erm like just like basic level care like just look after him like if my parents needed to go somewhere it would be expected that we would like go and like do like some sort of like babysitting I suppose but it's a bit different. Urm I feel like we didn't do anything of that sort of form like care wise til I was older'

> ‘Rebecca: I mean because obviously my mum had to work to pay the rent and everything and I sort of took on the role of big sister but also carer as well’

It is important to note that Rebecca’s sister has mild learning disabilities and mainly requires financial and social support. Therefore, Rebecca’s description of herself as a carer may not necessarily be related to her sister having learning disabilities. Mostly participants described supporting their parents with the care of their sibling but largely this was a secondary role. Participants also spoke about their parents protecting them from any major responsibilities.

Mothers were the primary carers in most families or shared the responsibilities with fathers. Participants spoke about helping their mum out with support:

> ‘Isaac: I think from about 14 I was attending meetings quite regularly with my mum, with social services and child services… ‘cause my dad works full time
> Me: mm
> Isaac: and I could fit things in around college and university life, fit it around school if I was lucky, so yeah’

> ‘Lucas: er I’d also go to his doctors meetings as well about statements, so I’d go with my mum ‘cause my dad wouldn’t be able go… erm and that would be just like discussing how he’s getting on and things like that… that’s the only really responsibilities… I think kind of really my mum’s done a lot in comparison to other people’

‘Megan: erm, so there would be times where I would look after him, like for example if my mum needed to go to the shop and things like that’

Owen: if anything got particularly bad and otherwise I don’t think I could particularly help in terms of like washing, in terms of helping him cook and things like that I was not the right age to provide proper support’
Me: mm
Owen: I don’t think my… I don’t think Liam [oldest sibling] particularly did either I think it was very much… I think my mum liked to look after him and my mum could look after him so she did’

‘Emma: so I never really had responsibility in that way but I did used to have to do like other bits for myself if my mum didn’t have the time and dad was out for work so just things just like making myself dinner or like making my pack up for school, things like that but yeah my parents have always been like so good ‘cause they just have like… tried to make everything like as easy as possible for me and I think they like have given up a lot to do that as well I would say like a lot of time and effort and things like that just trying to make sure that like Hannah gets all, like everything she can get like in the best possible and still allowing me to kind of have my own life as well as kind of… kind of not letting the fact that my sister is how she is kind of… define my life or take over… do you see what I mean?’

Emma outlines above that she had to take care of herself more because her parents were busy with her sister. Other studies have also found that young people may have to take more care of themselves or receive less attention from parents when they have a disabled sibling who requires a

high level of care (Pitten-Cate and Loots, 2000; Rossiter and Sharpe, 2001; Stoneman, 2005). Other participants mentioned supporting their sibling in their childhood and teenage years, however this support did not seem to extend beyond how any other young person may support their sibling. Young people whose sibling had higher support needs talked more about their practical support role, whereas participants whose sibling had milder needs focused more on the social support they provided. As mentioned above, some young people provided a secondary caring role for their sibling. In most cases, mothers were the primary carer for their disabled child. Jacobs and MacMahon (2016) conducted interviews with six siblings aged 16-22 with a brother or sister with learning disabilities living in a residential school. The participants spoke about helping their mothers care for their sibling and adopting a third parenting role for their sibling throughout childhood. Kao et al (2012) conducted qualitative interviews with children aged 8-14 who have a sibling with developmental disabilities and their parents. Some children said that their interaction with their peers was negatively affected by having a disabled sibling because they had to spend time caring for them. No participants in my study mentioned that their support role impacted negatively on their lives.

For many participants in my study, providing support to their sibling in childhood and adolescence was just normal. Woodgate et al (2016) carried out an ethnography with young people aged 7-25 who have a sibling with complex care needs to explore their participation in everyday life. They found that young people valued the role they had in their sibling's life, receiving support from their disabled sibling and giving support to them was an important aspect of their daily lives. Samson mentioned in his interview that his brother provides support to him. Mulroy et al (2008) found in their questionnaire study of parents of children with Down's Syndrome or Rett Syndrome that parents felt worried about the burden on their children without disabilities who assist with caring. Burke (2010) found in interviews, questionnaires and focus

groups with parents and siblings of disabled children that siblings shared caring tasks with their parents, young people did not see a problem with doing this but parents worried about the impact it might have on them. These studies highlight that young people may not view supporting their sibling as problematic but to parents this support may be viewed as a burden. The participants in my study may not have viewed their support role as a burden but just a normal part of their childhood. Overall most young people expressed that their parents (mainly their mothers) took on the primary caring role and protected them from having too much responsibility. However, some participants did take on a support role that extends beyond the level of support that any young person would provide for their sibling. The literature review in chapter 2 highlighted that sibling relationships throughout childhood can be supportive but can also involve conflict. This study found that when one sibling has disabilities, the sibling without disabilities may provide more support than what might be typical in any sibling relationship. As highlighted above, other research has also found this.

Distance and Embarrassment in Teenage Years

Like any other sibling relationship, participants spoke about some tension, distance and embarrassment in the sibling relationship during their teenage years. However, other people's judgements about their sibling's autism or learning disability seemed to amplify these experiences. Some participants talked about feelings of embarrassment in public:

> 'Richard: So I enjoyed Tom but some situations I would get slightly embarrassed with... if we're... most the time it would be talking to strangers but if it's family or friends I'd be OK with it but if we're in a shop and he got set off on not wanting the shoes he wanted I'd be like uh walk away and go look at some other clothes, that kind of thing.'

‘Richard: I am embarrassed to say that I’m embarrassed about him but I was growing up at the time kind of thing’

‘Megan: like, going out in public and things like that erm… most of the time me and my mum would just give up explaining to people like oh he has autism… like when we go out in public we get all these… kind of looks and it's kind of like… yeah ‘cause also yeah no there is a lot of embarrassment actually ‘cause I remember like when I was at my… erm 'cause the special needs school that my brother went to… they… like a lot of people from my school would like take the mick out of people that go there’

Other participants spoke about their sibling relationship becoming more distant in their teenage years:

‘Emma: ermm… I think… uhh… when I was a teenager especially but kind of all the way through school until I got to about probably like 18… I used to like… not want to tell people that like I had this sister... like I don’t know, I think I just used to be scared
Me: mm
Emma: about what people might have thought or said ‘cause it kind of seems kind of different to kind of… normal family and sib… do you see what I mean? Like normal siblings’

‘Owen: and then… I look back at it a bit and [sighs] what a dick [laughs] but you know it’s… I think it is a natural part of growing up and I think it was always difficult… just sort of… being around Matt ‘cause you don’t know the way that he’s going to react to your friends and stuff like that ‘cause he’ll go through this phase where he’ll just be [laughs slightly] like you know… when I brought my ex-girlfriend round erm you know he’d he’d hug her some days and

> say oh… start calling her his sister and then other days he'd actually tell her to f*** off so [laughs slightly]
> Me: mm
> Owen: so it's things with that it's… it's always difficult to judge… and when I was younger I was more conscious of that… I was more conscious that people would think about it and as I grew up I realised actually people don't care that much it's you know that's your brother and that's the life that you live'

Overall, some participants spoke about the sibling relationship becoming more distant in their teenage years and feeling embarrassed about having a disabled sibling. They spoke about the other people's reaction to their sibling's behaviour in public causing embarrassment. Emma spoke about hiding her sibling's disability from others. The term courtesy stigma was first coined by Goffman (1963) and can be understood as the stigma that a person may experience as a result of being close to a person with a stigmatising feature. People may be associated with the stigmatised person through choice or through social structures. Courtesy stigma has also been termed as 'stigma by association' (Byrne, 2001: 65). The sense of embarrassment experienced by some of the participants in my study can be recognised as a sign of stigma by association. Young people felt a sense of embarrassment because of their affiliation with their disabled sibling. Other studies have found that siblings may experience stigma by association in their childhood and teenage years. Welch et al (2012) used surveys with 239 parents and 84 siblings of disabled children who have used short break services in England. They found that short breaks allowed families to have a glimpse of a 'normal' family life, where they could go on outings without worrying about other people's reactions to their disabled child. One mother mentioned that her daughter without disabilities felt embarrassed when out with her disabled sibling as people stared when she squealed. This suggests that siblings of disabled children

may experience negative emotions as a result of the social stigma associated with disability.

Mulroy et al (2008) used surveys in Australia with 141 parents of girls with Rett syndrome and 186 parents of children with Down's syndrome. Parents reported that non-disabled siblings had experienced misunderstanding and insults from peers regarding them and their disabled sibling which had caused upset for them. Another parent commented that her daughter felt embarrassed by her brother's behaviour in public or when she was visited by friends. This study highlights that siblings may not only experience feelings of embarrassment to public reactions but may directly experience discrimination from others. Stalker and Connors (2004) conducted qualitative in-depth interviews with 24 siblings of disabled children in the UK. Five of the siblings in the sample reported being bullied at school because they had a disabled sibling. Mascha and Boucher (2006) conducted interviews with 14 siblings of young people with autism in the UK. They found that siblings were embarrassed about inviting their friends over to their house because their brother or sister's behaviour was different. Petalas et al (2009) interviewed 8 young people who have a brother with autism. They found that as a result of misunderstandings and negative attitudes from the wider public and friends that siblings felt embarrassed, anxious and angry. Some siblings decided not to talk to other people about their brother's autism. This suggests siblings may try to hide their association with their sibling.

In my study, Emma mentioned that she would hide that she had a sibling with autism from peers when she was younger. Other participants spoke about embarrassment when their sibling drew attention from others in public. Megan spoke about peers at her school making fun of disabled children. Some participants in my study suggested they had experienced stigma by association. Although some participants in my study spoke of

embarrassment and distance in teenage years, many participants also spoke fondly of the relationship with their sibling throughout childhood and adolescence. Some participants did not describe themselves as having a particularly close relationship with their sibling throughout their lives. Peter mentioned that he had a contentious relationship with his sibling Graham in earlier childhood and with his brother Adrian in his teenage years and present life. Overall, this highlights that every sibling relationship and family is different. The teenage years can be a time when young people are particularly self-conscious. Worries about what other people think may be heightened during these years and therefore young people might feel particularly embarrassed about having a disabled sibling around this time. Emma and Richard both stated that they cared less what people thought as they became young adults. Owen also mentioned above that as he grew up he gained more insight into other people's judgements. The literature review in chapter 2 illustrated that sibling relationships may become more distant in adolescence as young people's social circles widen. My study also found that some participants reported a distancing in the relationship with their disabled sibling as they became teenagers. However, young people experienced a unique sense of embarrassment about having a sibling with autism or learning disabilities during their teenage years, which in some cases led to a distancing in the sibling relationship. There was a sense of guilt expressed by some participants regarding this distancing. This suggests that people with a disabled sibling might feel more of a sense of duty to have a closer relationship with their sibling throughout the life course.

Changes to the Sibling Relationship in Young Adulthood

The transition to adulthood for both siblings caused changes in the sibling relationship. Luke talked about how moving out of the family home has impacted on the ways he can communicate with his brother:

> ‘Luke: I don’t, I feel like it’s a very artificial relationship in a sense of that and like he’s just got an ipod touch so he can like I message me erm so I’ll get probably... nearing a hundred messages a day’
> Me… wow…
> Luke: …just all the time and then they’re not conversations, so they’re just like emojis, or they’re like… I’m like ‘how was your day?’, he’s like ‘it’s fine’ and I’m like ‘oh what are you doing?’ and he’s like ‘nothing’ and I’m like, it’s quite hard then to initiate conversation… so… erm it’s a different form of relationship erm and holidays are really precious times erm because it means that I… especially for him and he finds it really really hard when I go back [referring to uni] erm and like when he’s at places that he has never really been without me’

Owen also mentioned the impacts of moving away from home on communication:

> Owen: erm but yeah no we do get on very well still erm I think he missed me ‘cause I’m in [university city] and he talks about that a lot, he talks about coming down a lot… which will probably never happen but it’s… he does call me every day to talk’

For both Owen and Luke, the sibling relationship is kept close by phone contact but the move away from home has caused some distance. They both seem to be struggling slightly with communicating regularly with their brothers and getting on with their own lives.

Generally, participants described an improvement in their sibling relationship as they transitioned to adulthood:

> ‘Emma: but then I got to a stage… It might have even been younger than 18, it might have been like the end of secondary

school when I had just like a really good group of friends where I just didn't really care any more

Me: mm

Emma: I used to tell them about her and then things like… things like when I used to have friends over like for I don't know birthdays or just coming round for the evening… like we used to just like, if Hannah wanted to like come and sit with us in whatever room we were in like we were fine with that'

'Richard: he's starting to grow up and I appreciate him more and do get less embarrassed of him because I'm an adult now, I'm a teacher so I understand it and I don't really mind what he gets up to as long as he's not abusive or threatening to anyone else it's fine.'

