

Children's experiences of having a younger
sibling with severe and complex special
educational needs
An interpretative phenomenological
analysis

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Psychology

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Student declaration

This work has not previously been accepted for any degree and it is not being concurrently submitted for any other degree.

This research is being submitted in partial fulfilment of the requirements of the Doctorate in Applied Educational and Child Psychology.

This dissertation is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is appended.

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Abstract

This research presents an account of a qualitative research study which explores the experiences of eight children who have a younger sibling with severe and complex special educational needs (SEN). The research body presents conflicting findings. Previous studies have found that growing up with a disabled sibling has negative outcomes, whilst others found the contrary. More recent studies present a balanced portrayal of positive and negative outcomes. In this research eight children aged between seven and thirteen years were interviewed. The interviews were analysed using Interpretative Phenomenological Analysis (IPA). Three Master Themes emerged from the analysis; Making sense of their situation today and tomorrow, the sibling relationship within the family and focus on feelings. Each theme is discussed and is illustrated by quotes from the participants. The discussion makes links between themes obtained in the analysis, psychological theory and previous research. The findings share similarities with the current literature in that the participants described both positive and difficult experiences. Alongside these similarities, new perspectives have been brought about by this research e.g. the importance of hope and positivity. The findings help to inform recommendations and implications for professional practice, with particular reference to the work of educational psychologists.

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Abbreviations

CAMHS	Child and Adolescent Mental Health Service
DCSF	Department for Children, Schools and Families
DfES	Department for Education and Skills
DoH	Department of Health
EP	Educational Psychologist
EPS	Educational Psychology Service
EYFS	Early Years Foundation Stage
IPA	Interpretative Phenomenological Analysis
NSF	National Service Framework
SEN	Special Educational Needs
TAMHS	Targeted Mental Health in Schools

Key terminology

Definitions are provided below of the key terms used in this thesis.

Siblings

Sibling is defined as each of two or more children or offspring having one or both parents in common; a brother or sister. (Oxford dictionary, 2011)

Severe and complex special educational needs

There is no fixed definition of severe and complex special educational needs. This term is used in the Special Educational Needs; Code of Practice, (DfES, 2001) which at the time of writing all Local Authorities still have a duty to have regard to it. Although the new Coalition Government is set to reform categories of special educational needs in the coming year. Within the Special Educational Needs; Code of Practice, (DfES, 2001) severe and complex special educational needs is used to describe children whose needs are described as severe and fall into more than one of the following categories:

- communication and interaction
- cognition and learning
- behaviour, emotional and social development
- sensory and/or physical

The children interviewed for this study all have a younger sibling who attend a Specialist Children's Centre. This centre describes the children who attend their resource as having "complex special educational needs" and so it was felt important to keep to the same terminology. Children who attend this resource typically have life limiting multiple pathologies and show serious delays in reaching developmental milestones. Their basic awareness and understanding of themselves and the world around them is limited. They have considerable difficulties in communicating with other people and the outside world and will require ongoing support to meet their basic needs.

Foreword

This foreword is provided to introduce the reader to this research, to address key points important to the overall approach used in this study and to provide an overview of this thesis.

The research presented in this thesis focuses on exploring children's experiences of having a younger sibling with severe and complex special educational needs. This thesis unfolds over several chapters;

Chapter one (introduction) highlights why this research topic was chosen, the context for the research and its rationale and aim. An introduction to the research paradigm, the importance of reflexivity and this research's distinctive contribution is also provided in this opening chapter.

Chapter two (literature review) describes the theoretical framework underpinning this research and provides a critical review of the literature relating to understanding the experiences of siblings of children with severe and complex needs. The chapter concludes with a synthesis of the literature review and theoretical framework and in light of literature review, the rationale and aim is restated.

Chapter three (methodology) includes information about the construction of the research design and methodology including four distinct phases in the completion of the research. Ethical issues relating to involving children in research are also highlighted.

Chapter four (findings), explores the analysis of the data collected which is organised within three master themes and nine integrated subthemes.

Chapter five (discussion) provides a critical discussion of the main findings of the research in relation to psychological theory and the wider research area. In addition a critique of the research methodology is offered together with reflections about the role of the researcher.

Chapter six (conclusion) concludes this thesis with a summary of the main findings and the distinctive contribution this research has made to the area of sibling research. In light of the findings, recommendations are made to inform the practice of professionals working with the families of children with severe and complex special educational needs, with particular reference to the work of Educational Psychologists. Ideas for further research and concluding comments, close this thesis.

Conventionally, academic writing is expected to follow a particular voice. Usually the writer is required to be objective and not personally present. However this research uses IPA and within this approach the researcher endeavours to understand the individual experience through interpretative analysis of the data. It was therefore decided to move away from tradition and write this thesis in the first person, in order to reflect the idiographic nature of the research.

The founder of IPA Jonathan A. Smith argues that “reflexivity is a central feature of understanding the nature of the person in psychology” (Smith, 2003 p.176). A key addition to this thesis is a section on reflexivity at several points throughout this thesis. This is to illustrate the importance of reflexivity in helping to provide a credible and plausible account of the participants experiences (Clancy, 2013).

“The sibling relationship is often the most complex and long term relationship a person will experience” (Seltzer, Greenberg, Orsmond, & Lounds, 2005, p. 5).

Chapter One: Introduction

1.1. Introduction to chapter one

This research aims to explore the experiences of children who have a younger sibling with severe and complex special educational needs (SEN). This opening chapter sets the scene and provides an overview of the context for the research.

The chapter begins with the genesis of this research, gained from personal influences and professional perspectives as an Educational Psychologist (EP) working in a Specialist Children's Centre in South London.

The research is framed within international, national and local contexts; the socio- political context in England and Wales and relevant government policy from current and previous governments are outlined. Key charitable organisations whose aim is to support the well being and lives of siblings in the UK and across the world are highlighted. The location of this research in a South London Specialist Children's Centre provides the local context for this research.

The rationale and aim of this research is clearly stated in this opening chapter, alongside the distinctive contribution that this research hopes to make to the field of sibling research.

The embedded epistemology is introduced to the reader in this opening chapter, alongside the chosen method of analysing the data: Interpretative Phenomenological Analysis (IPA).

Finally, the reader is introduced to the idea of reflexive thinking, which is a key tool used in this research to enhance transparency and bolster the quality of the research. An overview of chapter one concludes this introductory chapter.

1.2. Genesis of an idea

This research aims to explore the experiences of children who have a younger sibling with severe and complex SEN. I feel that it is important to describe the emergence and impetus for setting up the current research and to explain its originating genesis.

The idea for this research developed from a coalescence of professional experiences, conversations and observations and also personal influences and life experiences.

1.2.1. Professional influences

Interest in this area stemmed from my work as an applied EP in a London Borough. An EP works in a range of educational settings. They work at the individual, group or whole school level to help improve teaching and learning. In this instance, I work as an EP in a Specialist Children's Centre that offers early intervention, education, respite and family support for children under five years old who have severe and complex special educational needs.

Documentation produced by the Specialist Children's Centre to parents and professionals states that it specifically caters for children with severe and complex needs, including:

- Complex medical needs
- Severe learning delay, including children with sensory impairment and physical disability.

The Specialist Children's Centre is a resource that is open all year. Staff at the Specialist Children's Centre work with a range of partner agencies from social services, health and education services to meet the overall developmental needs of young children with severe and complex needs by offering a range of services and learning opportunities adapted from the Early Years Foundation Stage curriculum. The purpose of this adapted curriculum is to allow children to achieve at their own pace. Agencies work together to ensure that when the children leave at rising five years old, they make a positive transition to the most appropriate educational placement. Children start attending the Specialist

Children's Centre from two and half years and attend for two to five days a week depending on parental preference and the individual child's health.

In my role as the named EP for the Specialist Children's Centre, I support staff and provide consultation and psychological advice to help support children's learning and development. The severity of the needs of the children who attend the Specialist Children's Centre means that nearly all the children transition from this centre to a specialist school when they are rising five years old. In order to access a specialist school, they require a statement of special educational needs. The Specialist Children's Centre provides an educational setting in which the child's development can be observed over time and information can be gathered to inform the statutory assessment process, which leads to a Statement of SEN. The statutory assessment process is always undertaken during the child's time at the Specialist Children's Centre.

Under section 323 of the 1996 Education Act, I am asked to write a psychological report for each child attending the Specialist Children's Centre undergoing statutory assessment. When writing the psychological report, I collect information from several sources: observations of the child over time, consultation with staff and conversations with parents.

Children attending the Specialist Children's Centre have typically had difficult early lives, with periods in hospital due to ill health. In order to gather the parents' views and understand the child's medical history and the implications of their condition, several meetings are held with the parents, as it is important to give parents the time and space to retell their child's story. Great sensitivity and care are taken in these meetings, as I am mindful that distressing feelings and emotions can easily surface when parents retell difficult or traumatic events relating to the health and well being of their child.

Working in the Specialist Children's Centre for several years, I have had many discussions with parents of children with severe and complex SEN. Parents often speak about the pressure on family life created by long periods in hospital, multiple medical appointments and the care they administer daily. Some parents raise concerns about the impact this has on their other children.

Through these meetings, I began to question the experience of the brothers and sisters of the children attending the Specialist Children's Centre.

Within my role as the named EP for the Specialist Children Centre, I come into contact with siblings through family fun days facilitated by myself and the staff. During family fun days, I am able to observe first-hand the disabled child within the context of their family. I also come into contact with siblings in meetings that take place during school holiday periods when parents have been unable to find childcare.

There is one defining moment that can be pinpointed as the event that cemented my desire to complete this research. In a meeting in the school holidays with a single parent of a child with a highly complex medical condition, the parent had brought along her other child, aged ten years, as she could not find suitable childcare. When asked whether the child wanted to come into the meeting, the parent stated that the sibling had brought along his handheld computer as he was very used to waiting outside during meetings. The image of this sibling waiting outside the meeting room, playing alone, ignited my mission to study the experiences of siblings of children with severe and complex SEN. I felt that there were unique issues relating to their situation that are significant and may be overlooked by professionals working with their family. I decided that I wanted to be the vehicle for their voice to be heard.

1.2.2 Personal influences

Anecdotal evidence would suggest that a researcher's choice of research area can be influenced by professional and practical reasons. Early life events, in particular, can draw a researcher to a particular research area, as events that happen in their childhood are often the most poignant and influential.

Within my family, I am the middle child of three children. Interactions with my siblings provided opportunities for experiencing different emotions. The quest for parental attention and rivalry was evident in childhood and at times can still be evident today. My sibling relationships allowed for the safe experience of emerging emotions and feelings such as jealousy, anger and frustration. These difficult emotions sat alongside love and care.

Although I do not have a sibling with complex or severe SEN, when I was growing up my elder brother had difficulties in school and my younger sister struggled with literacy. Situated in a middle position in the family, alongside siblings with some degree of special educational needs, I gained some awareness of the experience of sharing parental attention with siblings who required a higher level of parental attention and intervention.

These childhood experiences helped shape my personality and interests and, alongside others factors, drew me to my chosen profession of educational psychology. The skills I have developed in empathetic and active listening, conflict resolution and negotiation could potentially be seen as stemming from my early experiences and helped to influence my interest in sibling research.

1.3. The context for the research

Before discussing the rationale for exploring the experiences of siblings of children with severe and complex SEN, I feel that it is important to place this research within a broader context. This section introduces the reader to the wider international position, particularly key international organisations which aim to meet the needs of siblings of disabled children. This is followed by the national socio-political picture, including key policies from the current and previous government that have been introduced into the education, social and health system and are pertinent to the lives of siblings of disabled children. Finally, my own position as a researcher and an educational psychologist will be highlighted, including the local context in which this research was carried out.

1.3.1 The international perspective

Internationally, there are a number of organisations specifically aimed at supporting siblings of children with disabilities. Possibly the largest and the most internationally renowned is the 'Sibling Support Project' in the USA. This is a national organisation committed to supporting the siblings of people with physical difficulties, illness or mental health difficulties.

The Sibling Support Project advocates that disability and illness can affect the lives of everyone in the family. Their aim is to improve the peer support and

information opportunities for the siblings of people with special needs and to increase parents' and professionals' understanding of sibling issues. They train professionals across the world on how to implement their Sibshop programme. They also sponsor Sibnet, the internet's largest forum for young and adult siblings, where participants can share issues and talk to others in a similar position. (<http://www.siblingsupport.org/> last accessed 13.4.2013)

Also originating in the USA is the Sibling Leadership Network, which is an organisation set up to provide a framework for promoting sibling issues and information exchange. The Sibling Leadership Network is comprised of leaders in the field who have extensive experience of many different sibling issues. The network consists of individual and state organisations that meet to develop annual action plans to support family policy initiatives which include supporting the needs of siblings. (<http://siblingleadership.org/> last accessed 13.4.2013)

Australia also has an internationally renowned sibling dedicated organisation called Siblings Australia (<http://www.siblingsaustralia.org.au>). Siblings Australia was set up to provide advice and support for the siblings of people with disabilities, mental health difficulties and long term illness. This organisation provides a range of resources for professionals, parents and teachers to help support siblings. It also provides online networking opportunities for families and siblings across Australia and worldwide.

1.3.2 The national social and political context

The section examines key political documents from the last ten years which are pertinent to the lives of siblings of disabled children and of relevance to professionals working with their families. Also outlined in this section is the UK's largest charitable organisation solely aimed at supporting siblings of disabled children, called Sibs.

The key political documents discussed in this section are as follows;

1. The Special Educational Needs and Disability (SEND) Green Paper: Support and aspiration: A new approach to special educational needs and disability (DfE, 2011)

2. The National Service Framework (NSF) for Children, Young People and Maternity Services (DfES & DoH, 2004), including:
 - a. Standard Eight of the NSF “Disabled Children and Young people and those with Complex Health Needs”

Documents which build on the recommendations made in Standard Eight of the NSF:

- b. National Framework for Children and Young People’s Continuing Care (DoH, 2010)
 - c. Aiming High for Disabled Children: Better support for families (2007)
3. Every Child Matters (DfES, 2003) and The Children’s Act (2004)

1. Special Educational Needs and Disability (Send) Green Paper: Support And Aspiration: A New Approach To Special Educational Needs And Disability (2011)

Since starting this research, there has been a change in political leadership in England and Wales from a Labour government to the coalition government formed by the Conservatives and Liberal Democrats in 2010. The new coalition government has made changes relating to meeting the needs of children with disabilities and their families.

Recently submitted is the Special Educational Needs and Disability (SEND) Green paper, Support and aspiration: A new approach to special educational needs and disability (2011). A Green Paper is a consultation document usually produced when the Government are considering introducing a new law. In this case, the thoughts and aspirations suggested in this document are likely to form part of the Children's and Families Bill currently going through Parliament.

This Green Paper sets out the coalition’s vision to establish a new single assessment process called the ‘Education, Health and Care Plan’, which is intended to replace the statutory assessment process and statements of special educational needs. It is hoped that this single assessment process will bring together the support families rely on across education, health and social care. It

is hoped that all professionals will work collaboratively with families to agree a plan that reflects their hopes for their disabled child from infancy into their adult life.

This document recommends that the local authorities and health services should support and meet the needs of the whole family. No specific reference is made to siblings except for noting the positive benefits of short breaks for the disabled child, providing opportunities for the parents to care for other siblings.

It is hoped that further documentation building on the recommendations made in this Green Paper may provide further reference to supporting the siblings of disabled children and that within their pledge to ensure that “every child and every family gets the help they need when they need it” (DfE, 2011), the siblings of children with disabilities are not forgotten.

2. The National Service Framework (NSF) for Children, Young People and Maternity Services (2004)

The NSF, published in 2004 by the Department of Health (DoH) and the Department for Education and Skills (DfES), is the previous government's ten-year programme to stimulate long-term and sustained improvement in children's health.

The NSF contains eleven separate documents known as standards, which together provide recommendations to improve the health and social care services delivered to children and their families. Standard eight is most relevant to this research.

a. Standard Eight of the NSF: “Disabled Children and Young People and those with Complex Health Needs”

Standard Eight of the NSF, “Disabled Children and Young People and those with Complex Health Needs”, is highly relevant to this research, as this document places the disabled child within the context of their family and its main objective is to improve services for the whole family.

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives. (DoH and DfES, 2004, p. 5)

The needs of siblings are highlighted in Standard Eight with reference to ensuring that appropriate mental health services are available for children and young people with complex health needs and their siblings;

Local Authorities, Primary Care Trusts, Child and Adolescent Mental Health Services should ensure that disabled children have equal access to Child and Adolescent Mental Health services and the siblings of disabled children. (DoH and DfES, Standard 8, 2004, p. 13)

It is suggested that multi-agency assessments undertaken address the support needs of siblings;

Local Authorities, Primary Care Trusts, NHS Trusts and schools should ensure that assessments include parents' needs for support with caring for a child and also address the support needs of siblings. (DoH and DfES, Standard 8, 2004, p. 8)

It is also recommended that when professionals are providing information regarding the disabled child's condition and treatment, appropriate and accessible information should be made available to the siblings of disabled children (DoH and DfES, 2004 p.29).

b. National Framework for Children and Young People's Continuing Care (2010)

In March 2010, the Government published the "National Framework for Children and Young People's Continuing Care". This document gives guidance to professionals on how to deliver the vision and standards for the care of disabled children set out in Standard Eight of the NSF.

This document makes recommendations to improve the lives of disabled children and their siblings. It proposes that professionals conduct a holistic and family-centred assessment of the child's continuing care needs and this document makes specific reference to the needs of siblings. It suggests that as part of the assessment, professionals ask the following questions:

- Are there any problems with the education of the child/young person or siblings?
- What understanding do siblings have of the child/young person's condition?
- Are siblings involved in care?
- Are the recreational needs of siblings and other family/carer's family members being met?
- Parent and siblings' views (DoH, 2010 p.40).

This document is one of the first of its kind that makes specific reference to the needs of siblings and highlights the need for professionals to consider their thoughts, feelings and well being when making an assessment of a child with significant needs.

c. Aiming High for Disabled Children: Better support for families (DfES, 2007)

Building on the recommendations made in Standard Eight of the NSF (2004) is the document "Aiming High for Disabled Children: Better support for families", published in May 2007 by the Department for Education and Skills (DfES). The vision behind "Aiming High for Disabled Children" is for all families with disabled children to have the support they need to live ordinary family lives. It describes how services should work together to improve outcomes for disabled children and their siblings by providing better and timely support to families.

Focused, effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their siblings, to help to improve outcomes for all. (DoH and DfES, 2007 p.12).

A further recommendation from this document that is relevant to the lives of siblings of disabled children is the recognition of the importance and significant benefits of short breaks for disabled children and their families, including their siblings. This recognises the call to provide enhanced services for disabled children and their families so that they are able to spend quality time together and have a break from their usual daily routine.

3. Every Child Matters (2003) and the Children's Act (2004)

The current government is currently in the process of formalising the Children and Families Bill to implement the changes to the law required to implement the recommendations made in their Green Paper "Special Educational Needs and Disability (SEND) Support and Aspiration: A new approach to special educational needs and disability" (2011).

At the time of writing, England and Wales remain under the legislative commitments of the Children's Act 2004, which sets out the previous government's vision for every child to have the support they need to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing, as detailed in "Every Child Matters: Change for Children" (DfES, 2003).

Although the needs of siblings are not specifically noted in "Every Child Matters" or the Children's Act (2004), some of the recommendations are pertinent to the needs of siblings of children with severe and complex SEN. For example, improving communication across services is particularly important for families who have multiple agency involvement and could help to highlight the needs of siblings, particularly if they have a caring role. The first and third key outcomes, "enjoying good mental health" and "enjoying and achieving at school and in the community", are particularly important when thinking about the needs of siblings.

The next section highlights the work of the UK's largest charitable organisation whose sole aim is to support the siblings of disabled children.

Sibs

Sibs charity was founded in the UK in 2002 by Monica McCaffrey. McCaffrey's work started when she ran workshops and support groups for parents of children with disabilities. Overtime she was regularly contacted for advice regarding siblings issues and this led her to realise that there was a need for an organisation in the UK to solely focus on supporting the siblings of children with disabilities.

Sibs was created to provide information and support for siblings but it also provides support for parents and professionals on how to support siblings. On its website (www.sibs.org.uk) it has a extensive range of support materials and on line resources for siblings, parents and professionals. Sibs also provides national training programmes and resources to help professionals set up and run siblings support groups.

Sibs also work alongside local government to promote sibling issues and develop initiatives that support sibling service development. Their long-term hope is to see every local government authority promoting the needs of siblings through a sibling service which provides group and one to one support for siblings who need help or advice.

1.3.3 The local context

The Specialist Children's Centre in London not only supplied the idea for this study but also became the location for the research and provided the sample population.

My dual position as a researcher and also a known professional to the families using the Specialist Children's Centre was beneficial in terms of recruiting participants but also created a possible bias, which will be discussed further in the methodology chapter.

Conducting this research within the local authority where I worked offered a number of practical advantages and allowed the study to run alongside my everyday work. It also meant that discussion about the research study occurred

both spontaneously with other professionals and colleagues and during formal supervision and informal professional discussions.

In the next section, the rationale for the research will be explained and the aims identified.

1.4 Rationale and aim

The aim of this research is to explore the experiences of siblings growing up with a younger sibling with severe and complex SEN.

In light of advances in medical techniques and practices in the past ten years, the prevalence of children being born with severe disability and complex needs has risen (Family Resources Survey, 2010/11). The Thomas Coram research unit (2008) estimate that 1.2% of the UK's child population has a complex or severe disability.

With ever-improving neonatal care and medical advances, the number of children born with severe disabilities is estimated to rise over the next twenty-five years (Costeloe et al, 2012). It is now much more typical for the disabled child to grow up within the family setting alongside their siblings rather than in specialist residential provision (Gooch, 1996). With this in mind, there is a greater need than ever before to develop a better understanding of how best to support families with a disabled child.

Research suggests that families with a disabled child have a very strong desire to do things together and be perceived as a whole family rather than the disabled child being supported in isolation (Greco et al., 2005). Documents produced by the current and previous government show an increasing awareness of a whole family approach. This includes a move from support services targeting the disabled child to the focus becoming increasingly family centred. Organisations are required to provide family-centred services which enable disabled children and their families to live regular lives (DoH and DfES 2004).

Research by Strohm (2002) supports holistic and family-centred practices. Strohm advocates that a disabled child will make the best progress when their parents and siblings are “all able to feel confident and emotionally supported” (p.172)

Although recent government documents are recommending that professionals seek out the views of siblings and incorporate their thoughts, feelings and current functioning into their assessment (DoH 2010), the views of siblings may still be overlooked by professionals working with the families of disabled children.

The rationale and aim of this research is revisited in Chapter Two following a review of the current research, which presents conflicting findings on a variety of psychological, social and cognitive outcomes.

The differing findings regarding how siblings experience growing up in a family with a disabled sibling gives justification for using a qualitative method of analysis such as IPA, which will illuminate the sibling experiences and will enable the children’s voices to be heard more directly.

There is increasing acknowledgement of the value of listening to the child’s voice in social research. This research espouses that children are expert informants about their own lives and experiences. They can be viewed as “active, competent, and reflexive constructors of their own worlds, who have a rightful place as social actors capable of influencing societal matters and policies that directly impact them” (Tay-Lim & Lim, 2013, p67).

In using IPA, a co-construction process develops, whereby the researcher and the participant are active participants and the resulting dialogical process plays a major role in the understanding of the phenomena. When completing interview research with children the role of the researcher is crucial in creating a supportive space to allow the child for free expression of their views. My longstanding professional role as an EP will help to ensure I am able to build rapport and allow the child’s voice to be heard directly.

My work within a Specialist Children's Centre and the skills I have developed through my work put me in a unique position to undertake in-depth interviews with children who have a sibling with severe and complex SEN. It is hoped that these in-depth interviews will allow a highly personal account of the child's idiographic experience to emerge. Through detailed analysis of these interviews, the richness and diversity of the experience with their disabled sibling can be explored and the lived experience be interpreted reflectively. Furnished with this knowledge, I hope to make recommendations to improve the understanding and effective working practices of professionals working with families of disabled children and in particular how to support the siblings of children with severe and complex SEN.

1.5 Research paradigm

Mertens (2005) suggests that researchers should examine their underlying assumptions about the nature of reality and knowledge, as their view of the world or chosen paradigm has implications for every decision made in the research process.

Within paradigms, there are epistemological, ontological and methodological assumptions, which provide a framework for the researcher and elucidate the purpose of the research and the kind of knowledge it may create. Whether implicitly present or explicitly acknowledged, these epistemological considerations underpin the researcher's belief about knowledge and how it can be acquired (Mertens, 2005).

The aim of this research is to attempt to understand the experience of a child growing up with a brother or sister with severe and complex special educational needs using IPA.

IPA has theoretical roots in phenomenology, hermeneutics and idiography (Smith, 2011). Epistemologically, IPA has its foundations in critical realism (Bhaskar, 1978) and the social cognition paradigm (Fiske & Taylor, 1991).

Critical realism can be thought of as constant and continuing features of reality that cannot be conceptualised. (Bhaskar, 1978; Finlay, 2006; Willig, 2008). The

meanings people attribute to the same experience will vary as they experience their own reality, through their own personal lens. "The social cognition paradigm is based on the assertion that behaviour and language reflects these differences in meaning either directly or indirectly" (Fade, 2004 p.647).

IPA also sits within a symbolic interactionist position. This suggests that the individualised meaning people attribute to an experience is negotiated within a social context (Smith, 1995). The researcher attempts to get close to the participants' personal world; however, it must be acknowledged that this can never be done directly or completely as this process will always be influenced by the researcher's own stance, hence the identification of the research as a process of interpretative activity (Smith et al., 1997) and the importance of bracketing out conscious and unconscious assumptions through maintaining a reflexive stance.

1.6 Reflexivity

To be a reflexive researcher is to show "thoughtful, self aware analysis of the intersubjective dynamics between researcher and the researched" (Finlay & Gough, 2003 p. ix). Reflexive thinking practices are crucial in psychological qualitative research. Without reflexivity and self examination, there is a danger of generating research that contains personal characteristics, preconception and bias (Finlay, 2003). Thus, reflexive tools have been used in this research to provide authenticity and to support the quality of the findings.

Reflexivity has particular relevance to research studies using Interpretive Phenomenological Analysis (IPA), as the findings are a product of the relationship between the participant and the researcher.

Within this research, I have attempted to maintain an inward critical gaze throughout all phases of the study, focusing how my background, assumptions, professional and personal position and behaviour have impacted on the research process. To help facilitate reflexive thinking, a research diary was used throughout all phases of the research, including noting pre-research and post-research assumptions, and ongoing peer review, supervision and

discussion were used to continually monitor and audit the research process. The practice of reflexivity is further discussed in the methodology section.

1.7 Distinctive contribution

This research study has been developed to contribute to a gap in knowledge in sibling research. It will build on previous sibling research by highlighting the experiences of an underrepresented group. Its distinctive contribution lies within the in-depth analysis of the experiences of siblings of children with severe and complex SEN. This research is the first of its kind to use of IPA to develop thick descriptions to illuminate the experience of siblings of children who have a younger brother or sister with severe and complex SEN. This contributes to the distinctiveness of this research.

1.8 Summary of chapter one

Chapter One has introduced the reader to this research study. This chapter began with an account of how personal and professional experiences led to the emergence and inspiration of the idea for this current research.

The social and political context in which this research is framed has been discussed, including government guidance which advocates that professionals consider the needs of the whole family when making an assessment of a child with a disability. National and international support organisations for siblings have been highlighted alongside the location of this research study at the Specialist Children Centre in London.

Factors such as a paucity of research adopting a qualitative and phenomenological approach, the call to give a voice to an underrepresented group and a push to provide more family-centred services to disabled children provide a rationale for this study.

The qualitative methodology was introduced, including an introduction to IPA as a means of capturing and exploring the meanings participants give to their experience.

Reflexivity as an ongoing process that pervades across this research has been highlighted. The chapter concludes with the distinctive contribution this study makes to the field of sibling research.

The next chapter will provide an extensive literature review in the area of sibling research and specifically research on siblings of children with severe disabilities.

Chapter Two: Literature Review

2.1. Introduction to chapter two

This chapter begins by placing this research within a systemic theoretical perspective and examining the conceptual underpinnings guiding this research. This provides a framework which, at its heart, names the family as a context for understanding sibling relationships, but also acknowledges wider influences. Theoretical concepts from family systems theory, bio-ecological models and a social model of disability are discussed in turn and then integrated in critical reflections. The sibling relationship is discussed, including factors influencing this unique relationship.

The latter half of this chapter focuses on current literature within sibling research, focusing specifically on studies which investigate the lives of siblings of children with severe and complex disabilities. The search strategy used to find key studies is described. The studies resulting from the literature search are presented so that studies with similar outcomes are grouped together. This is followed by a critical review of literature and a synthesis of the literature review and the theoretical framework. In the light of the literature review, the rationale and aims are revisited to show how this research study fills a gap in the current body of literature. Finally, a summary of the chapter is provided.

2.2. Theoretical frameworks

The theoretical framework underpinning this research is systemic. The adoption of theoretical models from other fields has stimulated research designs for studying siblings of children with disabilities. Discussed in this section are two system-based theories: the family systems theory (Munichin, 1974) and the bio-ecological model (Bronfenbrenner, 1979). The family systems theory is used to conceptualise the influence a disabled child can have on the family system and the bio-ecological model is a broader theoretical model viewing children's development as a result of their interaction with surrounding ecological systems, including those outside the home. Also discussed in this section is the social model of disability, which was developed in the 1970s as a reaction against the traditional medical model view of disability. Finally, this section examines

significant relationship dimensions that constitute important variables in the sibling relationship.

2.2.1. Family systems approach

Sibling relations do not take place in isolation and the family systems theory places the family as a context for understanding sibling relationships. “Relationships between brothers and sisters develop against a backdrop of complex, interconnected family relationships” (Stoneman & Berman, 1993, p. 3).

A family systems approach to the study of the family rests on the assumption that the family is a system, which contains different subsystems that mutually influence one another. This system cannot be understood by totalling the information on individual members instead it should be regarded as an organic whole: “human behaviour should be conceptualized at a level broader than the individual” (Kazak, Simms, & Rourke, 2002, p. 134).

The family therapy work of Munichin (1974) explored the family as comprising three subsystems: the spousal subsystems, the parental subsystem and the sibling subsystem. Events in any one subsystem have an impact in the other family subsystems and changes that accrue to one family member affect the entire family system. Therefore, the sibling relationship is influenced by a myriad of factors within the family. For Munichin (1974), understanding the interrelationships between these family subsystems was the foundation for beginning intervention in his structural approach to family therapy. For researchers, this model would suggest that it is impossible to understand the sibling relationship without considering the family system in which the siblings are placed.

2.2.2. Bio-ecological model

Within sibling research, the bio-ecological model views sibling development as being embedded within an interlocking web of relationships that form the child’s social environment. The child sits within the heart of a multiple system, the elements of which interrelate with each other directly and indirectly (Bronfenbrenner, 1979). The application of Bronfenbrenner’s bio-ecological

model to research on siblings illustrates the various systems, including systems outside the home, that may impact on a child and their family.

Bronfenbrenner describes five “layers” of environment and it is assumed that changes or conflict in any layer can influence other layers. Figure 2 illustrates these layers.

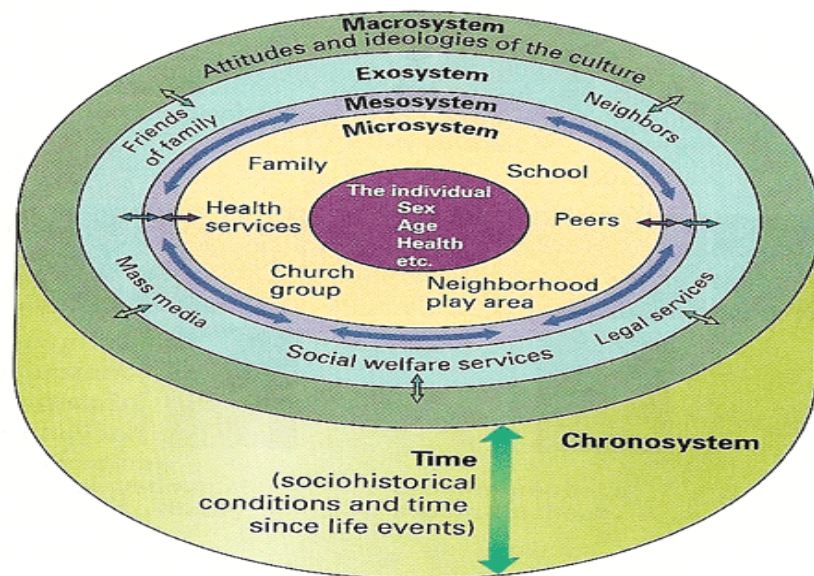


Figure 1: Bronfenbrenner's bio-ecological model. Adapted from <http://nlyingst.iweb.bsu.edu/edpsy251/courseconcepts/251/bronfenbrenner.html> accessed on 10.5.13

The microsystem is the layer immediately surrounding the child. It includes the relationships a child has with their immediate surroundings, including their family, peers and school. Within the microsystem, relationships are seen as bidirectional or mutual and can have the greatest impact on the development of a child.

The mesosystem unites the different microsystems within the child's world: for example, the relationship between the child's school and their parents.

The exosystem describes the layer between the child and an environment within which they do not function actively but which influences their life, such as their parents' workplace or changes in health care or community services.

The macrosystem describes the society in which the individual lives. Changes in the culture, ideologies and laws within the macrosystem will influence interactions in the other layers.

The chronosystem is concerned with the timing of different events over the course of the child's life. These events can be external, such as changing schools, or internal, such as physiological changes in adolescence. The patterning of these events will determine how the child reacts to them: for example, as they get older, they may react differently to environmental events such as transitioning away from home.

2.2.3. Medical model versus social disability model

The definition of disability has shifted over time and is influenced by varying societal, ideological and political context. Government policy and professional practice has been largely influenced by the medical model, which connects disability with ill-health, physical dysfunction and impairment (Oliver, 1990). Within this medical model, disability is an individual problem and people are defined in terms of their diagnosis and disability. In comparison, the social model of disability separates a person's limitations caused by their impairment from the societal barriers that can stop disabled people accessing mainstream life (Oliver, 1990).

The social model of disability advocates the need to understand the social, political and economic contexts in which disabled children and their families live (Shakespeare, 1996). It starts from the standpoint that all disabled people have a right to belong and be respected in their local community. Using this model, the strengths of the person with the impairment are highlighted and society endeavours to overcome the physical and social barriers that obstruct them.

A social model of disability is framed by how society views, understands and interprets human differences (Oliver, 1990). Therefore within this model, how children and families respond to the presence of a disabled child in their family varies depending on whether their interpretation is that something is wrong with their sibling or that something is wrong with the way in which society conceptualises disability. Frude (1991) suggests that a child's attitude,

behaviour and feelings towards their disabled sibling is a manifestation of the parental response to having a disabled child. Within the social model of disability, how society and how parents understand disability sets the stage for how children will react to having a sibling with a disability.

2.2.4. The sibling relationship

The significance of the parent and child relationship and the type of attachment formed is widely recognised to be of fundamental importance for human development (Bowlby, 1969). However, sibling relationships are just as significant, since brothers and sisters generally spend more time together than parents and their children. Furthermore siblings' lives overlap to a larger extent than with parents and their children, creating a longevity that is unparalleled in any other relationship. "Sibling relationships are usually the longest and most enduring of family relationships" (Mandeleco et al., 2003, p. 14).

The longevity of the relationship between siblings is unique, but also important is the role the siblings have in each other's development. A body of work over the last thirty years provides clear evidence that the sibling relationship influences development and behaviour (Whiteman & Christiansen, 2008). Daily interactions amongst siblings supply children with their earliest socialisation experiences. These childhood experiences give children the chance to learn about joint play, cooperation, sharing, conflict resolution, friendship and to experience different emotions such as jealousy, disappointment, anger and happiness (Gibbs, 1993).

In developing a model for sibling relationships, Stoneman (1993) identifies three relationship dimensions that constitute important variables in the sibling relationship:

- 1) Sibling role and role asymmetry;
- 2) Social engagement;
- 3) Affective tone.

Role relationships among siblings vary in their degree of symmetry. In general, sibling role relationships through childhood are asymmetrical, with older siblings

taking more authoritative, dominant roles in comparison to their younger siblings (Stoneman, 2001). Over time role relations between non-disabled siblings become progressively more even (Cicirelli, 1982), approximating the more equalitarian role sharing found between peers and friends. When one child has a disability, this normative pattern may not apply. Sibling pairs that include a disabled child may be on a trajectory that points them towards adolescent and adult sibling roles characterised by dominance of the nondisabled sibling rather than towards more symmetrical adult or adolescent sibling friendship. It is plausible that this role structure may deny individuals the equalitarian social friendship that makes many relationships between adult siblings mutually satisfying.

The second component of the sibling relationship is social engagement (the amount of time for which siblings are engaged with each other). During childhood, siblings can spend significant portions of the nonschool day playing and interacting together. Siblings differ in the amount of time they spend together and the activities that form the context for their interactions (Stoneman et al., 1984). Stoneman et al. (1984) found that some siblings are inseparable while others are more socially disengaged. When one sibling is disabled, their ability to engage in mutually satisfying play and games is limited by their cognitive ability and physical limitations.

