HOW DOES HAVING A CHILD WITH A PROFOUND OR MULTIPLE DISABILITIES AFFECT THE HOME/SCHOOL RELATIONSHIP?

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Abstract

This study explored how having a child with a profound or multiple disability affects the home/ school relationship in a multi-cultural Special School for Primary aged children. Research has highlighted the impact upon the family of having a disabled child in terms of coping strategies and how families with good and poor coping strategies differ. The purpose of the study was to consider how a model of systemic thinking called the Family illness systems model (Rolland 1994) might be used to understand the context in which a family might be operating, informing how the school might appropriately foster the home/school relationship. The study took a phenomenological approach using Interpretative Phenomenological Analysis (IPA) to explore the impact of having a disabled child upon the family; how this affects coping strategies of the parent, family functioning, and how this feeds into the expectations and experiences with school. 5 mothers were interviewed using semi-structured interviews. Interview data was analysed using IPA and three emerging superordinate themes emerged: 'making sense of life changing events', 'impact on family dynamics', 'impact of a child needing a special school'. These findings were discussed in relation to relevant literature and the initial research questions. Strengths and limitations of the research were acknowledged. Finally the findings of the study were considered in relation to educational psychology practice and for further areas of research.

Dedication

In loving memory of my father who died

25th January 2014

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CHAPTER ONE:

INTRODUCTION

1.1 Research context

Following the 1940 Education Act, children and young people were characterised by their disability if they were identified as having a special educational need and this was defined in medical terms. These children and young people were considered to be uneducable with the views of parents having little significance. It was not until the 1970 Education Act that the responsibility for their education was passed to the local authority. The Warnock report 1978, recommended that children with SEN should be specifically identified and that parents should play an active role in any decisions regarding their children and offered guidance as to how professionals should view their interactions with parents.

A more politicised view of disability was developing concurrent to this. The social model proposed that individuals were considered to be disabled by barriers within society, not by physical impairments of the body (UPIA 1976). The social model disablement movement stemmed from British Activists as a direct critique of the medical model of understanding of disability and particularly defined by Oliver in 1983 (Oliver1996). Disabling practices caused those with disabilities to be excluded and oppressed by society. The social model was a move away from the medical model's emphasis of within-child deficits that needed to be fixed and was seen as a tool for political change in Britain to create a society that removed all barriers (Shakespeare & Watson, 2002) The social model was closely interlinked with inclusive school practices where impairment was viewed as another form of diversity that could be supported within an adaptive school environment in contrast to the medical model of thinking where the onus was on the child to change in order to fit into the school system (Gable 2014). Shakespeare and Watson (2002) have criticised the social model for having too fixed a view that it is only society that disables,

ignoring the realities of pain and the negative impact upon the individual experience and the fact that some disabilities cannot be addressed by removing environmental barriers. This recognises that there may be multiple factors such as issues specific to the child and the demands, pressures and support that they have access to in the school system (Wendelborg & Tossebro 2010

The 1981 Education Act was the legislative response in bringing about fundamental reforms to SEN provision (Male, 2015). The Special Needs Code of Practice (DfES, 2001) attempted to set out how professionals should work in partnership with parents, and offered practical guidance for professionals working with parents of disabled children; unique knowledge and skills were regarded as central to the relationship. The Lamb Inquiry (DfES, 2012) was set up to acknowledge concerns that the current SEN process was not meeting parent's needs. In September 2014, the Children and Families Act came into force, with a new Special Needs code of practice 0-25 years (Department for Education and Health, 2014). One of the most important changes, and most useful to children and families is the requirement for joined up services to support families. An example of this within the Local Authority is a Providers Meeting where all Professionals who have submitted reports towards an Education Health and Care plan meet to contribute to common aims and objectives with parents and the child. This then becomes a collaborative piece of work, and a more focused document to meet the needs of the child. Parental views and the views of the child are recognised as an important voice in this process.

Families with disabled children have been identified as being particularly vulnerable due to pressures within the family and environmental and societal pressures, as evidenced by Contact a Family research, an organisation that lobbies on behalf of families. A report commissioned and titled 'Forgotten Families' (Contact a Family 2011), described the impact of isolation on families in the UK. The report identified that mental health issues such as anxiety, depression and breakdown, physical illness and lack of support to access work impacted upon the family. I in 5 participants identified that isolation had led to the breakup of family life. These identified

pressures provide a context to working with such parents and emphasise the importance of engaging with their voices.

1.2 Professional Background

Educational Psychologists are well placed in this process to seek out and listen to parental views and offer support to families as many of the children identified for their involvement will have been part of their case load for a number of years due to being placed in identified geographical 'patches' in the Local Authority. The stability of working in a particular geographical area for the Educational Psychologist and building up relationships with schools and parents, possibly over years is a strength of the service. I have been the EP for the Special School involved in the research for 10 years.

1.3 Rationale

My interest in the area researched has come about following a 2 year project in a Special School for primary aged children with profound and multiple disabilities that firstly focused on skilling staff to identify pupils who needed support with mental health issues to promote positive mental health, and secondly focused on developing staff resiliency when dealing with difficult situations with pupils and parents. Following on from conversations with staff and the head teacher it became clear that there were concerns around supporting parents and their own mental health issues. Having worked with a number of parents at the school through implementing a behaviour programme and supporting through the statutory process, I have become aware of the pressures that some parents encounter. In my research I wanted to explore the impact of having a child with profound or multiple disabilities upon the home/school relationship and how families felt that the school could support them more effectively. Over the past couple of years there has been an ongoing review of SEN within the authority and this is the context within the research has taken has taken place. Places within the SLD/PMLD special school provision with the borough has

been increased reflecting mainstream concerns about meeting complex needs and reflecting parental anxieties about how the educational needs of their children can be met.

1.4 Research question and aims.

To address the issues described within this section the research will focus upon the following question:

How does having a child with a profound or multiple disabilities affect the home/school relationship?

The main aims of the research are:

- To explore the impact of having a child with profound or multiple disabilities upon the home/school relationship
- To explore the parent's experience of school support
- To support the school in developing a model of support that could be utilized to understand and meet the needs of any family at times of crisis
- To explore a potential role for Educational Psychologists based on what is found out from families that could enable Educational Psychologists to offer more systemic and family orientated support

1.5 Purpose

Despite a range of research into the impact of having a disabled child upon family functioning and how this impact is worked out in professional relationships, little research has been carried out on the impact on relationships in schools and particularly special schools using systemic thinking.

The purpose of the research is to use a model of systemic thinking called the Family Illness Systems model (Rolland 1994) as a reflection tool to explore and understand the context and life stage in which a family might be operating, informing how the school might foster the home/school

relationship. Rolland (1994) suggests a model of the life cycle as a developmental framework. He suggests that there will be times of higher (centripetal) and lower (centrifugal) cohesion. Rolland identifies that if illness or disability is severe, then the family can become stuck in an overly cohesive cycle with all their energies focusing inwards. This can then affect how the family can interact with the outside world.

I want to explore how the concept of a family being 'stuck' in a centripetal phase might impact upon the home school relationship to enable the school to have a better understanding of the stress a family might be under and so develop earlier interventions with families rather than being reactive to times of crisis.

I have utilized themes from Begum's Intake Questionnaire (2007) (appendix 7, page 156) to develop semi-structured interviews which she developed in recognition of the particular experiences of mothers.

I hope that as a result of this research some different ways of working with families can be engendered to enable Educational Psychologists to offer more systemic and family orientated support.

1.6 Methodological Orientation

The research is exploratory in nature as this type of research aims to find out what is happening, seek new insights, ask questions and assess phenomena in a new light (Robson 2002). As there are no explicit hypothesis being tested, this research can be seen as being inductive. A more detailed discussion of the purpose and exploratory nature of the study can be found in the methodology chapter

1.7 Structure

Chapter One: Introduction. The introduction sets the scene for the research undertaken.

Chapter Two: Literature review.   In chapter 2, I review literature that is relevant to the research, examining literature around the complexities of family functioning; how interactions with professionals impact upon the family and how families develop resiliency and coping styles. The purpose of the review is also to identify existing research and its theoretical base and identify methodologies used in other studies researching the area.

Chapter Three: Methodology.   In chapter 3, I examine and explain the aims, methodology and design of the research. Methods used are highlighted and ethical issues are considered.

Chapter Four: Results. In chapter 4, I discuss the findings that emerge using Interpretative Phenomenological Analysis. The interviews were analysed case by case. Three superordinate themes emerged and are discussed.

Chapter Five: Discussion. In chapter 5, I consider an analysis of the lived experience of the mothers who participated in relation to the extant literature that was reviewed and to the initial research question. I also consider strengths, limitations and other possible areas for research. I conclude with the implications for the research for Educational Psychologists and personal reflections.

CHAPTER TWO:

LITERATURE REVIEW

2.1 introduction

This chapter explores previous research regarding the impact of having a disabled child in the family and the complexity of emotions, personal relationships and adaptions that a family with a disabled child encounter; how interactions with professionals impact upon the family and how families develop resiliency and coping styles. The purpose of the review is also to identify existing research and its theoretical base that allows me to make a unique contribution and to identify methodologies used in other studies researching this area.

In this chapter the systemic search of relevant research papers will be described in relation to the research question and aims. The search terms for inclusion/exclusion are stated. The search terms for inclusion/exclusion are stated. The relevant studies are discussed under four key areas identified within the searches.

These are:

- Risk/resilience and systemic thinking
- Positive/negative experiences of having a disabled child in the family
- Impacts on siblings and wider family
- Relationships with professionals

2.2 Data search criteria

A preliminary review of the Literature was carried out in October 2012 and then a further review using a systemic approach was undertaken between September 2014 and May 2015.

The following search engines were used:

- EBSCO Discovery base

- Google scholar

These searches used the following data bases:

- PsychINFO

- One Stop Shop for Journals

- British Journal of Educational Studies

- Contact a Family research base

In addition to the uses of electronic data bases, a hand search of the research papers was conducted to locate articles which may not have been identified via the use of an electronic base.

The following key search terms were used to locate relevant literature:

Scholarly articles for systemic thinking	Search 1
Scholarly articles for families with a disabled child	Search 2
Special school partnerships with parents	Search 3
Working with parents of disabled children	Search 4
Children with learning disabilities and siblings and impact	Search 5
Contact a Family and Professionals and Research and Family Life and Relationships	Search 6

Table 2.1: Key search terms

Reference sections of research papers were studied to identify links to additional research that was considered relevant.

2.2.1 Inclusion and exclusion criteria

To establish the relevance of the research papers that were located through the literature search, inclusion and exclusion criteria were developed (Table 2.2).

	Included	Excluded
1.	Research papers around the world written in English	Research papers not written in English
2.	Published articles	Unpublished articles (e.g. dissertations)
3.	Research papers that were published between 2000 and 2015	Research papers that were published before 2000 and 2015
4.	Research papers that were published using qualitative or mixed methods to explore parental experiences of raising a child with a disability	Research papers that were published using quantitative methods to explore parental experiences of raising a child with a disability
5.	Research papers that included families of children and young people with a developmental and/or physical disability between the ages of 0-18	Research papers that included families of children and young people with a developmental and /or physical disability above the age of 18
6.	Research papers that included parental experience of relating to Medical and Educational professionals	Research papers that included parental experience of relating to Social Services

Table 2. 2: Inclusion and Exclusion Criteria

The titles and abstracts of the research papers were read and assessed during the initial literature searches. A total of 53 papers were identified of which 38 fulfilled the criteria. Of these, 4 qualitative studies were chosen to be systematically reviewed and critiqued according to CASP (Critical Appraisal Skills Programme) criteria as examples of differing methodologies that could be considered for the research (See appendix 2: page 151, for table of papers reviewed for CASP).

A more discursive account of the literature will be initially provided followed by structured tables which will systematically review qualitative methodologies according to CASP criteria.

2.3 Theoretical perspectives

Literature searched highlights a common thread of experience of the emotional impact upon the mother of the unexpected birth of a disabled child and the process of coming to terms with this. There is also an acknowledgement of how this child will be viewed by a wider society (Ryan &

Runswick-Cole 2008, Crown 2009, Levine 2009, Gensler 2009 & Constantino 2010). Theoretical underpinnings seek to define these experiences highlighting a dichotomy between the psychoanalytical view of parenting a child as a decontextualized and medicalising view of disability and the discourse of human rights that identifies disabling environments (Watermeyer & McKenzie 2014, Ryan & Runswick-Cole 2008).

Watermayer and McKenzie (2014) define the psychoanalytical approach as one that locates the birth of a disabled child within a grief and bereavement model drawing on Freud's (1917) 'Mourning and Melancholia' where a staged process of bereavement concept is applied as an appropriate picture of parental loss. Explaining this approach the authors describe how different stages must be overcome if a heathy relationship with the child is to develop. Some of the features of these stages are also defined by Drotar, Baskiewicz, Irvin, Kennel and Klaus (1975). They are described as overwhelming shock; irrational behaviour; uncontrollable tearfulness; helplessness; denial; disbelief; sadness; anger and anxiety. The psychoanalytical approach recognising that grief is a staged process through which meaning can be reconstructed (Gillies and Niemeyer, 2006). Droter *et al* (1975) describe this process of grieving as chronic sorrow explaining how a dissonance between the expected child and disabled child can lead to a disruption of early attachment causing the mother to experience highly negative feelings towards herself and her baby. A complex picture can emerge of insecure attachment developing due to the state of mind of the mother and her feelings towards her child (Howe 2005).

Petterson (2010) described a model of 'mourning'; shock, denial, and disbelief followed by acceptance to illustrate the journey that some parents make. She identified that progressing through the family life cycle, periods of stability could be disrupted particularly at times of transition. In considering the impact that parental experiences of interacting with professionals can have upon family resiliency. Petterson found that parental reactions to having a child with a disability varied. Some parents mentioned periods of stress and sadness, while others experiences suggested the usefulness of the family life cycle as a context. Patterson identified

that for professionals to have an effective relationship with parents it was important how they interpreted parental responses, calling for relationships based on parental strengths rather than deficits.

A number of parents have described this process eloquently; Terry (2012) in response to the death of her daughter and Crown (2009), a clinical psychologist with a disabled child, who from personal experience considered the several phases and associated difficulties that many parents pass through. Based on her own experience she found the psychodynamic frame work helpful describing it as a 'crucial anchor'; citing the usefulness of a frame of reference in organising her experience. From her perspective, this process enabled her to navigate the ongoing and complex challenges of parenting a disabled child. Crown describes the process as transformative, moving from dark periods of intense emotion to finding ways of being a 'good enough parent'. She defines this for parents as finding their 'balance'. Constantino (2010) similarly describes episodes of intense anxiety, fear and loss, describing it as 'navigating through storms' citing this process as having to embrace transition as a parent as both a wanted and unwanted processes. This perspective identifies strong experiences and emotions.

Whilst acknowledging the unique contribution of the psychoanalytic approach of close attention to the internal, Waltermayer and McKenzie (2014) highlight that a weakness of this approach stems from being out of step with present day concerns with its use of politically sensitive terminology and human rights. Whilst not accepting this as the definitive experience of disability in families, the authors accept the importance of allowing for grief and overcoming struggle with difference.

The social model of disability rejects the understanding that disability is a medical and individual construct claiming that the social model can be seen to offer a direct challenge to that view. The medical view of disability follows from an understanding of deficit, an example being Autism, almost universally recognised as a medical condition that is real and biologically based (Goodley

& Runswick-Cole 2009). Within this view, parents can be put at a disadvantage as treatment of the symptoms enables professionals to maintain dominance and control (Case 2000). Within the social model of disability, the view pertains that disability is a product of a society that is geared towards the non-disabled. Research coming from a social oppression understanding of disability and childhood, has shown repeatedly that disabled children are more likely to suffer structural and material disadvantage than any other group (Godley & Runswick-Cole 2009) and the plight of many families who struggle with discrimination and the exclusion of their child gives value to politically driven idealisation (Watermeyer & Mckenzie 2014). Ryan and Runswick-Cole (2009) suggest that in a society that is viewed as 'ablest', parents can share the stigmatisation of their children, this view even represented within the family.   Mothers of disabled children can experience many of the discriminatory practices and attitudes that their children face with little consideration of the dimensions of parenting a disabled child.

Whilst acknowledging that the social model holds much truth, Watermeyer and Mckenzie (2014) argue that promoting a collective analysis can disallow feeling and avoid the complication of individual subjectivities, a view shared by Ryan and Runswick-Cole (2008) who argue that if oppressive structures were removed, leading to the disappearance of disability within society, disablism may disappear, but impairments will still remain for others.

 Overall Watermayer and McKenzie (2014) call for an integrated view; acknowledging the contribution of psychoanalytic understanding where the feelings of parents are supported and acknowledged, while addressing the material and contextual concerns that will impact on the family and child development. They state that there is a need for an understanding of disability that can challenge the fit between the effect of the disability on the child and the family, and the environmental barriers that they face together.

2.3.1 Stress and coping

When considering how families come to terms with having a disabled child, it would seem that the main focus of literature that explores the experience of having a disabled child as has already been discussed is one of stress, adaptation and the burden of care.

Receiving a late diagnosis has been identified as a particular stress factor for families (Baxter, Cummins & Polka, 2006). An experience is described by Maul and Singer (2009) as a 'tragedy metaphor' that has traditionally defined the manner in which families of children with developmental disabilities have been regarded. But research carried out interviewing parents and grandparents of children with developmental disabilities indicated that families were able to construct sustainable and effective routines that that complimented rather that disrupted the natural ecology of the family. A study by Hastings and Taunt (2002) shows that under reporting of more positive experiences of family resiliency is common.