For some of the participants in my study, the transition to adulthood caused changes to the sibling relationship. Peter mentioned that the relationship with his brother Graham improved in his teenage years and into young adulthood. Peter mentioned that Graham's difficult behaviours associated with his Asperger's were worse in childhood. Peter said that the relationship with his brother Adrian became worse in his teenage years, partly because he saw Adrian's behaviour as becoming more aggressive. This highlights that behaviours that might be associated with autism might cause strain to the sibling relationship at different stages of the life course, particularly if behaviours that might be associated with autism become more pronounced at certain ages. Emma and Richard spoke about caring less about what people thought about them having a disabled sibling as they became young adults. Owen also mentioned that as he grew up he gained more insight into other people's judgements about his brother's disability.

Cridland et al (2016) conducted interviews with 11 girls aged 12-17 who have a younger brother with autism. They found that the sisters acted as protectors and advocates for their brothers at school. The sisters also reported that they felt they had more empathy and understanding towards their sibling compared to when they were younger because they now had a better understanding of autism. Ward et al (2016) conducted semi-structured interviews with 22 siblings of young people with autism. They found that younger siblings focused on the strengths of their sibling with autism and wished they could play with one another more. Adolescent siblings focused more on what they had learnt from earlier experiences and seemed more protective of their sibling compared to younger children. This highlights that as young people become older, they may gain more of an insight into disability and the effect of this on their sibling and family relationships. This insight might develop in later childhood, adolescence, early adulthood or later.

Some participants spoke about their relationship improving in young adulthood because they no longer lived in the same house as their sibling. Others communicated less with their sibling in young adulthood because they moved out or were busy with their education or work. Some participants mentioned difficulties with upholding a supportive role over the telephone. Others spoke about how it was particularly hard for their sibling and family when they moved out because they provided a support role. Jacobs and MacMahon (2016) conducted interviews with six siblings aged 16-22 with a brother or sister with learning disabilities living in a residential school. They found that some young adults wished they could have more contact with their sibling living at residential school but this was difficult or unrealistic because of their own commitments, such as friendships, school, travelling or work. Rawson (2010) conducted semi structured interviews with 13 young people aged 17-23 who have a brother or sister who attend a residential school for complex needs. Four siblings mentioned that they were closer with their sibling when they lived

in the same home. Six siblings said they had a high level of contact with their sibling and had regular input with the residential school and their sibling's support. Overall, the sibling relationship in young adulthood varied for each participant in my study. The sibling relationship in young adulthood seemed to be affected by how close participants were with their family, how close they were geographically to their sibling and whether they were still living in the family home.

The literature review in chapter 2 highlighted that sibling relationships change during the transition to adulthood. Sibling relationships often become more distant and conflict lessens. As young people become more independent, siblings may play a less important role in their lives. However, siblings may still play an important role in people's lives and act as sources of support and guidance during the transition to adulthood. Wider family dynamics may also impact on the sibling relationship during the transition to adulthood. Participants in my study also reported a distancing in the sibling relationship during the transition to adulthood, particularly if they had moved out of the family home. My study found that most participants provided a supportive role to their disabled sibling in young adulthood. For some this supportive role did go beyond what might be expected in any sibling relationship. My study also found that the sibling relationship in young adulthood seemed to be affected by how close participants were with their wider family. Some participants reported that they started appreciating their sibling more as they transitioned to young adulthood. As discussed above, other research has found that young people's support role for their disabled sibling may change in young adulthood. Other research has also found that young people may appreciate their sibling more as they grow and understand more about disability and difference.

As mentioned in chapter 2, Bronfenbrenner's (1979, 1986) ecological systems theory outlines that the microsystem is the smaller system of

everyday life, with the family included in this system. The mesosystem refers to networks in a person's local community. The exosystem relates to contexts that impact on individuals' lives but that they are not directly engaged with. The findings in this chapter fit well with ecological systems theory. For example, the findings in this chapter highlight that as siblings grow older, the meso system might impact on the sibling relationship. As young people interact more with other social circles in their teenage and young adult years, the sibling relationship may become more distant. However, as the microsystem of the family is reliant on their support, they may be more involved in this system compared to other young people. The wider societal attitudes and policies relating to disability in the exosystem may also impact on the sibling relationship. For example, the attitudes towards disability in wider society may have led to the embarrassment experienced by some young people in my study. Overall, this study has found that young people's sibling relationships are affected by other relationships in the micro, meso and exosystem.

Summary

This chapter discussed the findings relating to the major theme 'The sibling relationship'. The first subtheme summarised and discussed participants' descriptions of their support role for their disabled sibling in their childhood and teenage years. Another key finding displayed as a subtheme was that like many sibling relationships, there was increased tension and embarrassment in the teenage years. However, for some participants other people's judgement about their sibling's autism or learning disability seemed to amplify these experiences. The final subtheme outlined changes to the sibling relationship in young adulthood. The findings in this chapter aim to answer the first research objective of this study, to explore young people's experiences, thoughts and feelings relating to the relationship that they have with their sibling with autism or learning disabilities. Overall this chapter has highlighted that participants

described their sibling relationship throughout the life course in similar ways to the general literature relating to sibling relationship outlined in chapter 2. However, having a disabled sibling did seem to affect the sibling relationship in some ways. This chapter revealed that some participants provided care and support to their disabled sibling during childhood which went beyond what might be expected in any sibling relationship. Having a disabled sibling may also cause more embarrassment and distancing in the sibling relationship during adolescence. This chapter has also shown that most participants provide a supportive role to their disabled sibling in young adulthood. For some this supportive role does go beyond what might be expected in any sibling relationship.

Chapter 7: The Impacts of Having a Disabled Sibling on Young People's Transition to Adulthood

Introduction

As mentioned in chapter 2, the five markers of the transition to adulthood leaving education, entering the job market, leaving the family home, partnership formation and having children have all been delayed in recent decades. There is also more variety in when these transitions happen for young people. This study found that some participants had reached certain markers and others had not. Some had left home and then returned, some planned on having children and others had not planned for this. Some participants wanted to get married and others were unsure. The experiences of participants in this study regarding the timing and order of these transitions are similar to any other young person. Overall, having a disabled sibling did not seem to affect the timing and order of the transition to adulthood for most participants. However, having a disabled sibling did impact on young people's aspirations, thoughts and experiences relating to these markers of adulthood. This chapter will outline the main findings relating to the impacts that having a disabled sibling had on young people's experiences of transitioning to adulthood. These findings will be presented using the six subthemes identified within the final major theme. These findings will be compared and discussed in relation to relevant literature and theory.

Impacts on Moving out of the Family Home

Moving out of the family home can be viewed as a key transition to adult independence for young people. For some participants, experiences of moving out of the family home were affected by having a sibling with learning disabilities or autism. Luke talks about the sense of freedom he felt moving away from the family home, where daily schedules are affected by his brother's needs:

> ‘Me: and what was it like, when you moved out of the home like your family home for the first time?
> Luke: (laughs) really really weird erm just because like I think weird just on the basis that it was quite freeing, erm like my family is very restrictive in the sense of… like because we have to be… because of James so like everything we do as a family is meticulously planned of like we’re going to leave at this time, we will like get in the car at this time and like erm just things like, we don’t have to go to the same restaurants and we can just go ‘oh we’re just going to nip out for dinner tonight’ or ‘we’re just going to like go to the shops’, we don’t have to plan that in… erm was just really really odd [laughs] erm I didn’t like… I think I noticed how unusual my family life was’

Megan also talked about the restrictions she experienced when she was living in the family home. These restrictions became too much for her and she moved into her boyfriend’s family’s home when she was 16:

> ‘Megan: erm… well I don’t know… things were getting like… quite difficult at home because obviously… Ben needs a lot of attention he needs like routine and everything… so like me being 16… like I wanted to go out and like do stuff but my mum still needed the routine for my brother, so like she would set the same like kind of rules for him as for me because it was… because otherwise he would like… you know like… kick off about it, erm so it was kind of like a bit too much so then I was like oh I’m going to move out’

For Megan, the impact of the rules imposed by her mum regarding routine was very difficult and contributed to her moving away from the family home at a younger age than most young people do. Luke had framed his family’s strict routine as normal, moving out was an eye-opening experience for him as he discovered different ways of living.

Although moving to university is a freeing experience for many young people, for Luke this was particularly freeing as his brother's needs impact heavily on family routines. Luke also expressed difficulties associated with moving out:

> 'Luke:… at times and I think I found that quite hard, just because I was like, I'd rather just know what was going on and like… a lot of that is related to James in the sense of like… oh like we're having this issue or that issue and I wasn't being told and I feel like I'd always been in the position of knowing first kind of what was going on'

This highlights that although moving out was a freeing experience for Luke, he also felt left out from his brother's life and support. Luke did not like the feeling that he was in the dark about what his family was going through. Luke also mentioned that he chose to go to university close to his family home so he could easily visit home to support his family. Emma talked about her decision to attend university in her home County:

> 'Emma: yeah I've been here for like 6/7 years now so yeah it's not too far from home
> Me: mm
> Emma: which is kind of good if stuff does happen, I don't think it was like something that motivated me to choose here
> Me: yeah
> Emma: but maybe in the back of my mind it's like it was, I don't know like
> Me: mm
> Emma: I would hate to kind of like when the thing happened on my year abroad I did feel quite bad for not being… around and also things like when I finish here I don't know whether… I don't know whether I would want to live here or move away but I think

> Hannah would kind of be in the back of my mind in case anything did happen to my parents'

This highlights that Emma's desire to move away is conflicted with her sense of duty to her parents and sister. Emma also expressed guilt at being abroad when her sister came home from a respite service with bruises and her mum was alone when this happened because her dad was away working. Rebecca also talked about wanting to be close to her sister so she can provide support when she needs it:

> 'Rebecca: or Lily wouldn't be able to, she'd be able to come but she'd only be able to stay for... it would only be a weekend where she could come round, it can't really… where oh she's feeling upset well she can just come down the road to me now instead of having to be… instead of if I were to move away, 3,4 hours away… yes we've got the phone but… phone's not as good as actually being there and… helping her if she needs anything'

Lucas also mentioned his plans about where he might live in the future being affected by his brother:

> 'Lucas: erm… but sometimes, but yeah so… definitely [names MA university city] next year and then we'll see… I suppose it's about making a compromise really kind of… erm thinking of myself but also thinking what about Rowan in the future?'

For some participants, there was a conflict between where they wanted to live in the future and their feelings of obligation to their families. They need to consider their role in their sibling's future support as their parents grow older and how this might impact on where they live. Some young people did not move too far away from their siblings because they wanted to be close to their families in case they needed some support. One

participant, Megan moved out of the family home earlier than most because she struggled with the routines put in place in the family home for her brother with autism. Luke talked about a new sense of freedom when he moved out, the participants in Tozer et al's study also reported this (Tozer et al, 2013: 484). Emma talked about her guilt when moving abroad for a year and that she was not there when an incident happened with her sister and her family were struggling. Rawson (2010) also found that some young people wanted to move abroad in the future but that they were worried about how they might support their sibling with learning disabilities whilst living in another country. Tozer et al (2013) carried out interviews with adult siblings of people with autism plus learning disabilities. Some adults talked about feelings of guilt when they first moved away from their families. Other studies have also found that siblings may feel guilt for not helping their families more in adulthood (Davys et al, 2010; Rossetti and Hall, 2015). Some participants also spoke about having to consider where they might live in the future alongside their sibling's support needs. Generally, most participants moved out of the home when they attended university, got a job, some returned after university and some remained living at home during university. This follows the patterns of most young people, a varied trajectory of living situation shaped around university education (Stone et al, 2014). However, for some participants there were considerations and feelings experienced concerning this transition that someone without a disabled sibling might not experience. Some participants' decisions regarding their moving away from the family home were also directly influenced by having a disabled sibling. Overall this research has found that having a disabled sibling might impact on young people's transition of moving out of the family home.