The final aspect of the sibling relationship is affective tone. This refers to the extent to which the sibling relationship is characterised by discord and high rates of conflict or is a close pro-social and caring relationship. Many sibling relationships swing between the two. "The relationship between siblings is one of the most powerful, longest lasting human relationships, characterised by a wide range of emotional responses that can quickly change from warm to hostile and back again" (Dunn & Kendrick, 1982, p.11).

Brody and Stoneman (1987) posit that the sibling relationship is influenced by the individual characteristics of each sibling, the composition and dynamics of the family and by the parenting approach used by the primary caregivers. The child-rearing and parenting strategies are also influenced by a number of factors, including the parental personality, their individual characteristics and

relationships within the family. Factors originating outside the nuclear family (e.g. social support, school, extended family) also exert undeniably important influences on family functioning, including the relationship between siblings. Hames (2008) suggests that sibling's understanding of disability derives from parental language and how relative abilities and disabilities is discussed.

2.2.5. Critical reflections

The theoretical framework for this study draws on different existing theories, which guide this research and suggest key variables that may influence the phenomenon under investigation.

Overall, the theoretical perspective of this research is systemic. Underpinning this study is the family systems theory (Munichin, 1974), which recognises that siblings influence one another in a complex and multi-factorial way and changes in one subsystem impact the family system as a whole.

Also informing this study is a bio-ecological model (Bronfenbrenner, 1979). This model views child development as a result of the interaction between child and the surrounding ecological systems, including those outside the home. It suggests that neither human development nor clinical practice can be understood in isolation from its ecological systems or socio-cultural environment. This theoretical perspective allows for the examination of the development of siblings not only in the home but also in the wider systems, such as school. This broader ecological model generates a wider perspective of the impact of disability on siblings.

Also described in this section is the social model of disability, which frames disability in terms of social relationships and the way in which human differences are interpreted and understood (Oliver, 1990). Within this model, how parents view disability sets the scene for how children interpret their siblings' behaviour. Work by Hames (2008) suggests that a child's understanding of disability is facilitated by the language and discussion of disability within the family. Also, within the social model of disability, societal beliefs, expectations and values around disability will influence children's understanding of disability and their experience.

In this section, the significance of the sibling relationship and the influence of the family and the wider system on the sibling relationship are noted. The work of Stoneman (1993) is used to describe three relationship dimensions which are important variables when studying the sibling relationship. It will be helpful to have an awareness of these key relationship traits when examining the sibling experience.

Different theoretical frameworks have been presented to describe the ideas, theories and principles that are relevant to the siblings' experience. The purpose of this has been to provide a useful tool and assist the researcher to make meaning from the subsequent findings. The next section provides a description of the literature search and a critique of the key studies found.

2.3. The literature search

The following section details the search strategy used to find relevant studies, including the key words used, the databases searched and the inclusion criteria applied in order to select the most relevant studies.

This research adopts an exploratory, qualitative design, with the aims being to enrich the understanding of the experience of siblings with a brother or sister with severe and complex special educational needs. It therefore seemed appropriate to implement a flexible search strategy that also provides a comprehensive and systematic coverage of the previous relevant research. The search strategy involved two steps.

The first step involved generating a comprehensive list of relevant journal articles and books. Literature searches were undertaken of the electronic database EBSCO host . A database search was undertaken regularly over a three-year period, with the last search being in June 2013.

The advanced search facility available in EBSCO was used to combine the keywords 'siblings' and 'experience', 'siblings' and 'relationship', 'siblings' and 'impact' and 'siblings' and 'adjustment' with the words 'severe and complex special educational needs'. This search produced zero results (N=0).

It was decided to replace the words 'severe and complex special educational needs' with 'severe disability', as this is a broader, more generic term. The advanced search facility available in EBSCO was used to combine the keywords 'siblings' and 'experience', 'siblings' and 'relationship', 'siblings' and 'impact' and 'siblings' and 'adjustment' with the words 'severe disability'. This search resulted in the retrieval of a total of 122 studies (N=122). The grey literature was searched, including unpublished theses and unpublished documents from sibling support organisations. Manual searching of reference lists from retrieved studies and the reference lists from documents found online on websites from sibling support organisations were also studied. This additional searching helped to broaden the search and ensure that studies had not been missed. The body of research resulting from the search can be found in Appendix 2.

The second step involved applying inclusion criteria to select the most pertinent and relevant studies. These inclusion criteria are detailed below.

- a. The study examined the impact, relationship, adjustment or experience of a sibling of a child with a severe disability.
- b. When selecting studies, I ensured that the type of disability featuring in the study was one that would typically allow access to the Specialist Children's Centre. This guaranteed that the studies selected were the most relevant to this research. Examples of conditions equated with a severe disability are the following:

Spina Bifida

Profound and multiple learning difficulties

Multiple disabilities

The application of this inclusion criterion was typically the key reason why studies were excluded. Studies were excluded where the disabilities featured were higher incident disabilities, e.g. dyslexia, dyspraxia and Autism Spectrum Disorders (ASD).

- c. Research participants were aged between 6 and 19 years.
- d. Articles were published in English and peer reviewed.

- e. Articles were published between 1990 and 2013 to ensure that they reflected a more current understanding towards disability.
- f. Articles provided a clear description of the design and methodology employed.

The application of the inclusion criteria led to the identification of thirteen relevant studies (N=13). Information on each study is provided in Appendix 1.

2.4. Themes emerging from the studies

In order to structure this literature review, studies with similar findings were grouped together. Looking at the body of studies resulting from the literature search, it seemed that the findings could be grouped under four themes.

1. Potential risks
2. Nil effect
3. Potential benefits
4. Positive and negative outcomes

The following section provides an overview and critique of each study. The selected studies were appraised on several dimensions, such as the methodology, process and evaluations (i.e. contextual information and data collection and analysis) and by evaluating the findings or results.

2.4.1. Potential risks

The literature contains studies which highlight the potential risks for a sibling growing up with a brother or sister who is severely disabled. These studies suggest that the siblings of such children may experience a range of negative consequences, including depression and mental health difficulties (Sharpe & Rossiter, 2002), distress and adjustment problems (Fisman et al., 2000) and upset, anger and resentment (Williams et al., 2010).

A qualitative study highlighting the potential negative effects was completed by Williams et al. in 2010. This study asked 151 parents to respond to the following open-ended question:

“Developmental disability in one of my children had had the following effects on the brother or sister without developmental disability” (p.42).

Statistical analysis revealed that 61% of parents identified concerns regarding an increased risk to the normally developing sibling, including poor peer relations, vulnerability and withdrawal, anger and resentment. This study relied almost entirely on maternal reports (90%), instead of talking to the children directly, thereby creating a lack of the sibling voice running through this study. It can be argued that using mothers as informants creates a subjective bias and the use of maternal reports can be criticised on the grounds that the mother's assessment of the adjustment of her non-disabled children may be affected by her own adjustment.

In an effort to quantitatively integrate the findings of past studies which examined the effect of having a sibling with a chronic illness on normally developing siblings, a meta-analysis of the research was undertaken by Sharpe and Rossiter in 2002. Fifty-one studies published between 1976 and 2000 and 103 effect sizes were examined through meta analysis. Although the aims were not explicitly stated it seemed the study had three intentions firstly to ascertain the overall impact of having a sibling with a chronic illness, secondly to establish whether this related to a specific domain and thirdly to determine whether these effects are related to any aspect of the methodology or features of the participants. Each study was coded by a first author and then checked by the second author. Coding related to the method, type of illness, age of sibling, comparison group and dependent variable. The authors found a small but significant negative effect. Sibling reports were less negative than parental reports. Depression, anxiety and opportunities for social activities was less for siblings of children with chronic illness than for control participants. These findings should be viewed with caution. Several studies were excluded from the meta analysis including studies without appropriate comparative or normative data and unpublished studies. In addition to this, the studies used for the meta analysis were all quantitative, these studies by their nature, lean towards the investigation of negative psychological functioning through the use of assessment tools which aim to measure the presence of maladaptive behaviour

or negative outcomes. Together, these issues, do not allow for a balanced portrayal of the possible effects of growing up with a disabled sibling.

Fisman et al. (2000) conducted a quantitative longitudinal study, which examined the adjustment of 137 siblings of children with chronic disabilities to the siblings of children of a non-disabled group. Diagnostic assessment tools, including the Survey Diagnostic Instrument and the Self Perception Profile for children, were completed by caregivers, teachers and siblings. These tools were completed initially and then at a three-year follow-up. Results indicated that significantly more adjustment problems and more externalising difficulties were found in siblings of children with chronic disability than with the control group. This study's validity was strengthened by its use of multiple participants and its longitudinal perspective. In terms of its limitations, the authors acknowledged its reliance on quantitative methods. An improvement to this research would be the use of semi-structured interviews, as this would have allowed for a greater degree of triangulation.

2.4.2. Nil effect

Studies undertaken by Dyson (1999), Magil-Evans et al. (2001) and Pit-Ten Cate and Loots (2000) do not support the view that siblings' psychological development and emotional well-being is damaged by having a brother or sister with a disability and these studies found little consequences of growing up with a sibling who was disabled.

A study by Dyson (1999) examined the correlates of self-concept, behaviour adjustment and social competence over a four-year period, comparing thirty-seven children who had younger siblings with disabilities with thirty-four children with non-disabled siblings. The results following administration of psychological scales completed by the parent and the non-disabled sibling indicated no difference in self-concept, social capability or behaviour adjustment in either time phase. This study used a rigorous experimental and longitudinal method as well as matched sampling and control over socioeconomic status, and children and parents acted as informants. The longitudinal nature of this study provides an interesting insight into whether psychosocial functioning changes over time. However, its focus on psychosocial functioning is quite restrictive and the

inclusion of other psychological measures would have given this study a wider perspective on growing up with a disabled sibling.

Reporting on their interviews with forty-three children, Pit-Ten Cate and Loots (2000) also found that having a sibling with a disability did not increase the likelihood of having psychosocial problems. Sibling interviews were organised around the following themes: the sibling relationship, the relationship between the siblings and their peers and the external community, the relationship between the siblings and their parents, adopted solutions, need for assistance and worries. Siblings also filled in the Coping Response Inventory Youth Form (CRI-YF). This study found no difficulties regarding psychological adjustment and siblings' answers reflected a healthy acceptance of their family situation. This study also showed no problems with peer relationships, while siblings showed gratitude towards their parents and a relative absence of negative feelings. This study's use of a mixed methodology increased its validity and allowed for a greater degree of triangulation. However, its sample selection may have caused a possible bias. All the siblings participating in this study came from families who belonged to a charitable organisation which supported families of children with disabilities. The support provided by this charitable organisation may have helped develop healthy family functioning and in turn led to healthy sibling functioning. Therefore the sample used in this study does not reflect the wider population which would include families who did not belong to a charitable organisation. The authors also noted that the parents' education level was generally higher than found in the population overall. Overall these factors could have created a possible bias which makes it difficult to generalise these findings

A study by Magil-Evans et al. (2001) compared the siblings of children who had cerebral palsy with a control group. Siblings were aged between thirteen and fifteen years and completed a number of inventories which assessed family functioning, life satisfaction and perceived support. Results showed that there were more similarities than differences in family functioning, life satisfaction and perceived social support among siblings and their families compared to the control families. The results of this study indicated that having a sibling with a disability did not make the period of adolescence any more demanding than for

those growing up without a disabled sibling. This quantitative study focused on adolescents, a population that rarely receives a single focus within sibling disability research, this adds to this studies distinctiveness but is also limiting. Based on their findings, the authors made an important recommendation for professional practice. They suggested that service decisions should not be based on the assumption that family functioning is directly related to the presence of a disability in the family. Instead, the authors recommended that each family have an assessment of their individual strengths and weaknesses.

2.4.3. Potential benefits

In contrast to studies which document the negative outcomes or nil effects suffered by siblings of children with disabilities, other studies have found that some siblings thrive and enjoy positive benefits from having a sibling with a disability.

Derouin and Jessee (1996) investigated siblings' perceptions of family disruption when a brother or sister had a chronic illness. Telephone interviews were conducted with fifteen siblings of chronically ill children and open-ended questions were used to assess the impact of the illness on the sibling and the family functioning. The age of the participants ranged from eight to seventeen years. Siblings identified many positive outcomes, including strengthening some family relationships, achieving more personal independence and experiencing satisfaction when seeing their ill sibling improve in health. In terms of limitations, the authors failed to note the demographic data of the participants. The small sample size (fifteen) makes generalisation difficult and the authors and I would question the efficacy of telephone interviews with children.

Two studies demonstrated that having a sibling with a disability may help to develop positive attitudes and key skills such as increased co-operation and self control (Cox et al., 2003; Mandelco et al., 2003).

Employing a qualitative design, Cox et al. (2003) examined the coping responses of siblings of children with disabilities by asking forty-six siblings (aged six to eighteen years) to respond to a sentence-completion activity regarding real or hypothetical stressful situations. Content analysis of these

reports revealed that siblings had developed proactive strategies to deal with daily stressors by taking personal responsibility for problem-solving to improve a stressful situation. Their findings suggested that a greater degree of involvement and responsibility in turn helped in the development of positive coping strategies for siblings. Caution should be exercised when interpreting these results, however, as the sample was not representative. All participants were from two-parent families and the majority were white and middle class. It is therefore difficult to generalise results across cultures and different socioeconomic groups.

Mandleco et al. (2003) explored the relationship between parental perceptions of family functioning and school-aged siblings' social skills and problem behaviours. A purposive sample of seventy-eight parents and their school-aged children and their teachers participated in the study. Fifty percent of the families had a disabled child in their family. Both parents were asked to complete the Porter-O'Leary Scale and Bloom's Family Functioning Measure. Teachers of the school-aged children completed an adapted version of the Gresham and Elliot Social Skills Rating System. Results indicated that siblings of both groups demonstrated a greater degree of social skills than negative behaviours, and siblings of children with disabilities showed more cooperative behaviour and self-discipline than siblings without a disabled brother or sister. The limitations of the sole use of questionnaire measures are acknowledged by the authors. A well matched control group would have added to the study's validity and the use of semi-structured interviews would have provided a greater degree of triangulation.

2.4.4. Positive and negative outcomes

In recent years, there has been a shift to a more balanced perspective, with more recent studies documenting both the positive and negative effects of living with a disabled brother or sister (Burke, 2012; Fleitas, 2000).

Burke (2012) notes that siblings may experience 'disability by association': that is, having a brother or sister with a disability gives a sense of difference to these children but this difference is constructed as a form of their normality. Burke used a mixed methodology to explore the impact of disability on sibling utilising

both questionnaires and interviews. The findings indicated that siblings expressed feelings of frustration due to the restrictions on their lives as a result of having a disabled sibling, but these feelings existed alongside the positive benefits their sibling brought to family life and to themselves, including increased maturity and understanding. One of the few UK based and recent sibling studies, Burke makes some very useful recommendations for improving professional practice to include a holistic assessment of a family's needs including the needs of siblings. This studies mixed methodology allows for a fuller exploration of the experience and its use of a control group enhances its validity. Conversely this studies weakness is in its very limited explanation of how the data was analysed.

A study by Fleitas (2000) named "When Jack fell down... Jill came Tumbling After: Siblings in the Web of Illness and Disability" uses the nursery rhyme as a metaphor to understand the issues relating to siblings of children with complex illnesses and disability. This article can be criticised on several methodological grounds. The description of the method of data collection and analysis is weak, making its reliability uncertain. Despite this, its reported findings are very interesting ; detailing the difference between the stressors and the positive attributes that siblings may experience as a result of their experience. "As a sibling living in the web of illness, she might incur emotional scars or develop protective calluses as a result of her experience" (Fleitas, 2000, p. 267)

Fleitas (2000) recommends that professionals should develop intervention strategies which focus on building the families' strengths and resiliency rather than focusing on problems. This chimes with the foundations of positive psychology, which is discussed further in Section 2.5.2: Balanced view or deficit based?

A study by Opperman and Alant (2003) used open-ended interviews to investigate the coping responses of siblings of children with severe disabilities. Interviews were completed with nineteen siblings and an editing analysis style was used to analyse their interview data. Analysis revealed that 32% appraised the overall situation as being negative and 21% gave a positive appraisal; the other participants gave ambivalent responses. Eight-nine percent of the

participants felt that society continues to prejudice disability and 63% admitted to not participating in family activities instead preferring their own company, while 79% could not name their sibling's disability and had no detailed knowledge regarding its implications. The authors acknowledged that their small sample size was not representative and that findings should therefore be interpreted with caution. The authors noted that a high percentage of ambivalent responses could be the result of the participants' attempt to regulate difficult or negative feelings. This may be the case, as ambivalence can be thought of as a way of managing the conflict between opposing thoughts and feelings.

A two-year study by Connors and Stalkers (2004) focused on the understanding and experiences of disabled children and their siblings. This study did not clearly meet the inclusion criteria, as it did not state the type of disability: instead, it noted that the disabled children had a 'range of impairments'. Based on this unclear description, typically this study would have been excluded from this literature review. However, this study was included in this literature review because it was one of the very few UK-based qualitative and exploratory studies, investigating the views and experiences of the siblings of disabled children. Findings from semi-structured interviews indicated that most siblings perceived their relationships and experience positively, with a few exceptions where sibling reported frustration and resentment. Some siblings reported being bullied because of their disabled sibling and restrictions on activities. The authors failed to address issues around reliability and validity in their methodology and as noted, there was considerable ambiguity regarding the nature and extent of the disabled child's impairments.

2.5. Ethnic families experience of disability

This research has been conducted in an inner London Borough where one in four residents are Black or Asian and the participants in this research reflect this cross cultural context. Six out of eight participants in this research study are from Black or Asian families.

There is a small strand of disability research which examines the effect of disability on minority ethnic families. Studies by Chandra et al. (1999), Hatton

et al. (2010) and Hubert (2006), suggest that family carers from minority ethnic families are at substantially higher risk of poor mental health and well being and can find it difficult to access appropriate services compared to their white counterparts. These studies examine the effect of disability on families, particularly parents rather than a focus on siblings from minority ethnic groups and so for this reason are not included in the literature review but have been explored in relevance to the family systems perspective, which would suggest that additional stress within the parental subsystem will have an impact on the other family systems including the sibling subsystem (Munichin, 1974).

The largest UK based study to explore the effect of disability on minority ethnic groups is by Chamba et al. (1999). In this study almost 600 parents of African-Caribbean, Indian, Pakistani, and Bangladeshi origin completed a questionnaire which aimed to explore their families' living circumstances, levels of informal support; experiences of using services and potential unmet needs. This quantitative survey was then compared with data on the circumstances and experiences of white families in an earlier study (Beresford, 1995). The findings of this study revealed that families from minority ethnic groups who are caring for a severely disabled child face additional disadvantage and problems in comparison to white families in similar circumstances. The concerns raised by carers related to three broad areas;

1. Problems relating to housing, family income and access to benefits. For example parents in the study were less likely to receive disability living allowance (DLA) and those with poor knowledge of English were least likely to be in receipt of DLA.
2. Problems relating to language communication and information. For example interpreters were not always provided and parents felt they were poorly informed about appropriate services for themselves and their child.
3. Lack of support from their own families and statutory services. Assumptions about minority ethnic families being more supported by extended family members than white families are not upheld by this

study. Parents received less emotional and practical support from their spouse/partner and other family members than the white parents in the Beresford study.

Later studies share similar findings to this large scale study. A study by Hubert (2006) surveyed the views of 30 family carers of people with learning disability from black and minority ethnic groups. The participants in the Hubert (2006) study were recruited from the same geographical location to this study (a south London borough). The study highlighted that the needs of carers from black and minority ethnic groups were not being adequately met including insufficient access to information about available services, poor communication between themselves and service providers and limited English meant that they struggled to initiate or respond to communication from service providers. Participants reported high levels of stress and social isolation including a lack of support from their family and wider community.

As highlighted earlier these studies focus on the needs and experiences of the carers of people with disability from minority ethnic groups, rather than specifically focusing on their siblings. A review of the literature has revealed the work of one group of researchers, whom have specifically examined cultural issues when exploring the psychological functioning and adaption of siblings of children with disabilities. (Lobato et al., 2005, Lobato et al., 2009 and Lobato et al., 2011). This body of work is based on comparative studies between Latino and non-Latino siblings of children who suffer with a wide range of disabilities including higher incidence disabilities and are living in the United States of America.

Latino families share the cultural value of familism (Magana, 1999) which places more emphasis on the needs of the group as opposed to its individual members and is characterised by interdependence and duty to the family (Marin and Marin 1991). This interdependent model of the self is the dominant cultural view across Latino cultures and is also seen in Japan and other Asian cultures (Kawanura, 2006). This is different from American and European cultures which value autonomy of the individual.

Lobato et al's (2011) work, comparing the psychological adjustment of Latino and non-Latino siblings of disabled children, is underpinned by eco cultural theory which would suggest that a child growing up in a culture that bestows significant value to sibling and family relationships would respond differently to a child raised in a culture where sibling relationships are of lesser importance (Bernheimer et al., 1990).

Lobato et al. (2011) found that Latino siblings are at greater risk of psychological disorders and impaired personal and school functioning in comparison to non-Latino siblings. Due to cultural sanctions against discussing family problems coupled with greater reluctance to express emotions, Latino siblings were less likely to share family based problems with their teachers. Latino siblings also had more school absences due to greater family obligations such as providing translation for parents at appointments, as well as greater anxiety separating from their parents. These difficulties coupled with other factors such as low income, poor housing and living conditions meant that these siblings had a heightened level of vulnerability.

In conclusion, these studies have highlighted the additional disadvantage minority ethnic families can face when caring for a disabled child.

2.6. Critical reflections

The following section provides my critical reflections on the studies selected for the literature review. In addition to this, I have also drawn reflections from the body of literature which was scrutinised when selecting studies that met the inclusion criteria. A list of studies before the inclusion criteria were applied can be found in Appendix 2.

2.6.1. Theoretical models

A key criticism of the body of literature is that in the absence of a substantive guiding theory, there is an implicit conceptualisation of the sibling relationship that normal and good sibling relationships are ones that are warm, supportive and lack conflict. This ideal relationship has become a research anchor, and in the absence of appropriate control groups, siblings in families where disability is present are often framed through this lens of normal sibling functioning.

It can be argued that comparing siblings of disabled children to 'normal sibling functioning' is somewhat unfair, as within any sibling dyad, there are periods of jealousy, conflict and a fight for parental attention. Problems experienced by the siblings or deviations from a normal relationship have been attributed to the presence of the disability or illness. Other possible causes of the identified difficulties may be overlooked. Furthermore, as 'normal' has multiple meanings and may inappropriately imply abnormal where it is not applied, these comparisons complicate our understanding of disability and its effects on siblings and families.

When studies do claim to be guided by a particular theory, such as a family systems approach, the trans-disciplinary and international aspects of the research can lead to wide variations in interpretation of each model or theory. Furthermore, researchers from different fields may hold different views on the characteristics of different disabilities or illnesses. Terms such as 'chronic illness' or 'physical disability' may have different interpretations depending on the discipline of the researcher and the research focus.

This lack of a dominant theoretical approach, along with differences in the interpretation of key terms, has meant that it is difficult to compare and contrast findings.

2.6.2. Balanced view or deficit based?

There is an issue regarding whether the sibling disability research provides a balanced portrayal of the key issues and concerns. From surveying the body of research to select studies that met the inclusion criteria, it did appear that overall, researchers were more interested in documenting dysfunction, focusing on assessing mental health difficulties and maladaptive behaviour, and certainly some of the studies described in this literature review used tools to determine patterns of dysfunction that resulted from having a sibling with a disability (e.g. Fisman, 2000; Sharpe & Rossiter, 2002). Over time there has been a move to a more balanced perspective, with the most recent studies (Burke, 2012; Graff et al., 2012) documenting both the positive and negative effects of living with a disabled brother or sister. This reducing focus on dysfunction and difficulty is in

line with the rise of positive psychology (Seligman, 2004) to identify character strengths and resilience factors rather than identifying stressors and risks. As noted earlier, some siblings thrive and benefit from having a sibling with a disability (Cox et al., 2003; Mandleco et al., 2003) and perhaps in time there will be an even greater focus on what distinguishes these siblings from others and what has helped them to thrive.

2.6.3 Informants

In the studies reviewed, the key informants varied. Some studies used parents and siblings as the key informants regarding the siblings' emotional and behavioural health (Dyson, 1999; Pit Ten & Loots, 2000), some sought additional information from the siblings teachers' (Mandleco, 2003; Fisman, 2000) and some just sought information from the siblings themselves (Opperman & Alant, 2003; Magil & Evans, 2001). Williams et al. (2010) sought only the views of parents. This variation regarding informants makes it difficult to compare the results of studies.

Researchers within this field should also be mindful of the sensitive nature of this subject matter. With this in mind, participants may be reluctant to share difficult or negative views due to feelings of guilt or shame and so results may be biased towards participants who respond with a greater degree of positivity. Bias may also exist in the recruitment of participants who have a more positive appraisal of their situation.

2.6.4. Methodological issues

The studies selected for this literature review and literature on sibling disability research as a whole display a high degree of disparity in relation to the findings. The inconsistency in findings may in part be attributed to several methodological limitations.

Across the body of research, there are many differing ways of collecting data, including checklists, observations, inventories, questionnaires, interviews and parental and sibling reports. These differing methodologies make it difficult to compare the results between studies.

In attempting to adopt robust scientific methodologies, it seems that there has been much use of standardised instruments in sibling research. The danger in using these instruments is that the instruments or questions chosen could influence the results. For example, instruments measuring negative or maladaptive behaviours could result in over-reporting of these types of behaviours, which may have been the case in the meta-analysis conducted by Sharpe and Rossiter (2002). Furthermore, the instruments used to measure important constructs about families and disability are often created for the general population and may not reflect the experiences of families with a disabled child and thus fail to capture constructs of particular importance for understanding the experience.

Studies using quantitative research designs contain contradictory findings and are difficult to reconcile with the single truth scientific method. When undertaking quantitative research in this area, perhaps adopting a smaller range of more specialised standardised assessment tools and well matched comparison groups within sibling research might help researchers to compare and contrast results more easily and identify variables that might impact on siblings.

In my view, whilst these quantitative studies offer important findings, they lack the depth and insights that qualitative research can offer in this area. For example, the use of interviews allows participants to explain their experiences and thoughts in their own words as opposed to fitting within a set category (Dew et al., 2008). Also, using qualitative methodology, such as semi-structured interviewing, researchers are supplied with descriptive data to examine qualitatively which gives insights into participants' experience. In addition, when investigators employ qualitative methods, inconsistencies and ambiguities need not be explained but rather are understood as part of the complexity of the individual experience.

Studies that have adopted a qualitative methodology have allowed a more in-depth study of siblings' experience, which has highlighted the language siblings used to reflect key constructs (Burke, 2012; Cox et al., 2003). Furthermore,

these qualitative studies have added a depth and understanding to results obtained from studies that have employed mainly quantitative research designs.

2.7. Synthesis of the literature and theoretical framework

Over recent decades, sibling research has steadily increased, and this reflects a growing awareness of the significance of understanding the sibling relationship and its impact on development and the family as a whole. This literature review demonstrates that researchers from a wide range of backgrounds and disciplines are interested in the effect that growing up with a disabled sibling has on other children in the family. Within the literature, a vast of array of different methodologies have been used and outcomes have varied widely.

A review of the literature highlights that children who grow up with a disabled sibling respond with considerable variability. Some siblings profit from the experience; others are seemingly not affected while others appear worse off for the experience (Schuntermann, 2007). Typically in an area of research, researchers build on what is already known. However, the lack of consistency in findings across sibling research literature and the lack of a clear logical progression in the way researchers have studied and understood this subject has meant that it is difficult to draw clear conclusions.

Alongside variability in findings and the use of different methodologies, the picture is also muddled by a lack of a prevailing and dominant theory. Early research took a pathological and medical model approach, frequently starting with the assumption that growing up with a sibling with a disability will inevitably have negative consequences. This is best illustrated by one of the very first studies to explore the impact of having a disabled child in the family; this study suggests that “a handicapped child makes a handicapped family” (McCormack, 1978, p. 12).

Later studies, use a variety of different participants to inform their studies (siblings, parents and teachers), highlighting the importance of placing siblings within the context of the family and the society in which they live, drawing on family systems theory (Munichin, 1974) the social model of disability (Oliver, 1990) and Bronfenbrenner’s bio-ecological model (1979). These models are

useful and the family systems model and the bio-ecological model share commonalities in the way the child is placed with the context of the family and the wider system. The social model of disability is also useful in helping families to reinterpret the meaning of disability in their lives. With this in mind as a way of framing sibling disability research, this research attempts to integrate theoretical concepts from family systems theory, a social model of disability and systems theory. A synthesis of these theories will help to provide a framework which considers the lives of siblings within the context of family and the social processes that surround them.

2.8. Rationale and aim

My long-standing work as an EP working in a Specialist Children's Centre has allowed me to witness some of the wide-ranging issues that emerge for families when a child has a disability. In the light of this work, I became interested in the experiences of the siblings within the family, as I felt that there were unique issues relating to their situation that were important and often overlooked.

The review of the literature suggests that research relating to the siblings of children with severe disabilities uses quantitative or quasi-experimental methods of data collection, in which participants complete batteries of tests and the results are used to highlight any psychological or behavioural effects of growing up with a disabled sibling (Sharpe & Rossiter, 2002). Qualitative methods have also been used, such as open-ended questions and interviews, allowing for a more idiographic study of siblings' experience (Burke, 2012; Graff et al., 2012).

The research literature can focus on the negative impact of sibling experiences and the assumption that siblings experience psychologically damaging effects as a result of having a disabled brother or sister. This study hopes to build on studies that take a more balanced stance through listening to the possible negative effects siblings may experience (depression, anxiety and increased care-taking) alongside positive outcomes (greater independence, empathetic skills and maturity).

The research literature is also largely based outside the UK, with the exception of some isolated research that has taken place in the UK (e.g. Burke, 2012; Connors & Stalker, 2004). The paucity of research within a UK context means that a contribution to a gap in current knowledge can be addressed by giving this underrepresented group a voice, which is heard not only by the researcher but also by a wider group of professionals working within the UK.

This area of research is given added impetus by the Special Educational Needs and Disability (SEND) Green Paper *Support and aspiration: A new approach to special educational needs and disability* (2011), which takes forward the Coalition Government's commitments to improve services for vulnerable children and support strong families. This advocates that education, social care and health services support and meet the needs of the whole family through a single person-centred plan.

The justification for using a qualitative methodology in this study is that it will enable the children's voices to be heard more directly. In using IPA, I hope to be able to explore the world of the participants, in order to describe their experience from their point of view.

Equipped with an enriched understanding of the particular issues relating to the experience of siblings, it is hoped that I will be able to identify and draw out the implications for professionals, particularly EP, so that there is an improved understanding of how best to support siblings of children with severe and complex special educational needs. Professionally, this is of utmost importance, as the primary role and function of the EP is concerned with facilitating positive change and improving outcomes for all children (Beaver, 2011).

Aim:

The primary aim of this study is as follows:

- To explore the experiences of children who have a sibling with severe and complex special educational needs

A secondary aim is draw out the implications for professionals working within children's services, particularly how they can support siblings of children with severe and complex special educational needs

2.9 Summary of chapter two

This chapter has examined and critically reflected upon the key theoretical models relevant to this research study. The search process used to identify key and relevant studies has been described. The studies resulting from the search process were clustered according to their findings and a critique of these studies was provided alongside a critique of the body of literature as a whole. The chapter concludes with the rationale for this study and the research aim used to guide this study. The next chapter provides an overview of the methodological approach to the study.

Chapter Three: Methodology

3.1. Introduction to chapter three

Chapter Three provides an overview of the methodological approach used in this research. The chapter opens by describing the paradigm within which this study is framed and the rationale for choosing a qualitative methodology. A detailed description of the process and phases in the data collection and the analysis using Interpretative Phenomenological Analysis is given. Following this, critical aspects of the research are discussed, including the practitioner-researcher role, permission and consent and ethical issues related to researching this sensitive area with children.

To conclude, a summary of this chapter is provided.

3.2. Research paradigm

This section provides an explanation of my current world view and the paradigm within which this study is framed. It also details how my world view and assumptions about the nature of reality have changed over my academic career.

A paradigm is a way of looking at the world: it provides a cluster of beliefs, which guide and direct the way research is conducted, and provides a broad framework for the rationale, values and ethical conduct of the research. Each paradigm “has its own set of philosophical assumptions and principles and its own stance on how to do research” (Neuman, 1999, p. 63).

Positivists maintain that the researcher and the researched person are independent of each other; post-positivists share a commitment to objectivity but they also acknowledge the possible effects of likely biases and researcher limitations (Mertens, 2005). The opposite pole to the positivist orthodoxy is a paradigm variously named interpretive, qualitative, naturalistic and phenomenological (Mertens, 2005). Within this paradigm, there is a belief that reality is constructed through human activity and individuals creating knowledge and meaning through their interactions with each other and with the

environment they live in. The aim of the researcher is to understand and comprehend the various social constructions of knowledge (Robson, 2002).

Mertens (2005) suggests that before commencing a study, researchers should examine their underlying assumptions about the nature of reality and knowledge, as their view of the world or chosen paradigm has implications for every decision made in the research process.

My world view has been influenced by past academic studies and interests. Choosing to complete science-based A-levels and then studying Experimental Psychology as a first degree, I was initially drawn to a positivist stance and was reliant on using quantitative and quasi-experimental methods, firstly to study the natural world and then later to study human interaction. Whilst training to become an EP, it became apparent to me that psychology and understanding human behaviour was different to the hard sciences and so an another epistemology was necessary.

Following training to become an EP and further reflection on how human behaviour can be explained and understood, my epistemological and ontological view shifted towards a constructivist perspective, recognising that truth and meaning is created via personal contact with the world.

When considering the focus of this study, I reflected on how my thinking, views and philosophical assumptions had changed over my career and influenced the nature of my work. Examining my assumptions about the world and how knowledge is acquired allowed me to understand the implications of these assumptions for how I had conducted research and systematic inquiry in the past.

My current view of the world reflects my journey from positivist roots through to constructivism, finally settling on a position that sits amid the two poles of positivism and constructivism: critical realism.

Critical realists hold the belief that the natural and the social world can be studied in a similar way and commit to the view that there is an external reality.

However, unlike positivists, critical realists do not agree that the researcher's conceptualization of reality actually reflects that reality (Bryman, 2008): instead, they would suggest that reality can only be known imperfectly because of the researcher's human limitations (Mertens, 2005).

The research paradigm links the researcher's world view and epistemological position to the choice of research design, methodology and process of data collection. In this study, a qualitative methodology was chosen and the approach for analysing the research data, Interpretative Phenomenological Analysis, sits within a critical realist position (Bhaskar, 1978).

Alongside an idea regarding the focus of the study, the methodological approach and research paradigm came together, not by a serendipitous accident but as a result of a desire to place this study within a paradigm that acknowledges reality but argues that our ability to know this reality is imperfect and to use a methodology which is qualitative and is concerned with the empathetic understanding of human experiences.

This research is also underpinned by its theoretical lens. Of significance to this research are the principles proposed within the social model of disability (Oliver, 1990), which stresses the need to recognise the social, political and economic contexts in which disabled children and their families live (Shakespeare, 1996).

This research is also grounded in the ecological model of child development (Bronfenbrenner, 1979), which suggests that siblings influence one another in a complex way and this sub-system impacts on the effectiveness of the family system as a whole. Within this ecological model, the impact of a child's illness or disability on siblings' development could be influenced by a myriad of factors including; the sibling relationship, the disabled sibling's condition and the implications of this, the siblings age, gender, their family composition and the family's social and material circumstances (Lobato et al., 2005).

In explicitly acknowledging my view of the world and driving theoretical stance, it becomes clear how these assumptions underpin the choice of research design, methodology and data collection.

3.3. Research design

The aim of this research is to investigate, using IPA, the perceptions and lived experiences of siblings growing up with a younger sibling with severe and complex special educational needs. This places a focus on understanding the meanings siblings place on their experience. A research design was chosen to answer this exploratory investigation.

Since exploration for understanding was the aim of this study, a qualitative methodology seemed most appropriate, as it provided an insight into the complexity of the experience of individuals taking part in the intervention. Although quantitative methods could be used (for example, through fixed response questionnaires), it could be argued that some of the richness of experience and perceptions would be lost using this method.

A mixed methodology was also considered: that is, combining qualitative and quantitative methods. This mixed methodology is compatible with the pragmatic research paradigm and it is seen as a practical solution to the criticisms levelled at purely quantitative or qualitative methods (Mertens, 2005). It could be argued that gathering data from a quantitative source, such as through the use of a fixed response questionnaire alongside qualitative methods, might maximise the validity of the research through the process of triangulation. However, the specific aim of this study was to explore the sibling experience, which, in my view, required a rich, in-depth, first person account of siblings' experience. This could not have been gained through any quantitative methods.

After considering various qualitative methods, a phenomenological approach seemed appropriate and attractive, as it acknowledges the subjective nature of reality and reflects my intention to explore the experiences of siblings from their personal perspective.

Phenomenology is a term encompassing both a philosophical movement and a range of research approaches (Finlay 2012). Phenomenology is primarily attributed to the work of Edmund Husserl. Later it was adapted by German

philosophers Heidegger and French philosopher Merleau-Ponty (Richardson, 1999).