 Breitkreuz, Wunderli, Savage and McConnell (2014) posited the question as to why it was that some parents and families, but not others were able to be resilient. A report commissioned by Contact a Family in 2003 concluded that the experience of having a disabled child could bring the family together and develop stronger relationships, but also contribute to the breakup of partnerships, with mostly the mother left as the sole carer. The majority of those taking part felt that having a disabled child caused problems in their relationships and for nearly 1 in 10, the problems were so overwhelming that separation had occurred. Contributing pressures were identified as adjustment to new roles, differing expectations running alongside significant emotional, social and financial adjustments. An important factor that emerged is that different coping styles affect the ability of the parents to gain support from each other and face pressures and changing circumstances. The research concluded that supportive couples protected one another from stresses and risk of depression associated with the care of a disabled child.

Using Ungar's (2011) social ecology of resilience, a framework that defines 'doing well' amidst out of the ordinary-challenges and hardships, families were asked to articulate their everyday experiences of raising a disabled child. The authors found that families who identified themselves as 'doing well' generally felt connected, had close-knit families and a strong sense of belonging to their community, with 'business as usual attitude'. In contrast, families who were struggling revealed that their lives revolved around disability. These families appeared more isolated, lacking social support and to be struggling financially.

Levine (2009), considering the particular adaptation of single mothers found a marked contrast between perceived public discourses of single mothers and disability, and personal experiences. Levine identified four particular key processes for single mothers that promoted a more resilient outlook; being able to reframe single parenthood as an empowering choice; 'normalising' the disability of their child in terms of parental practices; having confidence in the reality of their own experiences; and as with other definitions of 'coping' making a conscious effort to develop family networks.

2.3.2 Systemic Thinking

Within systemic thinking, much of the research involving the family is situated within the clinical context. This perspective considers how within the family context life cycle stages and intergenerational patterns can have an impact upon how a family interacts. Individual members can be affected by their own belief systems and the contextual issues of their lives, their own life cycle stages and a sense of their experiences and their interconnectedness with others (Illingworth, Forbat, Hubbard & Kearney, 2010). Illingworth *et al* (2010) write about the experience of cancer in a context of a whole - systems approach emphasising the need to understand the entire context in which people experience and make sense of illness and in particular their connectedness with others. Similarly research projects undertaken by Care Research Centre at Stirling University (2011) have concluded that illnesses such as cancer, do not just affect

individuals but that the whole family can struggle to cope especially during times of transition. The project highlighted that the background to these difficulties may be rooted in patterns of behaviour that have been handed down over generations with the whole family being linked and that solutions to supporting such families may involve understanding these links.

Taanila, Syrala, Kokkonen and Jarvelin (2001) describe how the birth of a disabled child can affect all the members of the family and cause a reassessment of family functioning.   They identified that to be able to cope, the family will use its existing resources, but also develop coping strategies to adapt and deal with an increasingly stressful situation. Coping is described as the process of trying to employ active processes and behaviours to try and adapt or deal with stressful situations. Taanila *et al* (2001) found that 'high coping' families displayed a strong feeling of togetherness and an ability to talk openly about positive and negative emotions and experiences creating a family system where responsibilities were shared. Families defined as 'low coping' in the study had children whose disabilities were diagnosed relatively late, and this factor of their difficult initial situation appears to be a contributor to cause the families' uncertainty, insecurity and frustration.

Developing the metaphor of a 'high coping family' or a family that is 'doing well', Patterson (2002) focuses on the family system as the unit of analysis and intervention for understanding resilience. He discusses the unique functions that families performed within an ecological context and the risk and protective factors that gave rise to resilience in families, describing family functioning as multidimensional.   Patterson developed the Family Adjustment and Response model, which emphasised the processes families actively engaged in to balance family demand with family capabilities. Significant risk was defined as an unexpected traumatic event, including the diagnosis of chronic illness or disability in a child. As families were pushed to their extremes, their functioning becomes worse or stronger. Growth occurred when a family was pushed just far enough to develop new capabilities. Patterson identified cohesiveness, flexibility, communication and meaning making as the protective mechanisms that contributed to family resilience.

2.4 Family Effect

Individual relationships within the immediate and wider family are all impacted by the change to family functioning that a disabled child brings to the family and as has been highlighted by Watermeyer and Mckenzie (2014) there is an acknowledgement of both an emotional and environmental impact.

Since the turn of the twenty first century there has been a shift in family focus to recognise the extended nature of the family (Carpenter & Rawson 2015). Previous developments tended to focus primarily on parent/child engagements. Contact a Family have commissioned a number of reports over the years to develop a research base around families and their disabled children, and to lobby on the behalf of families with influential bodies to engender positive change. A particular area highlighted is that of family life and relationships. Further experiences of families (2009) and Fathers (2013) continues to highlight ongoing issues. Now not only mothers and fathers, but siblings, grandparents' and 'significant others' can be part of a wider network of key supporters (Carpenter 1998, Carpenter & Rawson 2015). The effect of the birth of a child with a disability can be wide spread. When a family member has been given multiple disability labels the whole family can become vulnerable to experiencing a life history of both struggle and perseverance (Roth1992).

Because mothers and fathers may have differing understandings of their children's needs, for example in treatment of children with ASD (Johnson & Simpson 2013), these differences can be a source of stress for and between parents. A lack of participation in studies may equate to less understanding of father's concerns and fathers have been described as the 'peripheral' parent. .Both parents can equally show symptoms of stress which can lead to poor mental health outcomes, but only mother's stress is often widely recognised. Brageil and Kaniok (2011, 2014) considered demographic variables and father's involvement with their disabled children. The authors found that fathers were more interested in the needs of their child with disabilities and

were involved with their care when there was a willing partnership with their wives. The authors compared their results to a conceptual model proposed by Glenn (2007) that describes how parents whose relationships are caught in a negative cycle tended to follow a pattern where the mother feels unsupported in the raising of the child. Criticism of the father can result in increased marital conflict. Simmerman, Blacher and Baker (2001) considered whether the father's help with child rearing and mother's satisfaction with that help contributed to the mother's well-being or whether the father's help related to both parent's caretaking burden and marital adjustment. Results concluded that it did not appear to be the amount of help, but the participation of the father, and the mother's satisfaction with this that counted. Research around 'A parent's guide for Fathers' (2013), provided by Contact a Family, found from conversations with fathers that they usually reached acceptance of their child's disability at a different time to the child's mother, and communicating and accepting this this could be challenging and stressful to the partnership.

2.5 Impact on siblings and wider family members

There appears to be general agreement that non-disabled siblings are affected by the presence of in the family of a disabled sibling. A longitudinal study by Hames (2008), followed the siblings of disabled children over 12 years. It was found that developmentally by the age of about 7, siblings had developed an early understanding of the abstract concept of disability. Sibling adjustment was affected by the amount of information they received and the behaviour of the disabled sibling rather than the learning difficulty. Further studies also considering the developing understanding of a sibling of a disabled child came to similar conclusions (Ferraoil & Harris 2008, Fisman, Woolf, Ellison & Freeman 2000).

During the teenage years, an understanding begins to develop of causes and long term effect, and an awareness of impending personal responsibility of caring for a sibling into the future. Rawson (2009), interviewing young adult siblings, identified that many were concerned about holding responsibility for their brother or sister and whether they could maintain levels of care and

advocacy that had been maintained by their parents. Information from Contact a Family produced for siblings (2013) highlights issues caused by a lack of attention from parents, guilt at being the sibling without the disability, embarrassment, protectiveness towards the sibling and concerns about the future.

 A contributory factor to the resilience of the non-disabled sibling can be perceptions of how they are treated within the family. Aranson (2009) noted the impact of less parental time and attention, arising in fewer opportunities for socialisation. Siblings could also absorb parental discomfort around managing difficult behaviour leading them to experience their parents' shame and discomfort. Macks and Reeve (2007) identified an assumption that there will be more stress in a family with an autistic sibling, but their study found that siblings of children with autism appeared to have a more positive self – concept than siblings of non-disabled children. The views of the siblings of disabled children appeared markedly different to their parents; their parents having a more negative view of relationships within the family.   A reason suggested for these differing views was that the parents were so preoccupied with their autistic child that they did not have an accurate view of their other child, or that parents may project their frustrations and stress onto the non-disabled child. However Macks and Reeve (2007) cautioned that although having a sibling with autism may not be a risk factor in itself, when there were multiple demographic risk factors surrounding the family it could become more difficult for the non-disabled sibling to deal with the child with autism.

The role of grandparents can be vital in any family. Hillman (2007) considered that grandparents could have an immediate effect in terms of their support for the adult parent, but could also experience grief themselves and have difficulties adapting to their new role. In the hierarchy of relationships, maternal grandmothers were seen to be the most valued. Emotional and material support were described as particularly effective, but poor relationships could be exacerbated by new stressors and add to the emotional burden that parents had to carry. Any generational

conflict was identified as causing more stress to mothers (Hastings, Thomas & Delwiche, 2001). Mitchell (2007) noted that there had been little consideration of the support that grandparents offered to grandchildren, both disabled and non-disabled, and that although grandparents could be important within the family, their contribution was rarely considered by professionals. Emerging themes following workshops with grandparents (Contact a Family 2014) indicated similar concerns, identifying sensitivities around levels of support they could offer and that often the stronger relationship was with maternal grandparents. Good relationships depended on the quality of interactions before the disabled child was born.   Support from grandparents was identified as being especially welcomed from single parents, and valued by grandchildren.

2.5.1 Cultural Considerations

There appears to be a general agreement on the importance of gathering information to be able to understand the cultural context in which parents are situated. When undertaking a literature search of family centred practices and families of a child with a disability, Dempsey and Keen (2008) identified that the help valued by parents was directly related to consistent support in developing strong relationships. The authors identified that for families from many cultural backgrounds and a variety of demographic characteristics, cultural sensibilities could be an important factor. Begum (2007), working in a clinic for Child Development in Bangladesh, established through developing an intake questionnaire, that disability had a significant effect on families, especially the mothers, in terms of anger, shame and wider social disapproval. Lawrence (2014) exploring the views of Black African parents found parental acknowledgment of their child's needs rooted in religious belief systems, with often little understanding of disability within the wider community. Interestingly Lawrence also found that Black African families had a perception that white communities were more open and willing to access services and that within that community the child's need was not viewed as stigmatisation. Belief systems could appear to act as inhibitors in understanding, adapting and managing their children's needs.

However Krause (2002) has an alternative view, describing one's culture as being both inside and outside the person; a complex interaction of individual stories that are derived from thoughts, feelings intentions, and motivations of persons in a social system. She expresses the view that the human condition is culture free, and in all social systems there is a connectedness to each other. Allen (1995) through setting aside debates of Black family pathology, appears to agree, finding it useful to focus instead on families essential qualities.

2.6. Parental experiences of professional relationships

Parents of disabled children develop relationships with professionals almost from the moment their children are born or more intensely over time if seeking a diagnosis. Overall experience seems to indicate that a variety of variables can affect relationships and these can be viewed as both a positive and negative experience for parents, with effective family services promoting collaboration, affirmation and respect (Carpenter & Rawson 2015).

Professionals need to respect the strength of the family and not inadvertently undermine it (Roberts 1984). This seems to be a characteristics common in the behaviours of professional staff identified by parents. These are summed up by Whiting (2014) and Pollack Prezant and Marshak (2006) as establishing trust; valuing and recognising parental instinct; providing emotional and psychological support and being knowledgeable about the child's condition and needs; and engaging in advocacy. De Geeter, Poppes and Vasclamp (2002) highlighted three areas for proactive parental/professional co-operation that they deemed to be important. These were identified as opportunities to transfer experiential knowledge to professionals; opportunities to communicate their expectations for the future and preferences for the kind of support offered. Again identification of the undervaluing of parental knowledge gained through everyday experiences that was not available to professionals and could contribute to a wider understanding of the child was seen as lacking.

Parents are clearly seeking effective partnerships and interactions that are positive and focused, but without an imbalance of power (Carpenter & Rawson 2015). Gensler (2009) writing as a parent about the intense and mixed emotions that develop and change over time as a parent of a disabled child, described how parents could either be supported to develop the skills of initiative and advocacy in their relationships with professionals or they could become avoidant and withdrawn through repeated rejections of their knowledge and experience. She pointed out that as a parent it takes time and confidence to develop such relationships.

Leyser and Brobst Cole (2006) surveying parents about perceptions of their child's problems and the education services provided found that most parents were mostly satisfied. Within the school environment most disagreements appeared to arise when a child did not thrive and communication between home and school had broken down. The authors highlighted the need for a continued and ongoing effort to be made to engage with parents, particularly to give them confidence to participate in the roles expected of them. This included encouraging their rights and responsibilities, participating in active decision making and developing communication skills to enable themselves to interact effectively with educational professionals. Murray (2010) taking a personal perspective felt in her experience that true partnerships were only formed in school with classroom support workers who had the time and skills to develop the most personal relationships with her child. Her experience as a parent was similar to parents identified in the previous study, in that the dominant medical model defined relationships, where teachers because of the very nature of their status thought themselves to hold knowledge particular to their profession. She felt that it was only possible for partnerships with the professionals when they were able to value and enjoy her son for what he was.

2.6.1 Parental engagement with Educational Psychology Services

Relationships between parents and Educational Psychologists are also open to interpretations already discussed in parent–professional relationships and are not immune to the similar

misunderstandings of working partnerships with parents. Cross, Kirkcaldy and Kennedy (1991) surveyed parent's perceptions and satisfaction with early years EPS practice covering three areas: EP-parent communication; services received; and general satisfaction. Accessibility, explanation of role, interactions with parents and qualities of active listening were identified, and a general satisfaction with services received. Similar findings were identified by Dowling and Liebowitz (1996). Cuckle and Bamford (2000), exploring parents' expectations of EP availability, noted that where a child had complex needs an understanding of the role had additional challenges. The authors identified that a proportion of parents were dissatisfied with the time taken to receive services, confusion over the length of service involvement, frustration over perceived needs not being met and uncertainty about the Educational Psychologists role. Anthun's (2000) cross-cultural research focused on experiences and perceptions of quality. Parents identified the quality of EPS work and that school staff listened to Educational Psychologist's interventions.

2.7 Research papers reviewed according to CASP

A more discursive account of the literature has been provided and is now followed by structured tables which will systematically review 4 qualitative methodologies according to CASP (Critical Appraisal Skills Programme) criteria that could be considered for the research.

2.7.1 Research paper 1

Down (2010), using grounded theory, a systemic and social constructionist approach to examine relationships in healthcare settings, found that families valued the relationship with health care professionals, both as a support in stressful times and as a crucial context for sharing the care of the ill child. She identified that the interface between the family and professional systems could provide a positive context for promoting child and family wellbeing, but it could also be a source of tension and difficulty that impacted adversely on both professionals and families. Down noted that the child's illness required the family to open up boundaries to professionals, who may then

take over some of the roles that had been previously undertaken by members of the family making the families feel vulnerable and dependent.

Title	Relationships between healthcare staff and families in a paediatric hospital: a grounded theory study.
Aims	To explore personal clinical experience that suggested that the interface between family and professional systems could provide a positive context for promoting child and family well-being (physical and social). But could also be a source of tension and difficulty impacting adversely on both professionals and families.
Author, year and country	G. Down, 2010. (United Kingdom)
Methodology	Qualitative: Grounded theory.
Findings	Confirmation of the utility of focusing on the interrelationships between families, doctors and nurses.
CASP Critique	Aims of the research were clearly stated. Grounded theory method appropriate as it focuses on the interrelationships of individuals rather than the internal psychological world. Small sample size: 4 families, 4 doctors, 4 nurses. Use of semi-structured interviews. Participants were interviewed in a venue of their own choice. Ethical issues were taken into consideration. Limitation due to presence of potential researcher bias due to researcher implementing and evaluating the research. Implications: A greater understanding of the other and more choices about positioning through an awareness of the beliefs staff and families hold in relation to roles and relationships.

2.7.2   Research paper 2

Lalvani (2015) carried out a study using narrative inquiry to explore the perspectives of parents and teachers with regard to the meanings and implications of disability. Narrative inquiry was chosen on the grounds that the study was based conceptually and methodologically on a stance of multiple frames of reference rather than objective realities.   Lalvani discovered broad conceptual differences in teachers and parent's interpretations of the meaning of disability; teachers with a more medical model perspective and parents with a more sociocultural understanding.   Parents identified a disliking of labelling, specifically around disability as they perceived this could alter the way their child was perceived, whilst teachers found labelling helped them in terms of determining educational placement, planning specific learning programmes and developing leaning goals. Lalvani identified that constructs such as 'stigma', and 'otherness', were viewed differently, with some teachers not considering stigma to be associated with disability. Most teachers held the belief that parents were burdened by grief and levels of stress and that this process was likely to occur throughout the parent's lives.   Differences in interpretations of disability were seen to be a contributory factor to underlying conflicts between parents and professionals.

Title	Disability, Stigma and Otherness: Perspectives of Parents and Teachers
Aims	To explore the perspectives of parents with regard to the meanings and implications of disability.
Author, year and country	P. Lalvani, 2015. (USA)
Methodology	Qualitative, Narrative inquiry.
Findings	Broad conceptual differences in teachers and parent's interpretations of the meaning of disability, suggesting that teachers tend to locate disability within individual students, whereas parents located disability not solely in their children, but also in the contexts of cultural and educational discourses and practices.