Impacts on Planning for own Family Life

Two markers that are related to transitioning to adulthood are relationship formation and having children. In recent years throughout Western Europe, cohabitation outside of marriage has risen and the age of having children has increased (Kiernan, 2001; Billari and Liefbroer, 2010). Some participants spoke of marriage and having children as something they might want but had not planned for this yet. However, some participants had planned for this, partly because they have a disabled sibling. Luke and Lucas both spoke about having conversations with their current partners about their sibling living with them in the future:

> 'Luke: uhm so I've got a girlfriend who I've been with for about a year and a half uhm and we've had to have really difficult conversations of like I need to stay around this area… so like she's from down south… I like won't move down, further away like I can't really
> Me: mm
> Luke: I've been quite open about that and just being like yeah I would feel like I would have to have James in my care, so in the sense of like if like something happened to my parents… I would feel like I would have to have James living with me… uhm and that obviously has impacts for her as well… so [laughs slightly] those sort of things… she's been really fine about that, really great'

Having a disabled brother impacts on not only Luke's own life but on the life of his partner, as she will likely be involved in some way in James' support if she lives with Luke. Lucas also mentions talking to his partner about his brother living with them:

> ‘Lucas: erm but we’ll see, it depends on what my partner thinks at the time… she said I’m happy for him to live with us but it’s one thing saying it and then in reality’

For both Lucas and Luke, planning on how to cohabit with their partners in the future needs to be considered alongside the needs of their disabled sibling. Other participants mentioned that their partner would need to be accepting of their disabled sibling, otherwise they would not be with them. Emma was the only participant who mentioned that her own children might have autism:

> ‘Emma: but yeah… I don’t know whether… it probably is something I would have to think about though
> Me: mm
> Emma: like whether that like… like look into whether it would be a potential
> Me: mm
> Emma: not risk but something that might happen’

Owen spoke about how he thinks his experiences of growing up with a brother with learning disabilities will help him be a better dad when he has kids in the future:

> ‘Owen: mmhm yeah yeah I think, yeah I think I’d also make quite a good dad [laughs] you know… I think growing up with someone like Matt and having… you know having to explain yourself, having to… sort of control and you know erm tell off somebody that doesn’t quite understand is very much like having a child’

This highlights a positive impact of having a disabled sibling on family planning, young people may feel they have strong skills in support and care that are useful to parenting. As mentioned above, some participants

spoke about having to consider whether their sibling might need to live with them and their partners in the future and how this might be difficult. Tozer and Atkin (2015) found in their interviews with adults who have a sibling with learning disabilities plus autism that participants felt torn between supporting their siblings and their relationship commitments to partners and children. Some young people in my study were considering the ways they may have to balance these commitments in the future. Emma talked about how she has considered that her own children might have autism. Other studies have found that adults who have a disabled sibling worry about their own children having disabilities (Glasberg, 2000; Atkin and Tozer, 2011; Harland and Cuskelly, 2000; Guse and Harvey, 2010). Emma did not express worry or concern but the possibility of her children having autism is something she said she might need to consider if she decides she wants children. Interestingly Emma was the only participant who mentioned this. Perhaps because most participants saw having children as a far-off plan, perhaps they had not considered their children having autism or learning disabilities, or perhaps they did not want to discuss this. This mirrors the background literature on transitions, most young people saw having children as something a person does when they are further into adulthood.

Interestingly there were no gender differences regarding planning for families in the future. Some studies have identified that women plan for relationship formation and having children earlier than men (Roberts, 2011; Gordon et al, 2005; Oesterle et al, 2010; Kinlaw et al, 2015; Woodward et al, 2006). However other studies suggest that young men and women both plan for family formation at similar ages (Coyle et al, 2015; Willoughby, 2014; Hall and Willoughby, 2016). It is possible that young men in my study considered family planning more than their male peers might have done because their experiences of growing up with a disabled sibling have made them more caring and family orientated. It is also possible that the young men have considered their future family life

more because they are also planning for the role that they might play in their sibling's support in the future. More research is needed that considers the gendered experiences of young people who have a disabled sibling. Overall, this research has found that having a disabled sibling might impact on young people's plans for cohabitating with partners and having their own children.

Impacts on Occupation Choice

In recent decades, there has been an increased amount of young people attending university, contributing to delays in young people getting their first full time job (Ferri et al, 2003; Chevalier and Lindley, 2009; Kneale and Joshi, 2008). All young people in my study are either currently attending university or have done so and are now working full time. Several participants spoke about their choice of occupation being motivated by having a sibling with learning disabilities or autism. Isaac explains how his experiences of growing up with his brother have been beneficial to his career:

> 'Isaac: and people say that I was able to work with autistic kids a lot better than anyone else'

Richard is a teacher, he illustrated that growing up with a brother with learning disabilities and autism motivated him to choose this career:

> 'Richard: I mean I've got like so much time for the special needs children, maybe because of my brother
> Me: mm
> Richard: and the experience I've had of growing up and knowing him and that kind of stuff but I have so much time for any any child that has um said disabilities or learning disabilities or anything like that. I I love them to bits I care about them so much, I find them in

> the day and so how are you? How are you feeling? Have you got all your stuff today? Did you forget this? Have you got this? So, I think the natural thing in me of caring actually helped me towards teaching'

Luke mentioned that he plans to work with young people with learning disabilities and Rebecca works in a supported living environment with adults with learning disabilities. Rebecca and Luke did not say that their experiences with their sibling motivated them to choose these occupations. Even though they did not directly mention it, they may have become interested in this area because of their experiences of having a sibling with learning disabilities. Owen mentioned that his brother Liam (without disabilities) is becoming interested in a career in social care, Owen said he thought this might be because of his experience of growing up with Matt:

> 'Me: yeah I don't know with your brother with social care whether that's might be part of the motivation
> Owen: yeah I think it is'

Samson talked about potentially working in mental health support in communities after he has finished his sociology degree. Owen outlined how growing up with his brother with Down's syndrome contributed to his interest in history, the subject he studies at university:

> 'Owen: like I've always liked about history is the understanding part of it and like I think… like when I used to think about this I did used to put this directly on Matt and my experiences with Matt, like this trying to understand something that you can't quite relate to… somebody is sitting there with a totally different set of experiences to you 'cause the way Matt… not only the way Matt

takes in information but the way he puts out information is very very much different to a lot of people'

Owen has also done some volunteering at his brother's SEN school and has considered doing some volunteering with disabled children at university. Four participants did not express an interest in caring or humanitarian occupations, so having a disabled sibling does not mean that a person will follow this path. Marks et al (2005) conducted interviews with seven adults who have entered careers in special education and have a sibling with severe disabilities. They found that for all participants, their motivation for their career was partly due to their experiences of growing up with a disabled sibling. Burton and Parks (1994) compared the career aspirations of 30 young people with a disabled sibling and of 30 young people who do not have a disabled sibling. They found no significant differences in career aspirations. Tozer et al (2014) state that nearly all of the female siblings in their sample (the sample consisted of 14 women and 7 men) were in humanitarian profession like social care, teaching or nursing (Tozer et al, 2014: 298). However, it is important to note that women in general are more likely to be working in humanitarian careers (ONS, 2013c). All these studies contain small samples and therefore no sweeping generalisation can be made. Overall the findings of my study and other research suggests that having a disabled sibling might motivate young people to enter humanitarian careers. The skills and knowledge gained from having a disabled sibling may be particularly helpful in people professions. Some young people with disabled siblings may have other motivations for entering this type of career. Others may not want to enter this type of career at all.

Impacts on Skills for Independent Adult Life

The background literature relating to children who have a disabled sibling has identified that many children develop knowledge about disability and

skills such as communication and maturity because they have a disabled sibling (Petalas et al, 2009; Moyson and Roeyers, 2012; Mulroy et al, 2008). As mentioned above these skills can be beneficial for humanitarian occupations. These skills may also come in useful when young people have their own children. Some participants spoke about the skills that you can gain growing up with a sibling with autism or learning disabilities and how these are advantageous:

> 'Isaac: but every sibling I've ever met has been some of the happiest, joyful people you'll meet
> Me: mm
> Isaac: they just just enjoy helping their their brother or sister along… they'll do anything for them
> Me: mm
> Isaac: 'cause they know… I don't know what it is… I don't know if you're just mature [inaudible] or you get that independence quicker… deal with life as it comes along'

> 'Owen: I think certainly what I notice with siblings is like… you you tend to be able to spot them [laughs slightly] like you know people that know disabled people
> Me: mm
> Owen: and like largely I find that those are the people that is… the funniest and the most relaxed and you know that are sort of you know teacher material and head boy material, those sorts of… people that look like leaders tend to be'

These quotes highlight that some young people view themselves and other siblings as special because of the skills and experiences they have gained through having a disabled sibling. Megan discussed how the skills she has developed through growing up with her brother have been beneficial in her part-time job at an opticians:

> ‘Megan: erm and I feel like I talk to people differently and connect with people differently just because Ben has autism, just ‘cause… erm I don’t know it’s just like… I know what... how to deal with Ben so like if I had someone who’s like difficult or if like… I can spot the signs of autism like straight away like I can... if I’m talking to someone or like if I see someone in a shop or whatever I’ll be like oh they have some kind of autism, I can spot it, just because... just from being around Ben’

Emma talked about how having a sibling with autism has made her more politically aware and passionate about change:

> ‘Emma: and like when you like see first-hand the effect of certain policies like that they have on certain things and they know it’s like stuff that does directly affect my life and it does sometimes piss me off when people vote for things that only directly affect kind of their life but when you see like the way people are treated and the way that people… maybe not suffer but the way that… actually maybe suffer because people’s like… we do know a few people like family friends with autistic children who have a really shit time and like
>
> Me: mm
>
> Emma: get no help and get really desperate and when I see things like that it does kind of like motivate in other, like other parts of life to kind of… think about like… how crap like… how crap people can be to each other and how like much kind of unfairness there is and things like that, I think it has made me be a bit more like that’

Overall some participants mentioned that growing up with a disabled sibling helped them to develop a sense of independence and passion about life, gain knowledge about difference and acquire empathy and

communication skills. As mentioned above, the background literature relating to children who have a disabled sibling has identified that many children develop knowledge about disability and skills such as communication and maturity because they have a disabled sibling (Petalas et al, 2009; Moyson and Roeyers, 2012; Mulroy et al, 2008). This study has found that these skills and knowledge that develop in childhood are useful to young people in their adult lives. Overall this study has found that having a sibling with learning disabilities or autism can not only provide young people with the skills and experiences relevant to humanitarian occupations but also skills, knowledge and experience relevant to other aspects of their adult lives.

Impacts of Current Caring Role on Transition to Adulthood

Participants also spoke about their support role changing in young adulthood. The impacts of young people's current caring role on their lives varied. For participants who have moved away from home, their support role has generally lessened. Some young people spoke about the social support they provide for their sibling in young adulthood:

> 'Rebecca: erm… but yeah, it's more social support… she can, like I said she can wash pots, she can do all that sort of side of everything… erm but going out for dinner and stuff she's got to be with someone, she can't go to… say [specifies fast food restaurant] on her own and order her own food, she's got to have the support of someone being their 'cause she always thinks that she's not got enough money on her'

> 'Lucas: erm so we're going to see if he wants to go the London one [comic event] and I'll take him to the one in London but we'll see… 'cause it means getting a train and tubes… which is never kind of… he's been on a train before with me but tubes is something else…

and kind of busy London'

'Samson: so, it's that social and emotional thing which… err is the big thing that… that isolation… err that you know through health, through going for walks, through going for a… kind of… a cake or coffee or something like that, we're out in the social world and we're just sort of, you know… it does us both good to be honest I think really
Me: mm
Samson: erm and sometimes I think I almost… he provides me with support you know'

Samson's quote above highlights that the supportive relationship is not one way and that young people may receive support from their disabled sibling too.

Young people who still live close by to their sibling or in the same household seemed to provide more support. Richard talked about the support him and his parents provide for his brother:

'Richard: yeah, he does... he comes over... we do his washing because we can't trust him to, he can wash clothes but we can't trust him to you know dry them properly and iron them so we do that for him… and he comes around nearly every day, definitely every two days just to interact, what he's done, what he needs to find out with his... erm his life, his case 'cause you know with his son and other bits and bobs and his kind of claimants and what he gets from the council, money and stuff... So we do offer massive support so that's why he's around every single day.'

Isaac regularly supports his brother and is involved in negotiating with services regarding his care. Luke talked about the support he provides for

his brother when he visits home, he is currently attending university in the neighbouring city of his home:

> 'Luke: erm and it's just things like… erm making sure he's OK… like… so reading the signs when he's not OK… erm and just being like… erm and just doing things like, making sure he's in bed on time, like making sure his routine is the same… erm making sure that like that there's time he has that's like… erm yeah just making sure that… just things like cooking so like just making sure that he like if he wants to help you cook that it's like safe… so making sure that erm… so a lot of it's like… peremptory care like… making sure the knives are further away… making sure that you only use the back hobs… making sure that hot dishes go in the like sink to cool or whatever so it's… a lot of it is like… doing things to stop issues occurring'

Luke mentioned that he found it difficult moving away and being less knowledgeable about what is happening in his brother's life, particularly relating to his support needs. Most participants continued to provide support to their sibling in young adulthood. If they had moved away from home this support was more social support via telephone or internet communication or they would provide support when they visited home. Peter does not have a good relationship with his brother Adrian, he had a closer relationship with his brother Graham who killed himself. Peter did not talk about having a support role for his brothers, perhaps due to them not needing support because they do not have obvious support needs associated with their Asperger's and mental illness.