Within the sphere of research, phenomenological studies investigate the nature and meaning of a specific phenomenon. Its theoretical viewpoint is based on the view that an individual's behaviour is determined by the experience gained through their direct interaction with phenomena. During interaction with a range of phenomena, individuals attempt to understand them by attributing meaning to behaviours and events and thereby construct new ideas and experiences.

Phenomenology is particularly relevant to IPA researchers as it emphasises the importance and relevance of a focus on experience and its perception. Husserl's ideas around phenomenology suggest that in order to understand the experience we must step outside our everyday experience and adopt a reflexive position where we self-consciously reflect on experiences or ideas we may take for granted. This is the origins of bracketing off pre-conceived ideas and assumptions which can be used as a reflexive exercise in IPA studies in order to remain open to the phenomena and to help diminish bias, influence or presumptions (Finlay, 2008).

Another key body of writing particularly relevant to IPA is the concept of hermeneutics - the theory of interpretation. Heidegger, who began his career as a student of Husserl, is credited with the move towards hermeneutics; he argued that it was impossible to get a view of phenomena without some form of interpretation. IPA is tied to hermeneutic perspective as it acknowledges that in trying to understand the participant experience, a process of engagement and interpretation is required on the part of the researcher. This process of interpretation in IPA is considered iterative and an IPA researcher is likely to move back and forth through a range of interpretative steps rather than following a linear progression. This is known as the hermeneutic cycle and it is concerned with the interconnected relationship between the number of levels connecting the part and the whole.

The final major influence upon IPA is that of idiography which focuses on the individual and the particular. IPA is interested in the particular by investigating,

in detail, how particular lived experiences have been understood from the perspective of a small group of particular people (Smith et al, 2009). This is in contrast to traditional nomothetic approaches which focus on the generalisability of findings. The findings from IPA studies do not set out to make wide generalisations regarding the findings, as these findings are tied to the data. Instead, the researcher aims to explain the meaning the participants place on the phenomenon.

3.3.1. Data collection

A selection of methods can be used to collect data in phenomenological-based research, including semi structured interviews, analysis of diaries or personal texts, telephone conversations, participant observation and focus meetings. In this study, semi-structured interviews were used to elicit children's experience of living with a sibling with complex health needs.

A semi-structured interview approach was chosen in preference to a very open unstructured interview, as it was felt that the children might need some sensitive prompting to ensure that a broad range of issues were discussed. Also semi-structured interviews are regularly used in flexible qualitative research designs and are commonly used in IPA studies (Smith, Flowers, & Larkin, 2009).

Semi-structured interviewing creates opportunities to explore a phenomenon in a way that other methods cannot achieve e.g. questionnaires. Semi structured interviews using open-ended questions allows for the examination of the phenomenon (Robson, 2002).

King (1994) suggests that semi-structured interviews are useful "where a study aims to understand the meaning of the particular phenomena to the participants" (p.16).

Semi-structured interviews have preset areas of questioning, but the order can be adapted, questions may be altered, omitted or supplemented by further questioning and explanations can be provided at the interviewers discretion (Robson, 2002).

Semi-structured interviews provide a structured framework for the interview but they also provide openings to investigate and follow up on interesting comments or responses. They allow the researcher to set the agenda and adapt the line of questioning to help the participant so that they are able to share their thoughts, feelings and experiences. It is hoped that through my interviews, I will be able to access new and rich data.

Gray (2004) proposes the use of improvisation to aid the accomplishment of a good interview. Using improvisation the interviewer can change the format and questions to match the nature and feel of the interview. Furthermore the interviewer can change their language and phrasing to help create a relaxed and informal interview situation which can help to build interviewer and participant rapport. This flexibility and use of improvisation was considered particularly useful when designing an interview for children.

3.3.2. Data analysis

The interviews were analysed following Smith (1995) and Smith, Flowers, and Osborn's (1997) guidelines for Interpretative Phenomenological Analysis (IPA).

IPA was selected as opposed to other types of analysis because it is concerned with an individual's personal perception of a phenomenon, and not with an objective statement about the phenomenon itself (Smith et al., 1997). IPA recognises that the researcher's engagement with the data has an interpretative element, yet in comparison to other methods (e.g. Discourse Analysis and Grounded Theory) it takes an epistemological stance which requires a systematic methodology which in turn aids the researcher to enter the participant's cognitive world.

A key difference between IPA and Discourse Analysis is that Discourse Analysis investigates how people use language to describe an experience while IPA explores how people ascribe meaning to their experiences (Smith, Jarman, & Osborn, 1999).

Grounded Theory applies theoretical sampling, which aims to continue to collect data until no new themes emerge. Also the findings emerging from Grounded

Theory claim to generalise to the broader population, whereas IPA is more concerned with exploring divergence and convergence in small samples and enables the researcher to draw upon other theoretical frameworks to inform the interpretations of the material shared by the participants (Willig, 2001).

In this study, after considering several ways of analysing the data, IPA was chosen, as it acknowledges the subjective nature of reality and reflects intent to develop a deeper understanding of a situation from the point of view of those who have lived it. As an idiographic approach, it acknowledges that the children in this study are experts in their own experience. I feel this is particularly empowering for the participants and reinforces the significance and importance of listening to children and encouraging them to talk about their feelings and experiences. In addition to exploring the meanings participants give to their experience, IPA recognises a dual interpretation takes place; the participant makes sense of a phenomenon by talking about and interpreting their own experience and the researcher then explains and interprets the meaning of the participant's account during the analysis and writing up. This is known as the 'double hermeneutic' and it acknowledges that researcher will interpret the data through their own lens. Within the analysis stage, detailed analysis of the individual transcripts will occur before moving on to look for convergence and divergence across all the cases. It is hoped that this will provide a systematic way of capturing the participants experience and a full and interesting interpretation of the data.

3.3.3 IPA studies and children

It should be noted that within IPA studies participants are typically adults however a review of the literature reveals a small number of IPA studies have been conducted with children aged 12 years and younger.

To date the majority of IPA studies have been based on individual semi structured interviews with adults. A review of the literature indicates that researchers have conducted IPA studies with adolescent populations and a small handful of IPA studies have included children under the age of 12 years. I would hypothesise that researchers may be dubious as to whether children are

able to explain and describe their experience of a particular phenomenon. Also researchers may not feel they have the expertise to interview children.

Smith (2004) suggests that the guidelines for conducting semi structured interviews for IPA could be adapted when interviewing different participants groups such as children. Smith suggests that the noninterventionist stance of IPA interviewing which includes open questions followed by gentle probing will need to be more interventionist with children. "Children may require the researcher to take a stronger role in guiding them than is usual in IPA interviews" p.49.

Back et al (2011) used IPA, to describe how sexually abused children in Sweden experience legal proceedings. Face-to-face in-depth interviews were conducted with 10 children aged between 9 and 15 years old. The interviews were mainly carried out in the children's homes and although the authors do not comment on why or how this location was decided I can hypothesise that the researchers may have felt that this is where the children would have felt most comfortable (the abuse did not take place at home or by a family member). It was noted that questions posed in the interview were open ended to encourage the children to express their own personal perspectives. The authors make little other reference to how the method was adapted for children however they do comment that the reader should be mindful when interpreting the results as children may not have the linguistic abilities to explain or describe their experience fully.

Doutre, Green and Knight-Elliott (2013) interviewed six children aged between 11 and 13 years old who cared for a parent with mental illness. The study used semi structured interviews and photo elicitation techniques to explore how young carers experienced their lives. The participants attended three separate individual interviews in the school setting. In the first interview they were given a digital camera and asked to take photos of things that they were proud of, things they find challenging and things they found helpful. The photos were then used as a tool for discussion in subsequent interviews. The interviews were analysed using IPA. The authors commented that the children had generally found it a positive experience and seem to enjoy talking to a trusted adult. The

use of photographs may have helped to develop a deeper insight into the children's lives and supported the child in describing their experience. The use of multiple interviews would have helped build trust and rapport, particularly important when interviewing children.

Petalas et al (2009) used semi-structured interviews to explore the perceptions and experiences of eight siblings in middle childhood (9-12 years) who had a brother with autism spectrum disorder (ASD). The authors do not comment explicitly on how the methodological approach was adapted for children but I noted the following. The participants were given a choice of location for the interview. The interview schedule was carefully considered and piloted. Potential topics that would be discussed in the interview were provided to the participants prior to the interviews. The interview schedule contained a number of warm up questions specifically aimed at putting the participants at ease and subsidiary questions and prompts were included should a child have difficulty discussing a particular topic. The interviews were short, on average 21 minutes. At the end of interviews participants were given the opportunity to comment on the interview and the authors noted that all participants reported positively and none requested the interview be terminated.

Further discussion regarding important ethical and practical considerations when interviewing children is provided in section 3.6.

3.4. Reflexivity

Due to the qualitative nature of the research, it was essential that as the researcher, I remained aware of how I may influence the data, particularly the ways in which my personal characteristics, values, interests, past experiences and social identity can shape the outcomes of the research.

Personal influences could shape the research outcomes during the planning stage of research, during the interviews and also during the analysis and interpretation of the data. To ensure that there was an awareness of the influence of my beliefs and preconceptions on the research process and data analysis, the issue of reflexivity was addressed at all phases of the research process.

Although reflexivity is an important issue when collecting and analysing data in all qualitative studies, reflexivity is of particular importance in IPA studies.

Researchers using IPA need to be mindful of the 'double hermeneutic' (Smith & Osborn, 2003). This occurs as the participants talk about their experience and in doing so they are trying to make sense of their world, and as the researcher listens to the participants, they themselves are engaging in an interpretive process, as they are trying to make sense of participants trying to make sense of their world. Therefore, in the double hermeneutic the researchers influence on the analysis is acknowledged (Smith et al., 2009). The researcher interprets, through their own conceptual and personal lens, the interpretations made by the participants (Smith & Osborn, 2003). Within IPA, there is an acknowledgement that it is impossible to remain outside your subject matter. Rather than seeing these biases' as something that requires exclusion, IPA researchers are encouraged to reflect on their assumptions, values and pre-conceived ideas through reflexivity.

I have several years' professional experience working with children who have varying degrees of SEN. In my work as an EP for a specialist children's centre, I have met with the siblings of children who have severe and complex SEN and during this time formed views regarding issues that may be significant in siblings' lives. It was therefore imperative to remain cognisant of these personal assumptions around this topic, in order to provide a trustworthy account of participants' experiences and views. "It is crucial to undergo a process of reflexivity to provide a credible and plausible explanation of participants' accounts and avoid assumptions" (Clancy, 2013).

In developing my skills as a reflexive practitioner, I aimed to develop a greater awareness of myself. This included creating a table about my 'positionality' (Jootun et al., 2009) at the beginning of the research process. I reflected on my values, my beliefs, my ethnicity, my role and my personality, and considered how these factors could influence my research, particularly the data collection and the analysis (See Appendix 3)

I aimed to 'bracket' or suspend previous assumptions about the experience of growing up with a sibling with severe and complex SEN in order to see more clearly the phenomenon. 'Bracketing' requires the researcher to put to one side their own research assumptions or pre conceived ideas in order to remain open to the phenomena and to help diminish bias, influence or presumptions (Finlay, 2008). To achieve this I reflected upon my own assumptions about the experience of growing up with a sibling with severe and complex SEN at the start of the research process. These assumptions are summarised in my 'positionality' table (Appendix 3) in the category 'previous held beliefs and assumptions.'

In order to continue the thread of reflexivity a research diary was maintained before and during the interviews and also during the interpretative analysis. The research diary became a record of the thought processes, feelings and my response to the ongoing and changing demands of the research journey. Within the diary I recorded the conversations with friends and work colleagues and the thoughts, frustrations and celebrations that occurred during the whole of the research period. I also used more formal techniques to help structure my reflexive thinking. Adapted from (Morrow, 2009) I created table to ensure I covered the key domains of critical reflection which I found very much helped guide my thinking particularly during periods when I felt 'overwhelmed' (see Appendix 4 for a sample page from the research diary).

During the analysis of the data, I was aware that interpretations were based on my own conceptions, beliefs, expectations and experiences (Smith, Jarman, & Osborn, 1999). IPA explicitly acknowledges that direct access to personal meaning is impossible (due to the researcher's biases).

Keeping a diary was especially important while conducting the interviews but also during the transcription and data analysis process, as it assisted in the trail of my thought processes. The reflexive diary also provided a record of the emotions I felt during my research journey. In particular, anxiety around maintaining a balanced and open approach to the analysis.

Discussions in supervision with my supervisor and peer support group provided me with the reassurance I craved that the themes I had identified through the interpretation process were valid, relevant to the transcript and not biased. The supervision process required a degree of caution as I felt the need for affirmation that my analysis was sound and grounded in the data but I also needed to be vigilant of not allowing a third party to influence my interpretation of the data. Next time I feel I would require less reassurance and be more confident in the knowledge that my findings are a joint product; co-constructed by myself and the participants and that despite my best endeavours to remain open and unbiased I would accept and embrace the concept that my analysis and interpretation will be influenced by my own phenomenology.

In addition to the diary, discussions with my work-based supervision, university-based tutor and peer support group also stimulated reflexive thinking such as reflecting on how I draw on the skills I have developed as an EP to help build rapport with the participants

3.5. Phases in the completion of the research

The research was completed in phases which occurred over a period of twelve months. Reflection and on-going learning was built upon with each phase. The period of the research can be divided into four phases of development:

Phase 1: Preparation for the research

Phase 2: Conducting the research

Phase 3: Transcription

Phase 4: Data analysis

The first phase was the preparation stage: developing the interview schedule, conducting a pilot study, making subsequent changes and recruiting the participants. The second phase built on the work and lessons learnt from phase one: conducting the interview and hearing the children describe their experiences first-hand. The third phase was the most time-consuming but also the most illuminating, as transcribing the interviews allowed the experiences of the participants to be heard a second time and this created new insights into the

interview process. In the final phase, analytic attention was directed solely to the children's attempts at making sense of their experiences.

3.5.1. Phase 1: Preparation for the research

The first phase of the research journey consisted of preparing for the research. This included writing a research proposal which incorporated ideas for how the participants would be recruited, the interviews schedule and other considerations. This piece of work was then put forward for ethical approval from the University of East London. Once ethical approval was agreed, this was followed by recruitment of the participants and a pilot interview. The reflection and learning that happened in these initial stages helped to ensure that the interviews reflected the experiences of the participants.

3.5.1.1. Developing the interview schedule

The aim of the semi-structured interview was to ask the participants questions that would help to reveal their experience of being a sibling of a child with severe and complex SEN.

This research focuses on studying the meaning of the phenomena. Initially, it was thought that open and non-directive questions would allow the participants to express their perceptions of their experiences; however, through discussion in supervision, it was agreed that children might struggle with very open questions such as "tell me about your brother", so the interview schedule was made more structured using the general principles suggested by Robson (2002) to guide the construction of the schedule.

Robson (2002) notes that a semi-structured interview should contain certain elements including; opening comments, a list of headings and potential key questions, under each heading prompts and probe questions and final comments or questions.

The questions and topics used in the interview evolved out of the research questions and the themes emerging from the literature review. Also during this phase of designing a suitable interview schedule, a search was undertaken to ascertain whether a pre-existing schedule or format was accessible which could

be used again or modified. No appropriate interview schedules were found; although, some questions were loosely based on questions and topic areas used by Connors and Stalker (2003) in their study of 'The views and experiences of disabled children and their siblings'. Example of some questions that were adopted are: "What sorts of things do you do together?", "X can't walk/ can't see very well/finds it hard to learn things. Has anyone ever talked to you about that?" and "Do you ever help look after X?"

Much time was spent developing the interview schedule, and through supervision, the schedule was reviewed several times, which included checking for questions that were complicated, contained jargon, were leading or were biased. The overall flow of the interview was discussed and it was agreed in supervision that the interview should initially start with light topic areas such as describing who is in their family and describing what the family do together, leading to more sensitive questions around the children's understanding of their sibling's condition, what they tell their friends about their sibling and how their sibling's condition may impact on their lives.

Several amendments and changes occurred before a pilot interview schedule was created, which I felt would best engage the participants and illuminate their experiences (see Appendix 5 for the pilot interview schedule).

3.5.1.2. Research proposal and ethical approval

Ideas and thoughts regarding how the research was going to be conducted was laid down in a research proposal which included the nature and the scope of the research and how the proposed research questions would be addressed in a way that would meet the intended outcomes.

In addition to the research proposal, an ethics form was completed, which detailed how the research would be conducted in accordance with the British Psychological Society's "Ethics and Code of Conduct" (2011) and UEL's ethical standards and guidelines. The ethics form was supplemented with the interview schedule, information sheets explaining the research study and consent for parents and children.

The ethics form was submitted to the Ethics Committee of the University of East London in order to make certain that the research met necessary ethical standards. Ethical standards are created to make certain that research is executed in a manner that provides protection for those participating in the research and the researcher. Once the Ethics Committee had given the ethics form their approval (Appendix 6) and the research proposal had passed, the next phase in piloting the interview schedule and recruiting the participants was started.

3.5.1.3 Pilot interview

Prior to completing the interviews, a pilot interview was completed with a nine-year-old child who had a sibling with multiple health conditions. There were several purposes for carrying out this pilot interview:

1. To test the interview schedule;
2. To practice my interview technique;
3. To practice using the recording equipment;
4. To seek the views and perspective of a child/young person on the interview experience.

The main thrust of the study was explained to the parent of the pilot participant and it was made clear to the child and parent that their answers would not form part of the research study but their input would be invaluable in helping me practice the interview and also in providing feedback on the interview process.

The pilot interview prompted reflection on the importance of establishing a rapport, particularly at the beginning of the interview. Smith, Flowers and Larkin (2009) highlight that “Unless you succeed in establishing rapport, you are unlikely to obtain good data from your participant” (pg. 64).

In the pilot interview, the child was a little nervous, and so as an impromptu gesture at the beginning of the interview, the child was asked to draw a picture of their family, which then formed the basis of a conversation about their family. Afterwards when the child was asked her views on the interview process they highlighted the drawing at the beginning of the interview as “fun”. Offering the

child the opportunity to draw their family or sibling at the beginning of the interview was therefore incorporated into the interview process. Also following reflection on this pilot interview, it was decided to build in some extra time for rapport building at the beginning of the interview. This included asking general questions about home and school and providing the child with the opportunity to ask questions about the research and my work.

The format of initially asking the child to provide factual information about their family and their sibling and then later building to more subjective, feeling-related questions worked well and felt like a natural path.

The pilot interview created further opportunities to practice creating an engaging and fruitful interview experience which was not restricted to the pre-planned questions but was flexible and responsive to what was the child was saying. Also it was reflected upon in supervision that my years of experience of interviewing children would help to create a more natural and relaxed situation, which would allow the child to talk freely and be comfortable within the interview and help in the construction of a richer and more detailed account.

The pilot interview allowed reflection and review of the interview process and the experiences noted above meant that some small changes were made to the interview schedule (See Appendix 7 for the final version of the interview schedule). The final step in this initial phase was recruiting an appropriate sample and gaining consent.

3.5.1.4 Sampling framework

A sampling framework was created, to enable the selection of a group of participants who had similar sibling profiles. This type of data collection is called purposive or non-probability sampling, this is the opposite to random sampling . In this research participants were approached in relation to the criteria and relevance to the research question (Cohen, Manion, & Morrison, 2000).

The participants were aged between seven and thirteen years old to ensure that they had the ability to reason and think in an abstract way. A non-clinical

sample was selected so that the phenomenon could be investigated without additional factors such as special educational needs.

All the participants met the following criteria for inclusion in the study, so that the views of a relatively homogenous sample were obtained:

1. The participants were aged between seven and thirteen years old;
2. They had a younger sibling with complex SEN who attends the Specialist Children's Centre;
3. The sibling was currently not in hospital or suffering an acute or very serious period of illness;
4. The siblings lived in the same house;
5. The siblings shared parents.

Smith, Flowers and Larkin (2009) note that “IPA researchers usually try to find a fairly homogeneous sample, for whom the research question will be meaningful. The extent of this ‘homogeneity’ varies from study to study” (p49).

In this study the sample is relatively homogenous. Differences existed by age, condition of the sibling and the ethnicity and cultural background of the participants. Pragmatically, due the rarity of complex SEN it was impossible to find a sample that was identical on every criterion however there was enough homogeneity to ensure the research question was meaningful and common themes could be identified through the data analysis process.

3.5.1.5 Recruiting the participants

The participants were recruited from the Specialist Children’s Centre. When considering approaching families, potential families were discussed with the manager of the Specialist Children’s Centre, as she had an awareness of their current family situation. It was felt that it would not be appropriate to approach families where the sibling was currently in hospital or was going through a period of very serious ill health.

A list of potential families was drawn up and the parents were contacted by phone. Initially the research was explained broadly with the key facts: “This is a

new research project about the experiences of siblings of children who have SEN". It was made clear that the sibling would be interviewed alone and their details would be anonymised, the sibling could choose the location of the interview. It was explained that the siblings were not obliged to take part, and that they could withdraw from the research at any time and pass on answering any questions. It was also noted that all participants interviewed, would be given a small token of appreciation for participating in the research, a voucher. At the time of submitting the ethics application I circled no when asked if the participants will get paid. At a later stage I felt that it would be a kind gesture to give all the participants a very small token of appreciation. In hindsight, for the purpose of completeness and ethical conduct I should have informed the ethics committee of my new intention to give a voucher. This was an oversight and a learning point for future studies.

All the families contacted agreed to be sent written information about the research in the post (see Appendix 8). Parents would share the child's letter (see Appendix 9) with the sibling and determine their interest, and if they wanted to be interviewed, discuss their chosen location for the interview. They were offered a choice of locations for the interview: the Specialist Children's Centre, their home or their school. In giving the child/young person a choice of location, it was hoped to empower them and readdress some of the power imbalance created naturally between adult researcher and child/young person participant.

After two weeks, the families were contacted by telephone to check that they had received the written information and to find out whether the sibling was interested in participating in the research. Two parents reported that the sibling had declined the offer to participate in the research. Six parents said that their child (the sibling) wanted to be involved in the research. One family had two siblings who had both wanted to be interviewed, and after discussion in supervision, it was agreed that both children could be interviewed. During the telephone conversation, the location and day and time of the interview was agreed. It was made clear that the interview could not take place unless parent and child had both given written consent via signing the form at the end of the letters sent in the post. All parents agreed to do this and agreed that the child would bring the completed forms with them to the interview.

3.5.2. Phase 2: Completing the interviews

This section includes information about the second phase of the research: conducting the interviews with the recruited participants.

Eight interviews took place in February 2010. Following the wishes of the participants, six interviews were conducted at the Specialist Children's Centre and two interviews occurred at the participants' homes.

Before each interview, in simple terms, the aim of the research was explained to the participant, as was the importance of the interview within the research. The child's consent to participate in the research was also confirmed, as well as receipt of their consent form and their parent's consent form. At the start and the end of the interview participants were asked if they had any questions regarding the research.

The participants were asked to choose a pseudonym, as it was explained that their answers were anonymised and this name would be used in the research to identify them. Apart from their age, no other personal information was recorded.

Before starting the interview, permission to record the interview was confirmed and the voice recorder was tested to guarantee that it was operational and located in the best possible location to enable a high-quality recording.

It was explained to every participant that the recording made during the interview would be kept securely until they were transcribed and then the recording would be destroyed. All participants were assured that in the transcription any identifying information given in the interview would be removed or replaced with their chosen pseudonym where appropriate.

In order to ensure consistency, some basic rules here applied to every interview and some of the proposals made by Robson (2002), Gray (2004) and Silverman (2006) on how to conduct a good interview were followed. These included being prepared for the interview; being courteous and respectful; giving the participant

adequate time to respond; engaging in active listening (listening more than speaking) and taking a passive and a neutral position.

The interviews were approximately one hour long and were completed in conditions of complete privacy, in a private room with refreshments available when the location of the interview was not at the participant's home. Six interviews took place at specialist children's centre and two interviews took place at the participants' home. According to Seidman (1991, p. 40) the interviewer is the "taker" and the participant is the "giver"; for this reason, when deciding the location of the interview the interviewer should be willing to adapt to the requirements of the participant, (within reason and taking into account practical considerations such as noise and privacy). In this study the participants were given freedom to choose the location of the interview.

The interviews at home, allowed the participant to be seen within the context of their family, community and locality and I felt the participants were more comfortable and in a position of control in this setting. I was less at ease interviewing in the home setting as I was worried my presence was an inconvenience to the family. Furthermore I did not feel entirely confident that we would be free of interruption. The interviews in the specialist children centre were likely to have felt more formal for the participants however I endeavoured to create a relaxed and informal setting and the children seemed relaxed and I felt they spoke freely in both settings.

During the interviews the final version of the interview schedule was used to provide structure. In some interviews question order altered and some questions were omitted as participants had previously answered them in another part of the interview. When participants gave unclear answers additional questioning was used to help clarify their thinking and my understanding of their answers. I endeavoured to give participants plenty of time to think and respond by allowing moments of silence.

At end of each the interview, time was given for questions or queries. Where several interviews were held on the same day, they were spaced out during the day to allow time for the interviews to over-run and also to allow time to note

down thoughts, feelings, reflections and striking observations from the interview experience. At the end of each interview, the participant was given a voucher and a card thanking them for their time.

3.5.3 Phase 3: Transcription

This section explains the process of transcribing the interviews. The eight interviews were transcribed by myself in the months following the interview phase. This was found to be an important part of the research process, as the transcription of the interviews was the first step in the IPA analysis and it allowed me to become completely immersed in the data.

Kvale (1996) cautions against viewing the transcription process as being one of simple conversion, producing an alternative but essentially the same version of the interview. He argues that the transcripts should be 'decontextualised' conversations, which makes for an improved basis for interpretation.

The transcription process requires a series of judgments and decisions: for instance, whether to include all utterances or to 'clean up' the speech to make it more readable (Kvale, 1996). Smith, Flowers and Larkin (2009) note that there is a range of social interactions that may be selected for transcription and that the transcription is therefore a form of interpretative activity.

As only the content of the interviews is analysed using IPA, it was not necessary to include non-linguistic features of speech. Lindsay & O'Connell (1995) note that it is pointless to transcribe information that will not be analysed. However, a few non-linguistic features were included, such as notable pauses, laughter and repetition of words.

Once each interview had been transcribed, each interview was listened to another time with the transcription paper to guarantee that all data was dictated and punctuation added would not alter the meaning of the participants responses. During the transcription I couldn't help myself thinking about the meaning of what the participants were saying and the double hermeneutic as the interpretative element of IPA started to emerge. I was attempting to make sense of the participants making sense of their experiences.

The transcripts were formatted as recommended by Smith, Flowers and Larkin (2009) “with wide margins for ease of coding and space between each turn in the conversation” (p.74).

3.5.4 Phase 4: Data analysis

This section explains the process of data coding and analysis using IPA. The existing literature on analysis of IPA does not prescribe one method for working with the data. “IPA can be characterised by a set of common processes (moving from the particular to the shared and from the descriptive to the interpretative) and principles which are applied flexibly according to the analytic task” (Smith, Flowers, & Larkin, 2009).

There is no right or wrong way of completing an IPA analysis (Smith, Flowers, & Larkin, 2009); however, a number of papers provide a heuristic framework for analysis, a set of guidelines or common processes typically employed by IPA researchers to be used flexibly to allow the rigorous exploration of the participants’ experience, with many referencing Smith, Jarman and Osborn’s (1999) detailed account of the analytic process.

In this study, the analysis followed the guidelines in Smith et al. (1999). The data analysis fell broadly into six stages, which took place over a six-month period.

- Stage 1: Reading and re-reading;
- Stage 2: Recording initial themes;
- Stage 3: Combining initial themes to form emergent themes;
- Stage 4: Clustering emergent themes to form super-ordinate themes for each case;
- Stage 5: Looking at super-ordinate themes across all cases;
- Stage 6: Emergence of the main themes across all cases.

3.5.4.1 Stage 1 Reading and re-reading

The aim of the first stage of the analysis was to become immersed in the original data. To help with this, the original transcript was listened to again. This

also helped to visualise the participant during subsequent reading of their interview. The transcripts were read and re-read several times, and each time, I made notes of any thoughts, observations and anything that came to mind whilst reading. This process was close to free text analysis and these initial notes were recorded on the left side of the dialogue in a wide margin.

During the reading and re-reading, I became aware of recurring phrases, the participant's emotions, subtle and obvious, and the language they used. This process allowed for the noticing of the similarities and differences, echoes, amplifications and contradictions in the data.

Table 1 shows an extract from one transcript which demonstrates the initial noting stage of analysis during reading and re-reading in Stage 1.

Table 1: Extract from transcript to demonstrate stage 1

<i>Initial Noting</i>	<i>Interviewer:</i>	<i>Why do you think he can't walk or talk?</i>
Compressed during pregnancy? Weakness of legs caused by continually sitting and compression in womb. Use of a bit as minisation of pain or uncomfortable feelings	<i>Louise:</i>	<i>I think his legs all got a bit squashed down in the tummy there were three of us and then they got squashed down a bit and then he was always sitting down and he got always like a bit used to lying down and they he's got these legs that aren't that really that good to straighten up and not that strong enough So I think that's why</i>
	<i>Interviewer:</i>	<i>What causes it?</i>
Reconfirmation of compression in mother's stomach as aetiology Does she think they were all in the Mother's womb together at the same time? Disability caused by her and elder sibling sitting on her disabled sibling during pregnancy. Was she and her elder brother to blame	<i>Louise:</i>	<i>As I said it may be the squashing in the tummy. Cos when he was so small and we were growing out. He was so small and we couldn't see him that well so we may have sat on him.</i>

3.5.4.2 Stage 2 Recording initial themes

With a growing familiarity of the transcript, the second stage of analysis was completed in order to develop a more interpretative account of the data. This involved looking more closely at the language used and the subject matter of the talk and then developing an interpretation of the concepts underlying the talk. Each transcript was analysed with these three focuses in mind, using a different coloured pen for each task. These comments were written on the right side of the transcript. It was helpful to have used three different coloured pens, as this helped to create some order to a large volume of detail: this stage and the previous stage produced an enormous number of notes.

In this stage, initial themes started to emerge, of which there were many for every case, although there was repetition of themes which recurred throughout each transcript and at the end of this stage possible connections were beginning to emerge.

Table 2 shows an extract from one transcript which demonstrates the recording of initial themes during stage 2.

Table 2: Extract from transcript to demonstrate stage 2

Interviewer:	<i>Why do you think he can't walk or talk?</i>	Initial Themes <u>Linguistic comments</u> Descriptive/subject matter comments Conceptual comments
Louise:	<i>I think his legs all got a bit squashed down in the tummy there were three of us and then they got squashed down a bit and then he was always sitting down and he got always like a bit used to lying down and then he's got these legs that aren't that really that good to straighten up and not that strong enough So I think that's why</i>	<u>Minimizing language used to minimize the disability and maintain a positive stance e.g. a bit/ are that good.</u> Explaining aetiology, particularly related to his legs. How did the disability come about? An integrated sense of sibling maintaining a sitting position in the womb and her and her brother

		<i>contributing to the disability by squashing her brother.</i>
Interviewer:	What causes it?	
Louise:	<p><i>As I said it maybe the squashing in the tummy.</i></p> <p><i>Cos when he was so small and we were growing out. He was so small and we couldn't see him that well so we may have sat on him.</i></p>	<p><u>Describing a physical process.</u></p> <p><u>Reuse of the word 'squashing'.</u></p> <p>Minimise direct responsibility but indicate their (Louise and her elder brother) contribution to his disability</p> <p><i>Reinforcing this idea of being responsible for causing the disability</i></p>

3.5.4.3 Stage 3 Combining initial themes to form emergent themes

Stage 3 required an analytic move from working with the notes instead of the transcript . The aim was to reduce the large volume of detail created from the previous stages in order to create emergent themes. This required looking at the notes and reducing them into a concise statement or phrase (the title of the emergent theme) which captured the essence of the interpretation of the emerging analysis. "Emergent themes are usually expressed as phrases which speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual" (Smith, Flowers, & Larkin, 2009 p.92).

This stage was, at times, difficult, as the data did not always fit neatly into emergent themes and in order to ensure that the essence was retained, many emergent themes were kept independent. However, this meant that each case had up to twenty emergent themes. At the end of this stage, a master list of emergent themes was created for each participant. See Appendix 10 for the emergent themes for participant Louise.

Table 3 shows an extract from one transcript which demonstrates the recording of emergent themes during Stage 3.

Table 3: Extract from transcript to demonstrate stage 3

Interviewer:	Why do you think he can't walk or talk?	Initial Themes <u>Linguistic comments</u> Descriptive/subject matter comments Conceptual comments	Emergent Themes
Louise:	<p><i>I think his legs all got a bit squashed down in the tummy there were three of us and then they got squashed down a bit and then he was always sitting down and he got always like a bit used to lying down and then he's got these legs that aren't that really that good to straighten up and not that strong enough So I think that's why</i></p>	<p><u>Minimizing language used to minimize the disability and maintain a positive stance e.g. a bit/are that good.</u></p> <p>Explaining aetiology particularly related to his legs.</p> <p>How did the disability come about? An integrated sense of sibling maintaining a sitting position in the womb and her and her brother contributing to the disability by squashing her brother.</p>	Responsibility for the disability
Interviewer:	What causes it?		
Louise:	<p><i>As I said it maybe the squashing in the tummy.</i></p> <p><i>Cos when he was so small and we were growing out. He was so small and we couldn't see him that well so we may have sat on him.</i></p>	<p><u>Describing a physical process.</u></p> <p><u>Reuse of the word squashing.</u></p> <p>Minimise direct responsibility but indicate their (Louise and her elder brother) contribution to his disability</p> <p>Reinforcing this idea of being responsible for causing the disability</p>	Foetal Compression

3.5.4.4 Stage 4 Clustering emergent themes to form superordinate themes for each case

Stage 4 involved looking for connections across emergent themes. Each emergent theme was put on piece of paper and then laid out across the floor on a large piece of paper. Some themes that seemed incongruent were placed at the end of an imaginary spectrum: this created a map of how the themes related to each other and “enabled one to explore the spatial representations of how the emergent themes relate to each other” (Smith, Flowers, & Larkin, 2009 p.96).

Each emergent theme was then moved around so that themes that I felt gravitated towards each other were put together to form clusters of concepts that shared the same meaning. Smith, Flowers, & Larkin, (2009) calls this ‘abstraction’ which involves “putting like with like and developing a new name for the cluster” (p.96). The new clusters were then given a super ordinate theme label which described their essence.

A summary table of super-ordinate themes and emergent themes was created for each participant (See Appendix 10 for the summary table detailing the superordinate themes and integrated emergent themes and corresponding quotes for Participant Eight: Louise). Discussion in supervision allowed me to check that title of super-ordinate themes best described the cluster of emergent themes. As a consequence of this discussion some minor wording changed so that the title best described the essence of the theme. For example Tracy’s super-ordinate theme was changed from ‘inaccurate prognosis’ to ‘prognosis and hope’ as discussion within peer supervision led me to engage in a paper trail which revealed a narrative of hope running alongside a lack of understanding around prognosis .

See Appendix 11 for a table of all the super-ordinate themes across all the participants)

3.5.4.5 Stage 5/6: Superordinate themes across all cases and the emergence of the master themes

The final stage involved looking at patterns across all cases and bringing together all the superordinate themes for each case.

This final phase followed a similar process to the last stage, as each superordinate theme for each participant was printed out in a different colour and laid out across a floor (see stage 1, Appendix 12). This very visual approach meant it was easy to start to search for patterns and interrelations in the data by physically bringing super-ordinate themes together which were connected and related to each other. It was surprising how many similarities there were, as many superordinate themes were repeated across all the cases and clearly very potent. One of the first master themes that jumped out of this process was that of “responsibility of care” (see stage 2, Appendix 12). This theme resonated across all participants with a degree of polarization. For example six of the participants felt some degree of responsibility for the care of their sibling in contrast to two participants who did not take any responsibility. Slowly, over several attempts of moving super-ordinate themes together which shared a connection the most salient themes began to surface and my first attempt at creating master themes lead to the creation of eleven master themes (see stage 3, Appendix 12).

Overall, the analysis was a cyclical process and consisted of returning to the analysis and looking to see how master themes could be reconfigured and refined. This sifting and paring down was an iterative process which lead to several attempts at finding a set of master themes which captured the richness and diversity of the experience as described by the participants.

Stage 4, Appendix 12 shows a further attempt at creating a set of master themes. This attempt has only eight master themes as previous master themes had been collapsed and grouped together creating a more refined version of master themes. For example, “Diagnosis ignorance and myths”, “Knowledge gap”, “Prognosis accurate/ inaccurate” and “Myths” shared an interconnectiveness which allowed them to be grouped together and were relabelled “knowledge about the condition”.

The next phase occurred over several months with revisiting of the analysis and hovering over the master themes. At times I went back to the original transcript and notes to remind myself of how the themes emerged this allowed me to keep hold of the words and phrases that seemed to capture the essence of the experience for example “this is normal for me “ and “it’s actually quite nice having one”. I wasn’t content on eight master themes and reflected on how they could be refined further without losing the richness of the participant experience. I decided to bring all the positive and negative feelings together and create one overarching master themes named “Focus on feelings”. I also decided to bring together, the themes relating to how they played together and formed attachment. For some of the participants their way of forming a meaningful sibling relationship was to help with their siblings care and so it seemed a natural link to place, themes relating to care and playing together, collectively to form one master theme called “the sibling relationship within the family”.