CASP Critique	Aims of the research clearly stated.
	Narrative inquiry was chosen on the grounds that the study was based conceptually and methodologically on a stance of multiple frames of reference rather than objective realities.
	32 parents chosen using purposive sampling and 'snowballing' to elicit a wide range of ethnic, cultural linguistic and socio-economic backgrounds.
	30 teachers (including general and special education) were recruited through contacts with the author and additionally using the snowballing technique.
	Use of semi-structured interviews. Parents and teachers interviewed separately guided by open ended questions.
	The study uses the methods of inductive analysis. All coding and data analysis was done by the author.
	Limitation due to presence of potential researcher bias due to researcher implementing and evaluating the research.
	Differences in the interpretations of disability labels may underlie conflicts between teachers and parents during educational planning. Teachers need to be challenged about understanding that disabilities are absolute and parent's alternative perspectives seen as an additional problem.

2.7.3 Research paper 3

Within the school context, Lundeby and Tossebro (2008) using mixed methods; Quantitative questionnaire studies and qualitative interview studies, reported that most of the parents they interviewed identified a varied experience with teaching and other professionals demonstrating helpful actions as well as being in conflict with parents. A major concern identified by parents was that although they sought judgement and ideas and perspectives from professionals in

school, and had a willingness to follow that advice, it was commonly reported that their own knowledge was not recognised as important and was treated as subordinate to professional knowledge. This left parents with the impression that they were being deprived of the power to define what they felt were important needs for both themselves and their children.

Title	Exploring the experiences of 'Not being listened to' from the perspective of parents with disabled children
Aims	To explore parents experiences of not being listened to from their own perspective.
Author, year and country	H. Lundeby and Tossebro, 2008. (Norway)
Methodology	Mixed methods. Quantitative questionnaire studies and qualitative interview studies.
Findings	Most parents reported varied experiences with professionals with helpful actions as well as conflicts. Nearly all the parents reported 'not being listened to'.
CASP Critique	Longitudinal project following children with disabilities and their families every three to four years. This paper covers a four-year period.

A wide range of disabilities in the 31 children studied.

Requests for participation sent to parents whose children fulfilled a particular criteria.

Semi-structured interviews were used with open ended questions.

All interviews were conducted by the first author.

Ethical approval was sought.

Analysed using issue-focused procedures using matrices to categorise different themes.

3 categories of problems defined. Nearly all parents reported 'not being listened to'. |

| | Limitation due to presence of potential researcher bias due to researcher implementing and evaluating the research. |
| | Emphasises that without taking parents knowledge and experiences seriously and considering their understanding of a problem as worth looking into, it will be difficult to establish an open dialogue. |

2.7.4 Research paper 4

Heer, Larkin, Burchess and Rose (2012) chose IPA to explore the cultural context of care-giving amongst South Asian communities caring for children with intellectual disabilities, seeking to identify culturally appropriate support and interventions. A need was identified for services to move beyond simplistic cultural assumptions and engage more directly with parents.

Title	The cultural account of care-giving: qualitative accounts from South Asian parents who care for a child with intellectual disabilities in the UK
Aims	To contribute to the development of culturally appropriate support and interventions in children's intellectual disability service.
Author, year and country	K. Heer, M. Larkin, I. Burchess and J. Rose, 2012. UK
Methodology	Qualitative – hermeneutic and phenomenological
Findings	Three master themes emerged reflecting the primary concern of the participants: Making sense of the disability, Feeling let down by services and Looking to the future
CASP Critique	Aims of research clearly stated
	IPA was chosen as it aims to provide an in-depth account of participant's personal experiences of a certain phenomena, in this case caring for a child with intellectual disabilities

	Participants were recruited from two pre-existing groups. In total 9 parents took part. Participants in one group were Sikhs, the other group were Muslim
	Use of a semi-structured discussion schedule.
	From analysis (master themes and subthemes), three master themes emerge
	The findings provide an insight into how culture can shape the way in which disabilities are understood and experienced by South Asian communities. Main focus of IPA is to provide detailed accounts of the experience of a small number of participants rather than to generalise to whole populations.

The prime reason for choosing IPA over other qualitative approaches, and Grounded Theory could be considered as an alternative methodology, is because IPA is consistent with the epistemological position of the research question (Smith, Flowers & Larkin 2009) i.e. the focus upon people's experience and understanding of a particular phenomena which in my case is an exploration of the impact of having a child with profound or multiple disabilities upon the home-school relationship. With IPA there is also the assumption that the data engendered will tell us something about the participant's involvement in and orientation to the world.

 I shall be using a phenemological approach, IPA, to elicit these understandings.

2.8 Conclusion

A range of research has been reviewed covering the following areas

- Risk/resilience and systemic thinking

- Positive/negative experiences of having a disabled child in the family

- Impacts on siblings and wider family

- Relationships with professionals

There appears to be little consideration or utilisation of systemic thinking within the education context in exploring the impact that a child has upon family functioning and how this impact is worked out in relationships with schools, particularly in special schools. Much research considers stresses and strains upon families within the context of disability discourses and parental stresses but I want to take a more nuanced approach that attempts to explore personal experiences and individual perceptions, so informing more understanding of that experience for professionals to learn from and develop appropriate support.

CHAPTER THREE:

METHODOLOGY

3:1 Introduction

In this chapter the aims, methodology and design are examined. The purpose of this chapter is also to provide transparency about the research process. In qualitative research transparency is particularly important in acknowledging that research is not value free and that epistemological and ontological perspectives have a direct bearing on the research process and its outcomes.

3:2 Research Questions and aims

The research question for this study is:

How does having a child with a profound or multiple disabilities affect the home/school relationship?

The main aims of the research are:

- To explore the impact of having a child with profound or multiple disabilities upon the home/school relationship
- To explore the parent's experience of school support
- To support the school in developing a model of support that could be utilized to understand and meet the needs of any family at times of crisis
- To explore a potential role for Educational Psychologists based on what is out from families that could enable Educational Psychologists to offer more systemic and family orientated support

3:3 Methodological/Epistemological considerations

Within social sciences there has been a long standing debate about the relative merits of quantitative and qualitative methods. It has been described as the 'paradigm problem' (Clarke & Dawson, 1999). A paradigm provides a philosophical framework for the study of the world, and guides the researcher towards research methods and methodologies. Miles and Huberman (1994) see the paradigm debate as a distraction from concentrating on actual research, but Patton (1990) stresses that the researcher has to have a clear understanding of the fundamental features of the competing paradigm to make an informed methodological decision. At the centre of the debate is the issue of the relative merits of the two divergent paradigms. In the table below, Clarke and Dawson (1999) discuss the different ontological positions about the nature of reality between the two paradigms and their differences at an epistemological level.

Quantitative paradigm – realist ontology	Qualitative paradigm – relativist ontology
- Reality is something that is objective - Reality exists independently of human perception - There is a single reality that can be uncovered by applying the logic of inquiry found in social sciences - Although there is one social reality the constituent parts can be studied independently - By following rational methods of empirical inquiry the social researcher can find regularities and relationships and discover the causes of social phenomena - Truth is established by the application of rigorous and systematic scientific investigation	- There are multiple subjective realities - Individuals and groups will construct their own version of reality - Reality is not a single entity which can be subjected to objective measurement - The researcher's task is to ensure that the different versions of the truth are accurately recorded

Quantitative epistemology	
• It is possible to separate the researcher from the researched	• The researcher gets close to the data to understand the 'actors' point of view and so obtains social knowledge
• The investigator can hold an objective stance and remain detached from the phenomenon being studied	• The task of the researcher is to acquire insight and develop understanding
• Survey methods and experimental research designs limit interaction between investigator and the investigated	
• Systematic sampling techniques are used to control bias	
• The strategies used are interventions by nature	• The issue is one of scientific objectivity versus phenomenological subjectivity

Table 3.1: the different ontological positions about the nature of reality between the two paradigms and their difference at epistemological level. (Clarke *et al,* p 99)

The degree to which a researcher aligns themselves to the contrasting ontological and epistemologies outlined in table 1 will underlie their choice of methodology used to explore the phenomena under investigation. I have chosen to pursue a Qualitative methodology. Qualitative researchers tend to be concerned with meaning, how people make sense of the world and how they experience events and the attempt to capture the sense that lies within (Bannister, Burnham, Parker &Taylor, 1994). Qualitative researchers aim to understand 'what it is like' to experience particular conditions and how people might manage these. Qualitative research is also a means for exploring and understanding the meaning individuals or groups give to social or human problems (Creswell 2009; Cohen, Manion, & Morrison, 2007). Smith and Osborn (2007) define understanding as encapsulating both aspects of interpretation and understanding, which leads to

a rich analysis. Qualitative researchers also tend to be concerned with both the quality and texture of the experience (Willig 2008).

3:4 Purpose of the research

The purpose of my research is to consider how a model of systemic thinking called the Family Illness Systems model (Rolland 1994) can be used to help understand the context and stage in which a family might be operating, informing how the school might more appropriately foster the home/school relationship. Rolland suggests a model of the life cycle as a developmental framework. He suggests that there will be times of higher (centripetal) and lower (centrifugal) cohesion. Rolland feels that if the illness or disability is severe, then a family can become stuck in an overly cohesive cycle with all their energies focusing inwards. I want to explore how the concept of family being 'stuck' in a centripetal phase or at a more fluid lower cohesive phase might impact upon the home/school relationship in order to give the school a greater awareness and understanding of the stress that a family might be undergoing. I hope that the research will lead to the school having more understanding as to why the home/school relationship might be difficult at that time and will lead to the school developing earlier interventions with a family rather than being reactive to a more difficult situation. Although this model applies to families with a disabled child, I would hope that as a result of this research that it could be utilized to understand and support any family at a time of crisis.

Consultation following the SEN Green paper (2011) considered the ongoing role of the Educational psychologist, it was highlighted that respondents wanted there to be more face to face contact, more frequent home visits and work with families. I hope that this research will engender some different ways of working with families that could enable Educational Psychologists to offer more systemic and family oriented support. The research is exploratory. According to Robson (2002) and the classification of the purposes of enquiry, this type of research aims to find out what is happening; to seek new insights; to ask questions; to assess phenomena in a new light, and to

generate ideas and hypothesis for future research. The research is considered to be exclusively of a flexible design; the presentation of multiple realities with the researcher as data collector and a focus on participants views (Robson 2002). The research is taking place in a unique situation, in a moment in time with certain parents. New information will be revealed and Rolland's Family Illness Systems model will be used as a lens of curiosity following analysis using IPA.

It could be argued that elements of this research could also be regarded an emancipatory. Fox, Martin and Green (2007) describe emancipatory research as research with groups in society who are viewed as powerless and marginalized. Understanding the experience and perception of these people should shift the perceptions of others, but also change the perception of the participating group.   Fox *et al* (2007) describe how emancipatory disability research was highlighted following concerns raised by the Rowntree foundation in the 1990's that the medical model of disability focused on the individual working to overcome their disability rather than the society in which they lived being the focus of the research. Robson (2002) and Creswell (2009) define a feature of the emancipatory paradigm as focusing on the lives and experience of diverse groups that have traditionally been marginalized, creating opportunities and the will to engage in social action. Families of disabled children can be considered as a marginalized group. A report from Contact a Family (2011) describes the impact of isolation on families with disabled children across the United Kingdom. The survey received 1,148 responses. The aim of the survey being to find out more about the levels of isolation experienced and how it impacts on family life. The findings describe how:

- 72% of respondents experience mental health issues such as anxiety, depression and breakdown due to isolation
- 49% had felt so unwell that they have asked their GP for medication or have seen a counsellor
- 57% say lack of support means they are isolated and not able to work as much as they would like
- I in 5 (21%) say that isolation has led to the breakup of family life

An earlier report commissioned by the Mental Health Foundation – 'Bright Future's. Promoting Children and Young People's mental health (1999), although highlighting the positive benefits of good mental health, and identifying protective factors, also identified the cumulative effect of risk factors in engendering poor mental health. These were identified as parental separation and divorce, hostile family relationships, social isolation and socioeconomic depravation. Having a disabled child was identified as being a high risk factor for the child, family and community.

In the interviews that I have carried out with individual mothers, I feel that I have given them a voice to comment on some of the issues raised above, and that their views could lead to the school developing a model of support that could be utilized to understand and meet the needs of any family at times of crisis. I based some of the questions that I used to gain the views of the participants on an intake questionnaire developed by Begum (2007) (see appendix 3) in recognition of the particular experiences of mothers of children with disability, giving a voice to that particular group. Begum designed her questionnaire with two purposes in mind; first to enable the interviewer to learn about the particular skills and knowledge of the mothers and their children, and secondly to help the mothers get in touch with their own knowledge and skills and to speak out about their experiences and to give value to the personal journeys that they had made.

3:5 Pilot study

The aim of the pilot study was to trial the interview schedule with a parent.

The criteria for selecting a research participant for the study was:

- A mother of a profoundly disabled child
- The child not to be an attendee at the particular school in which the research was to be carried out

The participant for the pilot study was identified through involvement with one of the Nursery schools that I am responsible for. After having been involved in writing a Statutory report for her child, I became aware that the following September, her daughter would be attending the

particular school in which I was carrying out the research. On contacting the parent and explaining my purpose, she agreed to participate.

The format of the interview was to be semi – structured, as according to Smith *et al* (2007) allowing the interview to be guided by the schedule, rather than to be dictated by it. They summarized the advantages of this approach by the following:

- It facilitates rapport/empathy
- Allows a greater flexibility of coverage
- Allows the interviewer to go into novel areas
- Tends to produce richer data

They commented that the person taking part in the interview could be perceived as the 'experiential expert' (p 59) and so should be give the greatest opportunity to tell their story. Smith, Flowers and Larkin (2009) describe this as 'the space to think, speak and to be heard' (p 58).

For the interview schedule, I was interested in utilizing themes from an intake questionnaire devised by Begum (2007) (see appendix 6, page 156) who worked in the Shishu Bikash Clinic in Bangladesh with families of children whom she described as having intellectual disabilities. She discovered that stress, anxiety and depression were common concerns for the mothers who consulted her. Working from a narrative perspective, she wanted to develop a questionnaire based on the values of curiosity, respect and transparency that allowed the mothers to give an account of their own knowledge, skills and abilities rather than on understandings of expert knowledge. The overall themes for questions she identified were:

- A history of care
- Current acts of care
- Responding to blame and stigma

I equally wanted to be able to give the participants I would be interviewing a chance to tell their story including the opportunity to show their knowledge skills and abilities and so utilized themes and questions from Begum's questionnaire to develop my own (see appendix 7, page 159)

 Thus I clustered my questions under the themes of:

- A history of care
- Effect on the carer and wider family
- Engagement with professionals

A history of care

Using Begum's questionnaire and the heading of 'Current acts of care', I took the idea of exploring the ways the mother and wider family cared for the child. From 'A history of care', I utilized the first question around the initial understanding of the mother that their child was different from others, following with a prompt to explore feelings and coping mechanisms.

Effect on the carer and wider family

From the heading in Begum's questionnaire 'Responding to blame and stigma', I took the idea of exploring the impact that having a child with disabilities had on the family, following with a prompt to delve further into the idea of blame if appropriate. From 'Current acts of care', I utilized the idea of positive change in the mother, what others valued about them and to explore positive wider family support.

The third theme I identified was of relationships with professionals to include questions around support from outside the family and support from school, which was not covered in Begum's questionnaire. I did not use Begum's questionnaire in its entirety because it was too detailed and some of the questions were not relevant to the areas I wished to explore. Also Begum's questionnaire was set in the context of a Child Development Centre in Bangladesh operating in a different cultural frame work to that experienced by the mother's I wished to interview.

I utilized the concept of 'funnelling', (Smith *et al*, 2009, Smith & Osbourne, 2007) which is described as identifying specific topics and constructing the interview to work gradually towards them, in this case working from questions about the personal, to the family and then to

engagement with professionals (appendix 7, page 158). Smith *et el* (2009) also suggest the use of starting the interview creatively by getting the participant to draw or respond to an image and thus allowing them to relax into the interview. I decided to start the interview with a general question about the makeup of the family, and by myself recording this in a genogram (McGoldrick & Gerson, 1985) (appendix 8, page 160). As the interview continued, I also intended to utilize the recording of a 'timeline' to record major life events.

3.5.1 Pilot study design and response

A part of the purpose of the pilot study was to enable me to practice my interview techniques, and following the interview, I judged my interview style to be enabling. I found the use of a genogram to accompany the first question effective as a way of initially establishing a rapport with the participant. I also found the prompts to questions that I had devised as a useful means to further an interesting conversation. I did not attempt to use a 'timeline' to record major events as I judged that it would be too intrusive and could have interrupted that flow of conversation from that participant.

3:6 Methodological perspective

Qualitative methodologies have developed within social constructionist and phenomenological traditions. Social Constructionism highlights the fact that human experience is mediated within a historical, cultural and linguistic environment (Willig 2008). Meanings are not fixed, but continually created and renewed, and dependent on context (Forbat & Service, 2005). Groups construct a reality to make sense of their world (Fox *et al,* 2007). Fox *et al* comment that research in this area focuses on the way in which language is used to construct a discourse or a shared meaning between people.