Overall most participants have small roles to play in their sibling's support and their parents, and mostly their mothers, have the primary caring role. In young adulthood, most participants still provide support to their sibling, however this was more likely to be social support using technology if they

had moved away from home. Young people talked about providing support and helping when they visited their family home. Participants who still live at home have a similar support role to when they were children. However, Luke and Isaac did mention that they took on more responsibilities for their sibling as they grew older. Rawson (2010) found when interviewing 13 young people aged 17-23 who have a sibling with learning disabilities that six participants were involved in supporting their siblings living in residential care. The other participants expressed that they were not that involved because their parents did not want their young lives to be burdened with responsibility. This mirrors the findings of my study, some participants mentioned that their parents protect them from having too much responsibility for their sibling's care. Most participants in my study expressed that they have secondary or little involvement in their sibling's support in young adulthood and their parents, and mostly their mothers, have the primary caring role. For some participants, the secondary caring role they provide does impact on their young adult lives. Some participants have not moved too far away from home so they can provide support. Others provide support and although they do not see this as a burden, they take on more responsibility supporting their family than other young people might do. This study has found that having a disabled sibling may impact on young people's transition to adulthood in that they provide more support to their sibling and family during this time compared to other young people.

In Rawson's study (2010), six young people said they had a high level of contact with their sibling and had regular input with the residential school and their sibling's support. Those who were not as involved said this was because their parents did not want them to have to take on the burden of extra responsibilities. Emma was the only participant in my study who openly expressed guilt about not being around more for her family in young adulthood. Luke mentioned how it was hard for him moving out of

the family home and being less involved in his brother's support. The results from other studies also suggest that young people might feel worried, confused or guilty as they want to focus on fulfilling their own goals but also support their family (Tozer et al, 2013; Davys et al, 2010; Rossetti and Hall, 2015). This highlights a contention between familialism and individualisation. Familialism is where the needs of the family are seen to be held in the highest esteem (Letablier, 2013). Individualism refers to the needs of the individual and their pathway being more important than family needs (Elias, 1991; Beck and Beck-Gernsheim, 2002). This contention may be present for all young people when they are transitioning to adulthood. However, for young people who have a disabled sibling, the contention may be particularly pertinent because their sibling requires extra support from the family.

Impacts of Potential Future Care Role

I asked participants about how they might be involved in their sibling's future. Most participants spoke about their plans to take on a more primary supportive role as their parents grow older. Luke talked about his expectation that he will be the future primary carer for his brother:

> 'Luke: I don't see James being able to live on his own
> Me: mmm
> Luke: ever. I don't really ever see him be able to live in a home or anything… uhm so I feel like yeah… it'll highly possibly be that he will live with me. Or my sister.
> Me: mmm
> Luke: depending on who was in a better situation but I feel like I would always instinctively feel like I should'

Isaac also described his plans to take on the primary support role for his brother:

Isaac: they know… like I've always told mum I don't come to these meetings just to support you 'cause I feel like I've got to, I do it 'cause… we're all family and I love you and Harry

Me: mm

Isaac: and that's why I do it and when it comes down to me being the main responsibility, it's fine

Me: mm

Isaac: I'm ready for it… it doesn't faze me or worry me or make me anxious'

Both Isaac and Luke are quite certain that they will have a large role to play in their brothers' future support. Luke has sat down with his parents and spoke about the family's plans if anything happens to Luke's parents. Isaac said his family do not need to plan as they all just know he will take over his brother's support. For Luke, there was still some uncertainty whether it would be him or his sister who would be caring for his brother. Owen expressed that he will probably take on legal guardianship for his brother but this might be shared with his other brother who does not have disabilities:

'Owen: I think it will work out they'll… that in and around the same time I think so I don't know how involved I'll have to be

Me: mm

Owen: certainly with how independent he's been and the fact that we've got him in permanent, long term social care

Me: yeah

Owen: I'll certainly be responsible for it but I don't know if I'll have to be too active in it

Me: mm

Owen: but but I am quite prepared to be active in it, it's not… it's not something that I want to avoid but it's something that I don't think I'll have to do

Me: yeah

Owen: [inaudible]

Me: yeah, it's interesting erm that you've sort of got the guardianship… how was that sort of negotiated? Rather than like your brother say?

Owen: I don't really… yeah I don't really know… I think with my parents it's going to be shared between me and Liam'

Owen seems quite certain that he will take on more responsibility for his brother as he grows older, however there is some uncertainty about what this role will be and how it will be shared with his brother Liam. Lucas also illustrated that he is certain he will take on primary responsibility for his brother as he grows older, however he is uncertain what the role might be:

'Lucas: there's sort of been a conversation about what's going happen… it was quite morbid… but my parents were like you know like… where is Rowan going to live if we like pass away or whatever… erm so there's kind of the assumption that he'll either live with me erm or they'll figure out some kind of like communal living… which is quite common I think

Me: mm

Lucas: erm but we'll see, it depends on what my partner thinks at the time… she said I'm happy for him to live with us but it's one thing saying it and then in reality… erm'

Many participants seem sure that they will support their sibling more as their parents grow older, however there does seem to be a lot of uncertainty about what this might involve and how it might impact on their lives. Other participants have considered their support role in their sibling's future but there has not been a conversation about this with their

parents. Emma seemed very uncertain and slightly worried about what her role might be:

> ‘Emma: yeah, it’s a strange one and then if anything… I don’t know it sounds really awful but if anything was to happen to my parents I also like don’t really know what would happen
> Me: mm
> Emma: which is bad but I should probably actually speak to them about this just in general ‘cause like I probably will help them more resp… like… yeah
> Me: have you thought much about that? Sort of like in the future and your responsibilities?... potential
> Emma: erm… a little but not loads which is probably also quite bad… like I would always be there for her
> Me: mm
> Emma: but I also… uh this sounds really bad… I don’t know if I’d be able to like care for her in the same way as my parents do’

Understandably Emma was worried about whether she could handle the responsibility of being a full-time carer. I also asked Megan about her potential support role:

> ‘Me: erm what do you think might be expected of you in relation to his support in the future?
> Megan: erm… I don’t know kind of like the same as what I was saying like erm… just like looking after him and… [speaks quietly] every so often yeah… I don’t really know [inaudible, laughs slightly], yeah.’

Megan seemed uncomfortable and uncertain about her potential future role. She perhaps was anxious about this or had not yet considered what might be expected of her in the future. Samson talked about the

uncertainty felt in his family regarding the potential independence of his brother with autism. I asked him about his potential future support role:

> 'Samson: erm just an unconditional I will do my best to help in any way that I can
> Me: mm
> Samson: erm… but I've not thought through the practicalities of it… erm I guess 'cause I've been so you know sleep walking or just focused on my tasks that I've had erm
> Me: mm
> Samson: and err… yeah not thought about it'

Samson has not thought about his future support role, perhaps because his brother does not have high support needs. The other participants who had siblings with milder needs had also not really thought about their future support role, probably because their siblings could live relatively independent lives with low levels of support. Overall many participants are willing to support their sibling in the future, however for some there seems to be some uncertainty and anxiety surrounding this future support role. This potential future caring role therefore impacted on young people's current lives as some were already planning their own futures around the needs of their siblings. Others were worried or uncertain about their future roles which might have caused some anxiety for them.

When considering future caring responsibilities, many participants expressed a willingness to take on more of a primary support role as their parents grow older, others were more reluctant or seemed uncertain about how they might be involved in their sibling's future. Most participants did say that they would help their sibling in any way they can. Peter, who does not get on with his brother did not mention being involved in his brother's future. This highlights that not all siblings are necessarily willing to provide support to one another. Some young people

had made specific plans with their parents, others had had had discussions but the needs of their sibling in the future were unclear. Research studies that have explored the experiences of older adults who have a disabled sibling have found that planning within families about the potential support role of siblings in the future is varied, with some agreeing concrete plans about future care, some discussing the future ambivalently and others avoiding the subject. Dillenburger and Mckerr (2011) found in interviews with 29 older parents/caregivers of 27 people with developmental or intellectual disabilities that some participants spoke about not wanting to burden their other children with caring responsibilities, others had made plans that their other children would take on the primary caring responsibility. Bowey and McGlaughlin (2007) conducted interviews and questionnaires with older carers of 62 adults with learning disabilities. Some participants had made concrete plans with their non-disabled children about them providing care, others did not want to burden their children. Some wanted their non-disabled children to live with their disabled sibling, others wanted their son or daughter to go into residential care. These studies mirror my findings, some participants spoke about their parents preferring residential care and others preferring family care.

Davys et al (2010) received 21 questionnaires responses from siblings of adults with learning disabilities, they found that for 12 participants a full discussion regarding future support planning had been discussed between parents and non-disabled siblings, 7 participants reported no discussion had taken place and 2 were not sure. Davys et al (2015) discuss findings from an interview study conducted with 15 adults who have a sibling with learning disabilities. They found that future support planning varied across the families and that these plans lacked details or clarity. They found that the rationale for lack of planning varied also, some participants spoke about being unsure about their future lives and if they would be able to provide support, some participants said they just react to situations when

they come, others said lack of support and information from services meant they could not plan and others assumed someone else would take on the primary caring role. Some participants in my study mentioned uncertainty relating to the future which meant they could not really plan for their potential support role. Others said they just take things as they come in life. No participants in my study mentioned talking with support services about their future roles.

Taggart et al (2012) distributed questionnaires and conducted interviews with family carers of adults with learning disabilities. They found that some older parent carers wanted their son or daughter with intellectual disabilities to live with one of their siblings and others preferred the prospect of residential care. Some had made plans with their children regarding this and others had not. Some parents mentioned that they did not want to burden their non-disabled children with the care of their disabled son or daughter so they wanted them to eventually move to residential care. Some non-disabled siblings had already agreed to care for their brother or sister and were living in their parents' home to help support them or their sibling had moved into their home. Again, these findings mirror my own, planning for caring in the future was very varied. What is clear from my own and other people's research is that as parents grow older, siblings will potentially be the primary carers. Planning for this eventuality is unclear and anxiety provoking for some and for others there is a more of a clear plan.

Rawson (2010) found in her study that most participants did not feel prepared for their potential responsibilities in the future when their parents might lose capacity to care. A lack of futures planning for the family, knowledge about services and their potential future roles were identified by the participants. Participants also reported concern and uncertainty about the transition from child to adult services for their sibling. These findings mirror some of the feelings of uncertainty about

the future expressed by participants in my study. As mentioned in chapter 5, young people in my study also expressed concern when their sibling transitioned from children to adult services. Jacobs and MacMahon (2016) found in their interview study with six young people aged 16-22 who have a sibling with intellectual disabilities living in residential care that 5 participants had signed guardianship agreements. Most participants said they felt confident in visiting their sibling in residential care and with caring but felt unsure about communication with care professionals. All participants wanted their sibling to stay in supported living and all expressed concerns about future placements being appropriate for their sibling's further development.

In my study, only Isaac, Richard and Owen's siblings were in residential care, supported living or living independently. These participants did not express worry or anxiety about their future roles. Isaac and Owen were confident they would be responsible for their sibling in the future. Richard did not talk much about his future role, just that he would support his brother in any way he could. For these participants, their sibling had already moved out independently from the home so they perhaps felt that they could predict how their sibling's support needs might be managed in the future. For the other participants whose siblings lived at home, the future was perhaps less certain. Luke seemed certain his brother would live with him, he was accepting of this but acknowledged the ways this might impact on his life. For Lucas, Emma, Samson and Megan there was uncertainty about where their siblings might live in the future and what their roles might be. For Rebecca and Peter, their siblings were likely to be able to live independently and they did not express worries about the future, probably because their sibling will not need that much support. Owen and Luke both mentioned official documents they signed or might sign relating to their siblings' future care, no other participants mentioned this. Overall, this study found that the prospect of their potential primary caring role impacted on some young people's

current lives and plans for the future. More research is needed to explore the views of young adult siblings regarding their future roles and how services might support them and their families.

Summary

This chapter has outlined the findings relating to the third research objective of this study, to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to key markers of the transition to adulthood, such as: 1. Moving out of the family home; 2. Leaving compulsory education; 3. Choice of occupation; 4. Relationship and family formation. This research found several impacts on young people's transition to adulthood relating to having a disabled sibling. Young people expressed that having a disabled sibling impacted on their thoughts, aspirations and experiences relating to moving out of the family home, family planning and occupation choice. Having a disabled sibling also provided some young people with useful skills for living an independent adult life. For some participants, their current caring role for their disabled sibling impacted on their lives. The potential future support role that young people may take on for their disabled sibling as their parents grow older impacted on the current lives of participants and their future plans. Most young people in my study expressed that they could gain the adult independence they wanted but considerations of their sibling's and family's needs did need to be taken into account. Young people had secondary support roles so the impact on their lives was minimal. However, they were aware that as they and their parents grow older, having a disabled sibling might have more of an impact on their lives.