This process of reconfiguring continued until a final master list of three main themes from the group was created. Nested within each of the three master themes are sub-themes which were created from the essence of key superordinate themes from the group. Several discussions in supervision and revisiting of the final analysis resulted in some minor changes of the names of the master themes and sub-themes for example communicating with the outside world was changed to conflicts from the wider world to reflect the psychological dissonance participants described when out and about with their disabled sibling.

Appendix 13 demonstrates a tabulated version of how the master themes developed over time. Although four distinct phases have been shown in reality this process happened with much more fluidity.

3.6. Ethical issues involving research with children

This research aimed to explore the experiences of children and there are important ethical issues that relate to undertaking research with children and young people. These include issues relating to consent, ability to participate

within the research process, communication and power and status. In this study, as potentially difficult and sensitive issues were discussed in the interviews, aftercare agreements also needed to be considered to ensure the emotional well being of the children involved in the research.

3.6.1. Permission and consent

Over the years, increasing consideration has been paid to the concept of informed consent. Informed consent is closely tied to the notion of “competence” and is said to comprise three elements: understanding, wisdom and freedom/autonomy (Bersoff & Hofer, 1990). Macklin (1992) suggests that it might be more appropriate to seek consent from parents and ‘assent’ from children; this is the approach that was used in this research.

Parents of potential participants were contacted by phone. Following initial agreement by the parents, the families were sent further information. This included information addressed personally to the child, which included a photograph of myself and outlined in simple concrete terms the purpose of the study and what participation would involve for the child or young person. This pack also included information for the parent about the research and a parental consent form.

The participants and their parents were given several opportunities (during the telephone calls and before the interview) to comprehend the nature of the research and its rationale. It was also explained how the research hoped to understand the sibling experience which in turn could help inform and improve future policy and professional practice. It felt it was important to ensure families understood that they were not obliged to partake in the research and were able to pull out at any point during the research without disadvantage to themselves and they did not have to provide a reason. Children and parents were also reassured at several points throughout the research process that confidentiality would be maintained.

3.6.2 Children's ability to participate in research

One of the challenges in relation to completing research on children relates to the child's ability to communicate effectively their thoughts, feelings and experiences to the researcher.

Through my career as a teacher and EP, I had extensive experience in interviewing children and young people and was able to utilise these skills when interviewing the participants; however, as the purpose and nature of the interviews differed from the everyday work of an EP, it was important to consider the recommendations from key research regarding interviewing children for research purposes.

Scott (2008) notes that there are three factors that can help improve the quality of the data when undertaking interviews with children. The first relates to the suitability of the research subject and the method applied to investigate the topic. In this study, the research topic required children to talk about an experience that was integral to their lives and so it was deemed a sensitive but appropriate topic.

The second factor relates to the child's motivation and capacity to answer questions and communicate their subjective experience. Greene and Hogan (2005) suggest that the researcher must be open to the use of methods that are suited to the child's level of understanding, knowledge and interests. The questions asked should be relevant to the child's own life experiences and understanding of the world, be clear and pitched at the correct developmental level and be free from ambiguity (Greene & Hogan 2005). When designing the interview questions, extra care was taken to use open, non-leading questions and child-friendly language. One of the benefits of semi-structured interviewing is that the questions could be changed or modified if the child did not understand the question posed to them.

The final factor relates to the child's motivation to give honest and truthful answers, particularly as the power relations between the researcher and participants might alter the content and quality of the information. In order to empower children, Greene and Hogan (2005) suggest that research should

start from the perspective of the child. The interpersonal style of the researcher and the setting of the research should aim to reduce and not reinforce children's inhibitions and desire to please, which will otherwise limit the amount and value and validity of what they say. Fraser, Lewis and Ding (2004) suggest that researchers can seek to minimise power and status issues by using informal language or sitting in a position and at a level that is comfortable for the setting.

Careful consideration was also given in this study to the facilitation of interviewer and participant rapport. I endeavoured to be friendly, responsive and open in every interview. Scott (2008) suggests that good rapport will promote more honest responses, especially if the child really believes that his or her responses are truly confidential.

3.6.3. Participant care

The combination of perceived incompetence and weakness means that children are especially vulnerable to persuasion, advance influence and harm (Greene & Hogan, 2005). This was particularly important in this research study, as the nature of this research involved discussing potentially sensitive and emotive issues. With this in mind, it was important to put in place arrangements in this study to remove potential risks to mental health, well being, personal ideals and dignity.

I was aware that the research procedure had a potential to cause some discomfort to participants. It was explained to parents that I would not overly probe areas that appeared particularly difficult or distressing for the participant. It was explained that should the child/young person become very distressed at any point, the interview would be terminated and suitable therapeutic aftercare would be made available. This aftercare would be administered by myself, or if this was felt inappropriate, a trained therapeutic professional working within the Child and Adolescent Service was approached as another person who could, if required, provide aftercare.

It was hoped that the need for after care arrangements would be unlikely, as the skills of sensitivity and rapport building developed through my main job as

educational psychologist would be transferable to the interview process. This was the case and none of the children required any aftercare.

3.7. Summary of chapter three

This chapter started by introducing the major research paradigms in educational and psychological research. This led to an explanation of the paradigm in which this study is set - critical realism - and how my world view has changed over my academic career.

Within a qualitative research design, semi-structured interviews were used to gather data and the method chosen to analyse the data - IPA - was put forward. Also highlighted were the importance of reflexivity through the research process and the role of the researcher.

Completing the research consisted of four phases; preparing for the research, conducting the research, transcription and data analysis. These four phases have been carefully detailed in this chapter.

The ethical issues relating to completing research with children were discussed, including the importance of permission and consent, issues relating to power and status and participant care.

The next chapter will describe the findings of the research.

Chapter Four: Findings

4.1 Introduction to chapter four

This chapter presents the key findings with my interpretations of the children's experiences of having a sibling with severe and complex SEN.

The research aim was to explore children's experience of growing up with a sibling with severe and complex special educational needs. The methodology chapter (Chapter Three) described how each interview was analysed using Interpretative Phenomenological Analysis (IPA).

The analysis aimed to make sense of the participants' narratives by drawing together themes. Participants' experiences were analysed and then synthesised within themes to generate a combined analysis that embodies their different experiences. Key concepts became master themes within which sub-themes were identified.

I felt that it was especially important to preserve a sense of the personal experiences of each child as uniquely as possible. The dialogue between participants and myself has been interwoven to show raw dialogue alongside analytic commentary. The documented extracts from participants support transparency of the evidence base and allow me to draw the reader through the journey.

Each of the three master themes - 'Making sense of the situation for today and tomorrow', 'The sibling relationship within the family' and 'Focus on feelings' - is presented individually within this chapter, and within each master theme, sub-themes are presented. Several of the sub-themes had a common occurrence within the corpus of the data, while some other sub-themes relate only to certain participants yet capture a fascinating experience which provides additional depth to the analysis.

4.2 Overview of the participants

Table 4 provides demographical information about the participants, which helps to provide a context for the reader. To ensure confidentiality, the names of all participants have been changed and replaced by pseudonyms chosen by participants for themselves. I felt that this allowed the participants to feel an element of ownership and retain some individuality. The pseudonyms chosen by the participants were Beyonce, Sasha, Van Persie, Mona Lisa, Jessica, Tracey, Columbus and Louise..

Table 4: Overview of the participants

Pseudonym	Gender	Age	More than one sibling	Ethnicity
Sasha	Female	13 years	Yes	Black, African
Tracey	Female	11 years	Yes	Indian
Mona Lisa	Female	8 years	Yes	Black, African
Jessica	Female	9 years	Yes	Pakistani
Beyonce	Female	8 years	Yes	Black, Caribbean
Louise	Female	7 years	Yes	White, British
Van Persie	Male	9 years	Yes	Black, African
Columbus	Male	11 years	Yes	White, British

To ensure that the confidentiality and anonymity of the participants was maintained, information regarding the siblings' condition has not been included in Table 4, as I felt that the rarity the conditions suffered by some siblings would allow the participants to be easily identified. However, Table 5 provides information on the diagnoses and conditions of the siblings in this study and the impact of the condition on the siblings' functioning.

Table 5: Overview of siblings' diagnoses and its impact on functioning

Siblings diagnosis	Impact on functioning	Age of disabled sibling at interview stage
Lissencephaly Significant global delay Epilepsy	Severe psychomotor retardation and muscle spasticity Profound neurological impairment Very limited communication and interactive skills	3.3 years
Motor disorder Seizure disorder Significant cortical visual impairment	Significant visual loss Significant neurodevelopment difficulties Very limited communication Significantly impaired mobility	3.7 years
Down's syndrome Acute myeloid leukaemia (remission) Congenital heart disease Significant hearing impairment Significant speech and language difficulties Visual difficulties	Significant delays across development. Requires sign language	3.1 years
Athetoid cerebral palsy (four limbs) Severe global developmental delay Significant learning delay Significant communication difficulties	Severe impaired mobility Presents with involuntary, purposeless movements which interfere with communication, feeding and other skills Communicates through eye pointing	3.6 years
Severe neuromuscular disorder Respiratory difficulties	Profound weakness and deformity of joints, very weak muscle tone and strength, development delay and associated medical difficulties.	3.8 years
Prematurity (25 weeks) Hydrocephalus Congenital heart condition Epilepsy Visual difficulties	Global development delay Significant visual loss	3.1 years
Mitochondrial disease Heart disease Epilepsy	Muscle weakness Hearing difficulties Significant global development delay, including very limited communication skills	3.11 years

4.3. Presentation of the main themes and sub-themes

As an introduction to the findings and analysis, an overview is presented in Table 6, which details each master theme and the integrated sub-themes with an illustrative quote.

Table 6: Overview of main themes and sub-themes

<p>4.4 Master Theme One: Making sense of their situation today and tomorrow</p> <p>4.4.1. Normalising Sasha: Well probably it is different because of [Sibling] but I don't think it is that much different because she is just like another little kid.</p> <p>4.4.2 Diagnosis and aetiology: misunderstandings and dilemmas Louise: As I said it maybe the squashing in the tummy cos when he was so small and we were growing out, he was so small and we couldn't see him, that, well, we may have sat on him.</p> <p>4.4.3 Conflicts from the wider world Van Persie: I would say she is fine, she doesn't walk because she doesn't want to she likes sitting, don't know.</p> <p>4.4.4 Prognosis: remaining hopeful Louise: I think he will get better hopefully, his head will be stronger so we won't need to help that much more and then, he will learn what to do and what not to do.</p>
<p>4.5 Master Theme Two: The sibling relationship within the family</p> <p>4.5.1 Bonding through adaptive play and physical closeness Columbus: I don't do that much but I sometimes... not play with him, but I sort of like move his arms up and down and hold his hands and mummy says that it is like doing exercises.</p> <p>4.5.2 The nature of care, who does what; role and function Beyonce: Well I like, sometimes I like to feed her, usually I like to help her by getting a spoon. It's a nice a helpful thing to do. I get a spoon and I just give it to her and its really easy. She opens her mouth and it is really easy.</p>
<p>4.6 Master Theme Three: Focus on feelings</p> <p>4.6.1 Anger and Fear Mona Lisa: I feel frightened cos I thought she was going to walk and talk or run when she grows up but she never...but she was just a baby and started to get all weak her hands and head and her legs.</p> <p>4.6.2 Annoyance Columbus: Umm he's he can be umm quite annoying because I don't sometimes.... umm I always..... I can't have friends round because we've got to. We have to wait for sibling's bus or somewhere else or I don't know but for some reason and umm...</p> <p>4.6.3. Remaining Positive Louise: I think it is actually quite nice having one, exciting because you might get something quite special from him, something special from him.</p>

4.4. Introduction to Master Theme 1: Making sense of the situation today and tomorrow

This master theme unpicked how the participants attempted to integrate the notion of a sibling with a disability into their understanding of normal family life. Specifically this master theme explores how participants expressed the need for a normal family life through normalising their experience (Normalising: 4.4.1). The understanding that participants have of their sibling's diagnosis and their personal re-interpretation of this was also examined (Diagnosis and aetiology: misunderstandings and dilemmas: 4.4.2). The various narratives that participants constructed for the outside world were explored (Conflicts from the wider world: 4.4.3). The final sub-theme analysed how participants viewed the future for their siblings and how they developed a narrative which emphasised hope (Prognosis: remaining hopeful 4.4.4).

4.4.1. Normalising

Part of the process of normalising could be seen as describing the sibling in everyday terms. Mona Lisa and Van Persie both chose to list positive features, which could either suggest an aim to make the disability invisible or possibly that the disability is not the key feature in their experience of the relationship. The omission of vocabulary distinctively linked to disability is clear from these extracts, but Mona Lisa juxtaposes her positivity with the repetition of the word 'sad'. Despite feeling hesitant about describing negative qualities explicitly, her melancholy hinted at an awareness of the difference in her family and the sadness that this evokes. Van Persie similarly selects a list of attributes and then closes the conversation down, as if to avoid the potential for a negative association to emerge.

She's happy every day but sometimes she is sad, she is happy mostly but sometimes sad, when she is bored she is sad. She's funny because sometimes... when we take her to school my brother started screaming and then she copied him. She is a bit fun! Sleepy a bit and she is nice and a bit clever and kind. And she is a bit giggly (Mona Lisa, p. 6)

Giggly, always happy, happy, funny, she is cheerful, fun and that's it.
(Van Persie, p. 4)

Tracey's extract conferred some of the more tempestuous emotions to her sibling relationship and showed her ability to feel comfortable about these feelings. This may illustrate a more robust relationship between her and her sibling.

I would describe her, quite like she is really annoying (Tracey, p. 4)

Tracey furthermore described the practical difficulties which irritated her, in a very forthright manner. Tracey's sibling is partially mobile, which means that compared to other participants' siblings, she has a more direct impact on Tracey's life and affects the physical routines of family life, with the potential to disrupt them.

She grabs my things, my books and all that (Tracey, p. 4)

Sasha was able to explicitly express that she has an awareness that the situation is completely normal for her as it is her only experience of a family. Later in the interview Sasha reflected further on this question and expressed a degree of uncertainty about the concepts of 'difference' and 'normal'. She concluded that difference would only come about if a peer was an only child and without any siblings. This illustrated her need to reinforce her narrative that her disabled sibling is "just like another little kid" and suggested that her sister's disability is invisible in their relationship or that there was a desire to normalise her situation and not acknowledge her sister's disability.

I don't what it is not like growing up with a brother or sister with special needs as this is normal to me. (Sasha, p. 11)

Well, probably it is (different) because of (sibling) but I don't think it is that much different because she is just like another little kid....(Sasha, p. 11).

Most of my friends have little brothers and sisters but say if I got a friend who hasn't got any ... and is an only child or something then I could understand that it would be different for them as they wouldn't have any brother and sisters to share anything with, all of my friends have brother and sisters that are younger and older than them. (Sasha, p. 11).

Conversely, Columbus clearly felt that his experience of family life was different from others and the repetition of the word 'different' reinforces this idea. This is further underlined by his suggestion of the uniqueness of his situation: "I am the only one". It is striking that he had clear recall of his age when his disabled sibling was born, indicative perhaps of the significance of this event in his life trajectory and its implications for his subsequent family experiences. Throughout Columbus's interview, there was a sense that he experienced oscillating emotions towards his sibling and he endeavoured to find a balance between presenting both a positive and a negative picture of his experience. This need to present a balanced picture is illustrated in the second extract, which also reinforces Columbus's need to highlight the notion of difference, which not only relates to his sibling but also to his experience.

Umm different, really different to other people and a new experience I never knew I would have....have until I was six years old and I am the only one I think..... and.... and different and completely different (Columbus, p. 15)

He is nice, he's funny, well sometimes funny and he can be quite lazy and he is often sleeping and because, he umm goes to bed earlier than us about 7pm and he's..... quite different and umm he's different. (Columbus, p. 2)

Beyonce referred to her sibling using vocabulary possibly learnt from other family members and also appeared to be trying to reconcile conflicting emotions and the pressure that the sibling's disability may be having on family life. The desire to share her own life with her sibling was a strong drive. In the second extract, Beyonce also showed an awareness of both the similarities and the differences represented by her situation and that of other children without

disabled siblings. She also alluded to the aspect of caring for her sibling, whom she referred to as an annoyance: her suggestion that this is true of peers with younger siblings appeared to be a successful way for her to both minimise the disability and normalise her family situation.

Growing up with (sibling) isn't much of a problem. I can show her all the stuff I do and she gives me loads of company. (Beyonce, p. 11)

Interviewer: Is your life different from other children?

Maybe because they don't have a sister who is disabled but they might have a little sister who is quite annoying, it might be hard for them to do things and have to do things for them. (Beyonce, p. 11)

The need to minimise can also be shown by constructing a personality for the disabled sibling. Louise named her sibling's emotional states using her own imagination. Her sibling's very limited communication skills in reality prevent him from engaging in this level of interaction. The wish to have a full and meaningful relationship remains an on going desire.

He is quite cheerful as I said and he is normally always bored when he's just with Mum so that when we come home from school he is usually normally happy and I think that is really nice (Louise, p. 13)

Tracey expressed candidly the fact that she has her own life, separate from her sibling, a normal response for a rising teenager, and suggested normal family routines and her ability to live alongside her sibling.

I don't really spend time with her. I just spend time with her maybe kind like just one hour on a Saturday. On the other days I play football, do homework do work and stuff if I get time. (Tracey, p. 5)

This sub-theme examined the way participants normalised their experience. This was seen through the way Mona Lisa and Van Persie used everyday vocabulary to describe their siblings' personality traits, omitting any reference to disability. Sasha did not see any difference in her situation and she explained

that as it was her only experience of a family, this was her understanding of normal. She reinforced this idea of normality by describing her sister as 'just like any other little kid'. Tracey had little problem describing life with her sister; however, other participants, Columbus and Beyonce, presented a narrative that suggested difficulties reconciling conflicting emotions. The next sub-theme explores participants' understanding of their sibling's condition and the misunderstandings and dilemmas around this.

4.4.2. Diagnosis and aetiology: misunderstandings and dilemmas

This sub-theme represents the participants' understanding of their disabled siblings' diagnosis and its cause. It is characterised by misunderstandings on the part of the participants and also by dilemmas around the desire to know more information against the fear of finding out the truth.

The majority of the participants were of primary school age, making the specific medical vocabulary around diagnosis above their developmental stage. The need to make meaning without the developmental and conceptual understanding needed resulted in a range of interpretations.

Out of the eight participants, only two were able to give the correct medical term for their sibling's condition. Columbus was able to provide the correct medical term, its origin and a physical description of the condition. Although Columbus displayed a degree of medical accuracy, there was some confusion and hesitancy around explaining the condition. There was a strong attempt to define the condition more clearly but some uncertainty around understanding fully the nature of his sibling's condition.

Interviewer: Why is he different?

Because he's got ... Lissencephaly....it comes from Latin or something

Interviewer: That's a long word, isn't it? What does that mean?

Umm I think it means his brain is umm har....smooth or something...It means his brain is something or hard or smooth or straight or wiggly I don't know- so it's different.... I think it is a straighter brain (Columbus, p. 2)

Columbus's younger sister, Louise, also showed an awareness of the correct medical term for her sibling's condition but created a literal explanation for the term Lissencaphaly. Despite her disabled sibling being unable to communicate verbally and minimally non-verbally, Louise linked the name of the disorder with her need to connect with her sibling. As a result, she created an interpretation of her sibling's condition which expressed her desire that her sibling could display communicative intent and be able to have an interactive relationship with her. She has developed her own way of creating a unique and exceptional relationship which transforms the limited nature of their interaction into something meaningful for her.

Interviewer: Has it got a name?

Yes Lissencephaly

Interviewer: What does that mean?

I think it means listen (lissen) carefully (cephaly) to what he said and then you get to really really know what he means and the listen bit means listen carefully to what he said and then in it you will start to hear thislike tiny voice..... that is saying things and I think that is what it really is. (Louise, p. 10)

Three participants displayed a lesser degree of awareness and understanding of the correct name of their siblings' condition. Sasha and Jessica stated clearly that they were aware that their siblings' condition had a named diagnosis but both were unable or did not want to name the condition. Perhaps these participants felt that naming the condition or endeavouring to find out the name would bring a sharper reality to the situation. There is a suggestion in their comments that as children, they do not need to know about the specific nature of their siblings' difficulty, as this could be too difficult for them. This acts as self-preservation or self-protection.

I think it does have a name or something but I just don't know about it. (Sasha, p. 7)

It has but I don't know the name (Jessica, p. 8)

Van Persie named the condition pragmatically but his assertion that the condition had gone illustrated a swift move towards something more positive. With this positive spin on the sibling's condition, he glossed over her more serious needs, focussing on the positive aspect he felt more secure about expressing.

I don't know she can't..... She can hear though.... She has epilepsy but it has gone now (Van Persie, p. 7)

Ambivalence about finding out more information about the sibling's condition, including the name, is illustrated in Sasha's later comments, in which she described going to the hospital with her Mum and hearing professionals discuss her sibling. She showed an awareness that this situation provided a good opportunity to learn about the nature of her sibling's disability and condition; however, she noted that in this setting, "I don't really listen a lot". This comment suggests that she might purposefully block this channel for further information, again serving as a way of self-protection. She then went on to suggest with some ambivalence that she might like to know more about the nature of her sibling's disability.

Interviewer: Would you like to know?

Yes

Interviewer: Who would be the person who can tell you?

I don't know. My mum just tells that she has to take medication and stuff because she can't sit down. Sometimes I go with my mum to the hospital and they talk to my mum but I don't really listen a lot and so.....

Interviewer: And so if you listened hard would you know?

*Probably, I want to know cos it is kind of interesting and it's nice to know.
(Sasha, p. 7)*

Sasha's dilemma is recreated by younger participants. When asked, other participants also showed a desire to know more about their sibling's disability and nature of their condition but their answers revealed some hesitation regarding who or where they can get this information from. Two participants showed an awareness of the sensitivities around seeking this information from a

parent and in doing so highlighted a mirroring of avoidance between child and parent of discussing the nature of their sibling's disability. Mona Lisa's prediction that her parents would reply "I'll tell you later" suggests that there is an implicit acknowledgement that she felt, or her parents felt, that she was too young to know or understand and a suggestion that in time she would reach a point in maturity when she would be given information regarding the nature of her sibling's condition.

Interviewer: So have you asked questions about why she can't walk or talk?

Yeah, I asked my Dad one time, ummm, ummm but he was busy so he didn't answer. (Van Persie, p. 8)

Interviewer: Would you want to know why [sibling] can't walk or talk?

Yeah a bit

Interviewer: Who would be able to tell you why?

My mum and dad

Interviewer: What would you want to know?

Why it happened

Interviewer: What do you think they would say?

I don't know; they would probably say 'I'll tell you later'. (Mona Lisa, p 10)

Other participants, who were unable to name their siblings' conditions, attempted to use generic and commonly used terms, such as 'disabled' and 'special needs', to help define their sibling's condition. Tracey's statement "she needs special needs" is interesting, displaying a focus on the impact of her sibling's condition alongside an interest in naming it. She then went on to suggest that her sister's condition is a mystery and only comprehended by specialists. It is worth noting that Tracey's sister has a genetic birth condition with recognisable physical features, easily recognisable amongst lay people and professionals.

She needs special needs

Interviewer: Do you think it has a special name?

Yes I think it has name

Interviewer: Do you know the name?

No but I would be interested to know

Interviewer: Who do you think can tell you?

Kind of like...Maybe a specialist?

Interviewer: Do you think your parents know?

No I don't think they know (Tracey, p. 8)

Beyonce used the word 'disabled' with some hesitancy, accompanied by non-verbal gestures (covering her mouth). As an EP, I have honed the skills of active listening and this includes tuning into non verbal communication and in the analysis I spent some time thinking about the possible meaning behind this gesture. In Beyonce's interview the act of covering her mouth was a powerful non verbal communicative gesture which pointed towards a deeper reaction to the use of this word. Despite the word 'disabled' being used commonly and regarded as an acceptable term in society, Beyonce's hesitation about using this word and almost whispering it to me suggests her own interpretation may be linked to feelings of dishonour or shame which she may have integrated from her family responses. The dilemma here for Beyonce is that using this description despite its acceptability for professionals and a wider audience might not be approved of by her parents.

Interviewer: Why can't she walk or sit?

Ummmmm...She is disabled (covers mouth) and umm, she's.... because she'sss.....

Interviewer: Do you know whether it has a particular name?

Disabled? She's..... ummmmm (Beyonce, p. 6)

Within this theme, some participants showed highly complex efforts to explain their siblings' condition. Louise and Mona Lisa (both primary age), sought to integrate their rudimentary knowledge of pregnancy and child development into a narrative which gave personal meaning reflecting their own developmental stage and level of comprehension.

Interviewer: Why do you think he can't walk or talk?

I think his legs all got a bit squashed down in the tummy there were three of us and then they got squashed down a bit and then he was always sitting down and he got always like a bit used to lying down and then he's got these legs that aren't that really that good to straighten up and not that strong enough So I think that's why (Louise, p. 9)

Interviewer: What causes it?

As I said it maybe the squashing in the tummy. Cos when he was so small and we were growing out, He was so small and we couldn't see him that well we may have sat on him. (Louise, p. 15)

Louise's explanation is particularly complex, and I found it confusing on first hearing. Louise clarified later in the interview and contextualised the comments, explaining that in her mind, all siblings originally sat together inside a mother. Her sibling was the last born of three children. The notion of some shared responsibility for a sibling's condition was an undercurrent for Louise, as it was for Mona Lisa in this next extract.

Interviewer: Why do you think she finds it hard to walk and talk?

Maybe that's because (long pause) mostly I think that's because when she came out of my mum's belly, you see when they grow up, you know my baby brother, my sister holds him and makes him sit up, stand up but he is still a baby so he can't stand up, that might happen – that might be why. If (sibling) was a baby and just came out of my mum's belly and you try and stand her up and sit up and she might hurt herself and that is why she might get hurt and when she grows up that is why she can't walk or talk (Mona Lisa, p. 9)

Mona Lisa left the responsibility very open, using collective rather than nominal terminology. Mona Lisa tried to rationalise who might be responsible for the seeming anomaly of her disabled sibling. The struggle over the search for culpability caused her some emotional pain.

This sub-theme has examined participants' understanding and misunderstandings of their sibling's condition. Only two participants had

knowledge of the specific medical diagnosis relating to their siblings' condition and other participants used generic terminology to describe the nature of their difficulties. Most participants noted that they would have liked more information about their siblings' condition and there was also some confusion about who would be best placed to give them this information. Participants' answers also illustrated that they had developed an awareness of the sensitive nature of this subject, particularly in relation to asking their parents. Overall, the sub-theme highlights the dilemmas of accepting reality and how reinterpretations and the avoidance of fully understanding this reality can serve as self protection. The next sub-theme explores how participants manage the perceptions and responses of the outside world.

4.4.3. Conflicts from the wider world

This sub-theme moves the theme of making sense of the sibling's condition from the stage of internalising the understanding and making meaning of it, to dealing with the emotions surrounding communicating to the outside world and what information they are prepared to share with those outside the family. Throughout this theme, analysis highlights the internal struggles that participants have in managing how their siblings may be perceived by the outside world.

Minimising and an attempt to disguise their sibling's disability was a recurrent observation shown in explicit comments made by Van Persie and Beyonce. When faced with the question "*If someone came over to you at the park and said 'She/he is really sweet, why can't she/he talk and walk?', What would you say?*", responses included:

I would say she is fine, she doesn't walk because she doesn't want to, she likes sitting, don't know (Van Persie, p. 4)

I would just say that umm... she is ok and she's just ok and she is my sister and that she is ok, she is just asleep, or she is just is a baby and so she sits in the buggy or she can't sit properly. Because she has a problem she throws her arms up and she's and she's and she'sfunny (Beyonce, p. 7)

Van Persie's response shows an attempt to disguise the disability and his use of the word 'fine' indicates an attempt to reassure the other person that his sibling is ok; however, this may actually serve to self-reassure and minimise the likelihood that the other person might want to reflect the seriousness of the disability back to him, which emotionally might be difficult to manage. Beyonce's response highlights a similar process, whereby she repeated the phrase 'she's ok' three times and used her sibling's age as possible excuse for her mobility issues. However, as her thinking developed, she perhaps realised that her sibling's age would not be able to explain her involuntary movements and so she conceded that she has a problem; however, she later attempted to minimise this by ending her response with 'she's funny'.

When faced with the same question, Sasha also used the excuse of her sibling's age for her difficulties; however, Sasha indicated that she was aware that this would not be truthful and attempted to justify why she would be untruthful in this situation: "I don't really like people knowing about it". Sasha then felt the need to explain further that her need for privacy was not based on shame. This internal struggle between a desire for privacy but also not being ashamed reflects the conflicting cultural and societal messages around disability, which may be difficult to reconcile.

I would say something like, I don't know, umm I would say, she is not old enough, although she is really is. I don't really like people knowing about it. I am not ashamed of it or anything, it's just that I don't like people knowing. (Sasha, p. 9)

Later in the interview, Sasha returned to the concept of 'not being ashamed': when asked if there was anything else she wanted to add, Sasha reinforces this message by adding "maybe, there is nothing wrong with it, that it is normal". The prefixing of this statement with the word "maybe" suggests an uncertainty in her commitment to the statement she was making.

Interviewer: Is there anything else I should knowif this project is about the experience of having a brother and sister with special needs?

I don't knowprobably not, maybe there is nothing wrong with it, that it is normal and you shouldn't be ashamed of it (Sasha, p. 12)

Sasha, perhaps indicative of her teenage years, further elucidated on the complexity of trying to manage her own inner world, the reality of family life and the picture she felt would be validated and socially accepted by others. Sasha described her friend who had a sister with special needs and noted that she did not discuss her sibling's difficulties but is happy to talk about her in everyday terms. This statement highlights her understanding that it is acceptable to discuss your sibling with a disability just like any other sibling; however, there is an implicit line drawn around discussing any of the difficulties the sibling may face outside the family. It seems that Sasha's internal struggle with not being ashamed yet not discussing her sibling's difficulties and maintaining privacy is an important narrative and one that Sasha is finding difficult to fully reconcile.

My friend, she has a little sister who has special needs too and she is always asking about (sibling) but she probably thinks it is normal as well. She hardly talks about her little sister....She does talk about her, like if something funny happened at home, but she wouldn't talk about her special needs and stuff. (Sasha, p. 12)

Louise, one of the youngest participants, displayed some hesitation about discussing her sibling's difficulties with her friends and when asked specifically, replied that she would tell them "he is quite a good one". Louise had an internal construct of his difference but reconciled this by promoting a positive image of her sibling.

Interviewer: Do you tell your friends about [sibling]?

Not really

Interviewer: So do they know you have a brother with special needs?

Err, a couple of them do, not that many

Interviewer: Do you think you would tell them?

Probably yeah

Interviewer: What would you say?

Well I probably say, well I do..... but... he is quite a good one actually

(Louise, p.8)

This sub-theme has shown that when the participants are not in their family environment, the norms are different, and through this process, the participants may be faced with the disability becoming more visible and obvious, which in turn may be difficult to manage emotionally. Participants responded to this by a complex mix of minimising their sibling's difficulties or denying the presence of any difficulties whilst struggling with the untruthfulness around this narrative. There is an integral internal difficulty for the participants around talking honestly about the disabled sibling with adults in the wider world. For the child, responding truthfully about the extent of their siblings difficulties could engender feelings that they may find difficult to cope, suggesting a basic drive to protect oneself from situations that may evoke negative or difficult emotions. The final sub-theme examines the future and participants' need to remain hopeful.

4.4.4. Prognosis: remaining hopeful

Noted in the last sub-theme was the importance of focusing on positive aspects and minimising or denying the sibling's difficulties, which may all serve as self-protection. This next sub-theme relates to the participants' ideas about the future and particularly how they imagine their sibling will develop over time.

Closely allied to this is a narrative of hope which runs through participants' thoughts regarding how they feel their sibling may develop in the future. Participants' accounts vary in the extent that their hopes for the sibling's future are realistic.

It is important to note that medical opinion would suggest that none of the siblings in this research will go on to live independent lives. All would require a high level of assisted living and all have life-limiting conditions.

When Jessica and Mona Lisa were asked about their siblings' future, they envisaged that their siblings would be employed in the future.

Working, going to work, cleaning the house, doing a job (Jessica, p. 9)

She would have a job, if she wanted to (Mona Lisa, p. 11)

When imagining their siblings' future, Jessica and Mona Lisa found it difficult to envisage a realistic future for their siblings that related to their level of need. They had few reference points to hang any thoughts on and so their ideas around their siblings' future were based on normalised future options. This might be linked to the construct of making the disability invisible or irrelevant; however, this could be indicative of a societal lack of disabled adult role models. Without these alternative role models, it is easy to form an assumption of a normal future without assistance. Tracey highlights this further as after discussing her future plans to go to University, the interviewer asked her whether she thought her sibling would go to University and she replied:

Interviewer: Do you think [sibling] will go to Uni?

She'll be.... Yes I think she'll do it, yeah, ummm, yeah (Tracey, p. 9)

Sasha and Louise displayed a more realistic view of their siblings' future; however, their comments reflect a hopeful stance, which illustrates a continuing need to ensure that they were talking and thinking about their siblings' disability positively.

I think he will get betterhopefullyhis head will be stronger so we won't need to help that much more and then ... he will learn what to do and what not to do (Louise, p. 11)

Very big and no-one will be able to carry her. Hopefully by then she will be able to talk. Umm I don't know but I think she will be in a wheelchair unless she learns to walk and stuff and I would like her to still live with us (Sasha, p. 7)

Sasha's comments show some understanding that her sibling may not be able to live within the family home in the future; however, her desire for her sibling to remain living within the family illustrates a very close and protective relationship. Beyonce managed to hold on to hopefulness alongside reality.

I think she'll be needing lots of help by then, she'll be needing help with learning, help with needing to have a job, help with learning about the world. (Beyonce, p. 8)

Columbus was hesitant about discussing his sibling in the future; however, his comments reveal a realistic understanding of a possible future path for his sibling, and like Sasha, he indicated an assumption that he would be supporting his brother and be involved in his life and perhaps care in the future.

Ummm he might be..... he will be in his buggy. Yes he will definitely well not a buggy more like a wheelchair

Interviewer: Do you think he is not going to walk?

That is what they are saying.... Umm I don't think so... (Columbus, p. 14)

Interviewer: What kind of things will you be doing together when you are older?

I will besometimes be pushing the buggy around. I might be taking him somewhere. I don't know (Columbus, p. 15)

In my interpretation of these comments I drew on my wider experience of talking to children and gathering their views. In my experience I have observed a natural optimism which seems too often be part of children's narrative and for the participants in this research the need to remain hopeful is an important one.

The participants display their hope within both realistic and sometimes highly unrealistic ideas about the future. However, the extent to which their ideas are realistic is perhaps irrelevant; instead, what seems important is their need to remain hopeful, as this seems to help build resilience, provide comfort and act as a buffer to difficult and complex emotions.

4.4.5. Summary of master theme 1

The master theme has been analysed to show how participants have integrated and made sense of having a disabled sibling within their own family context. Their experiences highlight their current situation and their thoughts for the future. Key themes prevalent in this master theme relate to the importance of normalising and remaining positive and hopeful. Participants described their sibling and situation, seeking to avoid and minimise the reality of their disabled sibling. It seems their sibling's disability has become an integrated aspect of family life and their sibling was not defined by their disability; instead, the relationship is developed with the sibling and not with a disability being. Participants showed ambivalence in learning about their siblings' condition and behaviours relating to this seem to serve as a mechanism for self-protection. When not in the family environment, their siblings' disability becomes more visible: some participants showed unease in managing this situation and chose to deny and minimise their siblings' disability. The final sub-theme focused on the future and how participants envisaged their sibling's future. Participants' accounts varied in the extent to which their hopes for their siblings' future were realistic; however, running through all the accounts was the need to remain hopeful about their siblings' future.

4.5. Introduction to master theme 2: The sibling relationship within the family

This master theme relates to the nature of the sibling relationship and how it could be adapted within families who had disabled sibling. This theme begins with my analysis of how the participants build a relationship with the disabled sibling through interaction, which the participants modified to match their sibling's functioning levels (4.5.1. Bonding through adaptive play and physical closeness). The second sub-theme looks at how the nature of a disabled sibling relationship is further shaped by the additional need to care for and protect the disabled sibling (4.5.2. The nature of care, who does what; role and function).

4.5.1. Bonding through adaptive play and physical closeness

Columbus, Mona Lisa, Sasha and Van Persie described how they interacted with their siblings. Due to the nature of their siblings' disability and their level of functioning, Columbus, Mona Lisa and Van Persie described a form of adaptive

play in which their interaction highlighted an asymmetrical relationship whereby the participant (in this study, always the elder child) took on a role similar to carer, teacher or parent. Sasha and Van Persie described how they enjoyed being physically close to their siblings. Drawing on my knowledge of attachment theory from my work as an EP, I interpreted this description of need for physical closeness as a form of establishing attachment. For Sasha and Van Persei in the absence of being able to communicate meaningfully with their sibling or play co-operatively, they sought to connect through touch and physical closeness. This behaviour served as a way of bonding with their sibling and within my analysis reminded me of the primitive drive or 'skinship' used to describe the intimacy, or closeness, between a mother and a child to enable attachment. It seems being close to their sibling evoked these deep emotions and illustrated a way to find a connection with their sibling.