In contrast, phenomenological approaches seek to study the experiences of individuals. These approaches advocate the study of direct experience that is taken at face value (Cohen *et al*, 2007). There is an interest in the world as experienced by humans with particular contexts at

particular times (Willig 2008). Each individual holds a unique story and reality is what that person experiences. This should be researched in a celebration of what is unique about that individual (Fox *et al*, 2007).

In the table below Fox *et al* (2007) contrast key features of a socially constructed and the individually constructed world.

The socially constructed world	The individually constructed world
• The research process is usually inductive	• The research process is usually conductive
• The focus is on what can be made meaningful	• The focus is on how people make sense of their experience
• The research process is flexible in terms of the number of participants, or length of the interviews or observations	• There is a recognition that other people may make similar sense of their experiences, but that each account is unique
• The research process starts with a social phenomenon that the researcher wants to understand more about	• The research process starts with a personal phenomenon which the researcher wants to understand more about
• Rich qualitative data is collected from a meaningful sample of people	• Rich qualitative data is collected from a limited number of people
• Research illuminates particular situations – generalization is not normally possible	• The researcher recognizes that they co-construct the research
• The researcher recognizes their own position in the research	• The researcher recognizes their own position in the research
• Data is interpreted by the researcher	

	• Data is made sense of by the researcher by reflexivity
	• Findings are constructions that are not more or less 'true', but more informed and sophisticated than previous constructions

Table 3.2: The contrasting features of researching the socially constructed world and the individually constructed world. (Fox *et al,* 2007 pp 14 & 16)

3.6.1 Phenomenological research

In the last twenty years, there has been a considerable growth in phenomenological research, with different types of approach being adopted such as Interpretative Phenomenological Analysis (IPA), Grounded Theory and Ethnography. Smith, Flowers and Larkin (2009) state that the prime reason for choosing IPA over other qualitative approaches is because it is consistent with the epistemological position of the research question i.e. the focus upon people's experience and understanding of a particular phenomena, which in my case was an exploration of the impact of having a child with profound or multiple disabilities upon the home/school relationship. In IPA there is also the assumption that the data engendered will tell us something about people's involvement in and orientation towards the world. IPA is qualitative approach that is committed to the examination of how people make sense of their major life experiences (Smith *et al*, 2009) and the detailed examination of the personal lived experience (Smith 2011).   This present study adopts IPA as its methodological approach.

3.6.2 Interpretative Phenomenological Analysis

IPA researchers are especially interested in what happens when everyday life takes on a particular significance. Larkin (2007) describes IPA as a qualitative method of data analysis, with a phenomenological emphasis on experience which recognizes that during the gathering of data, meaning will be constructed jointly by the participant and the researcher and is a method which acknowledges the interpretative role of the researcher during data analysis.   Larkin, Watts and Clifton (2006) state that IPA requires us to hold two aims in mind; the first is to try and understand

the world of the participant and to describe 'what it is like' leading to a specific focus on an event, process or relationship. The second aim is to develop an interpretative analysis which enables the researcher to think about 'what it means' for the participants to have made these claims and to have expressed these feelings and concerns 'in this particular situation'

3:7 Epistemological perspective

Willig (2008, 2012) states that that IPA can be said to be compatible with the realist approach of knowledge production and from a realist position, data gathered from participants should provide information about the world and how things really are. IPA starts from the assumption that the accounts that participants give tell us something about their private thoughts and feelings and that these in turn are concerned with their experience. IPA aims to produce knowledge of what and how the participants think about the phenomena being investigated. A realist view is one that is committed to an understanding that there are underlying structures in the natural and social world that can be described, and that it is in the nature of human beings to reflect upon and to give an account of these actions and that a properly scientific approach to the study of these actions and experiences should engage with rather than try to screen out these reflections (Bannister, Burman, Parker & Polak, 1994). However, a realist approach can also be defined as a 'single reality', a 'cause and effect relationship', an 'absolute truth' (Robson 2002). Fade (2004) argues for IPA as being rooted in Critical Realism (Bhaskhar, 1978); what is true for those people in that context at that time in their lives. She defines Critical Realism as accepting that:

'Critical Realism accepts that there are stable and enduring features of reality that exist independently of human conceptualisation. Differences in the meanings individuals attach to experiences are considered possible because they experience different parts of reality'
Fade 2004 (p 647)

What kind of assumptions does IPA make about the world?

Willlig (2008) poses three epistemological questions about the kind of knowledge IPA produces and the assumptions that IPA makes about the world that is studied, and the role of the

researcher. These help us to position IPA epistemologically and ontologically. These are presented in the table below:

1.	What kind of knowledge does IPA aim to produce?
2.	What kind of assumptions does IPA make about the world
3.	How does IPA conceptualize the role of the researcher?

Table 3.3: Three epistemological questions about the kind of knowledge IPA produces, assumptions that IPA makes about the world, and the role of the researcher. (Willig 2008, pp 69 - 70)

What kind of knowledge does IPA aim to produce?

Willig (2008) suggests that although IPA aims to gain an understanding of how the participants view and experience their world, there is an acknowledgement that it is impossible to gain a direct and unmediated access into someone else's personal world. The objective is to obtain an insight into their world in relation to the phenomenon being investigated and the researcher is urged to engage with participant's accounts. IPA aims to produce knowledge of what and how people think about the phenomenon being investigated. The type of knowledge that is sought tries to capture and reflect as truthfully as possible something that is happening in the real world. The researcher is interested in the content and how it can shed light on the phenomenon of interest. Willig (2008) however does caution that a researcher's understanding of participant's thoughts is necessarily influenced by their own way of thinking and assumptions. The understanding requires interpretation. Both Smith (1996) and Larkin (2007) recognize that meaning is first constructed jointly by the participant and researcher during data collection, and acknowledge the subsequent interpretative role of the researcher during the analysis.

What kinds of assumptions does IPA make about the world?

Willig (2008) suggests that IPA is concerned with the way the way that people perceive the world and their subjective experience rather that the objective nature of this world. It assumes that

people can experience the same objective 'conditions', but in very different ways, and that meaning is given to events in their   lives that can shape and influence how their lives are experienced.

IPA does not ask if the claims are true or false, or whether perceptions correspond to an external reality, but how the life event is experienced. The importance of the personal lived experience of individuals and how they make sense of it being a requirement in understanding and giving voice to the concerns of participants (Smith 2011).   Participants are the expert, and are recruited because of their experience in the phenomenon (Reid, Flowers & Larkin, 2005).

How does IPA conceptualize the role of the researcher in the research process?

Willig (2008) states that IPA acknowledges that any insights or understandings gained are that product of interpretation and as such can only be gained through the researcher's engagement with and interpretation of the participants account, meaning that the researcher is implicated in the analysis. This means that the analysis is both phenomenological i.e. aiming to represent the participants point of view, and interpretive i.e. dependent on the researcher's own conception and standpoints. In the former position the 'phenomenological' understanding comes about through the researcher being the 'insider', hearing people's stories, their concerns, and prioritizing the participant's world view as central to the core of the account e.g. 'How has this phenomenon been understood by the participant?' In the latter position the 'interpretative' understanding comes about through the researcher being the 'outsider', attempting to make sense of the participant's concerns and experiences and shedding light on them e.g. 'What does this mean for this person in this context? (Reid *et al,* 2005, Larkin *et al*, 2006).

3:8 Philosophical Underpinnings of IPA

IPA has its theoretical roots in phenomenology, hermeneutics, and ideography (Smith 2011).

3.8.1. Phenomenology

Phenomenology is the philosophical approach to the study of experience (Smith, 2009). Husserl is founder of the phenomological approach (Larkin *et al*, 2006). He was particularly interested in finding a means by which a person might accurately come to know their own experience of a given phenomena, an event or situation that can be seen to happen or exist, Husserl separated that which is experienced (the what) and the manner in which it is experienced (the how) (Larkin, Prezi presentation 2013). In order to achieve the phenomenological attitude, Smith *at al* (2009) describe how Husserl developed a 'phenomenological method' intending to identify the core structures and features of the human experience described as 'bracketing' which entailed the putting aside of the taken for granted world in order to concentrate on perceptions of the world. They describe how his work has helped IPA researchers to focus on the process of reflection, and the attentive and systematic examination of the lived experience. Husserl was concerned to find the essence of experience, IPA attempts to reveal the particular experience. Heidegger developed a hermeneutic phenomenology. He argued that the person is always and indelibly person-in-context and that relatedness is a fundamental part of our constitution. It is not possible to step outside because we can only be properly understood as a function of our various involvement with that world, and the meaningful world is also a fundamental part of us. Heidegger defines this as 'Daesin' 'there being' (Larkin *et al*, 2006). This introduces the idea of intersubjectivity; the shared, overlapping and rational nature of our engagement in the world (Smith *et al* 2009).

3.8.2. Hermeneutics

Hermeneutics is the theory of interpretations, an analysis of the experience of someone else, rather than one's own. This analysis requires a process of engagement and of interpretation by the researcher. It is this process that gives IPA a hermeneutic perspective. It derives from the philosophy of Heidegger who has previously been discussed. He proposed the idea of the hermeneutic circle, seen as a dynamic relationship between the part and the whole i.e. to gain understanding of any given part, you have look to the whole, to understand the whole you have

to look to the parts (Smith *et al*, 2009). This has already been described as trying to gain the 'insiders' perspective. The researcher is required to make sense of the personal world of the participant, while the participant is trying to make sense of what is happening to them. This two stage interpretation can be described as 'double hermeneutics' (Larkin *et al*, 2006; Smith *et al*, 2007). The hermeneutic circle has been described as a way to think about method in IPA, an iterative process, moving backwards and forwards via a range of different thoughts, rather than a linear approach where each step follows on from each other (Smith *et al*, 2009).

3.8.3 Idiography

Idiography has been described as a major influence on IPA. IPA is idiographic because it prioritizes a focus on the particular rather than the general. It is committed to analysing each case in detail, an analytic treatment followed up by the search for patterns across the cases (Larkin *et al*, 2006). The best IPA studies will be concerned with a balance of convergence and divergence within the sample which not only presents shared themes, but also showing how the themes play out for the individual participants. Because of this intensive scrutiny of each case, IPA studies are usually conducted on relatively small samples (Smith 2011).

Fade (2004) describes from Smith *et al* (1999) a second way of using IPA; the theory building approach. The theory building approach is useful for evolving explanations in the form of models or narratives. These explanations from data are not seen as 'cause and effect' relationships, but evolving explanations from data, unifying themes, or one over-arching theme once the case by case analysis is done. Asking questions about the themes can help illuminate an overarching theme.

My choice of IPA, a phenomenological approach, with its interpretative and idiographic understanding of individual with the researcher being the 'insider', hearing people's stories and their concerns (Larkin *et al*, 2006) is pertinent to my research. I want to be able to give voice to

the participants involved about how they and their family's lives are impacted by having a child with a profound and multiple disability and how school can be developed to be supportive. As with Fade (2004) in taking IPA a step further, I would hope to connect the overarching pattern to Rolland's model (1994).

This has led me to reject a social constructionist approach, although acknowledging that it could be an alternative means of conceptualizing the participant's experiences.

3.9 Sampling and Participants

My interest in the area of research has arisen out of a three year project commissioned by the Head Teacher of a Primary Special School for children with profound or multiple disabilities. The Head Teacher was initially interested in developing skills in staff so that they would be able to identify pupils who needed support with mental health issues and promote positive mental health. As the project proceeded into the second and third year its scope broadened to consider how to develop staff resiliency when dealing with difficult situations with pupils and parents, and subsequently to consider ways of supporting parents with their own mental health issues. As I was now working on the project on my own, and having had difficulties engaging parents in a previous whole school initiative, I decided with the permission of the Head Teacher to consider another means to engage more effectively with a smaller number of parents. The outcome of which would never the less lead to a lasting impact in developing the quality of parent/school relationships in terms of more effective and targeted support for parents when it was most helpful to do so. Having worked with a number of parents at the school through the statutory assessment process, I was aware of the pressures that some families encountered. In my research I wanted to explore the impact on the home/school relationship of having a disabled child in the family and how families felt that the school could support them more effectively.

In IPA, participants are selected on the basis that they can offer a meaningful perspective on the phenomena of interest i.e. the selection is purposive and will typically contain 3 – 6 participants (Larkin Prezi presentation, 2013, Smith, 2011). The participants represent a certain perspective rather than a population. IPA also challenges the traditional linear relationship between the number of participants engaged and the value of such research as it wishes to maintain its idiographic focus (Smith *et al*, 2009). The group of participants also needs to be a fairly homogeneous, for whom the research is meaningful, and who will be chosen to participate because they can offer insights from a position of sharing an experience (Larkin Prezi presentation, 2013). Clearly individual differences mean that one needs to be pragmatic about the practicalities of sampling (Smith *et al*, 2009).

 I invited Parents to participate in the research who had already showed some interest in the ongoing project at the school and who had participated in a whole school questionnaire. 12 parents out of a school population of 54 had replied. I invited the 12 parents to participate in the research, sending them a letter of invitation, an information sheet and an informed consent from (see appendix 3: page152, appendix 4: page 153, and appendix 5: page 155).   I received 7 replies. One parent who responded removed her child from school shortly afterwards and another parent I was unable to contact despite numerous attempts which meant that I was left with 5 participants. This ensured that sampling remained purposive between the 3-6 participants recommended. IPA requires a sample as homogeneous as possible so that for the defined group that will be participants the research question will have some meaning. All the participants who responded were mothers with an age range of children from 4 – 9 years. All of the mothers had children whose disabilities required PMLD provision. One mother came from a minority ethnic background, one mother was a single parent and one mother had two children attending the school. Given the shared experience of parenting a profoundly disabled child, having engaged with similar professionals and that their children all attended the school in question, the homogeneity of this sample I felt, broadly fulfilled the criteria required.

Participant	Name (Pseudonym)	Child/children (Pseudonym)
1.	Nicky	Two children. A son Sam and a daughter Clare. Sam is disabled following birth complications.
2.	Barbara	Two children. A son, Colin and a daughter Caitlin. Both disabled.
3.	Jo	One daughter called Charley.
4.	Sue	Two children. Her younger son is disabled.
5.	Maryam	Two children. Eldest son Nadeem has sickle cell disease. Youngest son Osman is disabled.

Table 3 4. Participant details

3.10 Data collection

Semi structured interviews tend to be the preferred means for inviting a response that will engender a rich, detailed account and produce 'rich data'. The questions should be open, not closed or leading and should not make too many assumptions about the participant's life experience (Smith *et al*, 2009). This appeared to be a valid way of seeking the views of the mothers and enabling them to give voice to their own personal experiences and issues that were important and meaningful to them. As has already been discussed regarding the pilot study, the schedule was based on themes utilized from an intake questionnaire devised by Begum (2007) (see appendix 3, page 156), that covered a history of care, effect on the carer and wider family developing into questions regarding relationships with professionals. The questions, of which there were 10 were grouped under these headings (see appendix 7, page 159). The interviews took place in the participant's homes, as chosen by them. The location of the interview is important in terms of setting the participants at ease and enabling them to feel comfortable in talking before substantive areas of the schedule are introduced (Smith & Osbourne, 2007). I especially wanted to engender a positive rapport, knowing that some of the areas that I wanted to explore might be emotional and sensitive.

3.11 Analysis

Each interview was taped and then transcribed.

3.11.1 Data analysis

I drew upon the procedures for IPA as described by Smith *et al* (2009), Willig (2008) and Larkin (2007, Prezi presentation 2013).

Step 1: Reading and re-reading

I read through the transcript a number of times and also listened again to the recording. As recommended I read and noted that most powerful recollections of the interview experience to set them aside (described as bracketing) to help reduce the level of 'noise' and emotion (Smith *et al* 2009). I found this important to do as I had been drawn into the emotion of the responses of some of the participants, especially one mother who was tearful during part of the interview when expressing her loss of dreams and life expectation.

Step 2**:** Initial noting (see appendix 9)

In the right hand margin, using 3 different colours to represent descriptive comments (describing what the participants said), linguistic comments (noting the language used) and conceptual comments, I noted things that were interesting or significant to the participants. I also noted things that mattered to the participants in a reflective diary.

Step 3: Developing emergent themes (see appendix 9)

In the left hand margin, I noted emerging themes that reduced that volume of the data, but still captured the complexity. This process has been described as an example of the hermeneutic cycle where the original whole of the interview has become a set of parts through analysis, and

will come together as a new whole at the end of the process when it is written up (Smith *et al,* 2009).

Step 4: Searching for connections across emerging themes (see appendix 10)

The next step involved an attempt to introduce structure into the analysis by listing themes and thinking how they related to each other, forming natural clusters that shared meanings or references, leading to the identification of themes and subthemes (Willig 2008). The clustered themes were then checked again with the transcript to ensure that the themes linked back to the participant's accounts, reflecting the iterative nature of the process. Quotes illustrating the connecting themes were identified.

Step 5: Moving to the next case (see appendix 12)

Moving to the next participant's account I repeated the process, setting aside (bracketing) any ideas that might have emerged from the proceeding case.

Step 6: Looking for patterns across cases

Finally, I looked for connections between and across the interviews, identifying individual and shared meanings to identify superordinate themes that encapsulated the experiences of the participants.