Chapter 8: Conclusion

Answering the overall aim and research objectives

The overall aim of this research was to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. Three research objectives were set to answer this overall research aim. I will discuss below how and to what extent I have been able to meet the research objectives.

1. To explore young people's experiences, thoughts and feelings relating to the relationship that they have with their sibling with autism or learning disabilities.

The findings that directly relate to this research objective are located in chapter 6 of this thesis. In chapter 2, literature relating to sibling relationships across the life course was considered. This literature highlighted that throughout the life course, siblings may play an important role in a person's life. Siblings are often a similar in age family member that can help an individual develop and learn. This research found that some participants provide care and support to their disabled sibling which goes beyond what might be expected in any sibling relationship. This suggests that having a disabled sibling might encourage young people to provide more of a supportive sibling role. This also confirms findings from wider research, that young people may take on a secondary caring role for their disabled sibling. The literature in chapter 2 also highlights that sibling relationships generally become more distant as young people become teenagers. Participants in my study also reported a distancing from their sibling as they became teenagers. Some participants also reported heightened experiences of embarrassment about having a disabled sibling during this time. This suggests that one sibling having disabilities might cause more distance in the sibling relationship in adolescence because there is heightened embarrassment. Other studies have also found that

having a disabled sibling might cause heightened embarrassment for young people. There was a sense of guilt expressed by some participants regarding the distancing experienced during adolescence. This suggests that people with a disabled sibling might feel more of a sense of duty to have a closer relationship with their sibling throughout the life course.

Focusing specifically on young adulthood, the literature review highlighted that sibling relationships often become more distant and conflict lessens. Participants in my study reported this too, particularly if they had moved out of the family home. The literature review in chapter 2 also illustrated that siblings may still play an important supportive role in young adulthood. My study found that most participants provided a supportive role to their disabled sibling in young adulthood. For some this supportive role did go beyond what might be expected in any sibling relationship. Previous research discussed in chapter 6 also highlighted that young people may provide a supportive role to their disabled sibling during young adulthood. However, the research suggests this supportive role is affected by the move to independence for young people and their disabled sibling. Some participants in my study reported that they started appreciating their sibling more as they transitioned to young adulthood and their understanding about disability developed. As highlighted in chapter 6, other research has also found that young people may appreciate their sibling more as they grow and understand more about disability and difference. The literature review in chapter 2 suggests that changes throughout middle to later adulthood may affect the level of support that siblings provide for one another and the closeness of the sibling relationship. My study found that some participants were faced with the prospect of becoming the primary carer for their disabled sibling as their parents grow older. These findings are located in chapter 7 of this thesis. This highlights that individuals may have to provide increasing support to their disabled sibling throughout middle adulthood and into

older age. This may mean the sibling relationship becomes closer but might also cause conflict because of increasing care pressures.

The overall aim of this research was to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. This research has shown that the sibling relationship is entwined with young people's experiences of transitioning to adulthood and that the sibling relationship often changes around this time. Young people's experiences of their sibling relationship were affected by their sibling having a disability. However, the way the sibling relationship evolved for the participants from childhood to young adulthood was similar to the ways in which sibling relationships evolve where neither sibling has disabilities. This suggests that having a disabled sibling does not necessarily have a large impact on the ways in which the sibling relationship evolves earlier in the life course. However, this research has found that as participants grow older, they may need to take on a primary caring role for their sibling in middle to late adulthood which does signify a different sibling relationship dynamic compared to sibling relationships where neither sibling has disabilities. Overall the first research objective helped to answer the overall research aim as the findings provide important context to how changes in the sibling relationship impact on young people's experiences of transitioning to adulthood when they have a disabled sibling.

2. To explore young people's thoughts and experiences relating to how their transition to adulthood and their disabled sibling's transition to adulthood might impact on family life.

This study found that a lack of appropriate support from services when their disabled sibling transitioned to adulthood had an impact on some participants. Several participants reported concern about the stress and

anxiety their parents, and particularly their mothers, experienced around this time. This study also found that some participants thought that the move to independence for their disabled sibling had positive impacts on their family life. For example, there was less pressure on parents to provide care. However, for other participants, their sibling's transition to adulthood caused uncertainty and worry for them and their families. This was particularly linked with uncertainty about where their disabled sibling might live in the future and how they might manage their own safety. These findings highlight that family members of disabled people may experience disability by association. Some participants in my study suggested that the social effects of disability had an impact on their lives and on their parents' lives as their sibling transitioned to adulthood.

This study also found that participants expressed that their own transition to adulthood had impacts on their family's life. For some participants, their move from the family home caused disruption to their family's routines, which was particularly difficult for their sibling with autism. Some participants expressed that their families found it difficult when they moved out of the family home because there was a loss of a supportive role in the household. The findings in chapter 5 suggest that some participants thought their transition to adulthood and the transition to adulthood for their disabled sibling did have an impact on family life. However, some of the participants did not discuss how their transition and their disabled sibling's transition impacted on family life in their interviews, or only briefly discussed them. This could have been because I did not effectively prompt interviewees, or some interviewees may have felt there was not a big enough impact to discuss this matter. Participants whose siblings had lower care needs also talked about these impacts less, suggesting that having a sibling with higher care needs might have more of an impact on young people's thoughts about how their transition to adulthood and their disabled sibling's transition to adulthood impacts on family life.

The overall aim of this research was to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. The second research objective aimed to find out how participants thought their transition to adulthood and the transition to adulthood for their disabled sibling impacted on family life. I predicted this would be linked to young people's own experiences and aspirations relating to their transition to adulthood. Overall participants did seem to worry about their families as they transitioned to adulthood and as their disabled sibling transitioned to adulthood. This did affect some young people's experiences and aspirations. Some participants did not move too far away from their families because of the difficulties associated with the care and support for their sibling meant they wanted to be close by to support their family. Others felt guilty as they focused on their own independent adult lives and the support and care role fell more heavily on other family members. Some participants experienced worry about their families coping with the transition to adulthood for their disabled sibling. Some participants spoke about the positive aspects of their disabled sibling transitioning to adulthood on their own lives and the lives of their families. These findings suggest that the second research objective helped to explore how having a sibling with disabilities can impact on young people's experiences of transitioning to adulthood in positive and negative ways. However, most young people in the study spoke about being able to pursue their individual goals and aspirations which suggests that having a disabled sibling might affect young people's experiences whilst transitioning to adulthood but that this does not necessarily disadvantage them when pursuing their goals.

3. To explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to key markers of the transition to adulthood,

such as: 1. Moving out of the family home; 2. Leaving compulsory education; 3. Choice of occupation; 4. Relationship and family formation.

This study found that some participants did not move too far away from their family home because of their disabled sibling's needs. One participant moved out of the family home at 16 because the routines imposed by her mother to support her brother became too much. One participant expressed that they felt guilt when they moved abroad for a year because they could not be around if their family needed support. Some participants needed to consider where they would live in the future so they could support their sibling if needs be. Overall, young people followed similar trajectories to any other young person, most moved out when they went to university, some stayed at home to save money, some moved home after university and some moved out when they got a job. However, having a disabled sibling did affect young people's choices about where they moved to. Others had thought about where they might live in the future if they were to take on a more primary caring role for their sibling.

Having a disabled sibling also impacted on young people's relationship formation. Some participants mentioned that they only want to have partners who are understanding of their sibling's disability. One participant mentioned that if she decides she wants children, she might need to find out more about genetics and autism when planning for this. As discussed in chapter 7, other research studies have identified that some adult siblings worry about their own children having disabilities. This study also found that some young people were motivated to choose humanitarian occupations because of the experiences they have had growing up with a disabled sibling. Other participants mentioned that the skills and knowledge acquired from growing up with their sibling have been useful in their adult lives. This study also found that current caring

roles for their disabled sibling had an impact on young people's lives. Participants' potential future caring roles for their siblings also had an impact on how they were planning for their future.

This study found that participants did not have a primary caring role for their sibling. However, some were aware that as their parents grow older, they may have to take on a primary role and having a disabled sibling might have more of an impact on their lives. Other studies with young adult siblings have identified that young people are considering their future roles at this point in their life course. Some participants were uncertain about their future roles, others were confident about how they would be involved in their sibling's future care. This potential future caring role impacted on young people's plans for the future. Some did not want to move too far away from their families, others had spoken to their partners about their future roles. Others knew that they would have to factor this role into their future but were unsure of how they might negotiate this. Most participants talked about how having a disabled sibling impacted on their transition to adulthood. However, some did not discuss this at length and Peter did not discuss this at all. Participants whose siblings did not require as much support and care from others discussed the impacts less. This suggests that having a disabled sibling may have more of an impact young people's experiences of transitioning to adulthood when their sibling has higher care needs.

Overall, this study aimed to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. The third research objective focused on exploring young people's thoughts, experiences and aspirations relating to key markers of the transition to adulthood, such as: 1. Moving out of the family home; 2. Leaving compulsory education; 3. Choice of occupation; 4. Relationship and family formation. This study found that having a disabled sibling did impact on

most participant's aspirations, thoughts and experiences relating to the key markers linked to the transition to adulthood. No other study has specifically focused on how having a disabled sibling might impact on young people's experiences relating to their transition to adulthood. The third research objective seemed to draw a lot of interesting and relevant findings. This research objective was the most effective in answering the overall research aim. The first and second research objectives helped to provide context regarding young people's sibling relationships and family life as they transitioned to adulthood. In hindsight it might have been more effective to have one research objective that focused on context and an additional objective that focused on futures planning as this came out as a dominant issue in my discussions with participants. Overall this research has answered the research aim and displayed the associated findings, having a sibling with learning disabilities or autism does impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood. However, there were limitations to the study and the research aim could have been met more robustly. These limitations are discussed in the section below.

Limitations of the Study

One limitation of this research is the small sample size. The results of this study do not represent the population of young adult siblings. However, the results do provide some useful insight and might display findings that are relevant to other young adults who have a disabled sibling. The results of this study can also be used to inform future research studies with larger samples. Another limitation of this study is that only two participants have a sibling with learning disabilities only. All the other participants have a sibling with autism or autism and learning disabilities. This meant that comparison between the experiences of siblings of people with learning disabilities and the experiences of people with autism was limited. However other studies have compared the experiences of young people

who have a sibling with autism or learning disables (Knott et al, 1995; Pollard et al, 2013; Kaminsky and Dewey, 2001; Orsmond and Seltzer, 2007; Hodapp and Urbano, 2007). The disproportionate number of perspectives of people who have a sibling with autism means that the findings might be more representative of people who have a sibling with autism. Young people's siblings had a wide variety of support needs, some having very few needs and others needing full-time care. This difference in support needs provided some interesting comparisons. However, the young people whose siblings had much milder support needs did not talk as much about how having a disabled sibling impacts on their lives and their interviews yielded much fewer results. Therefore, focusing on young people whose siblings have higher support needs only might have produced more rich data.

Another limitation of this study is that the gender composition of participants was unequal with 70% being men. However, a positive aspect of this is that the other three studies that have explored the experiences of siblings in young adulthood have had more female participants than male participants (Tozer et al, 2013; Rawson, 2010; Jacobs and Macmahon, 2016). Matters of ethnicity and social class were also not addressed in this study. All participants had attended or were attending university, this means that the results may only be relevant to young people who have attended university. During data analysis, this study mainly focused on descriptive content in the transcripts. This means that linguistic, theoretical and conceptual findings that are relevant may not have been identified. My inexperience of analysing data meant I felt more confident analysing the descriptive aspects of the findings. In addition, focusing on the participants descriptions meant I focused on their aspirations, thoughts and experiences rather than becoming overly involved in my interpretation of the data (Smith et al, 2009). I did not seek validation from participants regarding their transcripts or the findings, seeking this feedback might have validated my findings (Yardley, 2008).

However, the time limitations of the study made this difficult, also the questions and discussion were sensitive in nature and it might have been difficult for participants to read back their transcripts. Overall this study does have limitations, however these limitations are justified considering that this was a small scale, exploratory qualitative study completed by a novice researcher.