Columbus's comments highlighted role asymmetry. In his first comment, he showed an awareness that his interactions with his brother did not fall within his construct of 'playing'. However, he described a highly physical interaction that received approval from his mother, as she suggested that this type of interaction was similar to physiotherapy exercises. Columbus furthermore seems to have intrinsically adopted the pedagogy of a teacher-type role, offering supportive praise to his brother for responses that he recognised as developmentally appropriate. For Columbus, this interaction served to facilitate an interactive relationship with his sibling whilst also allowing him to feel he was helping his brother progress and achieve.

I don't do that much but I sometimes... not play with him... but I sort of like move his arms up and down and hold his hands and mummy says that it is like doing exercises (Columbus, p.10)

I sometimes play with him and I sometimes say 'good boy' if he does....if he makes a noise with his noisy toys and so when he touches them and they make a noise and I and I ummm....play with him as I already said (Columbus, p. 5)

Mona Lisa and Van Persie also described how they had adapted 'playing together' to a form of physical play whereby they support their sibling with their mobility. This highlights how these participants have modified 'play' to match their siblings' developmental needs.

Interviewer: Do you play together?

Yes sometimes – I sometimes when I stand her up and I am holding her and my dad is letting me hold her and my mum says put her down because I am too young but my Dad lets me pick her up but my Mum doesn't cos she thinks I am too young (Mona Lisa, p. 7)

I help with her sitting up and sometimes I hold her and she stands on the floor and she bends one of her legs and then she bends the other one and then she starts to sit down on the floor (Mona Lisa, p. 8)

Van Persie described how he shared everyday routines, such as brushing his teeth, with his sibling. Sharing of these simple routines serves to connect him with his sibling. Van Persie also described a similar interaction to Mona Lisa, whereby his interactions suggest a desire to improve his sibling's mobility by encouraging her to stand. There is a sense that both participants want to help and support their siblings to develop in a recognisably normal way.

Sometimes I brush my teeth with her, yeah sometimes I make her stand as well, I hold her hands and she puts her legs on the floor and sometimes she drops (Van Persie, p. 6)

Sasha's comments illustrated that, she had developed an awareness of her sibling's favourite activities and had attempted to develop a more playful type of interaction which matched her sibling's cognitive functioning. Sasha's comments also suggest that she enjoyed seeing her sibling happy and has observed that her father plays a role in her sister's happiness and wellbeing. Observing her sister's happiness may serve to comfort Sasha as it provides reassurance that her sister is content and enjoys life despite her disabilities.

She is happy, when she is excited and stuff, she likes lights and colourful things and when her dad walks into the room and she hears his voice, she starts screaming like she is happy. (Sasha, p. 9)

I have this slinky, do you know what that is (interviewer-yes) and she loves it and she tangles them up and everything , she loves it (Sasha, p. 5)

Van Persie's next extract highlighted the importance of physical closeness in his relationship with his sibling. Van Persie described his need and joy to be physically close to his sister and to be able to connect with her at this most basic level. This physical connection may be of particular importance in light of the absence of his ability to form a connection in any other way, such as through verbal communication or through play. Also, having a sibling with such limited communication, when his sibling smiles in response to his kiss, this everyday gesture is transformed into a powerful and meaningful gesture which cements their relationship and connection.

Ummm, sometimes we sleep um together because I just want to sleep, with her ...and ...We are putting are heads together and we are kissing each other... (Van Persie, p. 5)

When I kiss her, she smiles a lot and she makes me laugh (Van Persie, p. 5)

Sasha also describes a similar process whereby she enjoys being physically close to her sister. So powerful is her need to connect with her sister that she describes how she feels they laugh together; however, she explains that in this situation, they are not sharing a joke - instead she is laughing alongside her.

Sometimes we just lie on my mum's bed and we just laugh about random things or she does and I laugh with her (Sasha, p. 4)

This sub-theme highlighted participants' desire and need to bond with their siblings and how they modify their interactions to enable them to connect and

develop a relationship with them. Within their responses, the participants expressed that part of the relationship they had with their disabled sibling involved bonding around care for them. The notion of caring is explored in the next sub-theme, which examines in detail the extent to which caring for their sibling is part of their experience.

4.5.2. The nature of care, who does what: role and function

The extent to which caring was a theme in the participants' descriptions of their experience of the sibling relationship varied. Beyonce returned to the theme of caring several times in her interview, underscoring its importance in her perception of her duty in her role as older sister. For other participants e.g. Sasha and Columbus, caring for their disabled sibling was the responsibility of a wide support system.

For Beyonce helping in daily family routines sat alongside a hint of the psychological burden she herself was experiencing from this. There is an implicit suggestion that perhaps this role was not always easy for Beyonce.

I wash the dishes, mostly I wash the dishes and clean the table, I wash the dishes or clean the table after dinner. I help a lot (Beyonce, p. 5)

Well I like, sometimes I like to feed her, usually I like to help her by getting a spoon. It's a nice a helpful thing to do. I get a spoon and I just give it to her and it's really easy. She opens her mouth and it's really easy, usually I just give it to her and it's really easy (Beyonce, p. 5)

Beyonce furthermore had a sense that this role could be a long-term endeavour and although she identified other family members helping, her sense of self was so closely wedded to this that she seemed unable at this point in her life to see beyond this very tight parameter.

Maybe me, maybe mummy, daddy, aunty, with feeding, cos I am the big sister so I will be helping. When Mummy and Daddy are not here.... I will be helping a lot because I am the big sister.....(Beyonce, p. 9)

Maybe I'll have a job, maybe I'll be helping the family a lot ... I'll be helping with mostly everything and be helping on special occasions. I will be there to help sayat Holy Communion. I will be helping the family a lot...I'll be helping the family with ... and say we had people coming for Holy Communion I'll be helping a lot I'll probably helping with dressing sibling....(Beyonce, p.8)

In contrast, Jessica, when asked, “Who helps your sister?”, replied “*My other sister but not mostly but mostly my mum helps her*”. In the extract below, Jessica abdicated the caring elements around her disabled younger sister to wider parts of her extended family and omitted herself totally. This was in stark contrast to Beyonce’s experience.

Interviewer: Does anyone outside the family help with S?

Yeah my cousin

Interviewer: Ok what do they do?

They help, they be kind to her, they help her not to hurt anybody

Interviewer: Anyone else?

My Aunt, my Dad or my Uncle (Jessica, p. 7)

Sasha described family scenarios where the experience of caring for her sibling felt shared within the family. The sense of personal burden around her disabled sibling did not seem to occur in her responses, but rather a sense of true co-operation was introduced and repeated in her extracts.

The school does, and my mum, my dad and me, and brother sometimes (Sasha, p. 5)

My mum, sometimes me, sometimes my brother, sometimes my dad, we will all take in turns (Sasha, p. 8)

Columbus described a range of ‘help’ which included the wider community, but his final comment of ‘not much else’ suggested that he had both an understanding and acceptance that the nuclear family are the main carers.

Sometimes different people help him, usually his teachers at school mainly and then other people here and there that come and visit him and see stuff but not much else (Columbus, p. 10)

For Columbus, the role of caring also came with the particular function of gaining parental approval with associated self worth.

I feel pleased when Mummy says well done for helping (Columbus, p. 19)

Beyonce, Mona Lisa and Van Persie indicated an awareness of the physical vulnerability of their siblings and the impact of this on their own role, so that they saw themselves as protectors.

She properly needs helps with herself like to make sure she doesn't hurt herself, to be protective cos if no-one there is to look after Sib she'll probably hurt herself kind of (Beyonce, p. 5)

She rolls on the floor and sometimes when she is laying on the floor sometimes one of her hands is like that and her other hand is on the floor and it might be hurting her. And sometimes when you try and sit her up and then she pulls herself back and then she bumps her head on the floor. (Mona Lisa, p. 9)

For Mona Lisa, this role was adhered to even to the detriment of her own physical needs and began to include emotional aspects of being a surrogate parent, where the need of the vulnerable child superseded her own.

Sometimes when she is about to bang her head on the floor I put my hand on the floor so she doesn't then I and then as she falls back and bumps her head on my hand and then I hurt my hand (Mona Lisa, p. 6)

Beyonce, despite being only eight years old, fully took on adult aspects of sole responsibility in order to ensure her sister's safety and well being. Beyonce felt a strong need to support her sister emotionally as well as physically.

At times I just try and keep her cheerful. Like, errr.. Sometimes I take care of her when she is bathing her and usually I just watch her bath but sometimes I have to look after her, especially when there is no-one there I have to watch. Maybe I have to look over her and check she is ok. I have to look over if no-one else is there (Beyonce, p. 5)

Van Persie succinctly drew together the triad of constructs he felt essential to his disabled sister's care: advancing her mobility, ensuring her safety and creating a setting for her emotional well being.

Help her walking make sure she didn't bang her head. Make sure you play a nice game with her (Van Persie, p. 10)

4.5.3. Summary of master theme 2

This Master Theme has examined the development of the sibling relationship. The sense that participants wanted to feel bonded to their sibling was evident in the way they had developed an interactional style to help foster a close relationship with their sibling. With some participants, this meant taking on a role similar to a parent, teacher or carer. The notion of caring came through quite strongly in some participants' accounts, whilst others did not see 'helping with their sibling's care' as a key part of their relationship or role, although all participants showed an awareness that their sibling required a higher level of care than the average developing child. For some participants their role in caring for their sibling formed part of a network of family members and the wider community that supported their sibling. From the last master theme, particularly within the sub-theme 'Prognosis: Remaining hopeful', participants indicated an awareness of the likelihood that the need to care for their sibling would continue into the future. The next theme explores the feelings coupled with being the sibling of a child with complex and lifelong difficulties and examines how some participants found it difficult to speak about difficult feelings and some preferred to speak about positive associations.

4.6. Introduction to Master theme 3: Focus on feelings

This Master theme focuses on the feelings associated with the experience of being a sibling to a child with a severe disability. Between them, participants identified a range of feelings. The range of feelings evoked by the participants include feeling angry and scared (4.6.1), feeling annoyed by their sibling or by the implications their sibling had for their life (4.6.2), and finally feelings associated with positivity and optimism (4.6.3)

4.6.1. Anger and fear

This sub-theme examined how some participants identified a range of complex negative emotions associated with their experience of growing up with a sibling who has severe and complex SEN. The feeling of fear, both for themselves and for their sibling, was explicitly expressed, as was the clear identification of anger.

Beyonce's comments illustrated a wariness and caution regarding physical closeness with her sibling. There was a strong sense of unease around expressing the negative emotions to me, and before she was able to share her feelings, she checked the confidential nature of the interview with me. Beyonce's caution in expressing these emotions highlights a societal, cultural or family narrative that is suggestive that it is not appropriate to express these negative emotions towards a sibling, let alone a disabled sibling.

I feel angry when- this is about (sibling) right? Are you going show this to Daddy?- just say ... when...ummm...I kind of feel angry when (sibling) kind of kicks me in the eye. (Beyonce, p. 10)

I feel frightened when (sibling) throws her arms round and round and she puts her arms right out and I am might get hurt myself. (Beyonce, p. 10)

At times it's hard with (sibling), it's hard to do things with (sibling) because she at times gets really hyper and she is waving legs and arms around and she is getting stronger. I try and help her. It can make it hard to do things with (sibling). She is getting stronger. (Beyonce, p. 5)

Once reassured, Beyonce shared negative emotions and described her anger resulting from being “kicked in the eye” and her subsequent fear regarding the possibility of being hurt in the future by the involuntary movements of her sibling. This fear and anger sit within the backdrop of the expectation that Beyonce’s care of her sister would be ongoing, which has been discussed earlier in extracts from Beyonce’s interview. This expectation to help, alongside fear and anger that she might be harmed by her sister if she gets too close, is difficult to reconcile and Beyonce’s final statement, “she is getting stronger”, suggests that she has further fears for her future safety in helping her sister.

Sometimes, Daddy, he says I have to cuddle her and look after her maybe every time , I have to cuddle her...because she is really excited to see me and I have to say hello to and I have to... look after her and watch her. Daddy says I have to cuddle her. (Beyonce, p.7).

In the above extract, Beyonce further indicated her hesitancy regarding physical closeness but also expressed how this would put her in conflict with her father’s instruction that she had to cuddle her sister. The repetition of the phrase “I have to cuddle her” illustrates a conflict between the need to conform to the parental instructions on how to respond to her sibling and her concern for her own physical safety.

Tracey and Jessica also identified that they felt frightened by their siblings, particularly because of the unpredictable nature of some of their siblings’ actions and uncertainty about their behavioural response to a given situation.

I feel frightened when she tries to pull my hair (Tracey, p. 10)

I feel frightened when she is banging something (Jessica, p. 9)

Louise, Mona Lisa, Sasha and Van Persie also indicated that within their experience they felt scared and frightened; however, the origins of the fear related to concern for their siblings. Being in close proximity to a high level of pain not in their realms of experience created anxiety, exacerbated by a sense of being an observer and possibly seeing this worsen over time.

Louise explicitly identified her concern for her sibling and her discomfort or sadness in seeing him cry. Louise suggested that when she was unable to identify her sibling's thoughts, as he was "staring somewhere else" she had created a narrative that turned this vacant and nonsensical gesture into a wonderful and meaningful expression whereby she believed that her sibling was looking at angels. So strong was her belief in this narrative that she went on to suggest that the angels could communicate with her sibling and in some way guide and instruct her sibling so that he "only cries when it is really bad". This powerful narrative provided comfort for Louise and indicated her need to minimise pain for her sibling and for herself.

Well I am quite worried about the enormous seizures as they make him cry (Louise p. 12)

I think he only moans more and I think the angels tell him cos he normally goes somewhere else at teatime or at lunchtime or something and stares somewhere else and I think he is looking at these angels and I think angels tell him what to do and what not to do. They tell him to only cry when it is really really bad (Louise p. 12)

Mona Lisa described her fear and disappointment in the prognosis for her sibling's condition. Her extract expressed hope but also within this was a misunderstanding of her sister's condition.

I feel frightened cos I thought she was going to walk and talk or run when she grows up but she never...but she was just a baby and started to get all weak her hands and head and her legs (Mona Lisa, p. 12).

Van Persie's comments underlined how fear could be compounded by misunderstanding or not having been given the full details of his sibling's condition. This resulted in insecurity and consequent deepening fear about potential worsening of the sibling's condition in the future.

I feel frightened when [sibling] bangs her head on the floor, when she is lying down and she trying to sit up and she can't, so she bangs her head.

Interviewer: And why is that frightening?

Because she might be more disabled? (Van Persie, p. 9)

4.6.2 Annoyance

This sub-theme relates to only two participants, Mona Lisa and Columbus. They were both able to articulate their annoyance in how they felt their sibling impacted on family life or their own life.

Several times throughout her interview, Mona Lisa returned to the concept of her hand being hurt as a consequence of the need to protect her sister from falling back or banging her head. Her annoyance seemed to originate from the physical pain caused by having to protect her sister. It is perhaps difficult a child of Mona Lisa's age (8 years) to understand why she has to abdicate her own well being for her sister's. This need to return to her 'hurting hand' may serve as a metaphor for wider issues. Mona Lisa seems to have awareness that she has to protect her sister and as a consequence her own well being comes second. However, Mona Lisa may not fully understand why this dynamic has arisen, as her sibling's disability is not entirely visible to her, although her final comment, "it is a bit hard and sad", suggests that she feels the impact of her sister's disability on her own life and her family.

Sometimes when she is about to bang her head on the floor I put my hand the floor so she doesn't then I and then as she falls back and bumps her head on my hand and then I hurt my hand (Mona Lisa, p. 8)

I feel annoyed when she starts pushing herself back because it really hurts my hand and makes my hand tired, she pushes herself backwards and she pushes herself onto my hand and then my hand feels tired (Mona Lisa, p. 12)

I am a bit annoyed when she bangs her head on my head and my hand really hurts and gets tired and she really screams and it hurts my ears

and I get annoyed. When my brother is asleep she screams and he gets quite annoyed. It's a bit hard and sad (Mona Lisa, p. 13)

Columbus also described his annoyance; however, his description suggested that these feelings originated from a sense that his sibling's disability disrupts elements of family life and particularly can obstruct his wishes. Extracts from Columbus' interview indicate that he was cautious about talking about this subject and his dialogue is filled with half-finished sentences and pauses. It seemed as if Columbus was trying to pick his words carefully as he was mindful perhaps of the negative connotations around being, annoyed, bitter or resentful of his sibling. All feelings that he may be experiencing but felt that it was taboo to talk about or admit to.

Umm he's he can be umm quite annoying because I don't sometimes.... umm I always..... I can't have friends round because we've got to ...we have to wait for [sibling]'s bus or somewhere else or I don't know but for some reason and umm...(Columbus, p. 3)

Yeah and sometimes I have to..., it is quite annoying because [sibling] I mean.....because if we have [sibling] with us we can't go on bike rides and stuff or go on any rides. If we are at the fair and Dad's at work and its down at the school fete or not the school fete but a fete and Daddy is at work and then mum can't go on rides with us, as she has stay with [sibling] and then we can't go on the big wheel usually (Columbus, p. 4)

The annoying things like not being able to go on rides, having to wait. If I feel sad whenwell I have probably told you it all.....when I don't get to go on rides and all that stuff (Columbus, p. 16)

And we have this crinkly paper which is over there and that makes a noise whenever he moves it makes it makes a noise and if we are watching the TV quietly and he is on that, we can always hear him. It is sometimes annoying but he doesn't do it all the time (Columbus, p. 18)

Tracey acknowledged directly that the situation with a disabled sibling is difficult. Tracey repeated the word 'difficult' in order to reinforce the adversity she felt her sister had created for the family. She acknowledged that this adversity mainly rests with her parents and she later identified clearly the exact nature of her sibling's needs.

It is quite difficult, difficult. My Mum and Dad are caring for her, like you need to, because, umm well using sign language is quite difficult (Tracey, p. 11)

Difficult, more, difficult, because she needs special needs, sign language and behaviour (Tracey, p. 12)

Tracey was the only participant to directly respond with an expression of difficulty, and the tendency amongst some participants was to move towards being hopeful and positive, as explored in the next sub-theme.

4.6.3 Remaining positive

Columbus and Louise had a narrative running through their interviews which focused on the importance of noting the benefits of having a disabled sibling.

This was a particularly strong theme for Louise, who was very keen to describe the benefits of having a disabled sibling. In her extracts, she noted that she felt that her sibling would provide her with 'something quite special'. There was a sense from Louise that it was important for her to maintain a sense of optimism and positivity about her situation. She had constructed a narrative that allowed her to feel that her experience was something unique and there was a sense that she felt lucky to have a disabled sibling and would seek to find positive associations at every opportunity.

I think it is actually quite nice having one, exciting because you might get something quite special from him, something special from him (Louise, p. 18)

Well I think it is a bit because having a special brother like this has really changed me ...I think it does cos I think if I didn't I would be a bit bored cos it's really exciting to play with him if I don't have anything to do (Louise, p. 18)

This need to frame her experience positively was reinforced throughout Louise's interview. When she described the adaptations being made to their family house, she described this as an exciting venture and showed delight in her feeling that that this would potentially make her sibling happy. Louise also envisaged that she could share this exciting change with her sibling. The need for her sibling to share her own personal emotions was paramount and superseded realism.

I think what is really exciting is that we are going to have a lift in our house and we are going to have a giant shower next to his room and it's very exciting having a new lift and think he is going to be really excited when he sees he is not going up the stairs anymore (Louise, p. 17)

Louise's need to connect with her sibling was further evidenced in the following comments. Louise transformed an unconscious gesture by her sibling into a purposeful act with special meaning. She reinforced her need to feel bonded to her sibling by creating a mutually reinforced interaction.

Well growing up I think it really nice going out with him because when we go out with him, it's really nice he normally got his hand down dangling down for us and like it is dangling down for us and his hands feels really cute and I think it is nice doing that (Louise, p. 18)

So strong was Louise's connection to her sibling that there was a sense of separation anxiety when she was separated from her sibling and her joy in being able to reconnect with him was evident.

I feel happy when he is home because I don't normally see him as he goes to school quite quick before we do and he comes home late (Louise, p. 16)

Columbus acknowledged that the experience of growing up with a disabled sibling set him somewhat apart from others and he repeated the word 'different' several times in the following extract. He also acknowledged the unexpected nature of this experience in his statement "a new experience I never knew I would have" and there was a sense that he remained in a period of adjustment. Following this, he displayed a need to reassure (perhaps himself) and remain positive and optimistic, as he noted "but is ok and there is nothing, nothing much to worry about", although his ending comment "but I don't really know" and the use of the word "much" suggest that he may not be wholly committed to this idea.

Umm different, really different to other people and a new experience I never knew I would havehave until I was 6 years old. And I am the only... I think... and and different, completely different. It is different because not everybody has a brother like [sibling]. I would say it is just a bit different but it is ok and there is nothing, nothing too much to worry about...but I don't really know (Columbus, p. 15)

Columbus spoke about the importance of celebrating his sibling's achievements, no matter how small. Celebrating when his sibling 'smiles' was something that caused family celebration and he typically shared this special moment with his Mother. Columbus noted that he felt proud when his sibling did "good smiles"

Well he can sometimes go....and he sometimes does tiny smiles but not like, like a really big one but he will sometimes do little smiles and other day Mummy saw him do one and they were like AHHHH! He's smiling! But we didn't really see him do it and he doesn't smile like very often and he just does a little one sometimes and not very often (Columbus, p. 8)

I feel proud when he smiles well and when he does good smiles and I always know when because my mum goes ahhhh and makes a loud noise and she's like well done [sibling]! (Columbus, p. 18).

4.6.4. Summary of master theme 3

Master theme 3 has focused on the exploration of the different feelings exhibited by the participants. The spectrum of feelings expressed illustrates the complex range of emotions suggested by the participants in their interviews. Analysis of the extracts highlights the difficulties and hesitancy some participants experienced in discussing negative feelings and emotions associated with their experience. Despite this, participants did speak openly and honestly about their experience, and in doing so, shared anger, fear, frustration, optimism, worry and sadness relating to their experience. The origins of these feelings seem subtly different for each participant and highlight the idiographic nature of the analysis.

4.7. Summary of chapter four

This chapter has provided an analysis of the experiences of children and young people who have a brother or sister with severe and complex SEN. The experiences were clustered within three master themes, and within each master theme, different sub-themes were identified. It is hoped that the analysis has captured something of the lived experience of the participants, and within the analysis, commonalities between participants were brought together and contradictions were also highlighted. The next chapter reflects upon the findings and places them within the existing literature and psychological theory. Also discussed is a critical evaluation of this research.

Chapter Five: Discussion

5.1 Introduction to chapter five

This chapter presents a critical discussion of the main findings of the research in relation to psychological theory and the wider research area. The extent to which the data analysis reflects or contrasts with the research literature is described. Also highlighted are the distinctive elements of the findings that deepens our understanding of the experiences of siblings. The second half of the chapter provides a critical evaluation of the methodology, sample selection and interview process. An overview of the reflexive stance taken in this study and reflections on my role as the researcher conclude this chapter.

5.2 Main findings

Before critically discussing the research findings in relation to the theory and the wider research area. It was felt important to provide a synthesis of the main findings;

The main finding of this research are:

1. Siblings integrated their disabled sibling into the normalcy of their family life.
2. When outside the family context, this normalcy was challenged and in response to this challenge participants attempted to minimise or deny their siblings' disability.
3. Most siblings were not well informed regarding the nature of their siblings' disability and its aetiology and correspondingly constructed individualised interpretations.
4. The importance of remaining hopeful regarding their sibling's life and future was a significant feature in reported experiences.

5. In the drive to bond with their severely disabled brother or sister, siblings adapted their interactions, creating a connectedness which was meaningful to them.
6. Siblings varied in the extent and the nature of care activities participated in with their sibling.
7. The experience of the sibling relationship was presented by participants in both positive and negative terms. The feelings displayed were entangled and meshed reflecting the dynamic process by which the siblings appraised multiple and contradictory feelings.

5.3 Discussion of the research findings

The central aim of this research was to "Explore the experiences of children who have a sibling with severe and complex special educational needs". From the analysis of the qualitative data, three master themes emerged, within which are nine integrated sub-themes. These findings were now be discussed in depth in relation to psychological theory and the wider research area.

5.3.1 Master Theme 1: Making sense of their situation today and tomorrow

a. Normalising

This initial master theme explored how the participants made sense of their lives with a disabled sibling. Explored within the first sub-theme, 'normalising', participants described their siblings using a range of everyday terms: "giggly", "clever", "kind" "annoying" "nice" and "quite lazy". According to Bogdan and Taylor (1992), the non-disabled person's ability to recognise individual personality traits is one of the aspects of humanness that maintain a human identity for the severely disabled person.

Alongside participants describing their disabled siblings in everyday terms the participants spoke of their relationships with their disabled siblings like any typically developing sibling dyad, with feelings of annoyance, fondness, affection and indifference. This suggests that within the family home, the

siblings' disability is invisible and an intrinsic part of normal family life. The participants endeavoured to promote and conserve this sense of normality through their narrative and description of their siblings.

This is in line with the findings of Stalkers and Connors (2004), who suggest that although siblings have access to society's view of disability, which is often associated with abnormality, within the family setting they seem able to integrate their sibling's disability and move the boundaries of normalcy to include their sibling. It must be taken into account that the participants in this study were predominantly of primary school age or late childhood. This perception that their family life is the norm will potentially be challenged as they move towards adolescence.

Columbus and Sasha, who are facing adolescence, explicitly suggested that their experience of family life, although normal for them, may be different from their peers who do not have a disabled sibling. This different perspective may reflect a growing capacity to see themselves in a wider social context. Theories of child development suggest that within late childhood and adolescence, young people start to become concerned about how they appear to others and become increasingly self-conscious about themselves and their situations (Erickson, 1959).

This increasing awareness of how they and their family situation may be judged is evident throughout Sasha and Columbus's interviews. Particular importance was attached to not presenting an overly negative view of their experience and both made endeavours to present a balanced portrayal of the effect of their disabled siblings on their lives. Reality as reflected to this age group by their peers may create a conflict, with the disabled sibling being one of the causal factors for psychological stress. Opperman and Alant's (2003) findings chime with this, as they found high rates of ambivalent feelings in the adolescent siblings of children with a severe disability. They suggest that these ambivalent feelings are a way of regulating stressful events and the difficult or negative feelings associated with having a sibling with a disability.

b. Diagnosis and aetiology: misunderstandings and dilemmas

The understanding that participants had of their siblings' diagnosis and their personal re-interpretation was examined in the subtheme 'Diagnosis and aetiology: Misunderstandings and dilemmas'. Understanding of the sibling's condition was fundamentally unclear for participants, with some variations: Louise and Columbus were able to name their sibling's condition, whilst for others there was considerable confusion and poor knowledge of their siblings' condition. Opperman and Alant (2003) found similar findings; their participants had some knowledge of their siblings' disability but could not correctly label the disability and had limited knowledge of its implications.

There is a real dilemma in this area for families around knowing and not knowing. Using the family system theory discussed in the literature review, it is possible to postulate that the relationships within the subsystem may be disturbed by the distress of explicitly discussing the full nature of the sibling's condition and prognosis. Some parents may feel that they are shielding siblings from potential distress by non-disclosure or minimal information; some may themselves be struggling with processing the emotions associated with the reality of having a disabled child.

Without clear explanation, participants (Louise, Mona Lisa and Van Persei) constructed their own explanations regarding the cause of their siblings' disabilities. This need to create an explanation in the absence of information is discussed by Fleitas (2000), who describes how, without explanation, children will create their own reality from the thoughts, feelings and behaviours being played out in front of them.

Participants who expressed a desire to know more about their siblings' condition had not pursued this. This intriguing finding may be explained by two further hypotheses. The first relates to self-preservation as expressed in the psychoanalytic tradition, whereby self-preservation from emotional distress may be activated when young children are instinctively aware that they may not be able to face some of the realities of having their questions answered (Freud, 1989; Rochlin, 1965).

The second hypothesis relates to the minimisation of potential stress for their parents; ambivalence here surrounding the desire to know may sit alongside an unconscious anxiety that the true explanation will disrupt the family system. In their book 'Brothers & Sisters: A Special Part of Exceptional Families', Powell and Gallagher (1993) suggest that a sibling's decision not to ask their parents about their siblings' condition originates from a desire to protect their parents from pain. They suggest that the child may fear that their parents may break down or reject difficult question. Mona Lisa's answer exemplifies this unconscious concern that her parents would reject her quest for further information (see below).

Interviewer: Would you want to know why [sibling] can't walk or talk?

Yeah a bit

Interviewer: Who would be able to tell you why?

My mum and dad

Interviewer: What would you want to know?

Why it happened

Interviewer: What do you think they would say?

I don't know; they would probably say 'I'll tell you later' (Mona Lisa, p. 10)

c. Conflicts from the wider world

When asked how they would describe their sibling to strangers, if they were asked directly about their siblings' impairments, responses included attempts to minimise their sibling's difficulties ("she doesn't want to": Van Persei, p. 5) or denial of any disability ("I would say she is not old enough although she really is", Sasha, p. 12)

This sub-theme explores the conflict that these responses indicate when the disability is shown to the wider world, outside the family context. This conflict can be seen as representing a move outwards from normalisation within the originating family system (as explored under the subtheme 'Normalising') to a time when the boundaries of family life become broadened in a wider social context. It is possible that the child's perception moves from the originating experience of their own family to comparisons of other families' situations. This

comparison process illuminates differences between their family and others and this experience may challenge family norms. Conflicts can emerge for the individual around the extent to which their sibling's disability is perceived as acceptable in this wider context. The unconscious desire to fit perceived social norms may result in a need to deny the reality of the situation against a wish to still accept the disabled sibling. Sasha, the eldest participant, explicitly described this conflict by denying the disability to others yet not wanting to appear ashamed of her sibling.

There was also evidence that participants were actively choosing to describe their siblings in a positive way to enquiring strangers. Burke (2010) suggests that “positive responses are an attempt to overcome the position of being demeaned by translating negative experiences into being valued” (p.1696). Within his paper, Burke (2010) develops his notion of ‘disability by association’: this suggests that living and growing up with a disabled sibling confers a sense of difference to the family, including the siblings. How this difference is interpreted by the sibling, the family and the wider community, Burke suggests, can in part determine the extent to which a sibling is empowered or disadvantaged by their situation. The perception and interpretation of disability sits within the social model of disability (discussed in Chapter 2: Literature Review), which suggests that disability is framed by how society views, understands and interprets human differences (Oliver, 1990).

d. Prognosis: remaining hopeful

Within the subtheme ‘prognosis: remaining hopeful’ extracts reveal a narrative of hope. Siblings describe their imagined future for their siblings and their future relationship with them. Although descriptions lay within a continuum of realistic to highly unrealistic, a strong narrative of positivity and hope prevailed. The avoidance of reality was also linked to the level of hopeful outcomes which the participants expressed in terms of the future for their disabled siblings. Positive Psychology is a growing branch of psychology that focuses on strengths, positive states and happiness. Positive psychologists are interested in maintaining levels of hope to build resilience and coping (Seligman and Csikszentmihalyi, 2000).

Dufault and Martocchio's (1985) model of hope highlights the need to recognise the function of hope in illness. Dufault and Martocchio (1985) divide hope into two areas: particularised hope and generalised hope. Particularised hope is specific and focuses on objects or things, whereas generalised hope encompasses a person's broad perception of the world and their understanding of what makes life meaningful (Dufault & Martocchio, 1985). It was suggested in the analysis that participants' narrative of hope might help to minimise difficult feelings and the deflection of reality helped to protect the self and the extension of self as perceived within the family unit. Dufault and Martocchio's (1985) model of hope would support this analysis. Their model suggests that remaining hopeful and positive about their sibling's future and prognosis would provide children with comfort, a sense of safety and a buffer to difficult feelings and emotions.

5.3.2. Master Theme 2: The sibling relationship within the family

This master theme focused on the nature of the sibling relationship and how the participants adapted their interactions to match their sibling's functioning levels and to create a sibling bond. Also discussed in this theme are participants' perceptions about who cares for their sibling and their personal role in this care.

a. Bonding through adaptive play and physical closeness

There was a narrative from several participants in this study regarding their relationship with their sibling, focussing around the development of shared activities. Extracts from participants (Columbus, Sasha, Mona Lisa and Van Persei) show a need to connect with their disabled sibling. The desire to create a sibling bond has its foundations in attachment theory, which describes the importance of the connection that develops in the long-term relationships between humans (Bowlby, 1969a).

Some participants in this study described how they engaged in joint play, although the nature of this play was predominately physical play or forms that engendered physical affection. Lobato et al. (1991a) suggest that siblings' ability to play together and develop close bonds depends partly on the skills of the non-disabled sibling in selecting activities that both the non-disabled and the disabled sibling can enjoy together.

Due to the limited cognitive and linguistic skills of their siblings, participants were unable to connect with them in typical play activities or through social exchanges; however, so strong was their desire to feel close to their siblings that they described how they connected with the siblings using physical closeness so that a sibling bond could be established and nurtured.

Within Bowlby's attachment theory, the construct 'meeting affectional need' may be in evidence here, with the need to interact and establish a bond generating adapted forms of play such that activities become response-oriented in order to meet the needs of the disabled sibling, but at the same time fulfilling the attachment need of the participant for reciprocity.

Stoneman's (2005) review of the research themes relating to siblings of children with disabilities suggests that high quality and mutually satisfying sibling relationships are a result of both siblings being able to acquire and enact roles that are mutually satisfying. The participants here appear to be finding this satisfaction in re-enacting a parental or specialist role where they aim to develop the skills of their siblings. Conversely, one participant explicitly expressed an absence of interaction with the sibling. Findings of previous research also report a variance in the level of reciprocity; some previous studies suggest that the relationships between children with disabilities and their siblings are positive, nurturant and satisfying (Derouin & Jessee, 1996; Cox et al., 2003), whilst others suggest that there is less sibling interaction (Williams et al., 2010).

b. The nature of care, who does what; role and function

This sub-theme explores the extent to which participants assumed the role of carer and how they perceived this role. Previous studies highlighted that siblings help in the caring and management of their disabled sibling (Burke, 2010; Williams et al., 2010).

Within this study, the notion of helping with the care of their sibling came through particularly strongly for one sibling in particular, namely Beyonce. Beyonce's focus on 'helping' became her own personal story of herself and her

long-term self concept. The unique focus on her own need to fulfil this role and its longevity - "I will be helping when mummy and daddy are not here" - speaks of over-identification with this role and is both touching and concerning in someone so young. Her narrative sits alongside other participants' more balanced view where there is a sense of there being a wider support system. For example, Sasha says "We all take it in turns".

The literature suggests that when children take on large responsibility for the care of a sibling, they are in danger of parentification. Parentification is created when a child supports an overtaxed parent by taking on duties that are usually completed by adults but in doing so sacrifices his or her own needs (Jurkovic, 1998). It was striking how one participant (Mona Lisa) reported being prepared to put up with a level of personal physical pain and yet did not seek to complain.

An on-going sibling care role creates a role asymmetry. Role asymmetry was discussed in the literature review and evidence of this asymmetry can be seen in this study where participants discuss elements of their relationship whereby they assume the role of parent, teacher, protector or carer.

The assuming of care-giving responsibilities by participants was evident in different ways. One could say that it is an aspect of a problem with care-giving creating stress, or as part of an individual's solution, in that involvement with the care of the disabled sibling is an active coping strategy. Columbus expresses that caring brings him positive feedback from others: "My mother says 'well done'". The transactional model of stress and coping provides a relativistic view of stress and coping (Lazarus and Folkman, 1984). This model assumes that there are individual differences in ways of adapting to stress. Differences emerge because individuals are exposed to different stressors in varying severity and because they possess different resources and evaluate events in different ways. This conceptualization helps to explain the variability in individuals' responses to stressors in general and specifically to those within their families.

5.3.3. Master theme three: Focus on feelings

One of this study's contributions to the field of sibling research is the exploration of the amplification of the range of feelings siblings experience when they are growing up with a brother or sister with severe and complex special educational needs. This study used a methodology that recognises the importance of personal accounts and the meanings participants place on their experience. The analysis revealed that siblings in this study held a range of mixed and sometimes conflicting feelings and emotions regarding their situation. According to Lazarus and Folkman (1984), emotional reactions reflect a person's appraisal process. The mixed array of feelings presented within siblings' accounts of their experience in this study reflects the ongoing and dynamic process by which siblings are trying to appraise multiple and sometimes contradictory feelings associated with their experience.

a. Anger and Fear

Within the subtheme of Anger and Fear, Beyonce, Tracy and Jessica described their fear regarding their own safety in relation to the unpredictable nature of their siblings' movement and physical actions. This is a finding that does not appear in the current literature. The need to feel safe fulfils the second level of Maslow's hierarchy of needs (Maslow, 1943). The need to feel safe and protected from harm is particularly important for children, as they are solely reliant on adults to provide for these needs. Parents and adults around these participants expressing this level of fear may not have fully taken on board the elevated concern these participants feel in relation to erratic and involuntarily hurtful behaviours exhibited by their siblings.