3.11.2 The Family System's Illness Model

The Family Illness Systems model (Rolland 1994) can be used to help understand the context and stage in which a family might be operating. Rolland suggests a model of the life cycle as a developmental framework. He suggests that there will be times of higher (centripetal) and lower (centrifugal) cohesion. Rolland feel that if the illness or disability is severe, then a family can

become stuck in an overly cohesive cycle with all their energies focusing inwards. As suggested by Fade (2004) in taking IPA a step further, I also wanted to explore if any overarching themes developed from considering whether the concept of a family being 'stuck' in a centripetal phase or a more fluid lower cohesive phrase might impact upon the home/school relationship and allow the school a greater awareness and understanding of the stress that a family might be undergoing and help them to develop earlier interventions of support. The Family Illness Systems model could also be informative to professionals, including Educational Psychologists to develop more nuanced family support.

3.12 Critical review of approach

In considering the limitations of IPA, Willig's (2008) view is concerned with experiences and meaning, looking at phenomena from the viewpoint of those who experience them. She posits that like all forms of phenomenological forms of research it is weakened by several conceptual and practical limitations. These concerns include:

- The role of language: language is the means by which participants communicate their experiences to the researcher. Phenomenological research gives value to the experience itself assuming that language provides the necessary tools to do this i.e. the representational validity of language. Willig (2008) argues that language can be seen to construct rather that describing reality. Because the same event can be described in many different ways, language can never be described as giving expression to experience, but adds to it, therefore making it impossible to directly access someone's experience. To this she adds an alternative view that language can proceed and therefore shape an experience, prescribing what we think and feel

- Suitability of accounts: the aim of IPA is to explore the lived experience and to understand what it is like to live in a particular moment attempting to capture meanings and experiences rather than identify people's opinions about it. Willig (2008) asks to what

extent do accounts provide suitable material and how successful are participants in communicating their experiences

- Explanation versus description: IPA focuses upon perceptions, gaining a better understanding of how the world appears to the participant i.e. their own perspective. It does not make claims about the world itself. Willig (2008) feels that this does not further our understanding of why such experiences take place or why there may be differences between participants. Phenomenological research may describe and document, but does not try to explain.

Larkin (2007) would argue that IPA's key distinctiveness is its recognition of experience, and its key strength is its openness to many interpretative approaches beyond that of the initial focus. Eatough and Smith (2006) state that IPA gives a central place to experience, while giving recognition to the many influences on it. Larkin (2007) acknowledges that in some of the existing published work there is a valid criticism of IPA in that the procedure itself can be seen to be flexible and fairly non-prescriptive, so that researchers fall short of the analytical target. There can also be a problem with work that is not interpreted and contextualized enough, in that the explicit content of the participants account is merely categorized or a described. This issue is acknowledged by Smith (2011) in his evaluation of the contribution of IPA.

In my opinion, IPA would appear to be a valid approach for my research. Larkin (2007) specifically suggests using IPA to understand family relationships and processes. He suggests that the challenges of this might be in knowing who to speak to and how to balance the diversity of perspectives that emerge. But that there is value in giving opportunities to marginal voices and accessing and understanding history and context. I would hope that this view has encapsulated my research ideals.

3.13 Reliability and Validity

Reliability and validity can rest on the assumption that it is possible to replicate good research, but a qualitative researcher can never claim that their work is replicable. The aim in qualitative research being not so much replicability as specificity (Bannister *et al*, 1994). There is also a strong argument that qualitative research should be evaluated in relation to criteria that is recognized as appropriate to it (Smith *et al*, 2009).

For issues of reliability and validity when using IPA, Smith *et a*l (2009) suggest four broad principles for assessing the quality of qualitative research as defined by Yardley (2000). These she defines in the table below.

Sensitivity to context	• close engagement with the idiographic and the particular • an immersive and disciplined attention to the unfolding account
Sensitivity to data	• verbatim extracts from participants to support the argument made • giving participants a voice • carefully written accounts
Commitment and rigor	• attentiveness to the participant when data is collected • the thoroughness of the study • analysis conducted thoroughly and systematically with sufficient idiographic engagements • the analysis must be conducted thoroughly
Transparency and coherence	• the degree of fit between research and done and the underlying theoretical assumption of the approach being implemented

Table 4. 5: Four broad principles for assessing the quality of qualitative research. (Yardley, 2000 in Flowers, Smith & Larkin 2009 pp 180-182)

Smith *et al* (2009) recommend facilitating an independent audit so that the trail of evidence can be followed. This is so that another person could follow the chain of evidence from initial documentation to the final report. Creswell (2009) also suggests a peer debriefer to enhance the accuracy of the account by asking ongoing questions so that the account will resonate with someone other than the researcher. This has been my Supervisor at work, who during regular supervision has asked me about my research.

The research will also have catalectic validity. For Cohen *et a*l (2007) this means ensuring that the research leads to action. As a result of this research, I would hope for the mothers who took part that a recognition of their individual skills and strengths and coping strategies will emerge from the opportunity to give voice to their individual stories and result in an improved experience of the world and a developing resiliency. One participant, who was looking to set up a support group for parents the disabled children from across the borough, is now running a flourishing weekly group. I would hope that the school will have a greater understanding of times of stress for a family and so tailor their support more effectively in the future.

3.14 Reflexivity

Reflexivity is described as the most distinctive feature of qualitative research. It is about acknowledging who you are, your interests, values and individuality, how this influences you as a researcher, but also with a critical examination. A failure to be critically aware and to know oneself can undermine the validity of the research (Bannister *et al*, 1994).

As an Educational Psychologist, experienced in working with children and parents, I have been involved in a number of parenting courses delivered to parents in individual schools and Children's Centres, both published and devised by the Educational Psychology Service. I also have day to day contact with parents in the schools that I work with through individual feedback on the work carried out with their child, individual parental requests and being involved in process such as

statutory assessment or Early Help reviews. This has provided useful skilling, for example developing active listening, and knowledge which I have utilized whilst carrying out this research.

I have also worked as a Respite and Shared Care Foster Carer for the last 12 years for Barnardo's caring for a number of severely disabled children. It is this interest in particular and being an Educational Psychologist in a PMLD school (as has previously been discussed and being involved in a three year project at the school) that has led to my research. I am aware that although I have some understanding of what it is like to care for a disabled child, I have no long term understanding of the impact this might have on my day to day life, and have been mindful as I have carried out the research to put aside any thoughts I might have had, and also to approach the interviews in the role of researcher. This was made easier by the fact that I only knew one of the parents who participated through statutory work, and that had been carried out a number of years previously.

3.15 Ethical Issues

Informed consent: A clear and explicit outline of the research was given to the participants at the outset to ensure that they were aware of the purpose of the research, who the results would be shared with, and their right to withdraw (appendix 5, page 155). This was presented in a written form as I previously had checked with the school about any literacy difficulties or English as a second language concerns. Before consent was obtained, I telephoned each participant to make sure that they understood why the research was taking place and what the likely outcome of the research might be.

Withdrawal. Participants were informed of the right to withdraw both initially and once they had agreed to participate in the in the research. This was explained verbally during the initial telephone consultation, and they were also asked to sign a consent form. This also gave the participants an opportunity for a friend or family member to check the form before signing.

Anonymity and confidentiality: Participants were told that they and the school would remain anonymous, and that name changes would be made to ensure that at all stages no information would be contained with the research that enabled them or anyone they referred to, to be identified. Participants were reminded at the beginning of each interview that the process was confidential unless they shared something that might indicate that they, or those around them were at risk of harm.

Risk: The main ethical considerations of the research could have arisen from talking to potentially vulnerable participants about their experiences of raising a disabled child, and the impact this may have had on the family. This could have had the potential to re-ignite feelings of grief or loss. If a participant should become distressed, I planned to follow up the conversation with a phone call to monitor their response and signpost them to a relevant agency that might be able to provide further support. There was a named Clinical Psychologist at the school, to whom I could have referred the participants if necessary. In one of my interviews one of the mothers did become tearful, but she did not want the interview to be stopped, or wanted further support via school or any other agency.

CHAPTER FOUR:

RESULTS

Parent Interviews and analysis

4.1. Introduction

In writing up IPA studies, Smith *et a*l (2009) suggest that results are presented in narrative account so that the reader can attempt to make sense of the lived experience of the participants, so participating in the hermeneutic dialogue. I have followed the approach recommended. In the Methodology chapter, I have described steps 1-5, considering each individual case. I will now present a rationale for step 6, which is looking for connections between and across interviews, and identifying individual and shared meanings. Following the approach as described in section 3.11, each interview was analysed using IPA. The interviews were analysed case by case. The aims of the analysis were to carry out a phenomenological exploration of the impact of having a disabled child upon the family and how this affects family functioning, coping strategies of the parent, and how this experience feeds into expectations and experiences with the school.

4.2 Looking for connections between and across interviews

Table 1 summarises the superordinate themes for each participant. Also included in italics are the subordinate themes that emerged for each participant.

Table 1: Summary of superordinate themes for each participant

Code: **Bold Heading = Superordinate theme**   *italics = subordinate theme*

Nicky	**Life's journey unfolds**	**Family dynamic impacted disability**	**Interactions with professional services**
	Initial grief, previous life seen as naïve, can only contain her own fears and emotions, fears about how the future will unfold, exclusion from her own peer group, gradual gathering to herself	*Male/female stereotyping, maternal parental relationship intensifies, maternal father's role enhanced, husband/wife drift, forced to prioritise her children, feeling she is being fair?, child's limitations limit family spontaneity, child impact on family functioning*	*Misfit of expert/parental dialogue, being survived as weak, confrontation is expected, personalised support is effective*
			School as an encompassing community
			Transition process into school throws up anxieties, school engages with her emotional need, school as a resource, school facilitates contact with peer group
Barbara	**Making sense of life changing events**	**How families change**	**Parental solidarity through shared experience**
	A dramatic change, loss of expected future, as alternative lifestyle	*Loss of expected child development, the changing substance of being a parent, limitations of family support, paternal role enhanced*	*Companionship for the journey*
			Relationships facilitated by school
			A conduit to other professionals, as a generic 'parent', as a mother of her children
			Hopes for the future
			New horizons, mutual support, development of personal equalities
Jo	**Requires total emotional commitment**	**Family relationships change**	**Indifference of a wider world**
	Developing resiliency, fear for the future	*The family defined, close family ties, impact of child's behaviour, disability causes wider divisions*	*Professional attitudes, who are they to comment?*
			School is pivotal
			Acceptance without stigma, school contains her anxiety, school validates her role as parent, school as a resource to be used
			The precious child
			Grief for what might have been, child valued for her own sake/who she is, child's humanity denied

	Life changing events and consequences	Family pulls together	Intrusion of professionals into family life	School is holder to supportive relationships
Sue	Pre-birth trauma and affect, initial child rearing gives no clue, having to bear bad news, ongoing material impact, trying to maintain daily control, role of mother amplified, developing new characteristics, seeking to make a difference	Child's needs have priority, affect on older sibling, sympathetic wider family network, husband and wife find a way through,	Disconnect between parent/specialist expectations, paid carers	Initial impressions set the tone, child feels safe, lack of reciprocity can lead to alienation, holding specialist knowledge, seeking to understand child, feeling in a position of weakness

	Impact on her core identity	How a family functions	Professionalism as a resource	School as a provider of specific support	Fear of unorganised time
Maryam	Impact of diagnosis, consequences of life changing events, responsibility is all hers, future hopes dashed, seeking a way out	Desire to be a mother, feeling deskilled, intergenerational affect, mother/daughter bond, equality of need and attention, diagnosis defines the child, an uncertain future, impact of disability on the marital relationship	Professionals as partners	Provides personal support, provides links to other services, facilitates share parental experience	Out of school support is pivotal

To achieve this analysis, I cut up the emerging themes for each participant individually and then grouped them into subordinate themes. From these subordinate themes, overarching superordinate themes emerged (see appendix 9: page 161, appendix 10: page 165 and appendix 11: page 175) which shows the whole process for Barbara). Between four to five superordinate themes emerged from the analysis for each participant (see appendix 12: page 178 and appendix 13: page 181). The final themes were considered if they were found to be present in three out of the five interviews. The superordinate themes were then compared to each other to reduce the data. There were no superordinate themes that were not represented in each individual interview. To structure the exploration and examination of each superordinate themes, subordinate themes were added.

Superordinate theme	Subordinate theme
Theme 1: Making sense of life changing events	Feelings of loss Future hopes reframed Personal effect Glimmers of hope
Theme 2: Impact on family dynamics	Adaptation of immediate family circumstances Changing role of parents and its impact Unsettling of wider family relationships
Theme 3: Impact of a child needing a special school	Transitioning into school Relationships at an emotional level Relationships at a professional level Facilitating a new peer group

Table 5. 2 describes the final superordinate themes.

Each superordinate theme has subordinate themes that reflect the primary concerns of each participant. Table 3 shows the frequency of the superordinate themes for each participant and which subordinate theme was common across the participants.

Table 3 Identifying recurrent themes

Superordinate themes (and subordinate themes in italics to aid structure)

Superordinate themes	Nicky	Barbara	Jo	Sue	Maryam	Present in over half of sample?
Making sense of life changing events						YES
Feelings of loss	Yes	Yes	Yes	Yes	Yes	
Future hope reframed	Yes	Yes	Yes	Yes	Yes	
Personal affect	Yes	Yes	Yes	Yes	Yes	
Glimmers of hope	Yes	Yes	Yes	No	No	
Impact on family dynamics						YES
Adaptation of immediate family circumstances	Yes	Yes	Yes	Yes	Yes	
Changing role of being a parent and it impact	Yes	Yes	Yes	Yes	Yes	
Unsettling of wider family relationships	No	Yes	Yes	Yes	No	
Impact of a child needing a special school						YES
Transitioning into school	Yes	Yes	Yes	Yes	No	
Relationships at an emotional level	Yes	Yes	Yes	Yes	Yes	
Relationships at a professional level	Yes	Yes	Yes	No	No	
Facilitating a new peer group	Yes	Yes	No	No	Yes	

I chose the order of the superordinate themes to be presented by starting at the level of the personal experience of the participants, the impact on family dynamics and then how the participants engaged with the school; relationships at a personal and professional level. My initial questions, which were the basis for the initial conversations with the participants, had been based around utilizing themes from Begum (2007) (appendix 3, page 156) that have been discussed in the previous chapter. These included opportunities for descriptions of care, coping with the recognition of disability, coping with blame, but also the acknowledgement of self-value and self-growth. The third theme I identified was of relationships with professionals to include questions around support from outside the family and support from school.

The final superordinate themes emerge around these considerations. The first superordinate theme of personal impact on the individual mothers of having a disabled child feeds into the second superordinate theme about how their individual families adapt to an unforeseen and unknown experience. The third superordinate theme about school engagement builds on previous experience of individual and family adaptation, relationships with professionals and expectations as the child enters school.

Each superordinate theme will now be described in more detail and illustrated with quotes from each parent. Parents are not identified to ensure all participants remain anonymous.

4.3. Superordinate theme 1: Making sense of life changing events

This theme describes the impact upon the mother after the birth of a disabled child, or diagnosis, the dawning realisation life will never quite be the same again, and glimmers of hope as life is adapted to.

4.3.1. Feelings of loss

For all of the mothers, there is a sense of the impact upon their core being and an adjustment from what they were originally anticipating from the birth of their children. For both Nicky and Sue, trauma started during their pregnancies as they were both expecting twins, but the outcome was that one of the babies did not survive; the surviving baby being disabled. For Barbara and Maryam, the awareness of something being wrong, and then a diagnosis to confirm those concerns is equally devastating. Jo had no concept that that her baby was going to be born with Downs Syndrome, and she struggles to come to terms with this.

Barbara describes how she and her husband having had two disabled children try to make sense of their lives, and re-define what it means to them to be parents*.*

Barbara: *we went through a very, very dark period when we sort of thought, you know they're going to end up in a care home and we're not going to have any grand kids and what's the future for them. We, we were very confused as to our role. Were we parents? Were we carers? Could we have that relationship with our kids that other people have. We were very jealous of other, other families. (4.147-155)*

She describes the process that they have had to go through as a bereavement, with the attending feeling of what might have been.

Barbara: *We also you know have a lot of dreams, and life we saw ourselves having has gone, and it's a bereavement, you know, it is a bereavement. (16.501-503)*

Jo equally describes the overwhelming feeling of loss. There is a sense of the emotional impact. She also finds it difficult to contemplate the future.

Jo: *at first I did nothing but cry. I just couldn't stop myself crying. I was post-natal as well so that did not help. But the whole idea of having a disabled child is massive – too big to bear. (12.337-341)*

For Maryam, her older son already having Sickle Cell disease, receiving the news about her second son is almost too much to bear. As with the accounts of Barbara and Jo, I got an eloquent sense of the loss that she has suffered.

Maryam: I don't want to be in that place any more. I think I wasn't feeling, things got too much then. I lost all sense of feeling. I just didn't know how to handle it because, um, his brother had already been diagnosed with Sickle Cell disease.   He has the severe form of Sickle Cell disease and he was, um, he was in hospital, he was admitted all the time.   All of a sudden, you know, I thought ok, I can deal with that, at least Osman is still strong, everything is ok, and that bomb shell just (pause), I was speechless about it now (emphasized), but at that time I was just ,um, I didn't have, I, I, I didn't have any feeling at all, because I did not know how to handle it, or deal with it, it was like, um, I just, I don't know how I tried. It, it, wasn't something that I think any mother expects (3:88-103)

Describing the news as a bombshell, feels like a fitting metaphor describing the fact that for Maryam her life will never be the same again and describing the emotional impact upon herself. This description of how she feels could be applied to all the mothers. For both Nicky and Sue, the fact that one child survives and one has not, there are contrasting emotions to contend with. Sue describes it as having to come to terms with both a funeral and a christening.   For all of the mothers there are strong emotions conveyed, that are difficult to come to terms with as for most people experiencing a bereavement, time can be a healer, but for these mothers theirs is a constant daily reminder of their loss.