Implications for Practice and Theory

Young people in this study and other studies worried about the transition from children to adult services for their disabled sibling. Local authorities and health and social care providers need to consider a whole family approach during this time. More funding needs to be channelled to improve the quality of transition services. Lack of appropriate provision for young disabled people and advice and support for them and their families can cause significant stress, uncertainty and anxiety. Family members, including siblings, should also be able to access support and advice regarding their roles during the transition to adulthood for their disabled relative. Of particular relevance to siblings of young disabled people is their potential future support roles. Social services should offer siblings advice and support families to plan for the future, providing this is what the families want. Young people who have a disabled sibling might struggle with difficult feelings and decisions relating to balancing their transition to adulthood and supporting their family. Services that offer support and advice to siblings of disabled people, such as the charity Sibs and sibling support groups run by charities need funding and research attention. Specific support groups and advice/support services could be aimed at young adults, as they might have different needs compared to children, adolescents or older adults who have a disabled sibling. This would mean that young people who have a disabled sibling can access information, advice and support that is specifically relevant to them.

Theoretically, this research has found that families of disabled people, including siblings, may experience 'disability by association' (Burke, 2010). Participants expressed that their families have been affected by disability, such as their family experiencing stress because of inadequate support from services. Some young people in the study also experienced stigma by association (Goffman, 1963; Byrne, 2001), they felt shame because of their association with their disabled sibling. Most participants resisted this stigma, particularly as they grew older and gained more insight into their sibling's disability. Overall, this research has confirmed the findings of other studies, that siblings of disabled people may experience disability or stigma by association. For young people in this study the contention between familialism and individualism was particularly apparent. This contention may be more problematic for young people who have a disabled sibling compared to other young people because their families may require more support from them. Ecological systems theory is also relevant to this study, this study found that young people's sibling relationships are affected by other relationships in the micro, meso and exosystem (Bronfenbrenner, 1979, 1986). Finally, this thesis identified that young people discussed how their transition to adulthood impacted on the lives of their siblings and parents. This relates to family systems theory and the life course perspective which outline that changes in people's lives impact on one another, particularly at points of transition.

Potential Future Research

Future research studies might apply a longitudinal methodology so that a whole life course perspective can be applied to explore siblings' experiences. More research needs to focus on life course transitions for siblings of disabled people. A large gap in this research area is gaining the perspectives of disabled people themselves regarding their sibling relationship and future support planning. Future research needs to

include the voices of disabled people, alongside their parents and siblings. Another key area for future research is considering how families from different ethnic backgrounds might manage the transition to adulthood when one sibling has disabilities. Future research needs to focus on evaluating service provision for families during the transition to adulthood for young disabled people. More research needs to focus on the specific experiences of young adults who have a disabled sibling. Larger research studies using both qualitative and quantitative methods need to be conducted so that the research findings from existing small qualitative studies can be examined on a wider scale. Finally, more research needs to focus on how families and services negotiate the roles of siblings in future care and support planning.

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Appendices

Appendix 1: Invitation to Interview Poster

What are young people's experiences of transitioning to adulthood when they have a sibling with learning disabilities or autism?

I am a Sociology PhD student at the University of Nottingham undertaking a research project that aims to explore how young people who have a sibling with learning disabilities or autism experience their transition to adulthood.
I would like to invite young people aged 17-24 who have a sibling with learning disabilities or autism to take part in the study. **The study will involve in-depth interviews, lasting around one hour.**

To be involved in the study you must:

- Have a sibling with learning disabilities and/or autism. Your sibling must have high support needs. High support needs means that a person needs support from other people to function in their day to day lives. The British Institute of Learning Disabilities defines learning disability as 'a general term that refers to individuals who find it harder to learn, understand and communicate. Other terms that are used to describe an individual's situation include complex needs or high support needs'. The NHS defines autism as: 'a condition that affects social interaction, communication, interests and behaviour.'
- Be aged 17-24.
- Not have a learning disability or autism yourself.

If you are interested in taking part or if you would like further details, please contact me by email: Georgia.Todd@nottingham.ac.uk

Thank you.

Appendix 2: Participant Information Sheet

University of Nottingham,
School of Sociology and Social Policy
Law and Social Sciences Building
NG7 2RD

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Information Sheet

Background

My name is Georgia Todd, I am a sociology student and I would like to invite you to take part in a study about how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to their transition to adulthood.

The research aims to explore what people's experiences, thoughts and feelings are relating to the relationship that they have with their sibling with learning disabilities or autism in young adulthood. The research also aims to explore how having a sibling with learning disabilities or autism might impact on young people's thoughts, experiences and aspirations relating to key markers of the transition to adulthood, examples of key markers are: moving out of the family home, leaving compulsory education, choice of occupation and relationship/family formation. This study hopes to make a contribution to research about siblings of people with learning disabilities and autism. This research helps to highlight common experiences of siblings of people with learning disabilities and autism, raise awareness of the potential needs of people with learning disabilities/autism and their families and inform health and social care providers about working with families.

To help you decide if you would like to take part, this sheet gives you some information about the study. Please feel free to ask any questions after reading this sheet.

What does taking part in the study involve?

This study will involve us having a conversation, you will do most of the talking and my role as the researcher will be to ask questions. I will ask questions about the relationship you have with your sibling with learning disabilities or autism, your thoughts about becoming an adult and your wishes and hopes for the future. With your consent, the interview will be recorded with a voice recorder and I will analyse what has been said in the interviews. This will be done by finding and thinking about 'themes', which are concepts or ideas that are relevant to the research aims. I will type up (transcribe) our recorded conversation and go through the transcript to find themes. I will compare the themes identified in our

conversation with the themes I find in interviews with other participants. Eventually I will identify a set of themes that link across all the different conversations I have with people. The interview will last for approximately one hour. I am the only person who will be conducting interviews and analysing the audio data. I am supervised by two members of staff from the University who also have access to the information regarding the study.

Who is being asked to take part?

I am asking young people aged 18-24 who have a sibling with learning disabilities and/or autism to take part in the research. The British Institute of Learning Disabilities defines learning disability as 'a general term that refers to individuals who find it harder to learn, understand and communicate. Other terms that are used to describe an individual's situation include complex needs or high support needs'. The NHS defines autism as 'a condition that affects social interaction, communication, interests and behaviour.'

Do you have to take part?

No, it is up to you to decide whether or not to take part. You can withdraw from the study at any time and without giving any reason. If you withdraw when the information collected so far cannot be erased, then this information may still be used in the project analysis.

What do I have to do?

You will need to give up to an hour and a half of your time for the interview. You will need to sign the consent form if you wish to take part.

What will happen after our conversation?

The results of the study will be included in the write up of the thesis. The thesis will be assessed by academics at my university and will eventually be available to read in the university library. The findings from the study may also be included in research papers/articles. Research papers/articles are short pieces of writing on specific topics relating to a piece of research. These articles are published in academic journals and can be accessed by students, academics and members of the public. I may also present the results of this research at conferences. I may present talks to people at academic and professional conferences about the findings of this research. Short quotes from our conversation may be used in the thesis, research articles or in talks at conferences. Quotes are used to highlight certain themes or ideas. Care will be taken to remove any identifying information from quotes.

I will be happy to send you a summary of the findings when the study ends if you would like this. If you would, please let me know on the day of the interview and I will make a note of your request. Or you can email me any time using the contact details at the bottom of this sheet to request this.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential, stored in a secure and locked office, and on a password protected computer system. Your personal data (address, telephone number) will be kept for up to 12 months after the end of the study so that I am able to contact you about the findings of the study unless you advise me that you do not wish to be contacted. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely.

Your name and location will be anonymised within the write up of the thesis and any other research outputs (e.g. research papers/articles, conferences, reports).

The only circumstance where confidentiality cannot be guaranteed is if you told me something that made me concerned about the safety of you or somebody else. If this happened, I would talk to you about my concerns and, if appropriate, I would have a responsibility to pass the information on to the appropriate professionals.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me and I'll do my best to answer your questions. My contact details are given at the end of this information sheet. You can also speak to my supervisors whose details are also at the end of this sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the School's Research Ethics Officer, Dr Simon Roberts (tel. 0115 846 7767, email: simon.roberts@nottingham.ac.uk).

What should I do to get more information about the study or if I would like to take part?

If you would like some more information or you are interested in taking part contact me by email:
Georgia.Todd@nottingham.ac.uk

You can also talk to my supervisors Rachael Clawson (Rachael.Clawson@nottingham.ac.uk) and John Holmwood (John.Holmwood@nottingham.ac.uk).

Appendix 3: Consent Form

School of Sociology and Social Policy
University of Nottingham



Participant Consent Form

Please tick the following boxes, and, if you would like to take part, sign below

I have read the Participant Information Sheet and understand the details of the study and have had the opportunity to ask questions.	□
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw when the information collected so far cannot be erased that this information may still be used in the project analysis.	□
I agree that short quotes from the conversation may be used in any report or publication relating to the research, as long as information that might identify me is removed.	□
I understand that the conversation will be recorded using an electronic voice recorder.	□
I understand that what I say will be confidential, and that this confidence will only be broken if I disclose something that raises concerns about the safety of me or other people.	□
I agree to take part in the above research.	□

Participant's name (BLOCK CAPITAL)	Participant's signature	Date
Researcher's name (BLOCK CAPITAL)	Researcher's signature	Date

Appendix 4: Interview Schedule

EXPLAIN THE INTERVIEW PROCESS AND RESEARCH AIMS. GIVE THE RESPONDENT THE INFORMATION SHEET TO READ. SIGN CONSENT FORMS. MENTION TAKING NOTES. REMEMBER TO GIVE SHEET AT END.

A) Sibling relationship

1. How old are you?

2. How many disabled siblings do you have?

3. What is/are their name/s?

4. How old are they?

5. What kind of disabilities do they have?

6. How would you describe your sibling's disability? What level of need do they have?

7. Do you have any other siblings?

8. How old are they? [Check gender of all siblings]

9. Who did you live with whilst you were growing up? What did your parent/s do for work whilst you were growing up?

10. What was the relationship like between you and [sibling's name] when you were growing up?

-How did the sibling relationship change when you became a teenager?

11. What is the relationship like with your sibling now?

-How has your relationship changed since your earlier teenage years?

-How often do you see your sibling?

-Do you have any responsibilities for your sibling? What are they?

-What responsibilities do your other sibling/s have? How supportive are they of your disabled sibling?

B) Moving out of the family home

12. Tell me about the places where you have lived since you were born up to where you live now.

13. (a) *[if left family home]*

-When did you decide to leave home?

-What was making the decision to move out of home like?

-What was moving out of the family home for the first time like?

-Where did your sibling live when you first moved out?

-Where does your sibling live now?

- How did the sibling relationship change when [sibling's name] first moved out of the family home?

-How did the sibling relationship change when you first moved out of the family home?

-Where do your other siblings live? What was it like when they left the family home?

[if left family home but has moved back]- What was moving back home like? What is it like living with family? What is it like living with [sibling's name]*?*

-What are your thoughts about where you might live in the future?

(b) *[if never left family home]*

-What is it like living with family?

-Where does your sibling live? *[If they have left home]* What was it like when they moved out of the family home? How did your relationship change when they left home?

-Where do your other siblings live? What was it like when they left the family home?

-What is it like living with [sibling's name]?

-What are your thoughts about where you might live in the future?

-How might moving away from home affect the relationship you have with your sibling?

C) Occupational aspirations and choices

14. What work, education or other activities have you been involved in since leaving secondary school?
    -What motivated you to pursue X do you think?

15. What activities is your sibling involved in at the moment?

16. What are your sibling's plans for the future?

17. How might you be involved in your sibling's future?

18. What do you think is expected of you in relation to your sibling's support in the future? Who expects this of you? How might your other sibling/s be involved in their support?

19. What are your aspirations for the future?
    -How might your plans affect the relationship you have with your sibling?

D) Relationships

20. Which people would you say you are closest to in your life at the moment?

21. Who do you go to if you need advice or support?

22. What are your relationship plans for the future?

23. Where do you see yourself in 10 years' time?

Interview conclusion

24. What else that we haven't already talked about do you think might be interesting to discuss in relation to the relationship you have with your sibling and your experiences about becoming an adult?

Thank you for taking part, please feel free to ask any questions.

Appendix 5: List of Support Services Given to Participants

Sibs: https://www.sibs.org.uk/
Sibs is a charity which aims to enhance the lives of siblings of disabled people by providing them with information and support, and by influencing service provision throughout the UK. There is an online support forum for adults and you can use the young sibs online chat if you are under 18. There are adult support groups based in Nottingham, Brighton, London, Birmingham and Manchester.

Samaritans: http://www.samaritans.org/
Tel: 116 123
Samaritans is an organisation that you can contact by phone, text, email or face to face in a local branch. You can talk to a volunteer about any concerns, worries or troubles you might be having.

Carers Trust: https://carers.org/search/network-partners
If you provide care for someone you can use the Carers Trust website to find a carers service near you.

Mencap: https://www.mencap.org.uk/
Mencap is a charity that supports people with learning disabilities and their families. There's lots of information on their website about learning disabilities and support services. They have an online community forum for family carers of people with learning disabilities.