Previous studies report findings similar to those presented by other participants (Mona Lisa, Sasha, Van Persei and Louise), which indicate that feelings of fear are rooted in concern for their siblings' wellbeing and future health (Fleitas, 2000; Connors and Stalker, 2004; Pit-Ten Cate & Loots, 2000). One EP, writing about her development of a sibling support group, suggests that 'most siblings worry about the future and the health of their brother or sister' (Dodd, 2004, p. 42). Advice from charities that support the siblings of children with disabilities suggests that anxiety and fear is often linked to limited information and understanding of the sibling's condition (Sibs, 2010). Correct and

developmentally appropriate information can help to put fear into perspective and knowledge can help siblings to cope (NICHCY, 1988).

An intriguing finding which is not featured in the literature and was only present in Louise's interview is the role of mysticism and spirituality in helping siblings to assimilate disability into their lives. Louise made reference to her belief that her sibling is being guided by angels. This belief in a higher power helped to facilitate Louise's meaning-making process and provided great comfort and reassurance during distressing moments. This interpretation, I feel draws on my own experience as a Roman Catholic and the doctrine of guardian angels within the catholic faith. It is this experience and belief that helped inform my analysis that angels were serving to provide comfort and guidance to Louise. An alternative explanation could be that this is a coping mechanism created by Louise informed by her imagination. The influence of spirituality has yet to be studied in relation to sibling adjustment but more research may help to clarify how it may help to provide protection and healthy adjustment.

b. Annoyance

One of the key benefits of this study was to provide a safe space for siblings to air difficult feelings. The literature suggests that this expression of difficult feelings and emotions is a healthy response, as unexpressed emotions can heighten vulnerability to negative psychosocial outcomes (Hollidge, 2001). The National Information Centre for Children and Youth with Disabilities (1998) suggests that for many siblings, difficult and negative feelings are not usually openly expressed in day-to-day situations, leading to the internalisation of the emotions, which can further complicate sibling relationships and may also be the root of psychological distress. Furthermore, Strohm (2004) notes that parents can find it difficult to listen to the concerns of siblings. This diminishes the sibling's ability to communicate negative thoughts or feelings can create the repression of negative emotions. This would suggest a need for siblings to have access to a safe and nurturing place to discuss and share their experiences.

Participants described some of the difficulties and limitations created by their siblings and expressed frustration and annoyance. The practical limiting factors

of a disabled sibling have very real impacts on time together, joint family outings and the whole range of daily activities. Mona Lisa expresses this in terms of her hand being hurt by her sibling and Columbus complained that his wish to go cycling was obstructed. Tracey, however was able to develop this train of thought to a level of conceptualization where she could be explicit about her sibling's needs and even understand the stress this caused her parents. This degree of separation of herself from the ultimate responsibility is in contrast to Beyonce's internalisation and potentially may yield a better psychological outcome for Tracey. This possibility would be a valid rationale for a more longitudinal study.

c. Remaining positive

The final sub-theme, 'remaining positive', was a very strong narrative running through interviews undertaken with Columbus and Louise. The participants wanted to ensure that as a researcher, I was aware of the benefits of having a disabled sibling. For example Louise's interview contained a strong sense of positivity about having a disabled sibling including highlighting all the unique opportunities her sibling provides such as having a lift and 'giant' shower built in her house and creating 'exciting' alternative play opportunities. Columbus described in positive terms the sharing of his siblings achievements with his mother, engendering a particular closeness based on a shared experience between mother and son. Other studies have shown that siblings will often identify a number of benefits to having a disabled sibling (Cox et al., 2003; Mandelco et al., 2003). The benefit of finding the good side of things is supported by research which suggests that maintaining a positive stance increases healthy psychological functioning (Taylor, Fuggle, & Charman, 2001).

5.3.4 Reflections on theoretical perspectives

Discussed in Chapter two, the literature review, are three theoretical frameworks which were presented; to guide this research, connect this research to existing knowledge and to provide a psychological framework to help make meaning from the participants experiences. The theoretical frameworks chosen to inform this study included two system-based theories: the family systems theory (Munichin, 1974) and the bio-ecological model (Bronfenbrenner, 1979). The family systems theory assumes that the family is a system which

contains subsystems which mutually influence each other. The bio-ecological model is a broader theoretical model viewing children's development as a result of their interaction with surrounding ecological systems, including those outside the home. Also discussed in the literature review is the social model of disability, which advocates the need to understand the social political and economic context in which disabled children and their families live (Shakespeare 1996).

These theories have been applied to help explain and understand the siblings' experiences and were used to provide a psychological framework to allow for a deeper appreciation of the sibling experience.

Family systems theory for example, provided a rationale for some parents' lack of explanation regarding the nature of their sibling's disability and why some siblings had not asked their parents about this condition, (see pg 134).

The social model of disability provided a rationale for participants' responses to enquiries from outside the home, about their sibling's disability and their need to minimise the disability by highlighting their siblings' positive attributes. It is these societal influences which contributed to a rationalisation for participants' positive description of their sibling to enquiring strangers, (see pg 136).

Bronfenbrenner's (1979, 1986) ecological systems theory, which proposes multiple levels of contextual influence on sibling relationships, appeared on reflection to be less influential in informing the analysis. More influentially were theories exploring the motivations for individual's responses; these theories helped to explain the idiographic nature of the experience. I would suggest that these have informed my analysis more roundly and helped me to grasp the meaning of participant's responses from an individual perspective.

Within the analysis stage, Attachment theory emerged as a theoretical perspective to help provide a rationale for the siblings drive to create a sibling attachment bond. Bowlby is considered to be the founder of Attachment Theory (1969a). At the core of Attachment Theory is the proposal that human infants have an innate, biologically based instinct, to be attached to their parents, in

particular their mothers. Bowlby proposed that the emotional connection between parent and child is critical to the development of the child as the nature of this relationship forms the basis of an internal working model of all future relationships. In this perspective, a child's relationship with the primary caregiver has long term implications for the quality of all other relationships including the sibling relationship.

From an attachment perspective, alongside their primary caregiver, children can form attachments to a range of familiar and important others in their social worlds. Bowlby defined attachment as a "lasting psychological connectedness between human beings" (Bowlby, 1969 p.194).

Given the ubiquitous nature of the sibling relationship within the family during childhood, siblings are prime candidates for attachment relationships. Extracts from participants (Columbus, Sasha, Mona Lisa, Louise and Van Persei) illustrated a strong to desire to connect with their sibling.

In childhood, attachment bonds between siblings may resemble and complement parent-child bonds, particularly in the case of older siblings who are responsive to an infant's needs. In this research extracts from Beyonce illustrated a high level of responsiveness to her sisters needs including taking on a large chunk of her sisters' day to day care. For Beyonce this meant that she was in danger of parentification and in an echoing of the primary care-giver in an attachment relationship, meant that at times she had to sacrifice her own needs.

Due to the limited cognitive and linguistic skills of the disabled siblings, participants were unable to connect with them in typical play activities or through social exchanges. So strong, however, was their desire to feel close to their siblings that they described how they connected with the siblings using physical closeness so that a sibling bond could be established and nurtured. Closely aligned to attachment theory is the notion of reciprocity which is associated with shared feelings of joy and pleasure. Douglas (2007) suggests that attachment is biological and evolutionary in nature, and that reciprocity can be seen as a mediator to the attachment process, rather than forming the basis

of attachment. This was in evidence in participants' accounts when they described their attempts of joint play.

Although not discussed in the literature review, another psychological framework which was used to help provide meaning to the participants accounts was the use of the psychoanalytic framework originally developed by Sigmund Freud (1856-1939). Freud's classical psychoanalytic theory, particularly his work on defence mechanism's and the self preservatory function of the 'ego', provides a possible motivation to explain why participants who expressed a desire to know more about their siblings' condition had not pursued this. According to Freud a defence mechanism is a strategy, unconsciously utilised to protect the ego from anxiety or conflict. Defence mechanisms also involve some degree of self deception, which is linked to their being unconscious and this in turn, is related to their distortion of reality. It is the slight distortion of reality and self deception which according to Freud acted as a shield to the participants from being overwhelmed or distressed by the true nature of their sibling's disability. Not pursuing knowledge about their siblings condition, afforded participants some breathing space to come to terms with their reality or to find an alternative way of coping. As a short term measure this mechanism is seen as advantageous, necessary and normal but as a long term solution to life's problems it can cause problems. At some point the participants may have to face the reality of their sibling's condition.

It is only with hindsight that it is possible to reflect on the theories presented in the literature review and their capacity to make meaning from the participants' experiences. It seems although the three theories presented in the literature review did help to provide a theoretical frame particularly when consider the participants experiences within the context of the family dynamic and the social processes that surround them, they fell short when thinking about the possible individual psychological motivations and basic drives that power our daily responses to life and life situations. On reflection, it seems in the same way sibling relationships are multidimensional so are the range of theories which can be used to help illuminate key dimensions of the sibling relationship and the forces that shape them.

5.4. Critical evaluation of the research

The following section provides a critical evaluation of this research study. Firstly I will use guidelines developed by Yardley (2000) and Smith (2001a) to assess the rigour and quality of this IPA study. Secondly I will provide a critical evaluation of this research study in relation to its research design specifically commenting on the sample selected and issues related to interviewing children.

5.4.1. Assessing the quality of the research

With the use of qualitative methods in health and psychology research increasing over recent years, there is increasing discussion among qualitative researchers about how the quality of qualitative research can be evaluated. Researchers are considering alternative ways of assessing qualitative research, as it is thought that the criteria of validity and reliability commonly applied to quantitative research are not appropriate nor in keeping with the ethos of qualitative study. With this in mind, guidelines have been developed to enable readers to evaluate reports of qualitative research: see, for example, Yardley (2000). In relation to IPA studies, Smith (2011a) has developed a guide to evaluating the quality of IPA research. In this section, both Yardley's suggested criteria and Smith's (2011a) guidelines are used to evaluate the quality and rigour of this research.

Firstly, Yardley's (2000) suggested criteria are used to evaluate the quality and validity of this study. Yardley (2000) presents four broad principles for assessing the quality of qualitative research:

1. Sensitivity to context;
2. Commitment and rigour;
3. Transparency and rigour;
4. Impact and importance.

In relation to the first principle, "sensitivity to context", the sensitivity and skill required by the interviewer in order to obtain good data were recognised as paramount when initially planning this research study because of the sensitive nature of the research topic. I appreciated that the fact that the participants were children and the highly personal nature of the interview required a highly

skilled and experienced interviewer who would be able to successfully navigate around the issues relating to interviewing children and could conduct an interview that would result in quality data.

.."obtaining good data requires close awareness of the interview process- showing empathy, putting the participant at ease, recognising interactional difficulties, and negotiating the intricate power-play where research expert may meet experiential expert" (Smith, Flowers, & Larkin, 2009 p. 180)

In section 5.6.3, I discuss in detail how I successfully conducted the interviews with children and how my years of experience of working with children helped me to build rapport and trust with the participants, which in turn helped to facilitate an open and honest interview.

The sensitivity shown to the context also continued into the analysis process. I took into account the language and meaning of participants' comments and also showed awareness of how imbalances of power, socio-cultural and parental views may have influenced the participants' narrative of their experiences. I also took into account and showed sensitivity to existing literature in the area of sibling research in the planning stages, which helped to orient the study, and in the discussion, the research findings were summarised in relation to previous findings and research literature.

The second principle, "commitment and rigour", relates to the researcher's in-depth engagement with topic and the care and degree of attentiveness during the interview process and also the analysis. I took enormous care when planning the interviews, creating a child-friendly information sheet, which was sent to all the participants prior to the interviews. I attempted to create an informal interview situation which allowed the participants to feel comfortable and at ease by allowing a choice of venues and times, and also by taking care to ensure comfortable low-level seating. I attempted to rebalance issues of power by allowing participants to choose their own pseudonyms.

Rigour is evidenced by the thoroughness and the resulting completeness of the data collection and analysis. I ensured that the sample was appropriate and

relatively homogeneous in line with IPA guidance described by Smith, Flowers and Larkin (2009) . During the analysis stage, I showed a high level of personal commitment and rigour by taking several months to fully immerse myself in the interview data, particularly spending appropriate time on each stage of the analysis process (as detailed in the methodology) to ensure a thorough, in-depth and systematic analysis. At each stage, I held in mind the importance of attending closely to what the participants were saying to ensure idiographic engagement.

Yardley's third principle, "transparency and coherence", relates to how explicitly the research study is described, particularly focusing on the cogency, the rhetorical power of the description and the way in which the research is presented as a coherent whole. Transparency is evidenced in this study by the way each stage of the methodology was meticulously accounted for in chapter three (methodology and in chapter four (findings): the way in which each theme was supported by excerpts from the data clearly illustrates the themes identified by the analysis.

I feel that this research study presents a thoughtful and coherent argument which illuminates commonality as identified through the three major themes but also accounts for ambiguities and contradictions within the data. The aim of the research was to explore and give voice to the personal perspectives of the siblings of children with severe and complex SEN. I feel that there has been a good "fit" between the research aim (to explore the experiences of siblings growing up with a brother or sister with severe and complex special educational) and the qualitative method of investigation and analysis chosen (IPA). In using IPA as a framework for analysing my qualitative research data I have been able to illuminate the sibling experience and allow the sibling voice to be heard more directly. IPA has also allowed for a deeper appreciation and understanding of their situation as described by them.

In using an interpretative approach like IPA, a core issue is the subjective element of interpretation. The impact of this was reduced through the utilisation of peer and supervisor support in a paper trail and credibility check whereby my peer(s) and my supervisor investigated whether the themes I had identified

through the interpretation process were valid and relevant to the transcript. This involved them engaging in a paper trail which required them to look back at the original transcript and follow my thinking through from annotations and notes of transcript to develop initial themes through to emergent themes, super-ordinate themes and main themes. (For an abbreviated version of the development of themes see Appendix 10, 11, 12, 13, 14) This helped to aid transparency and validity and I also kept a research journal to support my ability to be reflexive.

The final principle, “impact and importance”, relates to the distinctive contribution this study makes to the research community by enriching understanding, but most importantly, to the practical implications the study has for the community, policy makers and, particularly in this study, EP practice. The implications for EP practice and policy are discussed in detail in Chapter Six; however, as a precursor to this discussion, the findings from this study have already started to have practical use in my contribution to the Blue Sky project, which is a programme of support for parents and carers of children with complex special educational needs, through which I have has provided sessions on supporting siblings.

The data resulting from this research was obtained from a small sample of children who have a younger sibling with severe and complex SEN and were able to communicate their thoughts age-appropriately. The generalisability of the results needs to be met with caution. Clearly, the findings of this research represent the experiences of the eight participants and do not claim to represent all siblings who have a brother or sister with severe and complex SEN. The findings from IPA studies do not set out to make wide generalisations regarding the findings, as these findings are tied to the data. Instead, the researcher aims to explain the meaning the participants place on the phenomenon.

I will now move to the guidelines produced by Smith (2011a). These guidelines provide a benchmark in order to assess whether a study meets the minimal standards of acceptability for publishing IPA studies. According to Smith (2011a), in order for a study to be deemed acceptable, it should adhere to the following criteria:

- Subscribes to the theoretical principles of IPA: it is phenomenological, hermeneutic and idiographic;
- Transparent, so the reader can see what was done;
- Coherent, plausible and interesting analysis;
- Sufficient sampling from corpus to show density of evidence for each theme.

(Smith, 2011a, p.17)

This study is primarily centred on examining and understanding siblings' lived experience and thus adheres to the theoretical principles of IPA. The methodology explicitly details the process undertaken to obtain and analyse the data, creating a high level of transparency. The analysis and presentation of the findings suggests the individual nuance and the shared experience and each master theme is evidenced by extracts from nearly every participant. In total, this research provides an engaging and enlightening account of the experience of siblings of children with severe and complex SEN. As a whole, it adheres to the principles laid down by Smith (2011a), and it certainly meets the criteria for an acceptable IPA study

5.4.2 Sample selection

In line with the IPA's commitments to give a detailed account of the individual experience, the sample size was kept suitably low, with only eight participants. A small sample size helped to provide a thorough and in-depth understanding of the experience. Issues regarding the generalisability of findings from a small sample have already been noted.

Purposive sampling was used as the sampling method in this research. Families were contacted because of the particular family composition. Within my role as an EP for a Specialist Children Centre, I had easy access to families and siblings of children with disabilities. Issues relating to the dual role of practitioner and researcher are discussed in the section on the role of the researcher and reflexivity later in this chapter.

I had permission from parents to access background information detailed on the Common Assessment Framework (CAF) completed by a professional prior to

their child's entry to the Specialist Children's Centre. This document provided information on the participants' families, particularly ethnicity, family size, culture and socio-economic status.

As noted in Chapter three (methodology), parents were initially approached and asked to share the information pack with the siblings to determine their interest in participating in this research study. Two parents noted that their children (the siblings) had declined the offer to participate in the project. I was aware that children who volunteered to participate in the interviews were happy and willing to talk about their experience; however, there is clearly a group of children who fall outside of this area. This group may have had negative feelings towards their sibling or situation and thus they may not feel empowered to discuss their experience in an interview. A possible limitation to this research study is that the methodology, particularly the highly personal nature of a one-to-one interview, may exclude the views and experiences of participants who feel uncomfortable about discussing their experiences of having a disabled sibling.

Another limiting factor to this research study is that all the participants were older than their disabled siblings and therefore this study excludes the views and experiences of children who grow up with an elder disabled sibling. Birth order as a possible variable in sibling functioning and future qualitative research could include the experiences of children who are younger than their disabled sibling, which could be contrasted against the experiences of elder siblings.

5.4.3. Issues relating to interviewing children

Common within IPA research, semi-structured interviews were used in this research study to capture participants' experiences. Reflection and analysis of the interviews suggested that there were complex processes taking place within the interview sessions and much thought went into setting up the interviews, particularly as interviewing children brings a different set of issues in comparison to interviewing adult.

It was imperative that the participants felt comfortable to share their views and experiences. Cohen et al. (2000) suggest that there are potential issues that a researcher should consider when interviewing children, including establishing

trust, power imbalances, asking questions at the appropriate developmental level, use of vocabulary, encouraging inarticulate children to express their views and moving away from societal responses or what children think the interviewer wants to hear.

To help establish trust and overcome issues of power imbalances, participants were asked to state their preference regarding the setting of the interview (their home, the Specialist Children's Centre or their school). Interestingly, none of the participants chose their schools as the location of their interviews, perhaps suggesting a need to keep their home life private. Giving participants a choice regarding interview location enabled them to feel that they had control and also allowed them to choose a space which assisted them to feel relaxed and communicate freely and openly. Also, participants were deliberately asked to provide their own pseudonyms: this was to promote feelings of control and reassurance regarding confidentiality.

As the participants were children aged seven to thirteen years, the structure of the interview and the interview schedule were considered carefully to ensure age-appropriate language and a feeling of comfort to enable maximum participation. When interviews took place at the Children's Centre, I made certain that they were held place in a room with comfortable seating and throughout all the interviews I endeavoured to create a relaxed setting, the opposite of a traditional interview environment.

The interview schedule was designed to start with questions that were relatively easy, such as "Who is in your family?" and "What school do you attend?" and then build to questions regarding participants' feelings regarding their siblings. On reflection, my many years' experience in working with and talking to children helped to ensure that the language and tone of the interview was adapted appropriately to the age and developmental stage of the participants.

Although I had pre-prepared questions, I endeavoured to allow the participants to steer the direction of the interview to help facilitate discussions that captured the richness of the individual experience; however, because of this, not all questions prepared were asked in the course of the interviews and some

interviews focused more strongly on certain areas. This provides both benefits and limitations, as the variety provided richer data but might also have led to the exclusion of certain information and the collection of slightly varied information.

During the interview process, ethical procedures as outlined in the methodology chapter were adhered to. For instance, participants were told that they could stop the interview at any time, particularly as I was aware of the potentially sensitive nature of the interview. It is noteworthy that no participants asked to stop the interview, nor did they become distressed, and so the need for after-care was not used.

5.5. Role of the researcher and reflexivity

Reflecting critically on experiences, incorporating knowledge derived from new experiences and learning from critical reflection can be thought of as the distinctive quality of the adult learner (Brookfield, 1998).

In this research study, I moved from critical reflection, which utilises critical thinking skills, to reflexivity, which analyses the individual, inter-subjective and social processes that shape the research study.

Reflexivity implies the ability to reflect inward toward oneself as an inquirer; outward to the cultural, historical, linguistic, political, and other forces that shape everything about inquiry; and, in between researcher and participant to the social interaction they share (Sandelowski and Barrso, 2002, p. 222).

From the beginning of the course, critical reflection and reflexivity was paramount. Critical reflection was a continual process which occurred through formal supervision in work, personal tutorials at UEL, informal conversations with peers and through personal reflection. These times provided time to reflect upon new skills and knowledge and to develop a greater awareness and understanding of my own personal learning style. Critical reflection was also crucial during the interview and analysis phases to make certain that I was aware of my preconceived ideas and assumptions regarding the phenomenon.

In supervision, I discussed some of issues around my dual role, in particular reflecting upon defining my role as a researcher separately from my role as an EP. I discussed how the families approached for this research study only knew me in my role as an EP and how this could affect their participation in the study. Initially in terms of recruiting potential participants, family's prior knowledge of my work as an EP was useful and helped to provide a way in, to introducing my research. I then became concerned that because of my familiarity with the families they would feel obliged to take part in my research. In discussion with my supervisor, it was agreed that it was important to emphasise to all potential participants and their families that the decision to take part in the study would not affect the service they received from the EP service.

Notes in my reflexive diary prior to interview stage revealed another anxiety created by the duality of my role. I was concerned that as the participants were aware that I knew their parents I was worried that they would feel hesitant about sharing their true experiences for fear that I will report what they said back to their parents. To guard against this the confidential nature of the study was reiterated at several points while setting up the interviews and during the interviews themselves. I was also careful to ensure parents understood, that the interviews were confidential and they would not get any feedback. This was tested when one parent, in a meeting after the interviews enquired about the interview and I politely declined from providing any information.

Within the interview situation, my dual role was both enabling and disabling. Enabling as my familiarity helped to create an easy rapport and I hoped helped to lessen any participant anxiety. Participants awareness that I had prior knowledge of their disabled sibling created an interesting interplay in the interviews which meant at times it was helpful as it created a shortcut to co-constructing meaning but also meant at times I had purposely underplay my knowledge and be enquiring in order to encourage the participants to talk further about their experience.

I also discussed in supervision my anxiety regarding my ability to collect rich data from children. The success of the pilot interview reduced my anxiety and as I conducted more interviews my anxiety reduced even further. I was surprised

and delighted by the richness of the data collected and also the participants' ability to reflect and articulate their thoughts and feelings. It was discussed in supervision that the skills I had developed in my current role as an EP were particularly useful when interviewing, as this previous experience helped in building rapport and creating and conducting an interview situation which would capture a rich and full account of the participants' experiences.

Throughout the interview stage and during the analysis stage, I endeavoured to remain open so that I could explore the phenomenon without bias or presumption. Dahlberg et al. (2001, p. 97) describe this open stance: "Openness is the mark of a true willingness to listen, see, and understand. It involves respect, and certain humility toward the phenomenon, as well as sensitivity and flexibility."

In my endeavour to remain open, I used a reflexive diary to record my raw reactions, initial impressions, as well as my assumptions and biases regarding the subject. Also, after each interview, I recorded when participants' responses contradicted my assumptions. This process helped me to reflect on the impact of my beliefs on the interpretation of the data and was crucial during the analysis stage, as it meant that I could be surprised, and generally open to what was revealed.

I took time over the analysis stage, often revisiting the analysis after a period of a several days and weeks, as this process was found to be intensive and hard work which required a deep analytic focus.

During this phase, I was careful to record every step in the process, as this provided a paper trail which was then checked by a peer who investigated whether the themes identified through the interpretation process were valid and related to the transcript. This triangulation further enhanced the rigour and credibility of the results.

Throughout the research, I was aware of my social identity as a white female researcher. Although it is not possible to establish what effect ethnicity, culture,

or gender has on the research situation, it was imperative to stay cognisant of this via self-reflection.

The emotional aspects of completing this research study were discussed continually through formal and informal peer and supervisor supervision. This was particularly important because of the sensitive nature of the subject of this research study and also I found my emotional sensitivity heightened towards the later stages of this research study because of my personal circumstances, being pregnant with my first child.

To address the emotional impact of the research, I kept notes of my thoughts and feelings in my reflexive diary. I particularly found the emotional impact of listening to and making sense of the participants' experiences demanding. In supervision, I made space and time to reflect on the analysis in order to make sense of and interpret the meaning of the quotes. Also during the data analysis I made special arrangements to speak to a systematic family therapist to help me reflect upon and understand my emotional response to the data.

5.6. Summary of chapter five

This chapter has discussed the key findings in relation to psychological theory and previous research. It has also provided a critical discussion and evaluation of the research. This evaluative discussion was steered by the principles and guidelines set by Yardley (2000) and Smith (2001a) to assess the quality and rigour of this qualitative research. Also critically discussed was the sample selection and issues relating to the interview process and interviewing children. An overview of the reflexive stance running through this study and reflections on my role as the researcher concluded this chapter. The next chapter provides conclusions, implications for professional practice and makes suggestions for further research.

Chapter Six: Conclusion

6.1. Introduction to chapter six

This final chapter provided a summary of the key findings of the research and the distinctive contribution these findings make to the research area. In light of the findings, key recommendations are made pertaining to the work of all professionals working with the families of children with severe and complex SEN and also to the practice of professionals within my own sphere of work as an EP. Ideas for further research and my concluding comments close this chapter and this doctoral thesis.

6.2. Summary of findings

With the aim of exploring the experience of siblings who have a younger brother or sister with severe and complex SEN, the research found that siblings integrated their disabled sibling into the normalcy of their family life. When outside the family context, this normalcy was challenged and in reaction to this challenge participants attempted to minimise or deny their siblings' disability.

All but two siblings were not well informed regarding the nature of their siblings' condition and correspondingly constructed individualised interpretations. The importance of remaining hopeful regarding their sibling's life and future was a significant feature in some of the experiences. Siblings wanted to bond with their severely disabled brother or sister and in order to do this they adapted their interactions, creating a connectedness which was meaningful to them. The findings indicated that siblings varied in the extent and the nature of care activities they participated in.

The experience of the sibling relationship was presented by participants in both positive and negative terms. The feelings displayed were entangled and meshed reflecting the dynamic process by which the siblings appraised multiple and contradictory feelings.

6.3. Distinctive contribution

This research has created and interpreted new knowledge through developing original research about siblings of children with severe and complex SEN. This knowledge will help to provide further information and understanding about a unique group of young people, building upon the current research and providing a distinctive contribution to the research body.

The literature review showed that there has been a lack of qualitative research that has specifically investigated the lived experience of siblings, as previous research has rarely included the sibling voice and largely focuses on studies from outside the United Kingdom.

The core strengths of this study, which set it aside from most other studies in the sibling research field, are its use of a qualitative methodology, its UK-based context and its focus on the sibling voice and illumination of the sibling experience.

Due to my role as an EP working in a Specialist Children's Centre, I had unique access to the families of children with severe and complex SEN. This unique access and my long-standing experience in talking to children allowed me access to the personal accounts of siblings and also enabled me to build trust and rapport effectively. This highly personal approach meant that the views and experiences of siblings could be accessed directly, rather than indirectly through their parents' views or through the use of quantitative methods such as questionnaires.

This study was also unique in using IPA to analyse and understand in detail the experiences of the siblings of children with severe and complex SEN and to gain insight into how siblings make sense of their world. This method of analysis has not been used previously with this specific population.

I believe that in providing siblings with the opportunity to give their views on their experiences, I gave a voice to a group of children who may be seen as underrepresented. This provision of a space in which their voices and experiences were heard also validates the individual experience and allows this

experience to be viewed non-judgementally. It is also hoped that in providing a space for them to give their perspective, I enabled the children in this study to develop their skills and confidence in putting their opinion forward.

The findings from this study provide a distinctive and unique insight into the lives of siblings of children with severe and complex SEN. It is hoped that these findings may help to challenge stereotypes and prior beliefs, as they illuminate the positives in this unique situation alongside some of the challenges.

It is hoped that the findings will help to provide insights into how siblings can be supported and highlight key implications for professional practice, not just for EPs but for all professionals working with families of disabled children.

6.4. Implications for practice

This research has been conducted by an EP and the implications of this study are viewed and set within the context of EPs' work. It is widely recognised that the EP's role is diverse and the different contexts in which an EP can now work vary greatly:

EPs have important roles in improving the opportunities of all children and young people, both in terms of local authority statutory responsibilities and more universal early intervention and preventative support offered by the public and private sectors, voluntary and community groups and social enterprises (DFE, 2011, p. 5)

This research has important implications for all professionals working with families who have a child with severe and complex SEN.

The implications of this study have been divided into three areas.

- 1) The implications of this study for EPs working in schools. A significant amount of EPs' time continues to be spent working within educational settings, namely pre-schools, primary schools and secondary schools and also special schools.

- 2) The implications of this study for EPs working in community settings alongside a range of other professionals. Within my local authority, EPs work within and alongside educational settings but also work in a range of community settings, such as children's settings, CAMHS teams, Looked After Children specialist teams and TAMHS. I would suggest that the findings of this study contain key messages for all professionals working with families with complex needs: these include social workers, health professionals and mental health teams.
- 3) The implications of this study for EPs working within their own teams.

6.4.1 Implications for EPs working in schools

Within this traditional role, the EP is likely to work collaboratively alongside educational professionals within schools in supporting the needs of individual children. The implications of this research can be applied within this setting. Below is a list of suggestions:

- Firstly, EPs can highlight to schools and teachers the importance of the family composition of the children they teach. This may be especially relevant in secondary schools where parents have less contact with school staff and consequently know less about children's family composition. This research has highlighted that children seek to normalise their situation, which could mean that schools are not always aware of which children have siblings with severe disabilities.
- In being aware of which children in a school may have siblings with severe disabilities, EPs can explore the needs of this group of children with school staff through on going discussion or training. As demonstrated in this research, siblings' experience varies and can be both positive and negative. The EP could highlight the importance of counteracting negative assumptions by providing a more balanced account.
- Where the sibling is experiencing difficulties, teachers may value information and guidance on how to provide support. The EP can offer

specific advice to schools regarding supporting siblings of children with severe and complex SEN. This could include:

- Increasing awareness of disability issues using circle time or PSHE lessons to explore issues about disability
 - Providing information about sibling support groups that may be running locally as well as sibling support websites.
 - The school could provide additional one-to-one support. The sibling may welcome the opportunity to talk about their worries and concerns with a mentor or teacher with whom they have a good relationship. There would be opportunities at this point for EPs to help schools affirm sensitive approaches to individuals' requests for privacy, which was also highlighted in this research.
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- Within the school setting, the EP could themselves offer ongoing one-to-one meetings with a sibling wanting a space to talk or could encourage another professional to talk to the sibling through therapeutic communication. (See Appendix 15 for a guide for educational psychologists to help structure one to one meetings or therapeutic conversations with siblings who have asked for additional support)
 - An EP working within a special school may deliver a sibling support group for the siblings of the children who attend the special school.
 - Where the EP works within a specialist school setting, the EP may encourage school staff to engage siblings as part of their social programmes. Siblings could be invited to fun days at the special school to encourage a sense of shared involvement.
 - Special schools could provide particular support related to the need identified from this research: participants had limited understanding of their siblings' long-term prognosis and future life. It was felt that this may be partly due to the lack of experience siblings had in interacting and meeting adults with severe disabilities. Special schools could be encouraged to invite adults or the previous students to events in school

e.g. school fairs, school concerts. This could provide siblings a natural setting to explore the future for their own disabled sibling.

6.4.2. Implications for EPs working in other settings

As noted earlier, EPs work in a range of settings. Although traditionally their work is mainly in school settings, EPs can also work in other community-based settings within health, social services and education. This includes working in children's centres, residential homes, Sure Start and mental health projects and early intervention initiatives. Within these settings, EPs work alongside professionals from a variety of different backgrounds and disciplines. The implications of the research findings for EPs working within such settings are as follows:

- EPs can raise awareness of sibling issues with professionals from other disciplines. More awareness of the research in this topic and ideas to support sibling would help to ensure that siblings' needs are being met successfully in a range of settings. I am currently preparing a presentation on supporting siblings for a multi-disciplinary audience. I would encourage other professionals interested in sibling issues to continue to cascade this information to a wider audience.
- EPs working in settings where they have increased contact with parents of children with severe disabilities may consider engaging parents in a conversation regarding how to support siblings within the family. The EPs' listening skills and their knowledge and understanding of developmental psychology mean that they are well placed to discuss with parents the sensitivities of how they may wish to have conversations about diagnosis and prognosis which are appropriate for the sibling's developmental level. EP may also encourage other professionals to support parents with these conversations and could provide additional training and advice in this area.
- EPs are well placed to provide training or workshops to parents highlighting the needs of siblings. As a result of this research, I have already provided information sessions to parents of children with severe

and complex SEN. These training sessions have been part of an initiative running in my local authority called the Blue Sky project. The Blue Sky project is an eight-week programme to support parents who have a child with complex needs. As part of the programme, I have regular slot where I present my key findings to parents and provide advice regarding sibling issues. This presentation on 'supporting siblings' is now a regular feature in this programme and since completing my research I have run this session six times. Over time I have adapted my presentation slightly following personal reflection and from peer reflection with the programme co-ordinator. Changes made include, less research content and more time for parental discussion and questions and the inclusion of a book list including children's books which address sibling issues (See Appendix 16 for the latest version of my PowerPoint presentation and Appendix 17 for a thank-you letter from the Blue Sky project co-ordinator and the).

- EPs have particular skills in group work and engaging children and young people: they are therefore well placed to run sibling support groups in community settings as part of their link with special schools. I am currently in the process of acquiring funding to complete the training programme from the *Sibs* organisation so that I can set up a local sibling support group.
- A key recommendation for EPs working alongside health professionals is to increase awareness amongst health professionals around the importance of providing good support to parents at the point of diagnosis. This is crucial because it could be of great benefit in encouraging parents to have the confidence to discuss issues relating to disability more openly with siblings as they grow up.
- A key recommendation from this study is for EPs to encourage professionals completing assessments of children with severe and complex SEN and their families to integrate siblings' views, opinions and needs throughout the assessment process. This is particularly relevant to our social worker colleagues who conduct core assessments as a matter of course. I would recommend that these assessments should include an

assessment of the needs of the siblings and recommendations may include referral to local sibling support groups, one-to-one counselling and referral to the community-based projects. There is a need for a range of options to be available so that siblings can choose what suits them best, although it should also be borne in mind that not all siblings will want support. Assessment and need should be reviewed over time, as siblings may need different types of support as they get older.

For the above recommendations to be put into place, policy makers and practitioners should transform the needs of siblings into long term plans that support sibling initiatives. This should include support and funding for sibling initiatives and encouraging professional sensitivity to sibling issues. Siblings can often be missed and not be on anyone's agenda. Dodd, (2004) notes that the needs of siblings should be met through a partnership between parents and the agencies working with their families.

6.4.3 Implications for EP Teams

This current research also has implications for the EP service generally. Throughout this research process, I have endeavoured to raise awareness regarding sibling issues within my own profession by presenting this research to my own team and my doctoral colleagues. It is hoped that raising awareness of sibling issues among fellow EPs will help to develop ideas to support siblings, which in turn will ensure that siblings' needs are being met successfully in a range of settings.

Finally, I would like to highlight the importance of EPs developing professional practice and research skills. These skills are particularly valuable within the current climate of Children's Services where there is an increasing necessity for evaluation outcomes.

It is also valuable for EPs to develop research skills so that high quality research studies can be completed, which in turn help to build a knowledge base about professional practice in EP and inform evidence-based practice.

In encouraging EPs to complete high quality research, the research itself has the potential to be an intervention in its own right. It is hoped, for example, that the process of speaking to siblings, as conducted in this study, has provided an experience that was beneficial. Having an opportunity to tell their story (together with being allowed to decide what they chose to reveal) and being listened to provided participants with the space to think through and discuss their experiences.

6.5. Future research

More research which employs qualitative methods should be used to further explore and extrapolate the sibling experience. This would help to give a voice to an under-represented population and present an additional perspective to the body of quantitative methodology seen in this field.

Longitudinal qualitative research exploring the life journey of siblings would add depth to the research field and help researchers to understand how the sibling experience and relationship may change over time, particularly in light of the possible increased responsibility of care for their sibling as their parents grow older or pass away.

Further extension to this work, with an attempt to move away from the singular lens on sibling research could also provide useful insights. Research in this field could explore the importance of reciprocity in sibling relationships. This research could represent the views of both disabled children and their siblings. Naturally this type of research has been missing in the past due to limited communication skills of the disabled child. However I would challenge researchers to develop innovative methods to include those using alternative communication devices to ensure as full participation as possible.

An interesting new direction and area for further research is the relationship between a disabled child and a half- or step-sibling. This is a completely unexplored area and is particularly relevant given the dramatic rise in the number of families that do not conform to the traditional family model.