Reminders of the loss also continue with the growth and development of their children. Jo uses a very descriptive image that perhaps sums up the experiences that all the mother's encounter.

Jo: *But it wasn't until I was really at that age and my friend had had a two year old, mainstream, and he was just taking off in every way; toilet training, and speaking. Then I felt, my heart would*

sink. You get a sinking of the heart, but, um, you just have to pick yourself up to get on with it (5.130-136)

Jo describes the shock that she receives as she realises the developmental difference between her daughter and her friend's son. She describes it as a physical movement within her. It has a huge impact on her and it is interesting to reflect that this realisation for Jo is the beginning of her retreating into a 'safer' world of Special Educational Needs. For Nicky, meeting other disabled children like her own is something she finds overwhelming, as she does not have the emotional resources to deal with it.

Nicky: *For toddler groups and things we obviously went to the Deaf group. And there was a feeding group we went to, and a physical needs group. It was good, but it wasn't the right time for me. I got on with some of the parents, but I needed to keep a distance because I'd got these sort of, sort of blinkers on. I can't care about your child because it will upset me. I don't want to get to know you and worry about your hospital appointments and your physical difficulties and your illness and your ambulances because I've got enough of my own and I don't want to get close and care about that little lad or that little girl (16: 514-525)*

4.3.2. Future hopes reframed

For all of the mothers, there is a growing realisation of how the consequences of disability will effects each of their children in the long term.

For Nicky, Barbara and Sue, I got the feeling that the profound question about the future threw up more questions than answers. Answers could not be known, especially as they looked into the far future when they would no longer be able to care for their children.

Nicky: Um, but it was sort of (pause) even though you think you knew, so you were, sort of, quite prepared, there was still, sort of, I know it's real, what does it mean? Um, and it wasn't sort of will he wear hearing aids? And will he, you know, to me, it was, can he drive a car? Can he still get married? Has he got to marry somebody who's disabled? Who's going to want him? What happens when I die? And I think, who's going to look after him? (4.107-117)

Barbara: and you know you have visions of what your children was going to be like, and the dreams you that you have for the kids, you know walking them down the aisle and what job will they get. All of that sort of disappears literally overnight. And you know, as I've said, it's not having anything to replace it with, um; it's not knowing what's coming. Um, we went through a very, very dark period when we sort of thought, you know they're going to end up in a care home and we're not going to have any grand kids and what's the future for them (5.140-151)

Sue: My biggest fear is what would happen to Joshua if I die. You think, 'god, you know is there things in place for that?'' We're struggling when we're here. And you, nobody will look after him how we do. So I think, 'god, what will happen then'. It's not the natural order of things is it? Normally your children will leave the nest. Well, that will never happen to us (8.244-251)

The care of their children is lifelong and there are no easy answers as to who will have the long term responsibility of looking after them. There is also the sadness of not seeing their children go through the normal rites of passage. Sue's account particularly feels as if she is raging against the unnatural order of things that has been unwillingly thrust upon her. For Jo, her biggest fear, as a lone carer, is that as her child grows older, she will end up in care and this may be a nearer that she would like to anticipate.

Jo: my biggest fear is that I won't be able to handle her as she gets bigger and stronger and I don't want her to end up in care. There's been lots of instances where I've heard about parents, you know they do unfortunately end up in care because they can't cope. (18.520-527)

Her position of living with elderly parents, with no home of her own, leaves her vulnerable if her daughter's behaviour becomes unmanageable. There is a real sense of her uncertainty.

Jo: Because at the minute I feel like a very small fish in a big pond, and I don't … the future seems uncertain even because I need to sort her behaviour out (19.537-540)

Maryam also finds the future difficult to reconcile with her present situation.

Maryam: But you know that you will learn more, not just for you, but for your family and for your children, but how are you going to get more for them if this is the life, you know. So I try not to think about it. Just take a day at a time. That's the way it is for me. So it's giving me a whole perspective to life and what life should be. Is it about happiness? Is it about family? Is it about money? Is it about dreams? And honestly now I would settle for just normal happiness. I would settle for that and that is what I want for every day. I want to risk it, to try to put my family back together again and put it behind us and just start all over again (10.354-367)

It appears that she has considered that future concerns are not worth considering if she cannot even find happiness in the day to day situation. And so for her the priority is to try to reframe each day as an opportunity to prioritise her family as a whole.

4.3.3. Personal Effect

All the mothers describe personal affect; how they have had to adapt their personal circumstances and how they have developing new characteristics. The exceptions is Maryam, who feels that she has had to make huge personal sacrifices for little gain.

Nicky describes her previous world as idealistic and perhaps naive. She describes how her world changes in an instant, and how her previous life appears to takes on a scene from a Disney cartoon as if there is a sense of unreality about it.

Nicky: I think I've changed a lot, to be honest, um, (pause) and I sort of look back and perhaps envy myself slightly before Sam. Because you think, I did not have a care in the world. Um, you know, the worst thing that ever happened was I had a flat tyre on the car. That's nothing compared now, and I think, you know, I was truly perhaps carefree or ultimately happy, the world, I was perhaps in a totally big bubble where everything was quite nice and flowers and daisies and skipping along and then you just feel like a 'oomph' - car crash, sort of 'wow!'. Life isn't that, um, perhaps I was very sheltered growing up or something. But nobody had ever had a disability in the family, had a hearing loss (7.229-242)

Nicky's whole life has been home based and as a carer. Looking at her life, within the triumvirate of herself and her parents, she now feels valued in that role.

Jo and Sue both worked before having their children. Sue carries on, albeit in a reduced capacity. Jo has been refused flexible working rights that she is now fighting for. She views having had to be assertive about her daughter has developed skills that she would never have otherwise developed.

*Jo: There's things I do now that I, er. I mean I've got a tribunal coming up, through going into work, because of breach of flexible working rights. I did ask for flexible working rights, but they basically chose to let me go instead. So basically I've got a case. So I represent myself. I would **never** have done that. (13.353-359)*

I, I, I, feel that, um, it's highlighted my strengths and character that must have been there all along because otherwise I'd have just crumbled. Um, it's made me a stronger person. It's made me more assertive, um, proactive, I'll speak to anyone now. Um, I'll, um, I'll fight for her, and, and

engage in any way that I need to do for her. And also as a person, I tend to like, look out for my parents etc. and speak to authority figures because it really doesn't bother me (10.276-285)

Sue also has to adapt what she thought was her life trajectory, and personal fulfilment in her job and adjust her priorities.

Sue: *I was a very organised person and one of the things that I found very difficult was that things didn't go how I wanted and expected to go to plan. Um, my job, it was a good career, it was never just a place to go or a thing to do; I enjoyed it, but it's not my priority so much I should hope. Yea, the way you look at life is totally different (8.238-245)*

Sue appears to use her professional skills to sort out situations at work for her new situation and with agencies involved with her son. She uses her developed expertise to join organisations that make a difference in practice for other children who have similar disabilities to her son. She describes her skills as pure determination.

Sue. *Because if something's not right with the system, I'm not one of these that will moan about it, I will…It's like well, I've joined all the different things and that. So he went to Accident and Emergency, and it chaos, right. So I mentioned it on the Autism working group and it was put on the agenda. And we've met with the leader of Accident and Emergency, which I went to, and she's brought in, is going to bring in a flagging system (8.262-272)*

For Barbara the affect for her has been more personal. She identifies qualities that she feels have made her a better person and given her the capacity to enjoy her children for who they are.

Barbara*: in terms of myself, me and the person that I was, I'm perhaps, er, an awful lot more patient, er, a lot more understanding, a lot less judgmental. Um, I'm obviously an awful lot stronger than I thought I was (7.204-207)*

She goes so far as to conclude that if her children had not been disabled, she would have been less of a mother.

Barbara; you know, I've found that I often think that if they didn't have the special needs that they have, I probably wouldn't be the parent that I am now. I would probably have been you know, a little less patient with them, a little bit more nagging with them (7.215-220)

I think that it is worth reflecting on Maryam's differing experience to the other mothers. Maryam feels that her whole life has been transformed negatively from what her initial aspirations were and is dramatically reduced.

Maryam: Because you know, personally that I don't have a life (emphasized). I can't go out, I can't do anything, um, (pause), I have to stop working, um, I have to, (pause) at the moment let go of my dreams and aspirations and just take a day at a time. But then that is the difficult part because (pause), it's like sacrificing yourself and you lose you. (4:130-137)

I have to just forget about it, you know work, everything about me. All I wanted was to teach, you know. So I started um, doing research for my PhD so that I can teach, but then I realized, you know what, it's just impossible because I'm working 24 hours around the clock and then in the middle of the night I would wake up at 2 to make sure he is ok because he always, um, cover himself with the blanket over his head. The worst thing is that I have to wake up at 4 again to make sure he is ok and change his diaper and then 6 in the morning and then just, it was impossible and then. (Pause) Now when I think about it I think like, ok I'm 32 now. Who is going to employ me? (Laughs) And sometimes I feel I'm a total failure (9.327-341)

Maryam may have seen an academic route as a way of achieving independence within her cultural context, and so to be at home with two children, one who particularly needs her care, has pushed into a more traditional role that she was perhaps trying to escape. She had high academic aspirations that were just incompatible with the demands being made on her. This makes her feel she has failed.

4.3.4 Glimmers of hope

Despite their difficult individual experiences four of the mothers appear to be able to see glimmers of hope in their situations. For all of them it has been a Barbara has described, a journey which they are still travelling, but they are able to find hope along the way.

Barbara is able to find satisfaction in the 'Barmouth,' experience, a metaphor for a different life from that which she envisioned, and for which she still grieves, but which she can buy in to.

Barbara: Um, so we've had to make a lot of compromises in our life, but I feel we're sort of coming out of that period now and we've started to think, well, ok, we, we've had to give up on those dreams, but what dreams can we have. You know, um, the next best thing to Thailand is a beach in Barmouth. And we've got that you know. And, and so, I think you start to sort of come out the other end. But you know, that, that, feeling of darkness perhaps doesn't leave you. It just gets less, you know, and those dreams that you have don't sort of leave you, but they just become less (5.160-171)

For Maryam, there is a similar settling for a different outcome to perhaps the one she originally intended for her life. Of all the mothers, there is a feeling of the personal cost. She had high expectations of a successful academic career, which was reduced firstly by the illness of her first son and the disability of her second. She is able to find within all the anguish, some acceptance.

Maryam: so for me I am working towards happiness for the family and then if we have that then it's ok. I can live with that and just settle for that. So I think Osman's situation hasn't been, it's not a blessing, but it's not a curse either because I feel good things have come out of it. It gives you the actual perspective to life and what is most important. Then you also learn the good things about yourself and your strength. So things isn't a bad feeling any more, just it can feel a bit hard, but it's not bad. So I accept that (11.383-393)

Both she and Barbara appear to have given more in-depth consideration to their lives. Nicky, appears to bounce between despair when her thoughts run away with herself, and hope, when a more reasoned view prevails. She finds that by concentrating on smaller day to day issues that she can cope.

Nicky: What's going to happen if anything happens to us and where would you go and who would care for him and it's not fair on his sister to be expected to look after him because that would sort of affect her life, and things like this and you think, no actually, what's happening today or tomorrow. Let's do that first and deal then with those (4.125-131)

Jo is able to look at the situation of a friend and feel that in comparison, she is not doing so badly and put her own situation into perspective.

Jo: Well, I've got a friend who's got a child with Downs Syndrome who's also got other profound difficulties. I see how she copes and then I look at myself and I think 'well, you know, you're lot isn't so bad' (12.342-346)

All of these mothers show some adaptation to a degree in the on-going impact upon their lives of their disabled children.

4.4 Super-ordinate theme 2: Impact on family dynamics

This theme describes the how families have to adapt and change with the birth of a disabled child and how family relationships are impacted for better or worse.

4.4.1. Adaptation of immediate family circumstances

For each of the mothers interviewed, the birth of a disabled child made them by necessity examine their own and immediate family circumstances. For three of the mothers this led to more reliance on their own parents, one mother necessitating a move to a different country to realise this. The other mothers became more reliant on their husbands, with parents and close relations tending to offer more limited support. For one mother, Carers are also employed. It is interesting to reflect that for each family, there is an adaptation in core relationships. The arrival of the disabled child intensifies some relationships, throws up weaknesses in others. Material sacrifices are made that impact on how the family functions. With all families there is an acknowledgement of the support from Grandparents. It would appear that for all of the families of these disabled children, Grandparents are willing as much as they are able to sacrifice time and material loss to support their daughters.

For Nicky and Jo, relationships with, and reliance on their own parents has developed and deepened.

Nicky: *Obviously my parents are very active in our life. (1.18-19)*

Jo: *at the moment, I'm living with my parents, my mum and my dad. They're both in their eighties, early eighties. Um, I also live with my sister as well, who is three years older than me (1.3-6)*

For Nicky there seems to be regular contact; with her parents playing an integral role in her daily life and care for her child. There is talk of helping to bath, change the child; reading books at bed time. For Jo as a young single parent, she carries on living in the family home, with her child becoming part of an inter-generational family. For both Nicky and Jo, the mother daughter relationship in particular is valued. For each of these mothers at a vulnerable point in their lives, they turn back to familiar, valued relationships.

Nicky: I think relating to Sam, um, it's probably my dad. But supportive to me, you know, it's probably my mum (11.354-356)

Jo: …and just generally being there to listen to me, to listen to the good days and the bad days really (14.380-382)

Their mothers provide them with emotional support and validation of women that circumstances have turned them into. Jo describes the emotional toil the experience has caused her mother, and it can be assumed that Nicky's mother has experienced this too.

For the Grandparents there appears to be opportunity, if taken, to enhance the role, and to bring a new insight and purpose into their own lives. Nicky's father appears to view the arrival of his grandson as a situation to be embraced. He seeks out understanding and learns how to communicate.

Nicky: My dad does, um, a lot of sort of reading and signing. My dad, um, when Sam was diagnosed as sort of having a severe to profound hearing loss, um, my dad sort of straight away went out and bought books and sort of taught himself quite basic, being so, so he'll sort of sign and sing and sign to him (2.53-59)

The relationship between Grandfather and grandson is described as very close. The resulting affect is that the Grandfather's life is enhanced by this relationship.

Nicky: I think he gives my dad a sort of a reason. I think my dad, sort of always worked hard, worked long hours. He's sort of had ups and downs with his own health and as mum says, he wouldn't do anything if it wasn't for Sam you know (12.399-404)

Nicky's mother develops a trusting relationship with her grandson, that Nicky values.

Jo's parents with whom she lives, develop their role through seeking out an understanding of disability. There is a feeling that it is a struggle for them. Jo acknowledges that it is not an easy thing for them to adjust to, especially her father for whom, engaging with issues she perceives he has always found difficult.

Jo: For my parent's it's a generational thing. They never had anything like this in the family before. So there was a lot of research needed to be done on all sides. And it was trying to get my mum and dad interested in that research because they weren't used to that sort of thing (9.250-256)

It is clear that Jo sees her mother as the ultimate role; model describing her as having dedicated her life to her own children, and so finds it easy to develop an attachment with her daughter. For these Grandparents, perhaps the choice not to engage was not evident. For one it appeared a choice, but perhaps the emotional bond to their daughter necessitated it. For the other Grandparents circumstances thrust it upon them. For both it entailed changes to their own life styles to support their daughters. For Jo, who has received criticism for her multi-generational house hold, and who I feel is the greatest example of adaptation of immediate family circumstances, she sees nothing but good about her living circumstances.

Jo: Some people believe that it's a negative influence on Charlie. Too many people living under one roof. But what we've always found is that it's a positive thing because she's got different age groups and she's got a lot of influence from all different age groups that she actually benefits from we think, with the interaction with, with all of us. (1:24-31)

Maryam is from an African country via Holland. She initially moved to England because of her oldest child having Sickle Cell disease and needing the support of her mother, before her youngest son was diagnosed with Autism. Maryam values the support of her mother as a companion.

Maryam: My mum. I mean she's been very supportive of me, I mean, she's helped me a lot with Osman and with both the children. Sometimes some of her company helps me a lot because she is somebody I can talk to. It helps when she is around. (11.400-404)

But Maryam does not seem to be able to burden her parents with her deepest fears – what might happen in the future; and this appears to be a barrier.

Maryam: I always completely ask myself, 'What if I'm not there?' But I don't tell my parents this is being the picture because um, my mum is not strong enough. My dad has his own life going on, and I'm not going to ask him because he has his own life. (6.225-229)

It seems to me that this quote from Maryam summarises how the mothers ultimately must feel about the support received from their parents. However grateful they are for the support that they receive, in terms of emotional, time and material support, there is always a deeper need that remains that only they can bear the burden of. Sue and Barbara find that they have to adapt their relationships with their husbands in terms meeting the care needs of their children. Barbara has two children in close succession who are both diagnosed with Autism. This necessitates in both partners having to give up employment to share the care of their children as both of their parents work.