The National Autistic Society: http://www.autism.org.uk/
Tel: **0808 800 4104**
The National Autistic Society is a charity that provides information and support for people with autism and their families. Family members can contact their helpline for information, advice or support.

Appendix 6: Ethics Form

School of Sociology & Social Policy

Application for Research Ethics Approval for Students and Staff

SECTION 1: THE RESEARCHER(S)

To be completed in all cases

Title of project: How might having a sibling with disabilities impact on young people's experiences of transitioning to adulthood?

Name of principal researcher: Georgia Todd

Status:
- □ Undergraduate student
- □ Postgraduate taught student
- ☑ Postgraduate research student
- □ Staff

Email address: llxgt6@nottingham.ac.uk

Names of other project members: Supervisors: John Holmwood and Rachael Clawson

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To be completed by students only:

NAME IN CAPITALS

GEORGIA TODD

Student ID number: 4199760

Degree programme: Sociology PhD

Module name/number: N/A

Supervisors: John Holmwood and Rachael Clawson

SECTION 2: RESEARCH WITHIN OR INVOLVING THE NHS OR SOCIAL CARE

Does this research involve the recruitment of patients, staff, records or other data through the NHS or involve NHS sites or other property?

□ Yes

☑ No

If you have answered **YES** to the above question, ethical approval **MUST** be sought from the relevant NHS research ethics committee. Evidence of

approval from such a committee **MUST** be lodged with the School office prior to the commencement of data collection.

Does this research involve the recruitment of users, staff, records or other data through social service authorities (children and adult services) or involve social service sites or other property?

□ Yes

☑ No

If you have answered **YES** to the above question, then you must check whether or not the relevant social service authority has its own ethical scrutiny procedures. If appropriate, evidence of approval from such an authority **MUST** be lodged with the School office prior to the commencement of data collection.

Even where external ethical approval has been obtained from an NHS committee or social service authority, completion of this form is mandatory.

SECTION 3: FIELDWORK INVOLVING HUMAN SUBJECTS TAKING PLACE OUTSIDE THE UNITED KINGDOM

Does this research involve FIELDWORK OUTSIDE THE UNITED KINGDOM?

□ Yes

☑ No

If you have answered **YES** then you must follow the flow chart on the School's Research Ethics page to organize your overseas travel. All overseas research involving the collection of human data is referred to the University's Insurance Brokers for approval. You should not book flights or arrange fieldwork until you have received approval from the REC and the University's Insurance Department. Following receipt of ethical approval you should carefully read all the University' Insurance documents on the Insurance website and discuss your travel arrangements with your supervisor and the University's Travel Office ***before*** making any arrangements. The Ethics Form must be accompanied by Fieldwork Safety Plan that has been agreed and signed by the staff researcher/student and the PI/supervisor.

SECTION 4: THE RESEARCH

PLEASE EXPAND THESE BOXES TO PROVIDE SUFFICIENT INFORMATION TO ENABLE THE RESEARCH ETHICS COMMITTEE TO MAKE A DECISION ON YOUR APPLICATIO FOR ETHICS APPROVAL

Please provide details about your proposed research, as indicated in each section

1. Research question(s) or aim(s)

To explore how having a sibling with learning disabilities might impact on young people's experiences, aspirations and perceptions relating to their transition to adulthood.

2. Method(s) of data collection

Individual in-depth semi-structured interviews with young people aged 17-24 who have a sibling with learning disabilities.

3. Proposed site(s) of data collection

Various locations in the community: Participant's homes, public places, schools/colleges, within private rooms at charity offices and private rooms in the University of Nottingham libraries if respondent studies at the university.

(Please see University's Lone Worker Policy and Working Abroad Policy on the School's Ethics page: http://www.nottingham.ac.uk/sociology/research/research-ethics.aspx)

4. How will access to participants be gained? 'Sibs' is a UK based charity that supports children and adults who have disabled siblings. They have stated that they are willing to post an invitation for the study via their social media outlets and through their mailing list. The Carers Federations have also said they would be willing to contact potential participants on my behalf. They have said that they will pass on a letter explaining the study to siblings and parents of people with learning disabilities who use the service. They have also mentioned that I may be able to attend support groups or social events and approach potential participants. I may also need to contact other voluntary organisations to gain access to potential participants for the study if I have not received much interest. I will contact universities to advertise the study amongst students who may have a sibling with learning disabilities. I will ask university departments to circulate an email inviting potential participants to contact me if they are interested in being part of the study. I will also contact university unions regarding ways I may be able to advertise the study. Posters could be pinned on student union bulletin boards and the study could be advertised through university social media. I will ensure I receive

relevant permission from universities and unions before doing this. Sixth form schools and colleges will also be contacted to see if they would be willing to advertise the invitation to interview via their notice boards, mailing lists and social media. In addition, access will be gained through networking with family and friends.

SECTION 5: ETHICAL CONSIDERATIONS

Please answer each question by ticking the appropriate box. All questions in section 5 **must** be answered.

5.1 General issues

	Yes	No
Will this research involve any participants who are known to be vulnerable due to:		
Being aged under 18?	☑	
Residing in institutional care (permanently or temporarily)?		☑
Having a learning disability?		☑
Having a mental health condition?		☑
Having physical or sensory impairments?		☑
Previous life experiences (e.g. victims of abuse)?		☑
Other (please specify)…		☑
Will this research expose participants to any significant risk of physical or emotional harm?		☑
Will this research involve any physically invasive procedures or the collection of bodily samples?		☑
Will this research address sensitive issues, for example, abuse, illegal activities, sex, sexuality, drug use, serious illness? (This list is not exhaustive)	☑	
Will this research involve deception of any kind?		☑
Will this research involve access to personal information about identifiable individuals without their knowledge or consent?		☑
Will this research involve the collection of data from human subjects in a country other than the United Kingdom?		☑
Will this research expose the researcher to any risk of physical or emotional harm?		☑
I will inform immediately the School's Ethics Officer if I change the method(s) of data collection, the proposed sites of data collection, the means by which participants are accessed, or make any other significant changes to my research inquiry	☑	

5.2 Before starting data collection

	Yes	No
I have read the *Research Code of Conduct* guidelines of the University of Nottingham, particularly section 4 on Data, and agree to abide by them. The *Research Code of Conduct* can be found on the School's Ethics webpage: http://www.nottingham.ac.uk/sociology/research/research-ethics.aspx.	☑	
For those intending to work with children and/or vulnerable adults: I have read the University's *Guidance on the Protection of Children and Vulnerable Adults* The Guidance can be found on the School's Ethics webpage: http://www.nottingham.ac.uk/sociology/research/research-ethics.aspx).	☑	
My full identity will be revealed to all research participants	☑	
All participants will be given accurate information about the nature of the research and the purposes to which the data will be put	☑	
All participants will freely consent to take part, and this will be confirmed by use of a consent form. (An example of a consent form is available for you to amend and use.)	☑	
One signed copy of the consent form will be held by the researcher and another will be retained by the participant	☑	
It will be made clear that declining to participate will have no negative consequences for the individual	☑	
It will be made clear that participation is unlikely to be of direct personal benefit to the individual	☑	
Participants will be asked for permission for quotations (from data) to be used in research outputs where this is intended	☑	
Incentives (other than basic expenses) are offered to potential participants as an inducement to participate in the research. (Here any incentives include cash payments and non-cash items such as vouchers and book tokens.)		☑

For research conducted within, or concerning, organisations (e.g. universities, schools, hospitals, care homes, etc) I will gain authorisation in advance from an appropriate committee or individual. (This is in addition to any research ethics procedures required by those organisations, particularly health and social care agencies – see Section 2 above.)	☑	

5.3 During the process of data collection

	Yes	**No**
I will provide participants with my University contact details, and those of my supervisor, so that they may make get in touch about any aspect of the research if they wish to do so	☑	
Participants will be guaranteed anonymity only insofar as they do not disclose any illegal activities. This will be made clear before any data are collected	☑	
Anonymity will not be guaranteed where there is disclosure or evidence of significant harm, abuse, neglect or danger to participants or to others. This will be made clear before any data are collected	☑	
All participants will be free to withdraw from the study at any time, including withdrawing data following its collection	☑	
Data collection will take place only in public and/or professional spaces (e.g. in a work setting). If fieldwork takes place in the respondent's home please outline in Section 6 what steps will be taken to ensure your safety. You must read the University's Lone Worker Policy and may wish to consult the SRA researcher safety guidelines (Please see School's Ethics webpage: http://www.nottingham.ac.uk/sociology/research/research-ethics.aspx)		☑
Research participants will be informed when observations and/or recording is taking place	☑	

Participants will be treated with dignity and respect at all times	☑	

5.4 After collection of data

	Yes	No
Where anonymity has been agreed with the participant, data will be anonymised as soon as possible after collection	☑	
All data collected will be stored in accordance with the requirements of the Data Protection Act 1998	☑	
Data will only be used for the purposes outlined within the participant information sheet and consent form	☑	
Details which could identify individual participants will not be disclosed to anyone other than the researcher, their supervisor and (if necessary) internal and/or external examiners without their explicit consent	☑	
I will inform my supervisor and/or the School's Research Ethics Officer and (if necessary) statutory services of any incidents of actual or suspected harm of children or vulnerable adults which are disclosed to me during the course of data collection	☑	

5.5 After completion of research

	Yes	No
Participants will be given the opportunity to know about the overall research findings	☑	
Data must be submitted to the School office and will be retained (in a secure location) for 7 years from the date of any publication based upon them, after which time it will be destroyed.	☑	
All hard copies of data collection tools and data which enable the identification of individual participants will be destroyed	☑	

SECTION 6: ETHICAL APPROVAL

Declaration of ethical research

1. ***If you did not tick any of the shaded boxes*** *in section 5 of this form*, please sign and date below **and** get the checklist countersigned (see below for who the Application must be countersigned by).

   Keep one copy of this form for your personal records.

   Students who undertake research involving primary data collection on non-dissertation modules must submit the authorised Ethics Application Form along with their assessed work to Alison Haigh in the School Office.

   Undergraduate dissertation students who intend to conduct fieldwork should include **two hard copies** of the Ethics Application Form with their dissertation plans submitted to dissertation tutors in the autumn. Then assuming the Form is signed and authorised by their dissertation supervisor, **students should confirm this authorisation in a section discussing ethics in the text of the dissertation and append all ethics documents (Ethics Application Form, Consent Form, Participant Information Sheet and Fieldwork Safety Plan).** Failure to do so may incur penalties when the dissertation is marked. Some undergraduate module convenors will also distribute a short 'ethical declaration' that you will have to sign.

   Principal investigators and other researchers, including postgraduate research students and postgraduate taught students, should keep a copy of the authorised Ethics Application Form and Fieldwork Safety Plan on file.

   By signing this form you are agreeing to work within the protocol which you have outlined and to abide by the University of Nottingham's Code of Research Ethics. If you make changes to your protocol which in turn would change your answers to any of the above questions then you **must** complete a new form and submit a copy to Alison Haigh or for undergraduates to your tutor/supervisor.

Signed …  …… Date ……9/12/2016……..

2. ***If you ticked any of the shaded boxes in section 5 of this form, then you must complete SECTION 7 (below). You must then discuss all ethical issues arising, record the outcome, including the supervisor's and/or REO's response, and have this form countersigned (see below)***

Authorisation

This section **must** be completed in **all** cases - whether or not you have ticket any shaded boxes in Section 5.

By type of investigator the form must be countersigned by the following personnel:

Undergraduate student (no shaded boxes ticked) → module convenor or tutor/project supervisor

Undergraduate student (shaded boxes ticked) → module convenor or tutor/project supervisor → School Research Ethics Officer (REO)

Postgraduate taught student (no shaded boxes ticked) → dissertation supervisor

Postgraduate taught student (shaded boxes ticked) → dissertation supervisor → School Research Ethics Officer (REO)

Postgraduate research student → supervisor/upgrade panel → School Research Ethics Officer (REO)

Staff → School Research Ethics Officer (REO)

To be signed by Supervisor/PI.

Having reviewed the ethical issues arising from the proposed research:

x I am happy for the research to go ahead

Signed ……

Date 7.12.16

Role ……PhD co-supervisors



31.1.2017

To be signed by School REO

The Research Ethics Committee is happy for this research to go ahead as described



School REO Date: 1 February 2017

Note: **any** research protocols lodged with the School Office may be subject to review by the School's Research Ethics Officer

SECTION 7: FURTHER INFORMATION & JUSTIFICATION OF METHODOLOGY

One box should be completed for **each** shaded box ticked in section 5of this form.