6.6. Concluding comments

In summary, this study has illuminated the unique experience of the participants who have a younger brother or sister with severe and complex SEN. The analysis, using IPA, has allowed for a deep appreciation of participants' cognitive and affective reactions to their situation. Their experience detailed positive and negative aspects but most importantly this research reinforces the significance of listening to children and empowering children to talk about their thoughts and feelings.

The findings resulting from this research should not be viewed in isolation, as it sits within the context of the family, society and the current point in history. It is hoped that this research will help in challenging current practice, in highlighting the voices of an under-represented population and in supporting the current thinking, which highlights the need for holistic and family-centred practices.

References

- Back, C., Gustafsson, P. A., Larsson, I., & Bertero, C. (2011). Managing the Legal Proceedings: An Interpretative Phenomenological Analysis of Sexually Abused Children's Experience with the Legal Process. *Child Abuse & Neglect: The International Journal*, 35(1), 50-57.
- Beaver, R. (2011). *Educational Psychology Casework: A Practice Guide*, London: Jessica Kingsley Press.
- Beresford, B. (1995) The needs of disabled children and their families, Social Care Research, 76, Joseph Rowntree Foundation, York.
- Bernheimer, L. P., Gallimore, R., & Weisner, T. S. (1990). Ecocultural theory as a context for the individual family service plan. *Journal of Early Intervention*, 14 (3), 219-233.
- Bersoff, D. and Hofer, P. (1990). The legal regulation of school psychology. In T. Gutkin and C. Reynolds. *The Handbook of Social Psychology*. New York: Wiley.
- Bhaskar, R. (1978). *A Realist Theory of Science*. Hassocks, West Sussex: Harvester Press Bogdan, R., and Taylor, S. J. (Eds.). (1992). The social construction of humanness: Relationships with severely disabled people. In Ferguson, P., Ferguson, D. and Taylor, S. *Interpreting disability: A qualitative reader* (pp. 275-294). New York, NY: Teachers College Press.
- Bowlby, J. (1969), *Attachment and loss, Vol. 1: Attachment*. New York: Basic Books.
- Brody, G. H., and Stoneman, Z. (1987). Sibling conflict: Contributions of siblings themselves, the parent-child relationship, and the broader family system. *Journal of Children in Contemporary Society*, 19, 39-54.
- Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.
- Brookfield, S. (1988). Developing Critically Reflective Practitioners: A Rationale for Training Educators of Adults. *Training Educators of Adults: The Theory and Practice of Graduate Adult Education*. S. Brookfield, Editor. New York: Routledge.
- Bryman, A. (2008). *Social Research Methods*, 3rd edition. Buckingham: Oxford University Press.
- Burke, P. (2010). Brothers and Sisters of Disabled Children: The Experience of Disability by Association. *British Journal of social work*, 40 (6), 1681-1699.
- Cicirelli, V. (1982). Sibling influence throughout the lifespan. In M. E. Lamb and B. Sutton-Smith (Eds.), *Sibling relationships: Their nature and significance across the lifespan* (pp. 267-284). New York Psychology Press.

Chamba, R., Ahmad, W., Hirst, M., Lawton, D. and Beresford, B. (1999) *On the Edge: Minority ethnic families caring for a severely disabled child*, The Policy Press, Bristol

Clancy, M. (2013) Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse researcher*. 20, (6), 12-14.

Cohen, L., Manion, L. and Morrison, K. (2000) *Research Methods in Education* (5th Ed.) London: Routledge. Falmer.

Costeloe, K.L., Hennessy, E.M. and Haider S,. (2012). *Short term outcomes after extreme preterm birth in England: comparison of two birth cohorts in 1995 and 2006 (the EPICure studies)*. BMJ. Published online December 4 2012.

Cox, A. H., Marshall, E. S., Mandleco, B., and Olsen, S. F. (2003). Coping responses to daily life stressors of children who have a sibling with a disability. *Journal of Family Nursing*, 9(4), 397-413.

Dahlberg, K., Drew, N., and Nystrom, M. (2001). *Reflective Life world Research*. Lund, Sweden: S

Department for Education. (2011). *Support and aspiration: A new approach to special educational needs and disability*. London:HMSO.

Department for Education. (2012). *Support and aspiration: A new approach to special educational needs and disability*. Progress and next steps. London:HMSO.

Department for Education and Employment. (1996). *The Education Act*. London: HMSO.

Department for Education and Skills. (2003). *Every Child Matters*. London: HMSO.

Department for Education and Skills. (2004). *The Children Act*. London: HMSO.

Department for Education and Skills. (2007). *Aiming High for Disabled Children: Better Support for Families*. London: HMSO.

Department of Health. (2010). *National Framework for Children and Young People's Continuing Care*. London. HMSO.

Department of Health, Department for Education and Skills. (2004) *National Service Framework for Children, Young People and Maternity Services*. London: HMSO.

Department of Health, Department for Education and Skills. (2004). *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and Those with Complex Health Needs*. London: HMSO.

Department for Work and Pensions. (2011). *Family Resources Survey: United Kingdom 2010/2011*. London: HMSO.

Derouin, D., Jessee, P. (1996). Impact of a chronic illness in childhood: Siblings perceptions. *Issues in Comprehensive Paediatric Nursing*. 19, 135-147.

Dodd, L. W. (2004). Supporting the siblings of young children with disabilities. *British Journal of Special Education*, 31, 41.49.

Doutre, G., Green, R., Knight-Elliott, A. (2013) *Educational & Child Psychology*, Vol. 30 Issue 4, p30-43. 14p.

Dufault, K., and Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20(2), 379-391.

Dunn, J., and Kendrick, C. (1982). *Siblings*. London: Grant McIntyre Ltd.

Dyson LL. (1999). The psychosocial functioning of school-age children who have siblings with developmental disabilities. *Journal of Applied Developmental Psychology* 20(2): 253–271.

Erikson, E. H. (1959). *Identity and the life cycle; Selected papers, with a historical introduction by David Rapaport*. New York: International University Press.

Finlay, L. (2008). A dance between the reduction and reflexivity: explicating the phenomenological psychological attitude. *Journal of Phenomenological Psychology*, 39(1), 1-32.

Finlay, L. (2012) Debating phenomenological research methods, N.Friesen, T.Saevi & C.Henriksson (Eds.) *Hermeneneutic Phenomenology in Education: Method and Practice*, Sense Publishers.

Finlay, L., and Gough, B. (2003). *Reflexivity : a practical guide for qualitative researchers in health and social sciences*. Malden, MA: Blackwell Science.

Fiske, S.T. and Taylor, S.E. (1991). *Social Cognition*, New York: McGraw-Hill.

Fisman, S., Wolf, L., Ellison, D., and Freeman, T. (2000). A longitudinal study of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369–375.

Fleitas J. (2000) When Jack fell down...Jill came tumbling after: Siblings in the web of illness and disability. *MCN The American Journal of Maternal Child Nursing*. Sept-Oct 25(5): 267-73.

Fraser, S., Lewis, V., Ding, S., Kellett, M. and Robinson, C. (2004) *Doing Research with Children and Young People*. London: Sage in association with the Open University.

Freud, A. (1989). *Normality and Pathology in Childhood*. London: Karnac

- Frude, N. (1991). *Understanding family problems: A psychological approach*. Chichester: Wiley and Sons.
- Gallagher, P. A., Powell, T. H., and Rhodes, C. A. (2006). *Brothers and sisters: A special part of exceptional families* (3rd ed.). Baltimore, MD: Paul H. Brookes Publishing.
- Gibbs, B. (1993). Providing support to sisters and brothers of children with disabilities. In G. Singer and L. Powers (Eds.), *Families, disability, and empowerment: Active coping skills and strategies for family interventions* (pp. 343–363). Baltimore: Paul H. Brookes.
- Gooch, D. (1996). Home and away: the residential care, education and control of children in historical and political context. *Child and Family Social Work*, 1, 19–32.
- Gray, D. (2004) *Doing research in the real world*. London: Sage.
- Greco, V., Sloper, P., Webb, R., and Beecham, J. (2005). *An Exploration of Different Models of Multi-agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs*. York, UK: Department for Education and Skills. Research Report 656. University of York.
- Greene, S. and Hogan, D., (2004) *Researching children's experiences: Approaches and methods*. London: Sage.
- Hatton, C., Emerson, E., Kirby, S., Kotwal, H., Baines, S., Hutchinson, C., Dobson, C. & Marks, B. (2010). Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. *Journal of Applied Research in Intellectual Disabilities*, 23, 63-74.
- Hames A. (2008). Siblings' understanding of learning disability: a longitudinal study. *Journal of Applied Research in Intellectual Disabilities*. 21:491-501.
- Hollidge, C. (2001). Psychological adjustment of siblings to a child with diabetes. *Health and Social Work*, 26, 15-25.
- Hubert J (2006) Family carers' views of services for people with learning disabilities from Black and Minority Ethnic groups: a qualitative study of 30 families in a south London borough, *Disability and Society*, 21, 3 , 259 - 272 .
- Jootun, D., McGhee, G., and Marland, G. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, 23(23), 42-46.
- Jurkovic, G. J. (1998). Destructive parentification in families: Causes and consequences. In L. L'Abate. *Family psychopathology* (pp. 237–255). New York: The Guilford Press.
- Kawamura, M. (2005) A suggested social model focusing on the siblings of persons with disabilities. The University of Tokyo Japan

- Kazak, A. E., Simms, S., and Rourke, M. T. (2002). Family systems practice in pediatric psychology. *Journal of Pediatric Psychology*, 27, 133–143.
- King, N. (1994). The qualitative research interview. In C. Cassell and G. Symon, *Qualitative methods in Organizational Research*. London: Sage.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Lazarus, R.S., and Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lindsay, J., and O'Connell, D. C. (1995). How do transcribers deal with audio recordings of spoken discourse? *Journal of Psycholinguistic Research*, 24(2), 101– 115.
- Lobato, D., Kao, B., & Plante, W. (2005). Latino sibling knowledge and adjustment to chronic disability. *Journal of Family Psychology*, 19, 625-632.
- Lobato, D., Kao, B., Plante, W., Seifer, R., Grullon, E., Cheas, L., Canino, G. (2011). Psychological and school functioning of Latino siblings of children with intellectual disability. *Journal of Child Psychology and Psychiatry*, 52 (6), 696 -703.
- Lobato, D., Miller, C. T., Barbour, L., Hall, L. J., and Pezzullo, J. (1991). Preschool siblings of handicapped children: Interactions with mothers, brothers, and sisters. *Research in Developmental Disabilities*, 12, 387–399.
- Lobato, D., & Plante, W. (2009). The use of the Impact on Sibling Scale with families of children with chronic illnesses and disabilities. *Child: Care, Health, and Development*, 35, 505-509
- Macklin, R. (1992). Autonomy, Beneficence and Child Development: An Ethical Analysis. In B. Stanley and J. Seiber. *Social Science Research on Children and Adolescents: Ethical Issues*. Newbury Park, Calif:Sage.
- Magaña, S. (1999) Puerto Rican families caring for an adult with mental retardation: The role of familism. *American Journal on Mental Retardation*, 104, 466-482.
- Magill-Evans, J., Darrah, J., Pain, K., Adkins, R. and Kratochvil, M. (2001) Are families with adolescents and young adults with cerebral palsy the same as other families? *Developmental Medicine and Child Neurology* 2001;43:466-472.
- Mandleco, B., Olsen, S. F., Dyches, T., and Marshall, E. (2003). The relationship between family and sibling functioning in families raising a child with a disability. *Journal of Family Nursing*, 9, 365–396.
- Marin, G., & Marin, B. V. (1991). *Research with Hispanic populations*. Newbury Park, CA:Sage

- Maslow, A. (1943). A theory of human motivation. *Psychological Review*, 50, 370-396.
- McCormack, M. (1978). *A Mentally Handicapped Child in the Family*. London: Constable.
- Mertens, D. M. (2005). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods*. Thousand Oaks, CA: Sage.
- Minuchin, S. (1974). *Families and family therapy*. Cambridge, Massachusetts: Harvard University Press.
- Morrow, E. (2009). Teaching critical reflection in healthcare profession education.
- Neuman, W. Lawrence (1999). *Social Research Methods*. 4th Edition. Needham Heights, MA: Allyn and Bacon.
- Opperman, S., and Alant, E. (2003). The coping responses of the adolescent of children with severe disabilities. *Disability and Rehabilitation*, 25, 441-454.
- Oliver, M (1990). *The Politics of disablement*. Macmillan: London
- Oxford English Dictionary (3rd Edition, Revised) (2011). Oxford: University Press.
- Petalas, M., Hastings, R., Nash, S., Dowey, A., & Reilly, D. (2009). "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability Development and Education*, 56, 381-399
- Pit-ten Cate, I.M. and Loots, G.M.P. (2000). Experiences of Siblings of Children with Physical Disabilities: An Empirical Investigation. *Disability and Rehabilitation*, 22 (9), 399-408.
- Richardson, J.T.E. (1999) The concepts and methods of phenomenographic research. *Review of Educational Research*, 69, 53-82.
- Rochlin, G. (1965) *Griefs and Discontents* Boston: Little, Brown.
- Robson, C. (2002). *Real world research : a resource for social scientists and practitioner-researchers*. Oxford : Blackwell.
- Sandelowski. M., and Barroso, J. (2002). Finding the findings in qualitative studies. *Journal of Nursing Scholarship*, 34 , (3), 213-220
- Schuntermann, P. (2007). The sibling experiences: Growing up with a child who has pervasive developmental disorder or mental retardation [Electronic version]. *Harvard Review of Psychiatry*, 15(3), 93-108.

- Scott, J. (2008). Children as respondents. In Christensen, P. and James, A. *Research with Children: Perspectives and Practices*, Second Edition, London: Routledge
- Seidman, I. E. (1991). Interviewing as qualitative research: A guide for researchers in education and the social sciences. New York: Teachers College Press.
- Seligman, M., and Csikszentmihalyi, M. (2000). Positive psychology: An Introduction. *American Psychologist*, 55, 5-14.
- Seltzer, M.M., Greenberg, J.S., Orsmond, G.I., and Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, 43, 354-359.
- Shakespeare T. (1996). Disability, Identity and Difference. In *Exploring the Divide*, Barnes C, Mercer G. The Disability Press: Leeds; 94–113.
- Sharpe, D., and Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of Pediatric Psychology*, 27, 699–710.
- Silverman, D. (2006). *Interpreting Qualitative Data*. (3rdEd.). London: Sage.
- Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In: Smith, J.A., Harre, R. and Van Langenhove, L. (Eds.), *Rethinking Methods in Psychology*. Sage, London.
- Smith, J.A. (2011a). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5 (1), 9-27.
- Smith, J.A. (2011b). Evaluating the contribution of interpretative phenomenological analysis: a reply to the commentaries and further development of criteria. *Health Psychology Review*, 5(1)
- Smith, J., Flowers, P. and Larkin, M. (2009). *Interpretative phenomenological analysis : theory, method and research*. London : SAGE.
- Smith, J.A., Flowers, P. and Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In: Yardley, L. (Ed.), *Material Discourses of Health and Illness*. Routledge, London.
- Smith, J.A., Jarman, M., and Osborn, M. (1999). Doing Interpretative phenomenological analysis. In M. Murray and K. Chamberlain (Eds) *Qualitative Health psychologies: Theories and Methods* (p218-241). London. Sage.
- Smith J.A. and Osborn M. (2003) Interpretative Phenomenological Analysis in *Qualitative Psychology a Practical Guide to Research Methods* J.A.Smith (Ed) (pp51-81) London: Sage Publications.
- Stalker, K., and Connors, C. (2004). Children's perceptions of their disabled siblings: she's different but it's normal for us. *Children and Society*, 18, 218-230.

Stoneman, Z. (1993). Common themes and divergent paths. In Stoneman, Z. and Berman, P.W. *The effects of mental retardation, disability and illness on sibling relationships*. Baltimore: Brookes.

Stoneman, Z. (2001), Supporting positive sibling relationships during childhood. *Ment. Retard. Dev. Disabil. Res. Rev.*, 7: 134–142. doi: 10.1002/mrdd.1019

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, 43, 339-350.

Stoneman, Z. and Berman, P. (1993). *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges*. Baltimore, MD, England: Paul H. Brookes Publishing.

Stoneman, Z., and Brody, G.H. (1984). Research with families of severely handicapped children: Theoretical and methodological considerations. In J. Blatcher (Ed.), *Severely handicapped young children and their families: Research in review* (pp.179-214). San Diego, CA: Academic Press.

Strohm, K. (2004) *Siblings: Stories of everyday life with children who are different*. London: David Fulton Publishers.

Strohm, K. (2005). *Being the Other One: Growing Up With a Brother or Sister Who Has Special Needs*. Boston: Shambhala Publications.

Tay-Lim, J., & Lim, S. (2013). Privileging Younger Children's Voices in Research: Use of Drawings and a Co-Construction Process. *International Journal Of Qualitative Methods*, 12(1), 65-83.

Taylor,V, Fuggle, P, and Charman,T. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of their illness attitudes and perceptions? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 42, 953-963.

Thomas Coram Research Unit. (2008). *Report to DCSF Disabled Children: Numbers, Characteristics and Local Service Provision*. University of London.

UEL. (2011). Code of Ethics.

Wandsworth coucil (2014) Wandsworth Borough Council Bulletin

Whiteman, S. D.,and Christiansen, A. (2008). *Process of Sibling Influence in Adolescence: Individual and Family Correlates*. *Family Relations* , 24-34.

Williams, P.; Piamjariyakul, U.; Graff, J.; Stanton, A. Developmental Disabilities: Effects On Well Siblings. *Issues in Comprehensive Pediatric Nursing*, 33:39-55, 2010.

Willig, C. (2001). *Qualitative research methods in psychology: Adventure in theory and method*. Buckingham: Open University press.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

Yardley, L. (2011). Demonstrating validity in qualitative research. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 234-251). London: SAGE

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Appendix 1: Overview of studies resulting from the literatures search

Author(s), Date, Location	Type of Disability	Design and Methodology	Sample	Main Findings/Limitations
Burke, P. (2010) UK	Disabilities included; cerebral palsy, microcephalic and autism	<ul style="list-style-type: none"> Mixed methodology Sibling interviews and questionnaires Family interviews and questionnaires Data is drawn from two separate studies 	116 Families	<ul style="list-style-type: none"> Positive and negative effects are reported Discussion regarding the concept of 'disability by association'. Limitations: description of method of data analysis is very weak.
Cox, A., Marshall, E., Mandleco, B., & Olsen, S. (2003). USA	Multiple disabilities	<ul style="list-style-type: none"> Qualitative. Content analysis from sibling responses to a sentence completion activity focusing on coping responses 	46 Siblings	<ul style="list-style-type: none"> 65% of responses were proactive Siblings took personal responsibility for improving difficult situations. Cultural bias not only from the USA but all participants were white and from the same socioeconomic group. This makes generalizability difficult.
Derouin, D. & Jessee, P. (1996) USA	Chronic illness. E.g. Cystic fibrosis (CF)	<ul style="list-style-type: none"> Mixed methodology Self esteem measure completed by siblings Semi structured phone interviews conducted with siblings 	15 Siblings	<ul style="list-style-type: none"> Positives identified by siblings included strengthening family relationships, more personal independence Limitations; Demographic and control data was not reported. Small sample size making generalizability difficult . Efficacy of phone interviews not discussed
Dyson. L. (1999) Canada	Developmental disabilities. E.g. Physical and sensory difficulties	<ul style="list-style-type: none"> Quantitative Longitudinal study Diagnostic Instruments used to measure self concept, behaviour 	37 Siblings of disabled children	<ul style="list-style-type: none"> No group differences in self concept, social competence and behaviour at each period Psychosocial functioning was found to be linked to family

		<ul style="list-style-type: none"> and social competence over four year period • Matched group sampling • Positivist epistemology 		<p>psychological resources across all participants</p> <ul style="list-style-type: none"> • Limitations: Focus on psychosocial functioning is limited.
Fisman, S., Wolf, L., Ellison. D. & Freeman. T. (2010) Canada	Chronic disabilities	<ul style="list-style-type: none"> • Quantitative • Longitudinal study • Diagnostic Instruments used to measure adjustment and completed by siblings, teachers and care givers • Positivist epistemology 	137 Siblings including control group (4-18 years)	<ul style="list-style-type: none"> • Significantly more adjustment difficulties found in siblings at both points in times • Recommends a family centred approach to intervention • Limitations: Study reliant on self report measures
Fleitas, J. (2000) USA	Complex illness and disability	<ul style="list-style-type: none"> • Qualitative • Comments from siblings were received via two methods 1) Siblings were invited to share their stories on a website 2) Children were interviewed when visiting their siblings in hospital. • Social model of disability 	Data not provided	<ul style="list-style-type: none"> • A range of positive and negative themes were identified. The authors separates them into those suggesting stress and those suggesting resilience. • Limitations: The description of how the data was collection is minimal. No reference is made to how the data is analysed. No reference to demographic data. No reference to ethical considerations.
Ineke, C & Loots, G (2000) The Netherlands	Physical disabilities. E.g. Multiple impairments and cerebral palsy	<ul style="list-style-type: none"> • Mixed methodology • Semi structured interviews • Use of the coping response inventory youth form • Positivist epistemology implied 	43 siblings aged between 10-19 years	<ul style="list-style-type: none"> • Siblings reported difficulties communicating with siblings • Concern regarding future health of sibling • Acknowledgement of parents attempt to treat them equally • Limitations: Bias created by education level of parents (high) and all families were

				members of a supportive group. Therefore findings did not represent wider population
Magill-Evans, J., Darrah, J., Pain, K., Adkins, R., & Kratochvil, M. (2001) Canada	Cerebral Palsy	<ul style="list-style-type: none"> • Quantitative • Focus on adolescents siblings • Diagnostic Instruments used to measure self concept, behaviour and social competence over four year period • Matched group sampling • Positivist epistemology 	90 Siblings aged between 13-15 years	<ul style="list-style-type: none"> • Few differences found in family functioning, social support and life satisfaction • Recommends holistic family support focuses on strengths and resources • Limitations: Cultural bias, age range of siblings limited to adolescents. Limitations of standardised measures not stated.
Mandleco, B., Olsen, F., Dyches, T., & Marshall, S. (2003). USA	Developmental disabilities	<ul style="list-style-type: none"> • Quantitative • Diagnostic Instruments used to measure family functioning, social skills, cooperative and problem solving • Matched group sampling • Positivist epistemology 		<ul style="list-style-type: none"> • Siblings of children with disabilities scored higher in cooperation and self control than siblings of children without disabilities • Limitations: the sole use of diagnostic instruments and their limitations are acknowledged by the authors
Opperman, S. & Alant, E. (2003) South Africa	Severe disabilities 1Q below 50	<ul style="list-style-type: none"> • Qualitative • Semi structured interviews • Data analysed through coding to describe the coping responses of siblings • Social constructivist epistemology 	19 Siblings (12-15 years)	<ul style="list-style-type: none"> • Siblings expressed feelings of guilt • Siblings felt they received limited information and guidance • There was an avoidance of participating in family activities • Limitations: small sample size, different cultural bias as not UK

Sharpe, D. & Rossiter, L. (2002) Canada	Chronic illness	<ul style="list-style-type: none"> • Meta analysis • 51 Studies published between 1976 and 2000 were used in the meta analysis • All studies examined the effect of chronically ill children on their sibling. • 	51 Studies	<ul style="list-style-type: none"> • Statistically significant negative effect reported • Smaller amount of negative outcomes were found in the more recent studies in comparison to the older ones. • Limitations: Meta analyses only used quantitative studies which may have had an emphasis on reporting dysfunction and negative consequences
Stalker, K. & Connors. C. (2004) UK	Disability not defined further	<ul style="list-style-type: none"> • Qualitative • Semi structured interviews • Data analysed through content analysis • Social constructivist epistemology 	24 Siblings (7-13 years)	<ul style="list-style-type: none"> • Siblings did not perceive their sibling as different. • Siblings generally perceived their experience as positive • Some frustration and resentment was reported • Limitations: The disability of the siblings was not defined and small scale study makes generalizability difficult.
Williams, P., Graff, J. & Stanton, A. (2010) USA	Developmental disabilities. E.g. Spina bifida, cerebral palsy and seizure disorder	<ul style="list-style-type: none"> • Qualitative. • Descriptive study using pre existing data • Content analysis from parental responses to an open ended question 	151 Parents (90% Mothers)	<ul style="list-style-type: none"> • 363 themes identified • 61.1% reflected negative manifestations • 1.7% indicated no risk • 37.2% reflected positive outcomes • Limitations: lack of sibling voice, over representation of Maternal voice

Appendix 2: References from the body of literature

- Abrams, M. S. (2009). The well sibling: Challenges and possibilities. *American Journal of Psychotherapy*, 63, 305-317.
- Aksoy, A., & Bercin Yildirim, G. (2008). A study of the relationships and acknowledgement of the non-disabled children with disabled siblings. *Educational Sciences: Theory and Practice*, 8, 769-779.
- Aronson, S. (2009). Am I my brother's keeper? Challenges for siblings of autistic children. *Journal of Infant, Child, and Adolescent Psychotherapy*, 8, 49-56.
- Atkins, S. (1989). Siblings of handicapped children. *Child and Adolescent Social Work*, 6, 271-282.
- Atkins, S. P. (1991). Siblings of learning disabled children: Are they special too? *Child and Adolescent Social Work Journal*, 8, 525-533.
- Auletta, R., & DeRosa, A. P. (1991). Self-concepts of adolescent siblings of children with mental retardation. *Perceptual and Motor Skills*, 73, 211-214.
- Bagenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population based study. *Journal of Mental Deficiency Research*, 25, 291-307.
- Banta, E. M. (1979). Siblings of deaf-blind children. *The Volta Review*, 81, 363-369.
- Barr, J., McLeod, S., and Daniel, G. (2008). Siblings of children with speech impairment: Cavalry on the hill. *Language, Speech, and Hearing Services in Schools*, 39, 21-32.
- Barrerra, M., Chung, J., Greenberg, M., & Fleming, C. (2002). Preliminary investigation of a group intervention for siblings of pediatric cancer patients. *Children's Health Care*, 31, 131-142.
- Barrett, P. M., Fox, T., & Farrell, L. J. (2005). Parent-child interactions with anxious children and with their siblings: An observational study. *Behaviour Change*, 22, 220-235.
- Bat- Chava, Y., & Martin, M. (2002). Sibling relationships of deaf children: The impact of child and family characteristics. *Rehabilitation Psychology*, 47, 73-91.
- Benderix, Y., & Sivberg, B. (2007). Siblings experiences of having a brother or sister with autism and mental retardation: A case study of 14 children from 5 families. *Journal of Pediatric Nursing*, 22, 410-418.
- Burke, P., & Montgomery, S. (2000). Siblings of children with disabilities: A pilot study. *Journal of Intellectual Disabilities*, 4, 227-236.

- Chambers, C. R. (2007). Siblings of individuals with disabilities who enter careers in a disability field. *Teacher Education and Special Education*, 30, 115-127.
- Christiansen, L., Hutman, T., Rozga, A., Young, G. S., Ozonoff, S., Rogers, S. J. & Sigman, M. (2010). Play and developmental outcomes in infant siblings of children with autism. *Journal of Autism and Developmental Disorders*, 40, 946-957.
- Coleby, M. (1995). The school aged siblings of children with disabilities. *Developmental Medicine and Child Neurology*, 37, 415-426.
- Conway, S., & Meyer, D. (2008). Developing support for siblings of young people with disabilities. *Support for Learning*, 23, 113-117.
- Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological issues. *International Journal for the Advancement of Counseling*, 21, 111-124.
- Cuskelly, M., & Dadds, M. (1992). Behavioural problems in children with Down syndrome and their siblings. *Journal of Child Psychology, Psychiatry, and Allied Disciplines*, 33, 749-761.
- Cuskelly, M., & Gunn, P. (1993). Maternal reports of behavior of siblings of children with Down syndrome. *American Journal on Mental Retardation*, 97, 521-529.
- Cuskelly, M., & Gunn, P. (2006). Adjustment of children who have a sibling with Down syndrome: Perspectives of mothers, fathers, and children. *Journal of Intellectual Disability Research*, 50, 917-926.
- Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with Down syndrome: Perspective of mothers, fathers, and siblings. *American Journal of Mental Retardation*, 108, 234-244.
- Desautels, M. (2008). *Sibling relationships*. Unpublished doctoral thesis. University of Birmingham.
- Dew, A., Balandin, S., & Llewellyn, G. (2008). The psychological impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental and Physical Disabilities*, 20, 485-507.
- Dodd, L. W. (2004). Supporting the siblings of children of young children with disabilities. *British Journal of Special Education*, 31, 41-49.
- Doody, M., Hastings, R., O'Neill, S., & Grey, I. (2010). Siblings relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities*, 31, 224-231.
- Dyken, P. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation*, 43, 360-364.

Dyson, L. L. (2003). Children with learning disabilities within the family context: A comparison with siblings in global self-concept, academic self-perception, and social competence. *Learning Disabilities Research and Practice, 18*, 1-9.

Faraone, S., Biederman, J., Krifcher Lehman, B., Spencer, T., Norman, D., Seidman, L., Kraus, I., Perrin, J., Chen, W., & Tsuang, M. (1993). Intellectual performance and school failure in children with attention deficit disorder and in their siblings. *Journal of Abnormal Psychology, 102*, 616-623.

Ferraioli, S. J., Hansford, A., Harris, S. L. (2011). Benefits of including siblings in the treatment of autism spectrum disorders. *Cognitive and Behavioral Practice*. Advance online publication.

Floyd, F., Purcell, S., Richardson, S., & Kuperschmidt, J. (2009). Sibling relationship quality and social functioning of children and adolescents with intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities, 114*, 110-127.

Gamble, W. C., McHale, S. M. (1989). Coping with stress in sibling relationships: A comparison of children with disabled and nondisabled siblings. *Journal of Applied Developmental Psychology, 10*, 353-373.

Gass, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology and Psychiatry, 48*, 167-178.

Giallo, R., & Gavidia-Payne, S. (2006). Child, parent, and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research, 50*, 937-948.

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders, 23*, 147-163.

Greene, J. (2010). Support groups for siblings of children with autism spectrum disorders : perspectives of siblings and group leaders. Unpublished doctoral thesis. University of East London

Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectations for future caregiving. *Psychiatric Services, 50*, 1214-1219.

Griffiths, D., & Unger, D. G. (1994). Views about planning of the future among parents and siblings of adults with mental retardation. *Family Relations, 43*, 221-227.

Grissom, M. O., & Borkowski, J. (2002). Self-efficacy in adolescents who have siblings with or without disabilities. *American Journal of Mental Retardation, 107*, 79-90.

Guite, J., Lobato, D., Kao, B., & Plante, W. (2004). Discordance between sibling and parent reports of the impact of chronic illness and disability of siblings. *Children's Health Care, 33*(1), 77-92.

- Hannah, M. E., & Midlarsky, E. (1999). Competence and adjustment of siblings of children with mental retardation. *American Journal on Mental Retardation*, 104, 22-37.
- Hannah, M. E., & Midlarsky, E. (2005). Helping by siblings of children with mental retardation. *American Journal on Mental Retardation*, 110, 87-99.
- Hasman, L. & Zafron, M. L. (2010). An analysis of online resources for parents, siblings, and other caregivers of adults with intellectual disabilities. *Journal of Consumer Health on the Internet*, 14, 33-41.
- Hastings, R. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37, 1485-1492.
- Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, 44, 189-202.
- Heller, T., & Keiling Arnold, C. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1)-16-25.
- Hodapp, R. M., Glidden, L. M., & Kaiser, A. P. (2005). Siblings of persons with disabilities: Toward a research agenda. *Mental Retardation*, 43, 334-338.
- Hodapp, R. M., & Urbano, R. (2007). Adult siblings of individuals with Down syndrome vs. with autism: Findings from a large scale study. *Journal of Intellectual Disability Research*, 51, 1019-1028.
- Hollidge, C. (2001). Psychological adjustment of siblings to a child with diabetes. *Health and Jones, K., Welsh, R. K., Glassmire, D. M., & Tavegia, B. D. (2006). Psychological functioning in siblings of children with attention deficit hyperactivity disorder. Journal of Children and Family Studies*, 15, 757-763.
- Kaminsky, L., & Dewey, D. (2001). Sibling relationships in children with autism. *Journal of Autism and Developmental Disorders*, 31, 399-410.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychiatry and Psychology*, 43, 225-232.
- Kendall, J. (1999). Sibling accounts of Attention Deficit Hyperactivity Disorder (ADHD). *Family Process*, 38, 117-135.
- Kilmer, R. P., Cook, J. R., Taylor, C., Kane, S. F., & Clark, L. Y. (2008). Siblings of children with severe emotional disturbances: Risks, resources, and adaptation. *American Journal of Orthopsychiatry*, 78, 1-10.
- Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology, Psychiatry, and Allied Disciplines*, 36, 965-976.

- Knott, F., Lewis, C., & Williams, T. (2007). Sibling interaction of children with autism: Development over 12 months. *Journal of Autism and Developmental Disorders*, 37, 1987-1995.
- Lardieri, L., Blahcer, J., Swanson, H. (2000). Sibling relationships and parental stress in families of children with and without learning disabilities. *Learning Disability Quarterly*, 23, 105-116.
- Lobato, D., Kao, B., & Plante, W.(2005). Latino sibling knowledge and adjustment to chronic disability. *Journal of Family Psychology*, 19, 625-632.
- Lynch, D. J., Fay, L., Funk, J., & Nagel, R. (1993). Siblings of children with mental retardation: Family characteristics and adjustment. *Journal of Child and Family Studies*, 2, 87-96.
- Macks, R. J., & Reeve, R. E. (2007). The adjustment of nondisabled siblings of children with autism. *Journal of Autism and Developmental Disorders*, 37, 1060-1067.
- Marks, S. U., Matson, A., & Barraza, L. (2005). The impact of siblings with disabilities on their brothers and sisters pursuing a career in special education. *Research and Practice for Persons with Severe Disabilities*, 30, 205-218.
- Mash, E., & Johnson, C. (1983). Sibling interactions of hyperactive and normal children and their relationship to reports of maternal stress and self-esteem. *Journal of Clinical Child Psychology*, 12, 91-99.
- Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *British Journal of Special Education*, 31, 199-206.
- Orsmond, G., Kuo, H. Y., & Seltzer, M. M. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism*, 13, 59-80.
- Petalas, M., Hastings, R., Nash, S., Dowey, A., & Reilly, D. (2009). "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability Development and Education*, 56, 381-399.
- Petalas, M., Hastings, R., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism*, 13, 471-483.
- Phillips, R. S. C. (1999). Interventions with siblings of children with developmental disabilities from economically disadvantaged families. *Families in Society*, 6, 569-577.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 45, 855-865.

- Powell, T. H., Salzberg, C. L., Levy, S., & Itzkowitz, J. S. (1983). Teaching mentally retarded children to play with their siblings using parents as trainers. *Education and Treatment of Children, 6*, 343-362.
- Rawson, H. (2009). 'I'm going to be here long after you're gone'- sibling perspectives of the future. *British Journal of Learning Disabilities, 38*, 225-238.
- Reagon, K. A., Higbee, T. S., & Endicott, K. (2006). Teaching pretend play skills to a student with autism using video modeling with a sibling as model and play partner. *Education and Treatment of Children, 29*, 517-528.
- Regehr, K., & Feldman, M. (2009). Parent-selected interventions for infants at-risk for autism spectrum disorders and their affected siblings. *Behavioral Interventions, 24*, 237-248.
- Rimmerman, A., & Raif, R. (2001). Involvement with and role perception toward an adult sibling with and without mental retardation. *Journal of Rehabilitation, 67*, 10-15.
- Rivers, J., & Stoneman, Z. (2008). Child temperaments differential parenting, and the sibling relationships of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 38*, 1740-1750.
- Roberts, S. (2012) Siblings of children and young people with autism : an exploration of typical siblings' constructions, perceptions and coping responses Unpublished doctoral thesis. University of Cardiff
- Roeyers, H., & Mycke, K. (1995). Siblings of a child with autism, with mental retardation, and with normal development. *Child: Care Health and Development, 21*, 305-319.
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems, and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability, 31*, 77-86.
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies, 10*, 65-84.
- Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with disabilities. *Mental Retardation, 43*, 354-359.
- Senel, H., & Akkock, F. (1996). Stress levels and attitudes of normal siblings of children with disabilities. *International Journal for the Advancement of Counseling, 18*, 61-68.
- Sharpe, D., & Rossiter, L. (2002). Siblings of children with chronic illness: A meta-analysis. *Journal of Pediatric Psychology, 27*, 699-710.

Silver, E.J., & Frolinger-Graham, M. J. (2000). Brief report: Psychological symptoms in healthy female siblings of adolescents with and without chronic conditions. *Journal of Pediatric Psychology*, 25, 279-284.

Slomkowski, C., Choen, O., & Brook, J. (1997). The sibling relationships of adolescents with antisocial and comorbid mental disorders: An epidemiological investigation. *Criminal Behaviour and Mental Health*, 7, 353-368..

Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, 43, 339-350.

Tattersall, H. J., & Young, A. M. (2003). Exploring the impact on hearing children of having a deaf sibling. *Deafness and Education International*, 5, 108-122.