Barbara: Obviously having the kids back to back and I wasn't very well, um, with a post-natal illness with the pregnancies and whatever, so I hadn't gone back to work, um, but Luke had to give up work to help me care for the kids, because it was pretty impossible (1.33-38)

For Barbara and her husband, this brings added concerns about how they will cope financially. Sue and her husband both need to continue to work to pay for the upkeep of the house they bought just before their disabled son was born.

Sue: Yes, well when we moved into this house we was expecting twins – when we bought this house. So, er, one of the things is that we both need to work for us to keep the house (6.178-181)

For both Barbara and Sue, support from their parents is restricted by age, although Barbara's parents make a significant material contribution through buying a caravan at Badmouth. The impact on Sue is that when she has to work, paid carers are employed. This brings her mixed feelings both in the commitment of the carers and their intrusion into her life.

Sue: Yesterday we had his um, Carer here, his personal assistant, and um, she was saying… Well, he got up at 4 o'clock in the morning and I was trying to get ready for work and was drying my hair and he jumped on the bed and I couldn't stop him and I was sitting on the bed with my hair dryer, and he stood on the bed, she was saying 'oh you can't, you shouldn't be letting him in your bed, what are you going to do in ten years' time'. And I thought, 'you know, you don't live here, it's not like 'oh, now Joshua, you can't do that, and will you listen to me. Will you stop

jumping on my bed'? You know your normal behaviour, sort of like; it doesn't quite fit. And I thought 'You know him'… (14.452-465)

Despite the limited close family support, Sue still see feels that her support is effective.

Sue: I think of us as a family unit. I don't think of things from outside. Both family members have been very supportive. (10.308-310)

In 4 out of the 5 families, there are siblings. Barbara has two disabled children, who because of their disabilities need individual care. In three of the families there are siblings affected by the birth of a disabled child. This appears to lead to uneasiness about having to prioritise one child over another, and trying to treat each child fairly, but acknowledging that the needs of the disabled child are consuming. Nicky expresses these frustrations.

Nicky: 'Can you read me a book mummy', 'yes, but you'll have to wait' and I hate to say 'you'll have to wait', because he's not more important than her, they're both the same, but I do feel that she's very often pushed to the side (6.195-199)

She is also aware that her daughter might have a feeling of jealousy that she has difficulties understanding. Maryam's older son also has Sickle Cell disease which is an added worry for her. She feels her son's frustration that she does not have enough time to care for him as well as she would like to.

Maryam**:** *At the moment I have a son who is frustrated and feels he is being ignored and I understand because he is being ignored (10.370-372)*

Sue, although acknowledging the extra burden she is placing upon her son in being the older sibling, sees the lovely child that he has becomes because of it. She sees him as adding value to the family structure.

Sue: there's only 20 months between them – so he's had to grow up. But it's made him into a really lovely person, but he's got that awareness that other children of his age don't really have, and probably aren't even going to have as adults. So it's been an eye opener for us having him. For Freddie's that's his life – that's how it's always been. He's been through a lot, but he gives Joshua lots of love. That's how it's always been (3.71-79)

For any sibling there is an adaptation in circumstances when a new baby is born, but for these siblings in particular there is the added knowledge of having to always come second, even if this is not what their mothers would choose, and even if they can see the qualities that have developed in their children as a result. I think that Sue sums up the essence of what all the families experience in that the disabled child becomes central to how a family functions and the day to day impact on the immediate family.

Sue: I think he's the centre of the family, everything else revolves around what he needs. Freddie, everybody, we all revolve around Joshua and if he gets his sleep. It depends on how our family day is going to be. We can't have days out or anything. It all depends on what mood Joshua is like (1.17-22)

4.4.2. Changing role of parents and its impact

Relationships between parents appear to be put under the spotlight by the birth of a disabled child and highlight not only different expectations and ways of coping, but male/female roles become more defined.

Nicky describes how the shock of losing one of their twins, and the surviving twin being disabled was experienced differently by her and her husband. To her it seemed that he was either insulted or embarrassed about it, exacerbated by the fact the he has two older children from a previous marriage. Although not explicitly described, the feeling is that this proves he can be a proper father, and so feels let down by the disability of this son.   Nicky's own capacity for coping does not initially extend to being able to support her husband. There is a sense that they follow their own paths to coping, and meet up again at another point.

Nicky: Um, it was perhaps difficult to support him, perhaps I felt, I feel the same, so I think we've both sort of had to appreciate that we're both in the same situation here but we'll just find our own way and get together at the end of it, and we did and we have and we've sort of worked out (11.366-370)

It could perhaps be said that said that the role and relationship that her father has developed with her son, has fulfilled some of the role that perhaps Nicky feels her husband should be taking. For Barbara and her husband, it appears that the experience they have been though has been joint and his role much appreciated.

Barbara: I know that there's you know, lots of mothers do this journey on their own, um, and I am so grateful that I haven't had to (8.249-251)

There is a sense of mutual support. Because there are two disabled children to parent, and he is home based as she is, they appear to have worked at a similar parenting style and there is no sense of the distance that one feels with Nicky and her husband. As has been described before they have had to both make the decision to give up work due to the needs of their children and perhaps because they have equally had to make this sacrifice, rather than the Father carrying on at work, with the mother being the main carer, this has led to more understanding of each other's needs.

Barbara: I think it helps that as parents we both, we both pretty much parent in the same style and that really helps.   And there's no compromise, no conflict between the two of us (8.262-266)

 For her husband, Sue feels that it not until a school has to be decided upon that he faces the reality of their son's condition and that he will need a Special school. It was as if accepting the reality of his condition would make it come true. Sue also appreciates her husband's support, but feels that the situation that they have had to face together has left them isolated and may be too reliant upon each other.

Sue: I think, Alan and I together really, we're a team against the world and it feels very isolated, just your little group (10.321-324)

Barbara comments that because to outsiders they are seen as a 'tight' team, that they perhaps do not get a much outside support as they would wish because it appears as if they are coping. She is the only mother to state that she is concerned because her husband does not have anyone

else to turn to support for. So for both Barbara and Sue, it appears that the strength of support between husband and wife can also have a negative affect in terms of being seen as not being in need of outside support and being too self-sufficient.

Barbara: The downside of that is that we probably don't get as much help as everybody else, because they think, oh well, they've got each other (9.269-271)

In contrast Maryam finds it difficult to understand her husband's attitude towards her disabled son. They did not find out until their son started Nursery that he had a disability. She feels her husband's detachment, and lack of understanding is putting too much responsibility on to her.

Maryam. Honestly I don't have a lot of faith in my husband to take care of him because, um, it is quite difficult because he has his something going on, and I'm stuck with the children, and he doesn't understand him (6.202-206)

Maryam feels the marriage is struggling because all of her energies are put into looking after the disabled child, and that this role is expected. Of all the accounts, Maryam appears the most isolated and disappointed. At no point does she describe her husband as a father; but also Maryam does not appear to be able to acknowledge that he may have had similar emotions to her in adapting to having two children with additional needs. The different adaptations seem to have no commonality.

Maryam: … and at the same time I feel like the communication at home has broken down. Because I mean people deal with these sort of things in different ways, but, um, men deal with it differently and mothers deal with it differently, but when you are in it 24/7, when you are being the mother and you being the main carer, I think it affects you a lot (5.123-130)

Although Jo is a single parent without any involvement from the father of her child, it is interesting to observe that her sister steps into the role of being the other carer. Jo appears to need to identify a significant other in her life to share this responsibility.

Jo: For instance if I - me and my sister are the main carers. She hasn't got a father, so my sister was my birthing partner; she's been there all along. So she plays the part of the second carer. Charlie is very aware of this (2.56-60)

In two of the families, male/female roles become more defined between husband and wife. In Nicky's family, there seems to be a stereo-typical division of roles for herself and her mother, with the females undertaking the caring, messy roles, while the males are describes as having all the fun.

Nicky: *I think the women, me and my mum take on the roles of sort of cleaning um, and sort of, nose bleeds or sick with reflux or opening his bowels is a sort of women's job (both laugh). The men seem to have all of the fun roles, perhaps the play roles (laughs). Sam currently likes to play football, but obviously not being able to walk constantly, um, its, it's not something he can do independently, kick a football in the goal posts, so my dad or Sam's dad big Sam, um, are the ones who play football or take him to the park, or um, play, play outside, or play games or play wrestling, or play cars (2.42-53)*

It is interesting to reflect that perhaps in a time of crisis, more traditional roles are taken on as coping mechanisms as these roles appear more 'natural' and easy to fall into i.e. the female mothering role; the male 'activity' based roles. Even in Barbara's equal partnership with her husband, in her view the adjustment that he has had to make to his life is greater and more costly than hers, and in her opinion he has given up aspects of his manhood.

Barbara: Um, you know, he's sacrificed far more than me. I know that Luke would tell you, you know that as, as the man, he's the bread winner and things like that you know, and he's had to,

he's had to put his family first, before you know, before that sort of manly, manly image if you like (8.251-257)

In Maryam's relationship with her husband, it feels that these roles are already delineated, and becomes more reinforced so that her role is reduced even more by being the main carer. It may well be that here is also cultural reinforcement of her role, that becomes more defined because of the family circumstances.

4.4.3 Unsettling of wider family relationships

In the families there is implied dissonance with wider family members that adds to the sense of the mother's reliance on close family members. Jo is the most explicit about this.

For Jo, the birth of her daughter has a profound effect on relationships with her brother and his family that has also caused a strain for the whole family. There appears to be a feeling of resentment towards the way that the familial home has been opened up to her, and the impact of the disability of the child that everyone has to adapt to a lesser or greater extent.

Jo: The impact on the family has been profound to be honest. We've got my mother, my father, my sister, myself and Charlie; and the other half of my family are my brother, my sister-in-law, my niece, my nephew, who live not too far away, um, in Leicester, and um, the impact that their attitudes towards the disability had are quite different. They have, haven't been very supportive, they haven't been as involved as they could be. In the first instance when I had Charlie, they told me because of my circumstances I maybe should consider giving her up. Which I really didn't think was their place to say (7.204-217)

Jo describes how that side of the family used to be regular visitors, but as soon she makes the decision to bring her daughter home, they stop coming. There is as sense here of dissonance about how disability is viewed.

Jo: Then they started avoiding, they wouldn't come round, and she was only a baby then, with only sort of the needs of a baby (8:221-223)

As Jo's daughter gets older, and her disabilities become more evident, she comments that her brother finds it more difficult to even be in the same room with her daughter for more than an hour. Although Jo is the most explicit of the five mothers about how wider family relationships are affected, but it seems to me that the feelings contained here are probably common across all the cases. Jo clearly describes the awkwardness some people feel when face with a disability, which can be particularly painful when it comes from family members.

Barbara briefly mentions an extended family on her mother's side who do not have much contact. Sue only mentions an Aunty and another family friend; no other relatives. Nicky does not mention other family members, and because Maryam has moved to this country, she has not extended family network. This reality forces the families to look at the closest relationships for support.

4.5 Super-ordinate theme 3: Impact of a child needing a special school

This theme describes how transition into school; how relationships with school are established and developed, contrasting with previous professional experiences. The mothers find a new peer group in which to establish mutual relationships.

4.5.1. Transitioning into school

For all of the mothers interviewed an underlying issue is how they are viewed as mothers of disabled children, and the doubt that they can find in their capacities to fulfil this role. What does the role means to them and how others construe they should fulfil it? This means that for some of the mothers, when they first bring their children to school there is a question in their minds as to how they will be received. For all parents there is often an uncertainty of role and expectations when a child start school, but for mothers of disabled children, this identity can be fragile.

For Nicky, there are two situations highlighted she was transitioning from; firstly having been part of the Team Around the Child Multi-Agency support that facilitated the assessment for a Statement, and had supported her since the disabilities of her child were pinpointed, and then the having to 'let go' and let the school take responsibility for her child.

Nicky: *You know obviously you want (pause) you know, going through the statementing process was a ... It's just a living hell (laughs) trying to get everything done (21.677-680)*

Having come through anxiety of the statementing process to get her son into school, Nicky is faced with the major re-definition her core role.

Nicky: *As Sam started, obviously all the services I've talked about, coming into the home were taken over at school. The teacher of the deaf going into school, a physiotherapist in school, the doctor's in school, the Nurse is in school, um, the Speech and Language therapist – everybody's in school, and all sort of, what do I do? They were like 'you're just his mum', and that sort of hit me a little bit. Whoa, how do I be his mum? Cause I've always been, you know, let's do our physio now, let's get you splints on, let's put your gaits on, watch the tele, then we'll do this, then we'll feed you, little and often and then I'll try and teach you finger feeding, speech and language therapist have said do this and then we'll play this game, then we'll do this and then then you must have a bath and then we must use this cream and must have his medicines and he must do this and a lot of that sort of went to school and it was like what am I going to do? How am I, and it was like, you just, you just laugh, and it's like, what does a mum do? (15.468-467)*

Nicky comments that she even had thought about just sitting outside the school in case as a mother they needed her so initially difficult does she find it to relinquish the role that has been all consuming and with which she identifies herself. A role she has struggled through much personal adaptation to gain.

Barbara also manifests uncertainty in her role through being unsure of what her relationship with the school should be. She feels that there are areas of concern that she does not want to bother the school with. There is a feeling that to do so will make her look as if she is not coping as the

mother of disabled children, again reflecting the journey of uncertainty as a mother that has got her thus far.

Barbara: And the school have been helpful, but as I've said you know, you, I think that you kind of feel like that perhaps there's stuff that you can't go to them for you know. It's not a huge problem, then maybe you should look somewhere else. You know you don't want to bother them. You know you don't want to be seen as a nuisance and you don't want to be seen that you're not coping. You know there is that element of it (11.334-342)

These feelings of initially holding back in the relationship might also be a factor of the constant interactions with different professionals with differing expectations of what a mother of a disabled child is, which can be a seemingly major part of the life of a mother of disabled children. In contrast, Jo is more than happy to send her child to school. Jo's experience perhaps reflects her younger age and experience as a mother still living at home with her own parents. She sees the role of a Special Needs Teacher as vocational, as a gift; and as such is happy to hand her child over to an 'expert' with no doubts in her mind.

Jo: That's why I made the decision to send her to special school because in my mind to be a teacher of special, special needs children is a vocation (6.153-156)

The second she got to school … she was cleared to go to special school, everything just changed, it calmed down. I felt frantic before then. There were … there was play workers, physiotherapists, speech and language therapists, all coming into the home (14.389-395)

For Jo, then when her daughter started school, she felt a great relief. She sees it as a haven from intrusion into her home by outsiders. This is in direct contrast with the feeling that Nicky has, who has found the support of the expert team helpful, but for Jo appears to be just too intrusive. Sue has an older son at a mainstream school, so has experience of transition. For her it is the personal relationship with the member of staff is that is important.

Sue. I think it when it was in the Early Years. I think, um, the Teacher, Jenny and that I think she was that approachable, and she was like really bubbly as well. At school I felt it was more of a family unit. It was just nice when you went there (9.339-403)

5.4.2. Relationships at an emotional level

School can contain anxieties particularly for three of the mothers. For two of the mothers, after their initial hesitations, relationship develops. One particular mother whose son is one of the older children finds that her relationship becomes difficult due to personality clashes.

For Nicky, Jo and Maryam, it appears that relationships develop positively. Nicky finds that she develops good communication channels with the school and appreciates the expertise of the staff. The feedback she gets from the school enhances the communication and understanding of her child and contains her initial anxieties about how he will be received.

Nicky: Um, you know the staff, they're just, if you wanted it, you have it, anything! Um, you know if I was sort of, I need to know what Sam's eating in the day, I need to know if his bowels are open or if he's constipated, do I need to get him medication and things like this. But you can, if you need them, you can! Nothing's too much trouble. They are always wanting to make your life as easy as possible and the communications fab (17.548-556)

You just can't fault any of it. You can pick up the phone and speak to anybody because they're experienced. You know they've had children like Sam in the past and I haven't (17.562-565)

For Jo the school contains all the anxieties she has. The way that the school equally looks after the physical needs of her child as well as her learning needs impresses her and for Jo this normalises the educational experience of her child. Jo has experienced a feeling that her child has been marginalised because she is not a 'mainstream'. Jo's interpretation of her daughters experience at a pre-school level has highlighted this for her, because she feels her daughter is

rejected because of her physical need. At school, in her eyes, citing a graduation ceremony, her daughter is being given an education as good as any 'mainstream' school can provide.

Jo: Because you, you just; because they're out of your care and you worry that they're somewhere else. And you don't want to be trouble with anyone else. You don't want you child to be any trouble to anyone else. You get that sort of a feeling, um, and that's the sort of feeling that I have got. But in Ashtree, I've never felt like that. I've never felt, I mean if she does a nappy on her, they're used to it. And that helps me, that has helped me a lot and Charlie has come on in leaps and bounds since she's been there (14.411-422)

She's going up a year next year so … that's quite exciting. She had a graduation, and's something else that they do. A little graduation   ceremony.   So they do their very best for the Children. They try to make them feel as mainstream as possible. That's the other thing that I like. (16.462-468)

Maryam also feels that she can contact the school about anything. Her relationship feel more distant, and information seeking to sort out issues in her life, but an equally valid relationship with the school. In contrast to these mothers, relationships for Barbara and Sue feel more reserved. Barbara is seeking an equal relationship with the teachers. There is a sense that she finds this difficult to do. She regards her experience as a mother bringing her two disabled children up thus far to be the equivalent of their teaching expertise. It feels very much that she is seeking a relationship on equal terms and it feels she is defensive and unsure. Later on in her conversation, however Barbara states quite strongly that she feels that the needs of parents should be equally considered by the school, perhaps looking to school for some emotional containment as well.