Ethical issue **PLEASE EXPAND THESE BOXES TO PROVIDE SUFFICIENT INFORMATION TO ENABLE THE RESEARCH ETHICS COMMITTEE TO MAKE A DECISION ON YOUR APPLICATION FOR ETHICS APPROVAL**

This research will involve in-depth individual semi-structured interviews with young people aged 17 and above.

Rationale for chosen methodology and/or how ethical issue is to be addressed:

This study aims to interview young people who have a brother or sister with learning disabilities who are in their last year of compulsory education (aged 17-18) and young people who have left compulsory education (aged 18-24). This will allow for comparisons in young people's perceptions, experiences and aspirations relating to their transition to adulthood before and after they have transitioned from compulsory

education. This research involves potentially vulnerable participants, young people aged under 18 will be direct participants and young people with learning disabilities will be indirectly involved in the study. I will have specific protocols in place regarding disclosures of abuse in relation to children or vulnerable adults. Consent from a guardian/parent will be sought for young people aged 17. I will ask young people to share the consent form with their parent/guardian for their signature before I interview them.

Supervisor/REO's response (including whether ethical issue has been satisfactorily addressed):

Georgia has discussed this issue with both supervisors, we are happy to support this rationale. Georgia will only be interviewing participants who have the capacity to consent to taking part.

Ethical issue:

Sensitive topics will be discussed in interviews, young people will be asked about their family lives, relationship and family formation, the relationship they have with their sibling with learning disabilities and their future plans regarding supporting their sibling with learning disabilities.

Rationale for chosen methodology and/or how ethical issue is to be addressed:

At the start of the interview I will recap information provided on the Project Information Sheet and will check that participants feel happy to continue. I will monitor the wellbeing of participants throughout the interview, taking note of body language in addition to what they say and provide them with the opportunity to end the interview at any time should they so wish. I will use my social work skills and knowledge to aid me in this.

I will provide a list of support services to participants to make participants aware of organisations that they can contact should they wish to discuss any issues that might arise. Participants will be provided with my contact details and assured that they can contact me any time after the project if they have any concerns after the interview.

I will inform participants how the data and their information will be stored, anonymized and analysed and encourage them to discuss any concerns that they have.

Supervisor/REO's response (including whether ethical issue has been satisfactorily addressed):

Georgia has considered this issue and discussed in supervision. She has carefully thought through what the implications of discussing sensitive topics might be. It is also our belief that the skills and knowledge she gained whilst training on a social work MA will enable her to ask questions sensitively and recognize any signs of distress and manage them appropriately.

Ethical issue:

Respondents will be given the option for interviews to take place within their home, in a public place, at school/college, within a private room at charity offices or within a private university library room if the respondent is studying at the University of Nottingham.

Rationale for chosen methodology and/or how ethical issue is to be addressed:

As this research involves the discussion of sensitive issues, it seems appropriate to offer participants the choice of talking in a private space where they feel most comfortable, which may be their homes. A risk assessment has been completed using the 'fieldwork safety policy and action plan' and submitted with this form. My mother will be aware of the dates and times that I am interviewing respondents in their homes. I will communicate with my mother immediately prior to the arrival at the respondent's home and when I have left the respondent's home. My mother will be given an envelope with the participant's address written in it and only open this if I have not made contact with her by an agreed time or if she is concerned about my safety. In accordance with appendix 4 of the 'University's Lone Worker Policy', throughout my fieldwork I will remember the risks involved when travelling to and from locations in the community and the risks involved in being in people's homes. I have worked as a care worker and conducted visits to families' homes so have experience of assessing risks when entering people's homes that I do not know. I also have a social work MA, this course trained me to assess and manage risks in people's homes.

Supervisor/REO's response (including whether ethical issue has been satisfactorily addressed):

Again, this issue has been discussed in supervision. It is anticipated that many interviews will take place in public spaces, for example in school (with necessary permission from the Headteacher), in university or at the premises of one of the voluntary sector organisations supporting Georgia with recruitment. However, on some occasions it will be appropriate to talk to participants in their own homes. Georgia has completed an MA in social work and has experience in visiting people in their own homes. The risk of harm to her from participants in this research study is low, particularly as many participants will be recruited via organisations and schools. Georgia has considered issues such as times of day to visit, visiting during daylight hours, positioning herself near the door within the room the interview takes place etc. She will also put a system in place whereby she will inform a close relative of the start/end times for interviews and will contact this person at the end of the interview.

School Research Ethics Officer on behalf of

Research Development Group

September 2015

Appendix 7: Thematic analysis process

Stage	Process
Stage 1: Familiarised myself with the data	I familiarised myself with the data and got an idea of the themes that might be emerging from the data (during data collection and transcription).
Stage 2: Initial coding	I assigned codes to each section of the data (codes listed below): • A different kind of sibling relationship • Admiration for disabled sibling • Care less what people think about sibling as transition to adulthood • Career/occupation choice motivated by experiences of having disabled sibling • Class capital advantage • Clear plan as parents grow older • Close family network • Different transitions for disabled sibling • Embarrassed about sibling in teenage years • Family caring better than institutional care • Family embarrassment • Family finding hard to 'let go' and encourage independence of young disabled person • Family having to adapt to needs of disabled sibling • Family struggles with social services • Guilt at moving away because of sibling • Guilt when not around to help family • Having a sibling with disabilities/autism makes you more aware and knowledgeable • Having disabled sibling as a motivator for independence • Having disabled sibling helps develop skills • Independence for disabled sibling good for family • Insight into sibling's disability matures with age • Is it normal, not knowing any differently than life with family • Lack of information from services • Less severe needs means less caring responsibilities • Misconceptions and confusion about sibling's disability • More severe disabilities impacts on closeness of sibling relationship • Mum giving up work to care • Mum taking on primary caring role

	• Sibling without disability provides normality for parents • Not moving far away because of sibling • Older sibling having more responsibility for caring • Parents not paying enough attention • Parent's protecting sibling from impacts of sibling's disability • Parent's protecting young person from sibling's problems when they have moved out • Planning for caring for sibling in the future • Realising sibling 'not normal' when exposed more to outside world • Relationship in teenage years • Relationship in young adulthood • Relationship with partner affected by having a sibling with disabilities • Services helpful but post code lottery • Sibling moving out earlier because of impact of sibling's disability • Sibling not expected to take on caring role for sibling • Disabled sibling on college courses • Sibling's disability impacting on family life and relationships • Stigma from public • Strained relationship in young adulthood • Strong sense of social responsibility and caring about people • Struggles with mental health for sibling with autism • Support role lost for family when young person has moved out • The 'normals' not understanding disability • Transition for disabled sibling difficult for family • Uncertainty about future of sibling and their own caring role • Uncertainty about own children having disabilities/autism • Wanting to pursue own dreams • Worrying about disabled sibling • Older generation not understanding disability • Young person avoids planning because of sibling and family life • Young person concealing that they have a disabled sibling • Young person does not want to burden family with their problems • Young person expected to care for sibling more as they grow older

	• Young person lives close to sibling and family
Stage 3: Grouping codes together to search for themes	I grouped the codes into potential themes. **Theme 1: Sibling relationship** • Young person concealing that they have a disabled sibling • Worrying about disabled sibling • Strained relationship in young adulthood • Stigma from public • Sibling's disability impacting on family life and relationships • Relationship in teenage years • Relationship in young adulthood • Realising sibling relationship 'not normal' when exposed more to outside world • Parents not paying enough attention • Older sibling having more responsibility for caring • More severe disabilities impacts on closeness of sibling relationship • Misconceptions and confusion about sibling's disability • Is it normal, not knowing any differently than life with family • Care less what people think about sibling as transition to adulthood • A different kind of sibling relationship • Admiration for disabled sibling • Embarrassed about sibling in teenage years **Theme 2: Impact of transitions and disability on family life** • Lack of information from services • Young person does not want to burden family with their problems • Worrying about disabled sibling • Wanting to pursue own dreams • Transition for disabled sibling difficult for family • The 'normals' not understanding disability • Support role lost for family when young person has moved out • Struggles with mental health for sibling with autism • Stigma from public • Sibling's disability impacting on family life and relationships • Disabled sibling on college courses • Sibling not expected to take on caring role for sibling

	• Services helpful but post code lottery • Parent's protecting young person from sibling's problems when they have moved out • Parents not paying enough attention • Not moving far away because of sibling • Sibling without disability provides normality for parents • Mum giving up work to care • Mum taking on primary caring role • Misconceptions and confusion about sibling's disability • Is it normal, not knowing any differently than life with family • Independence for disabled sibling good for family • Different transitions for disabled sibling • Family caring better than institutional care • Family embarrassment • Family finding hard to 'let go' and encourage independence of young disabled person • Family having to adapt to needs of disabled sibling • Family struggles with social services • Close family network **Theme 3: Sibling as carer?** • Young person does not want to burden family with their problems • Uncertainty about future of sibling and their own caring role • Planning for caring for sibling in the future • Parent's protecting sibling from impacts of sibling's disability • Older sibling having more responsibility for caring • Not moving far away because of sibling • Less severe needs means less caring responsibilities • Clear plan as parents grow older **Theme 4: The impacts of having a sibling with disabilities on transitioning to adulthood** • Young person expected to care for sibling more as they grow older • Young person lives close to sibling and family • Young person does not want to burden family with their problems • Young person avoids planning because of sibling and

	family life • Worrying about disabled sibling • Wanting to pursue own dreams • Uncertainty about own children having disabilities/autism • Uncertainty about future of sibling and their own caring role • Strong sense of social responsibility and caring about people • Sibling moving out earlier because of impact of sibling's disability • Relationship with partner affected by having a sibling with disabilities • Parents not paying enough attention • Not moving far away because of sibling • Insight into sibling's disability matures with age • Having a sibling with disabilities/autism makes you more aware and knowledgeable • Having disabled sibling as a motivator for independence • Having disabled sibling helps develop skills • Guilt at moving away because of sibling • Guilt when not around to help family • Clear plan as parents grow older • Career/occupation choice motivated by experiences of having disabled sibling • Care less what people think about sibling as transition to adulthood **Unused codes** Older generation not understanding disability Class capital advantage
Stage 4: Reviewing themes	I assigned subthemes to group the codes together and moved the codes and subthemes around to form major themes and sub themes within them. **Theme 1: The impacts of transitions on family life** Sub theme 1: Different transitions for sibling with disabilities Sub theme 2: Struggles with transition services Sub theme 3 Impacts of disabled sibling's transition on family life Sub theme 4: Impact of non-disabled sibling's transition on family life

	Theme 2: Becoming adults together: the sibling relationship Sub theme 1: A different kind of sibling relationship? Sub theme 2: Normality of sibling relationship Sub theme 3: Distance and embarrassment in teenage years Sub theme 4: Changes to the sibling relationship in young adulthood **Theme 3: Sibling as carer?** Sub theme 1: Support role in childhood and teenage years Sub theme 2: Young person's support role in young adulthood Sub theme 3: Futures planning: young people's future roles **Theme 4: The impacts of having a sibling with disabilities on transitioning to adulthood** Sub theme 1: Occupation choice motivated by experiences of having disabled sibling Sub theme 2: Impacts on moving out of the family home Sub theme 3: Impacts on planning for own family life Sub theme 4: Young person does not want to burden family with their problems Sub theme 5: Worrying about sibling's future Sub theme 6: Responsibility to help people Sub theme 7: Having a sibling with disabilities provides you with skills for independent adult life
Stage 5: Defining, naming and checking themes	I decided to collapse the third theme as the findings were not significant enough to form a major theme. I reorganised the subthemes from theme 3 into the other three major themes. I renamed some of the sub themes and moved them around to ensure they fit in with the three major themes. I also excluded two sub themes as they did not relate closely enough to my research aim. **Theme 1 The Impacts of Transitions on Family Life** Sub theme 1: Family Struggles with Transition Services Sub theme 2: Impacts of Disabled Sibling's Transition on Family Life Sub theme 3: Impacts of Non-Disabled Sibling's Transition on Family Life

	Theme 2 The Sibling Relationship Sub theme 1: Support Role in Childhood and Teenage Years Sub theme 2: Distance and Embarrassment in Teenage Years Sub theme 3: Changes to the Sibling Relationship in Young Adulthood **Theme 3: The Impacts of Having a Disabled Sibling on Young People's Transition to Adulthood** Sub theme 1: Impacts on Moving out of the Family Home Sub theme 2: Impacts on Planning for own Family Life Sub theme 3: Impacts on Occupation Choice Sub theme 4: Impacts on Skills for Independent Adult Life Sub theme 5: Impacts of Current Caring Role on Transition to Adulthood Sub theme 6: Impacts of Potential Future Care Role
Stage 6: Display themes	The findings related to the three major themes were presented, discussed and analysed in separate chapters and linked to relevant theory and research.