Taylor, J. L., Greenberg, J. S., Seltzer, M., & Floyd, F. J. (2008). Siblings of adults with mild intellectual deficits or mental illness: Differential life outcomes. *Journal of Family Psychology*, 6, 905-914.

Taylor, V., Fuggle, P., & Charman, T. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of their illness attitudes and perceptions? *Journal of Child Psychology and Psychiatry*, 42, 953-962.

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, 6, 267-286.

Verte, S., Hebbrecht, H., (2006). Psychological adjustment of siblings of children who are deaf or hard of hearing. *The Volta Review*, 106, 89-110.

Williams, P.D. (1997). Siblings and pediatric illness: A review of the literature. *International Journal of Nursing Studies*, 34, 313-323.

Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., Sanders, S. (2003). A community based intervention for siblings and parents of children with chronic illness or disability: The ISEE study. *Journal of Pediatrics*, 143, 386- 393.

Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., Sanders, S. (2002). Interrelationships among variables affective well siblings and mothers in families of children with a chronic illness or disability. *Journal of Behavioral Medicine*, 25, 411-424.

Wilson, C. (2009) *Siblings of children with ADHD, chronic illness and developmental disorder : psychological impact and interventions*. Unpublished doctoral thesis. The University of Hull

Yirmiya, N., Pilowsky, T., Feldman, R., Baron-Cohen, S., & Sigman, M. (2006). The development of siblings of children with autism at 4 and 14 months: Social engagement, communication, and cognition. *Journal of Child Psychology and Psychiatry*, 47, 511-523.

Appendix 3: Positionality

	Reflexive commentary
Motivation for the research	<ul style="list-style-type: none"> • To give a voice to underrepresented group • To present the views of siblings • To allow the siblings to feel important • To allow siblings to share their thoughts • To complete a doctorate • To add to the research field
Ethnicity	<ul style="list-style-type: none"> • White, lower middle class • Third generation immigrant family • Will I be able to relate to children from a wide range of ethnicities?
Previous held assumptions/beliefs	<ul style="list-style-type: none"> • It is difficult and upsetting to have a sibling with severe needs • Do you have to partially abdicate needs/wishes as the siblings comes first • Less parental attention • Concern/worry about the sibling health • Concern/worry about what will happen in the future
Power relationships	<ul style="list-style-type: none"> • Adult (researcher) and child (participant) creates a natural power imbalance. It will be important to readdress this power balance as much as possible. Give control back to participants via use of pseudonyms/ choice of location/able to change their minds.
Current role	<ul style="list-style-type: none"> • Current dual role as researcher and practitioner. This greats duality is helpful because I have easy access to a sample to interview and less helpful as siblings may be cautious in speaking freely and openly (fear of telling their parents their true feelings). It will important to reiterate confidentiality.
Gender/Age	<ul style="list-style-type: none"> • Female researcher. My gender is not a significant factor for the participants nor in the interpretation of the results.
Previous life experiences-personal	<ul style="list-style-type: none"> • Do not have a sibling with severe SEN however being middle of three children with mild SEN I have some experience of having to share parental attention with sibs who require more input than me. I must not allow my own feelings about this experience influence the interpretation of the data. It will be important to bracket these thoughts and feelings.
Previous life experiences-professional	<ul style="list-style-type: none"> • Paradoxical influence? Previous work as an EP may bring greater contextual knowledge/understanding and skills in interviewing children. However this may bring more fixed ideas and previous held assumptions. Importance of bracketing this away.
Values	<ul style="list-style-type: none"> • I value listening to children. • I value the importance of research • I value the importance of women conducting research • I value helping others (particularly those I perceive as less fortunate than me?) Do perceive the siblings as less fortunate- discuss in supervision

Appendix 4: Sample research diary

This is an excerpt from when I was half way through the interview stage

	Ideas /thoughts	Actions/Next steps
Personal	<p>Finding the interview stage personally very tiring. I am conscious in my desire to produce a rich interview = rich data. Careful not to repeat questions. Careful to talk less and listen more. Careful to record non-verbal communication. Careful to monitor my responses.</p> <p>Participants are engaging well although still very anxious I will not collect rich data.</p>	<ul style="list-style-type: none"> • Repeat bracketting off exercise • Talk to peer support group • Discuss with supervisor/therapist emotional reactions • Attend IPA support group
Interpersonal	<p>Rapport built during interviews.</p> <p>Careful in my relationships with the parents and restate the confidential nature of the interviews (parents will get no feedback). Reflect on duality of professional/researcher role in regard to participant and parent.</p>	<ul style="list-style-type: none"> • Restate confidential nature of interviews to participant and parent • Repeat that the research is not related to my work in the SCC. The participant can choose to opt out.
Contextual	<p>Confirmation that specialist centre was a good context for undertaking the interviews. It would have been very different if the interviews had taken place in the participants in school. Participants seemed at ease. Also during the school holidays helped create a separation from school.</p>	
Critical (Political, ethical and social contexts)	<p>Consider power imbalance. Ensure I am sitting in a lower chair during interviews and informal setting helps. No use of desk.</p>	

Appendix 5: Pilot interview schedule

Exploring the experiences of having a sibling with complex needs SEN	
Pilot Sibling Interview Schedule	
Biography:	
Name:	Interview date:
Age:	Code name:
D.o.b:	
Siblings:	
Introduction:	
<ol style="list-style-type: none">1. Confidentiality This research project is to help us find out all about what it is like growing up with a brother or sister like x.2. I will be asking you some questions3. If you don't understand anything I say please ask me to explain again or some such words.4. There are no right or wrong answers. It is important to say how you feel. We need to know exactly what YOU think.5. Your answers will help with my project about what is like having a brother or sister with special needs.6. Explain confidentiality, and how the findings will be used, and that they may, if they wish, at any time, stop and leave, or not answer any questions they don't want to, and also explain how the information will be used, and to tell you if they want to stop and have a rest at any time.7. Consent (Check parents and child's form is signed)	
1. Family	
<ol style="list-style-type: none">a. Who is in your family?b. How old is (siblings)?	
Prompts - How would you describe x, y, z (members of their family)	
What do they like to do? What are they like?	

<p>2. You</p> <ul style="list-style-type: none"> a. How would you describe yourself? b. What would other people say about you? (Mother, teacher and friend). How would they describe you? c. What are your favourite things to do? What do you enjoy doing?
<p>3. Sibling</p> <p>Thinking of you brother or sister (use nickname if they use one)</p> <ul style="list-style-type: none"> a. What does x look like? b. How would you describe x to your friends? c. What is his/her favourite toy or thing to do?
<p>4. Time together</p> <p>Thinking of your time together</p> <ul style="list-style-type: none"> a. How do you like to spend time with x? b. What things do you like to do together
<p>5. Caring for Sibling</p> <ul style="list-style-type: none"> a. What does x need help with? b. Who helps x? c. How do you help care for x? d. Who helps x from outside the family?
<p>6. Understanding of siblings difficulties</p> <ul style="list-style-type: none"> a. X can't walk/see/move very well? Why do you think that is? b. Who talks to you about x?, what do they say?
<p>7. The outside world</p> <ul style="list-style-type: none"> a. What do you tell your friends about x? b. What do you think others think about x?
<p>8. Your Future</p> <ul style="list-style-type: none"> a. What would you like to be when you are older b. What do you hope you life will be like for you when you are 20, 30?

<p>9. Sibling's Future</p> <p>a. What do you think x will be like when he/she is 10, 20, 30?</p> <p>b. What things will you be doing together?</p> <p>c. Who do you think will help look after x when they are older?</p>
<p>10. Thinking about their life together</p> <p>a. How is your life the same/different from other children?</p>
<p>11. Thinking about how you feel</p> <p>a. In relation to your sibling does anything make you feel... happy, frightened, worried, excited.... (Could use sentence completion, if struggling to think of feelings)</p>
<p>12. Main research question</p> <p>a. What is like growing up with a brother/sister like x?</p>
<p>13. Is there anything else you would like to tell me?</p>
<p>14. Is there anything you would like to ask me?</p>

Appendix 6: Approval from Ethics Committee



Dear Irvine,

Application to the Research Ethics Committee: Exploring the experiences of having a sibling with multiple needs - A phenomenological study (A Teuma).

I advise that Members of the Research Ethics Committee have now approved the above application on the terms previously advised to you. The Research Ethics Committee should be informed of any significant changes that take place after approval has been given. Examples of such changes include any change to the scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely

Simiso Jubane

Admission and Ethics Officer

s.jubane@uel.ac.uk

02082232976

Research Ethics Committee: ETH/11/40

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed:.....Date:

Please Print Name:

Exploring the experiences of having a sibling with complex needs SEN	
Sibling Interview Schedule	
Biography:	
Name:	Interview date:
Age:	Code name:
D.o.b:	
Parents:	
Siblings:	
Introduction:	
<ol style="list-style-type: none">1. Confidentiality This research project is to help us find out all about what it is like growing up with a brother or sister like x.2. I will be asking you some questions3. If you don't understand anything I say please ask me to explain again or some such words.4. There are no right or wrong answers. It is important to say how you feel. We need to know exactly what YOU think.5. Your answers will help with my project about what is like having a brother or sister with special needs.6. Explain confidentiality, and how the findings will be used, and that they may, if they wish, at any time, stop and leave, or not answer any questions they don't want to, and also explain how the information will be used, and to tell you if they want to stop and have a rest at any time.7. Consent (Check parents and child's form is signed)	
Before we start is there anything you would like to ask me?	
<ol style="list-style-type: none">1. Family<ol style="list-style-type: none">a. Who is in your family?b. Can you draw everyone in your family doing something?<ol style="list-style-type: none">i. Prompts - How would you describe x, y, z (members of their family)ii. What do they like to do? What are they like?	

<p>2. You</p> <ul style="list-style-type: none"> a. How would you describe yourself? b. What would other people say about you? (Mother, teacher and friend). How would they describe you? c. What are your favourite things to do? What do you enjoy doing?
<p>3. Sibling</p> <p>Thinking of your brother or sister (use nickname if they use one)</p> <ul style="list-style-type: none"> a. What does x look like? b. How would you describe x to your friends? c. What is his/her favourite toy or thing to do?
<p>4. Time together</p> <ul style="list-style-type: none"> i. Thinking of your time together b. How do you like to spend time with x? c. What things do you like to do together
<p>5. Caring for Sibling</p> <ul style="list-style-type: none"> a. What does x need help with? b. Who helps x? c. How do you help care for x? d. Who helps x from outside the family?
<p>6. Understanding of their Disability</p> <ul style="list-style-type: none"> a. X can't walk/see/move very well? Why do you think that is? b. Who talks to you about x?, what do they say?
<p>7. The outside world</p> <ul style="list-style-type: none"> a. What do you tell your friends about x? b. What do you think others think about x?
<p>8. Your Future</p> <ul style="list-style-type: none"> a. What would you like to be when you are older b. What do you hope your life will be like for you when you are 20, 30?
<p>9. Sibling's Future</p> <ul style="list-style-type: none"> a. What do you think x will be like when he/she is 10, 20, 30? b. What things will you be doing together? c. Who do you think will help look after x when they are older?

<p>10. Thinking about their life together</p> <p>a. How is your life the same/different from other children?</p>
<p>11. Thinking about how you feel</p> <p>a. In relation to your sibling does anything make you feel... happy, frightened, worried, excited....</p> <p>Could use sentence completion if struggling to think of feelings</p>
<p>12. Main research question</p> <p>What is like growing up with a brother/sister like x?</p>
<p>13. Is there anything else you would like to tell me?</p>
<p>14. Is there anything you would like to ask me?</p>

Appendix 8: Written information to parents and consent form

Dear _____,

Thank you for taking the time to talk to me on the phone as promised here is some more information about my sibling research project.

I would really like to speak to your son or daughter to find out what the experience is like for them growing up with a brother or sister with special needs. I hope to meet with your child once or maybe twice, at a location of your choice (X Specialist Children's Centre, your home or your child's school).

The discussion we have together will be tape-recorded. The information recorded will be confidential and will not be passed to any other professional nor be placed on your child's record. Your child's name will be not identifiable in any written report. The tapes and any documentation will be stored in a locked cupboard in my office and after completion of the study this information will be destroyed after three years. The findings from this study will be included in an unpublished thesis and later lodged in the University Library. Findings may also be used in published works and may include quotations from some of the interviews, however no real name nor personal details would ever be associated with these quotations and so no particularly individual (s) could be ever be identified.

If you are happy for your child to take part in this research study please sign the form below. I must point out that your child is not obliged to take part. You are free to withdraw your child at any time and you do not have to give a reason. Choosing to participate or not will not affect your child's future treatment at X Children's Centre.

Should you have any questions about the study please do not hesitate to call me on 020 871 8744 or email me at ateuma@****.gov.uk . If you have any queries regarding the conduct of the programme please contact the Secretary of the University Research Ethics Committee: Ms D Dada, Graduate School, University of East London, Docklands Campus. London E16 2RD (telephone 0208 223 2976 email d.dada@uel.ac.uk)

Kindest Regards



Anna Teuma

Educational Psychologist

Parental Consent

Your name:

Name of child:

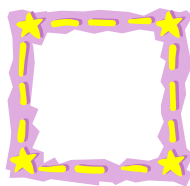
- I agree that my child can take part in the study
- I understand I can withdraw my child at any point without giving a reason

Signature:



Appendix 9: Written information to children and consent form

My name is Anna Teuma.



Here is a picture of me

I work as an Educational Psychologist at X Specialist Children's Centre where your brother/sister attends. I am currently doing an exciting new project. In this project I want to find what is like to have a brother or sister who needs extra care and support.

I want to find out:

- about you
- how you would describe your brother or sister
- what you like to do together
- how you may help with their care

I would really to like to meet with you so that we can talk and maybe do some drawings and other activities.

I would like to meet with you, it will probably take about an hour. I could meet you at X Specialist Children Centre or at your home or at your school the choice is yours.

If you would like to be in my project you need to sign your name below and your parent will need read and sign their form too.

Thank you,

Anna Teuma

Name _____

- I have read this leaflet or it has been read to me
- I would like to take part in the project
- I understand I can leave at any point if I change my mind and I don't need to give a reason



Signature _____

Appendix 10: Summary Table for Participant Louise

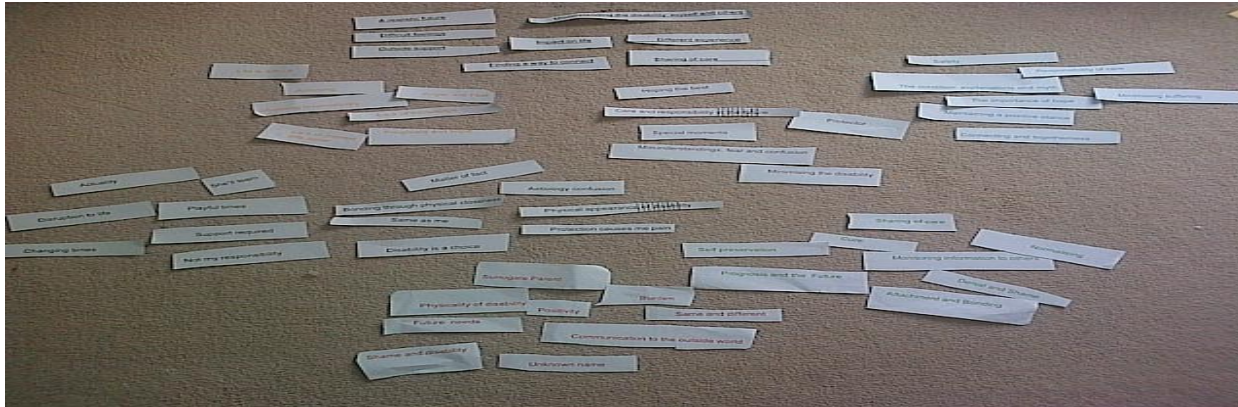
Super Ordinate Theme	Emergent Theme	Page	Key phrases
The condition: explanations and dilemmas	Fetal compression: Explanation for the disability	Pg 9 Pg 15	Squashing in the tummy
	Unexplainable	Pg 9	They don't really know much about it
	Supernatural guidance	Pg 12	Angels tell him
Future	Progressing	Pg 9	He can practice standing
	Hope and the preferred future	Pg 11	Hopefully his head will be stronger
Worries	Pain and distress	Pg 12	I am quite worried about the enormous seizures as they make him cry
	Safety	Pg 16	He is on a new thing and he will fall off
	Minimising discomfort	Pg 6	We need to put more cushions down
Responsibility of care	Future care	Pg 13	I want to look after him when he is older
	Shared responsibility of care	Pg 13	Aunty and Granny
Experience	Affirmative	Pg 13	He is quite cheerful
	Benefits	Pg 17	It's very exciting we are having a new lift
	Life enhancing	Pg 18	It's really exciting to play with him
Attachment	Missing and reconnecting	Pg 16	I feel happy when he is home
	Uniqueness	Pg 18	Something special from him
Support	Physical closeness	Pg 18	His hands feel really cute
	Support from others	Pg 8	Next door helps as well
	Safety in the physical environment	Pg 6	He doesn't bang his head

Appendix 11: Super ordinate themes across all participants

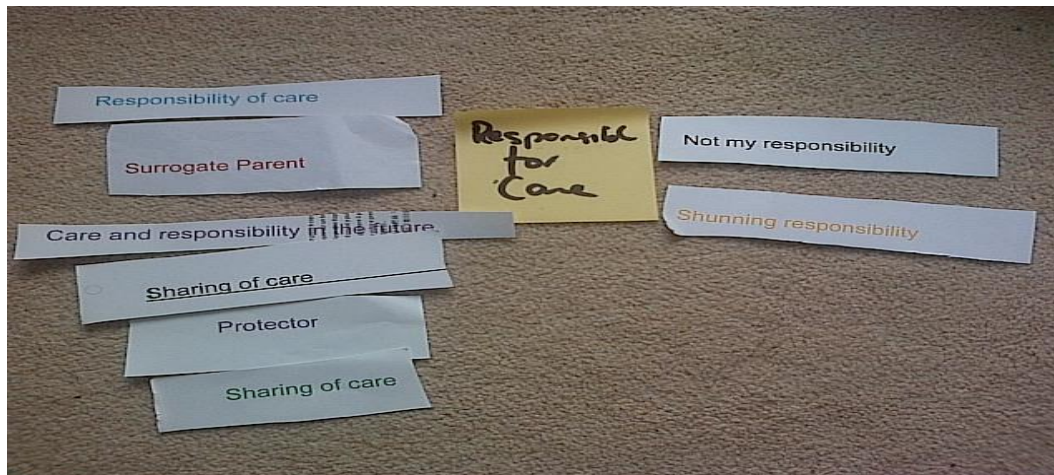
Super Ordinate Themes across all Participants							
Participant 1	Participant 2	Participant 3	Participant 4	Participant 5	Participant 6	Participant 7	Participant 8
Beyonce	Sasha	Van Persei	Mona Lisa	Jessica	Tracy	Columbus	Louise
Duty	Prognosis and the Future	Minimising the disability	Aetiology confusion	Disruption to life	Prognosis and hope	Understanding the disability: myself and others	The condition: explanations and myth
Physicality of disability	Attachment and Bonding	Special moments	Physical appearance of disability	Not my responsibility	Anger and Fear	Impact on life	The importance of hope
Surrogate Parent	Monitoring information to others	Misunderstandings, fear and confusion	Bonding through physical closeness	Playful times	Lack of knowledge	A realistic future	Minimising suffering
Communication to the outside world	Denial and Shame	Protector	Protection causes me pain	Support required	Life is difficult	Sharing of care	Responsibility of care
Burden	Cure	Hoping the best	Disability is a choice	Actuality	Shunning responsibility	Different experience	Maintaining a positive stance
Unknown name	Normalising	Care and responsibility in the future	Hopes dashed	She'll learn	Lack of interest	Difficult feelings	Connecting and togetherness
Positivity	Sharing of care		Matter of fact	Changing times	Annoying little sister	Finding a way to connect	Safety
Same and different	Self preservation		Same as me			Outside support	
Shame and disability							
Future needs							

Appendix 12: Development of the master themes

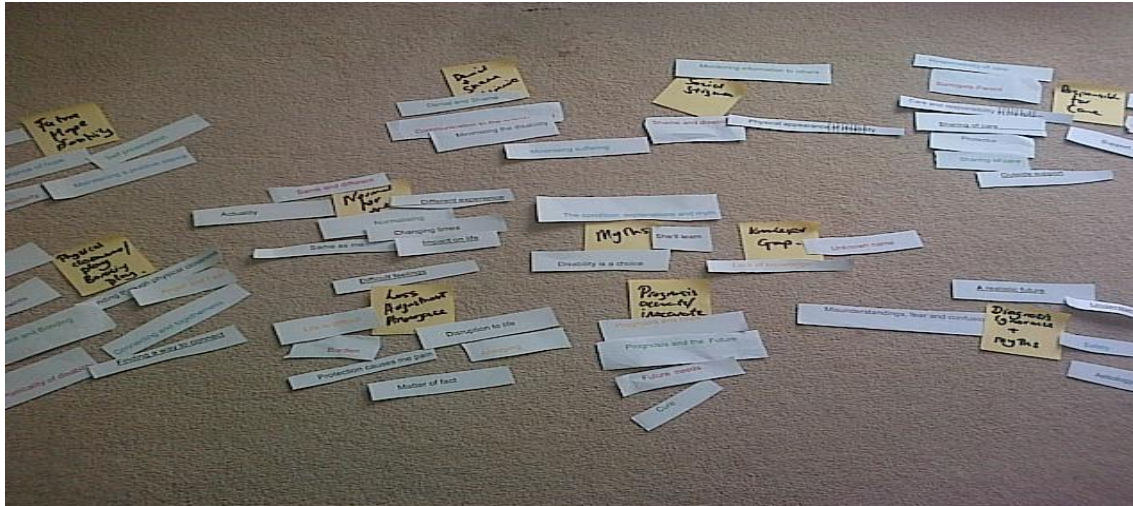
Stage 1: Super-ordinate themes for every case, laid out across the floor, in order to search for relationships in the data.



Stage 2: Starting to consider how super-ordinate themes could be connected and related to create master themes.



Stage 3: First attempt at creating master themes. This lead to the creation of eleven master themes



First eleven master themes


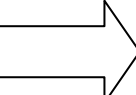

1. Physical closeness/physical play/bonding through play
2. Responsible for care
3. Diagnosis ignorance and myths
4. Knowledge gap
5. Prognosis accurate/ inaccurate
6. Social stigma
7. Myths
8. Loss/Anger/Annoyance
9. Normal for me
10. Minimising denial and shame
11. Future hope and positivity

Stage 4: A further attempt at creating master themes. This lead to the creation of eight master themes



1. Physicality
2. Responsibility
3. Knowledge about condition
4. Communicating to the outside world
5. Attachment/relationships/play
6. Future
7. Normalising
8. Feelings positive/negative

Appendix 13: Tabulated development of master themes

First attempt at creating master themes 	Further attempt to create master themes 	Preliminary version of Master themes with integrated subthemes 	Final version of Master themes and integrated subthemes
1. Normal for me	1. Normalising	Making sense of their world <ul style="list-style-type: none"> • normalising • knowledge about the condition • communicating with the outside world 	Making sense of their situation today and tomorrow <ul style="list-style-type: none"> • normalising • the diagnosis and aetiology: misunderstandings and dilemmas • conflicts from the wider world • prognosis remaining hopeful
2. Knowledge gap	2. Knowledge about condition		
3. Prognosis accurate/inaccurate			
4. Diagnosis ignorance			
5. Social stigma	3. Communicating to the outside world		
6. Minimising denial and shame			
7. Bonding through play	4. Attachment/relationships/play	The relationship/attachment <ul style="list-style-type: none"> • Playing together • Responsibility for care 	The sibling relationship within the family <ul style="list-style-type: none"> • Bonding through adaptive play and physical closeness • The nature of care, who does what role and function
Physical closeness			
8. Physical play	5. Physicality		
9. Responsible for care	6. Responsibility		
10. Loss/Anger/Annoyance	7. Feelings	Feelings <ul style="list-style-type: none"> • Positive/negative 	Focus on feelings <ul style="list-style-type: none"> • Anger and Fear • Annoyance • Remaining positive
11. Future hope and positivity	8. Future		

Appendix 14: Subthemes and master themes.

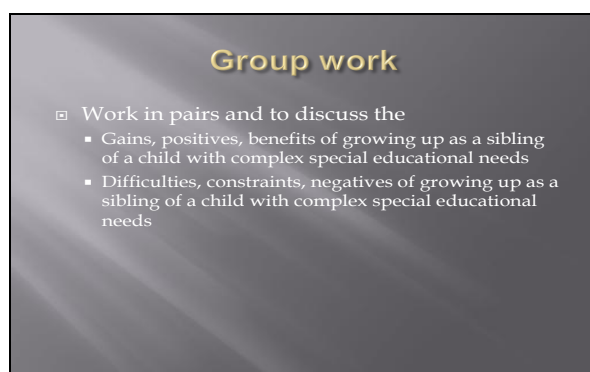
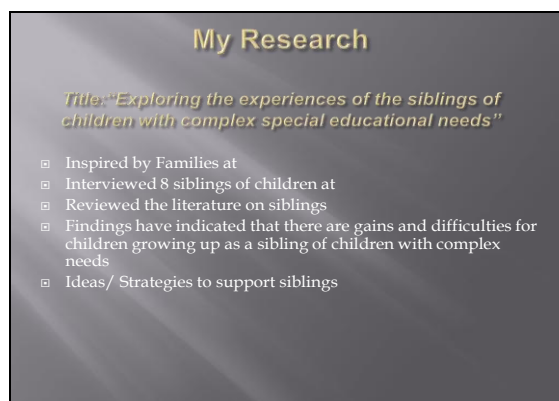
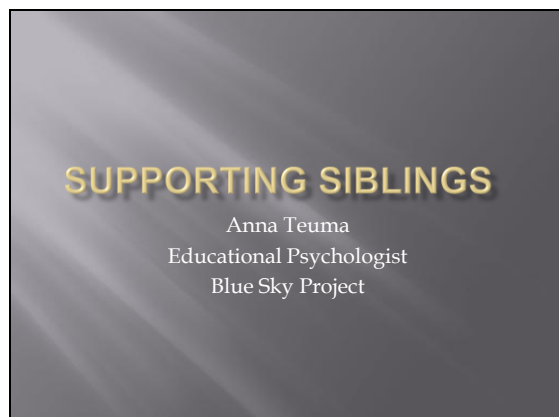
Table demonstrating how Super Ordinate Themes across eight participants were integrated to form Sub Themes and overarching Master Theme Themes. *P= participant

Super Ordinate Themes across participants	Sub theme	Master Theme
Matter of fact (Participant 4) Minimising the disability (*P3) Annoying little sister (P6) Normalising (P2) Different experience (P7) Same and different (P1) Connecting and togetherness (P8)	Normalising	Master Theme 1: Making sense of their situation today and tomorrow
Understanding the disability: myself and others (P7) The condition: explanations and myth (P8) Self preservation (P2) Actuality (P5) Misunderstandings fear and confusion (P3) Lack of knowledge (P6) Shame and disability (P1) Aetiology confusion (P8)	The diagnosis and aetiology: misunderstandings and dilemmas	
Minimising the disability (P3) Communication to the outside world (P1) Monitoring information to others (P2) Denial and Shame (P2) Maintaining a positive stance (P8)	Conflicts from the wider world	
She'll learn (P5) Same as me (P4) Prognosis hope (P6) The importance of hope (P8) Prognosis and the future (P2)	Prognosis remaining hopeful	

<p>Future needs (P1) A realistic future (P7)</p>		
<p>Finding a way to connect (P7) Bonding through physical closeness (P4) Special moments (P3) Attachment and Bonding (P2)</p> <p>Duty (P1) Not my responsibility (P5) Sharing of care (P2) Responsibility of care (P8) Sharing of care (P7) Surrogate Parent (P1) Protection causes me pain (P4) Protector (P3)</p>	<p>Bonding through adaptive play and physical closeness</p> <p>The nature of care, who does what role and function</p>	<p>Master Theme 2: The sibling relationship within the family</p>
<p>Physicality of disability (P1) Anger and Fear (P6) Disruption to life (P5) Minimising Suffering (P8) Hopes dashed (P4) Misunderstandings fear and confusion (P3)</p> <p>Protection causes me pain (P4) Difficult feelings (P7) Annoying little sister (P6) Impact on life (P7)</p> <p>The importance of hope (P8) Maintaining a positive stance (P8) Connecting a togetherness (P8) Finding a way to connect (P7) Different experience (P7)</p>	<p>Anger and Fear</p> <p>Annoyance</p> <p>Remaining positive</p>	<p>Master Theme 3: Focus on feelings</p>

<h1>Guide for talking to siblings of children with disabilities</h1>	
15. Family	<ul style="list-style-type: none"> a. Who is in your family? b. Can you draw everyone in your family doing something? <p>Talk about picture</p>
16. Sibling	<p>Thinking of your brother or sister (use nickname if they use one)</p> <ul style="list-style-type: none"> a. Tell me about him/her <ul style="list-style-type: none"> i. What does x look like? ii. How would you describe x to your friends? iii. What is his/her favourite toy or thing to do?
17. Time together	<ul style="list-style-type: none"> a. Thinking of your time together <ul style="list-style-type: none"> i. How do you like to spend time with x? ii. What things do you like to do together
18. Caring for Sibling	<ul style="list-style-type: none"> a. What does x need help with? b. Who helps x? c. How do you help care for x? d. Who helps x from outside the family?
19. Understanding of their Disability	<ul style="list-style-type: none"> a. X can't walk/see/move very well? Why do you think that is? b. Who talks to you about x?, what do they say? c. Who could you ask, if you wanted more information about x?
20. Sibling's Future	<ul style="list-style-type: none"> a. What do you think x will be like when he/she is 10, 20, 30? b. What things will you be doing together? c. Who do you think will help look after x when they are older?
21. Thinking about their life together	<ul style="list-style-type: none"> a. How is your life the same/different from other children
22. Thinking about how you feel	<ul style="list-style-type: none"> b. In relation to your sibling does anything make you feel... happy, frightened, worried, excited.... <p>Could use sentence completion if struggling to think of feelings</p>
23. Further help/advice	<ul style="list-style-type: none"> a. Who do you think you could talk about.. (any of the issues raised) b. Signpost to other organisations e.g.sibs group, sibs forum, consider referral to other services e.g. CAMHS

Appendix 16: 'Supporting Siblings' presentation as part of Blue Sky project



Strengths, Gains and Positives!

Research has indicated the following:

- Increased tolerance of difference/ diversity. More empathy and awareness of those with needs.
- Deeper understanding of challenges of others and the advantages most people take for granted.
- Developing a level of maturity that is greater than same age peers
- Increased frequency of pro-social behaviours (helping others, empathy) in the long term learn to be less selfish.
- A wealth of understanding about how to support children/people with special needs
- Career opportunities

Difficulties, constraints, negatives...

Research has indicated the following:

- Lack of parental attention
- Confusion
- Different feelings; anxiety, concern, resentment, jealousy
- Pressure to make up for sibling's difficulties by excelling in schools or sports
- Extra caring duties- less time for developing friendships

Quotes from my research

Knowledge about the condition

"I think it does have a name or something but I just don't know about it"

"I could ask my mum cos she was the first one to see him and the midwife told her a lot about it"

"I don't know. I think it's probably called children who can't walk or sit"

"I think his legs all got a bit squashed down in the tummy there were 3 of 'em and then they got squashed down a bit and then he was always sitting down and he got always there he used to lying down and they he's got these legs that don't hold really that good to stand him up and not that strong enough... So I think that's why"

"I think he might be able to hear because he can hear the sound pudding because when it is pudding time for him he always makes a noise. I'm always so proud of him"

"I feel frightened when she bangs her head on the floor when she is lying down and she's trying to sit up and she can't, so she bangs her head. And why is that frightening? Because she might be more disabled?"

Quotes from my research cont..

Feelings

"I feel happy when... she is happy, when she is excited and stuff, she likes lights and colourful things and when her dad walks into the room and she hears his voice, she starts screaming. (with delight)"

"I feel frightened when she went to hospital I remember when she was really younger she had to go to hospital every two weeks everytime she had a cough or something because she had a fit or something"

"I feel frightened cos I thought she was going to walk and talk or run when she grows up but she never... but she was just a baby and started to get all wobbly and shake and when her mum and dad and her big"

"I kinda of feel angry when she kinda of kicks me in the eye...."

"I feel frightened when she throws her arms round and round and she puts her arms right out and I am might get hurt myself"

Quotes from my research cont....

□ Helping

"Well I like, sometimes I like to feed her, usually I like to help her by getting a spoon. It's a nice a helpful thing to do. I get a spoon and I just give it to her and it's really easy"

"At times I just try and keep her cheerful. Like, errr. Sometimes I take care of her when she is bathing her and usually I just watch her bath but sometimes I have to look after her, especially when there is no-one there I have to watch. Maybe I have to look over her and check she is ok. I have to look over if no-one else is there"

□ The sibling experience

"I don't what it is not like growing up with a brother or sister with special needs as this normal to me"

"When she is older she will be very big and no-one will be able to carry her. Hopefully by then she will be able to talk. Um, I don't know but I think she will be in wheelchair unless she starts to walk and stuff and I would like her to still live with us"

Parental consideration

□ Pre-schoolers

- Can't understand the exact nature of their sibling's needs
- Will notice some differences and will try and to teach their sibling to do things

□ School age

- Develops a better understand of their sibling needs
- May have conflicting feelings about their sibling (love, resentment, guilt, loyalty, protection)
- May be willing/ wanting to help or not
- Happy to talk to friends about their sibling or not

□ Adolescents

- Can understand more complex understanding of siblings needs and post 16 implications
- May ask more detailed or provocative questions
- May be embarrassed in front of friends or not
- Caring duties??

Helpful Resources

□ Websites

- <http://www.sibs.org.uk>
- <http://www.sibspace.org>
- <http://www.thetree.org/siblingsupport>
- <http://www.siblink.org>

□ Books for parents/professionals on sibling issues

- Brothers, Sisters and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities* by Robert Lebold (1994)
- Brothers & Sisters: A Special Part of Exceptional Families* by Thomas Powell & Peggy Gallagher (1993)
- Listening to Siblings – The Experiences of Children and Young People who have a Brother or Sister with a Severe Disability* by Janet Kitchiff (2003)

□ Fiction for young siblings

- We'll Paint the Octopus Red* by Stephanie Stave-Rodden & Pam Devito (1998)
- Are You Alone or Different?* By Nancy Morley (1994)
- Wings to Go, Alex!* By Robin Palmer & Elizabeth Wolf (1999)
- My Brother, Matthew* by Mary Thompson (1992)
- Our Brother has Down syndrome* by Shelley Castro (1988)
- The Summer of the Sycamore* by Betty Rogers (1984)
- Princess Peet* by Kathleen Muldown (1989)
- Welcome Home, Billybean* by Marlene Fanta Syger (1988)
- Just Because* by Rebecca Elliott (2010)
- Sometimes* by Rebecca Elliott (2011)
- Susan Laughs* by Joanne Willis and Tony Ross (2001)

Books for younger children

□ Just Because

- Rebecca Elliott
- Just Because* Pp. 1st edition (20 Aug 2010)
- About the same bond between an young brother and his disabled sister, and the things they love playing and doing together. His sister has a wheelchair

□ Sometimes

- Rebecca Elliott
- Sometimes* Pp. 1st edition (1 May 2011)
- About the same children in Just Because. The sibling talks about his feelings and how they help each other when his sister has to have a hospital stay

□ Susan Laughs

- Joanne Willis and Tony Ross
- Susan Laughs* Pp. 1st edition (2001)
- A disabled girl and her disabled brother take part in everyday activities; the focus is on disabled child.

□ My Brother John

- Joanne Zeffert
- My Brother John* Pp. 1st edition (30 Jun 2006)
- Joanne takes about her brother John who has a hearing aid and a cochlear implant. It is about everyday activities and the sibling also explains her brother's deafness.

□ We'll Paint the Octopus Red

- Stephanie Stave-Rodden & Pam Devito
- We'll Paint the Octopus Red* Pp. 1st edition (1 Oct 1998)
- A young sister looks forward to doing things with her new baby brother when he is born. When her dad tells her that her brother has Down's syndrome, she starts to think about not being able to do the things she hoped to do. They find new ways to have family fun.

□ Our brother has Down's Syndrome

- Shelley Castro
- Our brother has Down's Syndrome* Pp. 1st edition (17 Aug 2000)
- Down's Syndrome, what about having a brother, a toddler, who has Down's Syndrome. There are family photos on each page and it explains Down's Syndrome.

Appendix 17: Letter from the co-ordinator of the blue sky project

Wandsworth Council

Children's Services Department
Town Hall Wandsworth High Street
London SW18 2PU

Please ask for/reply to: Karen
Schumacher
Telephone: 020 8871 8744
Fax: 020 8871 6086
Email: kschumacher@wandsworth.gov.uk
Web: www.wandsworth.gov.uk

Our ref:
Your ref:
Date 13/12/11

Dear Anna,

Re: The Blue Sky Programme for Parents and Carers

Thank you so much for delivering your presentation on "supporting sibling with special needs". The parents were very appreciative and really loved the real life examples that you provided.

I look forward to you delivering this session again, as part of the blue sky programme.

Many Thanks



Karen Schumacher
Blue Sky Co-ordinator

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