Barbara: Um, you know, we very much want to be a part of whatever's happening in the school and I think that helps as well because it gives you a sense of identity and it gives you a sense of community. Um, you know, its simple things, like how can we help Caitlin and Colin do this? How can we help them do that? Um, you know communication and behaviour wise, anything to do with

the children themselves as opposed to the services. Um, you know I feel that the school are a huge help with that. You know I do feel like the teachers, um, are probably the second people that know your kids as well as you do, you know. Um, there aren't many people in terms of professionals that you can say, well you know, I know they spend as much time with my kids as I do. So I know they're going to have seen what I've seen and will, you know, have an equal sort of opinion. (11.354-372)

Sue feels that the relationship that she first had with the school in the Early Years is now more distant. As her child has grown older, communication has become more difficult with him, and equally in her opinion so has her communication with school. She feels that she does not understand how he is being taught and has no idea what to ask school about. There is a sense of frustration in the relationship. School holds knowledge and information about her son that she needs; but she is not able to obtain it. She uses a strong metaphor, describing her experience to that of being in a foreign country and not being able to understand what is going on.

Sue: You don't know what you…I suppose, I think where ever you go, if you went to a foreign country you wouldn't know how to ask for something. I just feel that sometimes it's a bit like that, I don't know what to ask them. Because I don't know what they can offer. So unless they…they are the ones that should, instead of me going 'oh I want this' which I don't know, because you don't know what you need sometimes in a situation, you can't see the wood for the trees. (12.369-376)

Whereas now you sort feel a bit as if you are on the outside of things. You're not really sure what they do. They do explain, but I don't just seem to get what they do now, because he's gone to um, TEACCH way of teaching him, and I still don't understand. I've asked them to give me a print out, but I still can't my head around what it is (13.403-409)

4.5.3. Relationships at a professional level

Three of the mothers share the common experience of having difficult relationships with some of the many professionals they have to engage with. There are examples of feeling that they are being talked down to; their experience not being acknowledged; their children not being valued for who they are; in contrast to how parents are treated at school.

Nicky's early experience of dealing with professionals in the hospital is one of feeling unvalued, that her knowledge of her own child is not recognised. She feels overwhelmed by professional knowledge and vulnerable because she has to accept what is said whatever.

Nicky: And then looking back as well, I do think in the very early weeks, months perhaps with Sam, you know, you have to ultimately trust the professionals because you don't know anything (8.247-251)

And it took me a while then to think 'you can question this, you can ask why, you can say no. Because ultimately I am the boss! You're not all better than me because you're more qualified' (8.261-265)

Nicky finds that she often has to battle with services as her child gets bigger. And this attitude of condescension persists.

Nicky: And a lot of this you know you do sort of probably as a parent of a disabled child. Personally I feel I get up most mornings ready to go into battle and I've got to fight again and I've got to fight to get this (18.583-585)

Nicky's early experience of Specialist support through Early Education services; teachers of the deaf and the Deaf Society are identified as being particularly helpful pre-school. What Nicky identifies about school is that in her view is any one is approachable, and there is a willingness to share expertise, and that experienced view is valued by her.

You just can't fault any of it. You can pick up the phone and speak to anybody because they're experienced. You know they've had children like Sam in the past and I haven't. I don't know what's going to happen when he's ten or eleven or twelve of course, and you know obviously staff do (17.562-567)

Throughout Jo's conversation before she talks about her daughter starting school, there is the feeling of 'other, outside influences' she regards as malevolent towards her child. This is typified in her feelings towards social workers who she feels just treat her daughter as a commodity, not a child who although disabled has feelings as much as any child.

Jo*: I've had lots of, um, times where I've felt like, and this is again outside influences, I've felt like I've got an animal rather than a child. Um, the attitudes are such that treat her not as a child, but more as an animal and that breaks my heart because I feel like shouting from the rooftops, 'she's my child, she's not mainstream, but she still has feelings'. Those feelings are becoming more and more in focus as she's getting older. She does feel, she does hurt, and what has annoyed me along the way, services even, social, social workers etc., they treat them like an object rather that a person. We'll just do this for them, put them there. They've got no feelings, they won't actually be upset or worried, and they, that infuriates me to be honest because they can be just as damaged through having, um the wrong type of care for instance, or the wrong type of care package, as any mainstream child. So, yeah, I think, er, I would love to see more focus on the fact that they are someone's child, someone's loved child not just another special needs child*

(6. 177-199)

Jo expresses strongly held feelings that are obviously painful for her and sum up some of her experiences that she has had with professionals who she feels should have better understanding. She uses a stark description of her child being perceived as an animal with no humanity, wanting to make everyone listen to her experience and value that she attributes to her daughter. It is no wonder that in Jo's opinion, as has already been stated she views teaching at a special school as vocational. She mentions this concept a number of times.

Jo: So then that sort of highlights the fact that for me, the people that work with special needs children um in a school environment, a special school environment, I think they are fantastic. It is a vocation definitely (15.422-426)

For Jo, like Nicky it feels as if there is a reciprocal relationship with staff. She goes on to mentions a time when she worked in partnership with school over a behaviour intervention for her daughter, appreciating the partnership engendered between home and school.

As with Nicky, Maryam has good experience with specialised services, but not with Professional services, citing poor communication and poor personal relationships. Again she contrasts she contrast them with school; the ease of access and relevant information.

Maryam: because I didn't know where to turn to, and so I talked to the school, and they were very helpful. So these organizations are amazing and if they weren't there, honestly if it was the Disability team, you wouldn't get anywhere. There are so many offices and so many people, they forget. But with the school, and you know some of the charities, you get where you want to go. It is much easier (13.457-465)

School is also a conduit for accessing professional services for parents and it appears that within this more controlled environment, three of the mothers find the services more accessible.

Nicky appreciates it that all the services she used to access at home are now available in school, such as Speech and Language Therapy services; Physiotherapy services. Jo gives an example of a multi-agency meeting that the school facilitated to help with her daughters behavioural problems in school and at home.

Jo... I think it was when she was going through a particularly bad patch with her behaviour and um, they called a meeting basically with all the professionals who needed to be there and myself to decide what they could be doing as a school and to help with the process of trying to get um,

her levelled out basically and it's been; we made a plan, an action plan and it was a consistent thing, it wasn't something that just went by, you know, by the wayside, it was continuity and that's very important (17.482-492)

For Maryam, it's the schools ability to filter information and give pertinent advice that she appreciates.

4.5.4. Facilitating a new peer group

For four of the parents, the attendance of their children at the school facilitates a new peer group. An issue for many of them has been the falling away of friends as the disability of their children becomes apparent adding to further isolation. At school they find a likeminded peer group and through this acceptance and friendship.

Nicky describes how her friend's attitude toward her only helped to emphasise her isolation and exclusion from 'normal' motherhood, making her feel increasingly alone.

Nicky: *I do feel I lost a lot of friends. When they were little it was fine as we all went along and did the same things. Then sort of friends from school or work of a similar age, their children then were going to Crash Bang Wallop, all local, but Sam can't and he has to just sit in his seat then, sitting there next to me doing nothing and dribble and have to have medicine and then they're all toilet training and they stop asking you and you think they're embarrassed and they want to go and play at the park and Sam can't. And it's sort of why aren't you talking to me anymore and I've got nothing to talk about because Sam can't do it. He's not said his first word, took his first step, done his first picture, he's done nothing and he's just the same and he's three years old. So I've lost a lot of friends (15.495-510)*

Maryam finds it difficult to keep up with her former friends because it is too painful for her to know how they are getting on with their lives, and the contrast with her reduced circumstances is too great as it reminds her of her former life.

Maryam: And sometimes I feel I'm a total failure. I don't call my friends anymore because I don't want to hear about how nice their jobs are or how great life is because it reminds me **that mine is not.** *(Laughs - emphasized) And then you start, you know you feel the isolation that it brings you because um, I think what can I go on and do with this thing (8.340-344)*

Barbara also articulates the feelings of disappointment that the impact of having disabled children has brought to those she would have previously considered to be her friends. The embarrassment that Barbara feels leads to her withdrawing from her circle of so called friends.

Barbara: You know, um, your social life disappears and your friends you had before disappear. You know we've had a lot of cases when people that we had a lot to do with, um, before the children got their diagnosis disappeared pretty soon after, and um, you know because their children couldn't cope with it, or you know, why bring my child round there when their kids aren't going to play, and you know all of that sort of thing (15.472-480)

For both Barbara and Nicky, finding parents at school with who they have common experiences and who talk about issue with no embarrassment is an eye-opener. In the Parent Support Association, Nicky finds parents who normalise the experience of having a disabled child.

Nicky: it was just such a relief to have people sort of, you know, talking about wee, poo and nappies, and where to get this, because no other five year old, seven year old, nine year old needs nappies, you know laughs). These people want the same as me! (Laughs) This is fab! So sort, of socially that's really nice (17.543-548)

For Barbara the finding of other parents with similar concerns is an eye opener for her; to find acceptance among one's peers.

Barbara: Um, the Parent's Association. Meeting the other parents was a huge step for us. Um, it's sort of made our journey a lot more positive. Um, we was in a very, very dark place when we first went to the PSA, when the kids first went to Ashtree. And meeting other parents, um, not just sort of in advice terms. They kind of opened our eyes (9.292-299)

She goes on to describe how she has been able to re-establish a social network that has a shared identify and knowledge. There are parents of older children who are able to pass on advice; they have journeyed further. Everyday information is exchanged that makes daily life easier. The example she give is of the phone number for the nappy service. Out of these links Barbara is able to establish a sense of purpose for herself.

Barbara: *Um, this last week and next week, um, we're going up to the caravan, and um, one of the families from the, from the school are coming with us, so, um, you know, it's that kind of thing we've been able to perhaps offer that supports other parents. So that makes you feel, you know, that sort of thing, it makes you feel like normal because you do lose your identity, you do sort of think well, who am I? You know, what can I offer? What sort of thing can I do that will make a difference you know, to my kid's life and perhaps somebody else's life? (10.332-333)*

Maryam finds the knowledge and advice passed on from parents of older children who have attended the school helpful. She also finds that she has commonality with parents that she did not realise, and so is perhaps not as alone as she thought.

Maryam: And then we got these meetings and you realize that most of them have the same problems, especially the ones with Autism. Autistic children, they have the same problems as you and your worries are the same as their worries (17.619-624)

I have described and discussed the three superordinate themes arising from conversations with five mothers of disabled children. In the next chapter, I will discuss these finding as they relate to relevant literature.

CHAPTER FIVE:

DISCUSSION

5.1 Introduction

The purpose of this final chapter is to draw together a consideration of the research findings which will be discussed and reflected upon in relation to the aims and research question. There will also be a critical analysis of methodological issues in terms of strengths and limitations. Possible implications for future research and implications of the research for the role of Educational Psychologists and professional practice will be considered. I will conclude with a reflective analysis.

5.2. Discussion of research findings

The research question for this study was:

How does having a child with a profound or multiple disabilities affect the home/school relationship?

The main aims of the research were:

- To explore the impact of having a child with profound or multiple disabilities upon the home/school relationship
- To explore the parent's experience of school support
- To support the school in developing a model of support that could be utilized to understand and meet the needs of any family at times of crisis

- To explore a potential role for Educational Psychologists based on what is found from families that could enable Educational Psychologists to offer more systemic and family orientated support

I have chosen statements from a Prezi presentation by Larkin (2013) to sum up why IPA an appropriate qualitative approach for this study.

'We choose an experience'

'We aim to get experience close rather than to direct experience per se'

'We focus on the meaning of experience (event, process, relationship)'

'We remember that participants and researcher are both interpreting – 'double hermeneutic''

'We prioritise each case as a case and then consider convergence and divergence across our data set'

(Quotes taken from slide 28)

Larkin, Watts and Clifton (2006) tell us to hold two aims in mind when carrying out IPA. What it is like in trying to understand the world of the participant? What does it mean for the participants to have made these claims and to have expressed these feelings in this particular situation? Larkin *et al* (2006) argue that IPA offers the researcher the opportunity to engage with the research questions at an idiographic level in which the participants lived experience is coupled with a subjective and reflective process of interpretation. This process is explicitly entered into by the researcher who makes inferences cautiously, but is also willing to make interpretations. These interpretations discuss meaning, cognition, affect and action and they would argue, may be drawn from a range of theoretical perspectives as long as they are developed around the central account of the experiences of the participants. IPA is stated as being inductive (bottom up rather than top down) and does not test hypothesis and prior assumptions are avoided. In my research as part of the analysis I have used Rolland's Family Systems Illness model as a lens through which to interpret the experiences of the participants using his theory as a priori approach, rather than just using an inductive bottom up approach in traditional IPA methodology. Nothing is value free and as a researcher everybody comes with some pre-conceived ideas. Using Rolland's theory

explicitly to tease out how well this makes sense of the transcripts is novel. The relevance and usefulness of this model will be discussed later in the chapter,

5.3. Discussion of the themes

Superordinate theme	Subordinate theme
Theme 1: Making sense of life changing events	Feelings of loss

Future hopes reframed

Personal effect

Glimmers of hope |
| Theme 2: Impact on family dynamics | Adaptation of immediate family circumstances

Changing role of parents and its impact

Unsettling of wider family relationships |
| Theme 3: Impact of a child needing a special school | Transitioning into school

Relationships at an emotional level

Relationships at a professional level

Facilitating a new peer group |

Table 5.1: Describes the final superordinate themes

Discussion of the themes is considered using literature already discussed in chapter 2, with the drawing on of some additional literature.

5.3.1. Making sense of life changing events

- Feelings of loss

- Future hopes reframed

- Personal effect

- Glimmers of hope

Of the participants that were interviewed, all expressed in eloquent ways the initial impact upon themselves, on their core being, of having a disabled child. For three of the mothers, the disability

was immediately clear after the birth of their children. For the other two, it was a growing realisation that something was wrong. These feelings were described in terms of bereavement, jealousy of other families, being overwhelmed, isolation, and emotional impact. Maryam described the effect on her life as a 'bombshell', Jo as 'a sinking of the heart', Barbara as 'a dark place'. These collective experiences were reflected in the parallel and personal experience of Crown (2009) and Constantine (2010). Crown related her experiences to the psychodynamic framework, which helped her to organise her experiences in terms of an unfolding development and a relational and internal experience. She described several phases that parents might pass though until they were able to find what she described as their 'balance'.

A common experience described by some of the participants was of being rooted in the immediate, but also having concerns about the distant future. Two of the mother's foremost thoughts were of how the disability would affect their child as they got older. Would their children be able to get married? As mothers would they see grandchildren? Sue expressed fears that as a family they are already struggling – so how would they manage in the future? Jo and Barbara had fears that if they were unable to cope that their children might have to go into care. In their longitudinal study of parental stress Baxter, Cummins and Pollack (1995) identified that these fears were common. Parents questioned identified similar common concerns regarding the future development of their child, the child's care and health. How would their child cope in the community, and the unknown future?

Four of the participants were able to identify areas of personal development. Barbara felt that she has developed better and different parental qualities. Nicky identified that the experience had enabled her to mature. Sue and Jo identified a new determination. Sue used her experience to join an Autism working group consequently changing practice at her hospital, Jo was able to represent herself at a work tribunal. Levine (2009), although describing the experience of single mothers, described qualities such as these as a developed resiliency, not the expected outcomes and expectations of an 'on looking world'.

Barbara was able to sum up eloquently how she attempted to reframe her life. She described how she and her husband had dreamt of the ideal hippy life living on a beach in Thailand, but had to substitute this with a caravan in Badmouth, North Wales. Badmouth became a positive metaphor for her altered circumstances.

Maryam, the one mother whose experience differed, expressed that her life was too different from her initial aspirations for her to identify any positivity for herself. At present she saw her own life in terms of self – sacrifice. Undergoing similar experiences herself Crown (2009) identified periods of worry, loss, anger, guilt and loneliness, but had the ultimate hope of seeing a transformative process emerge.

5.3.2. Impact on family dynamics

- Adaptation of immediate family circumstances

- Changing role of parents and its impact

- Unsettling of wider family relationships

For all of the participants there was an immediate change in family circumstances that affected wider family members too. For two of the mothers, a greater reliance on maternal parents developed. This type of intensified relationship was identified by Hillman (2006) as the more natural precedence within a family in these circumstances. For Jo, her parents provided her with a home, which she identified as a positive experience in her life, but outcome of this was an emotional toll on her parents also noted by Hillman. Maryam identified a limited relationship with her mother. For Nicky, her parents became an integral part of her and her son's daily life. For her father in particular, the interest and involvement with her son gave new value to his own life. Mitchell (2008) identified that grandparents could be a source of support like Nicky's, but equally a potential stressor as identified by Sue and Barbara. In both of their accounts, Grandparents

were hardly mentioned, and certainly not with the same regard as the other mothers. Their relationships appeared distant and did not seen to be supportive.

Four of the participants had two children. An uneasiness emerged about having to prioritise one child over another in terms of time and attention. Only Sue highlighted any difficulties, acknowledging the responsibilities they had put on their older son, but also describing the positive qualities that had developed. He was within the age range of 7 - 11, which Hames (2008) described as being when a child was more able to describe the impact of having a disabled sibling, and also take more personal responsibility. One sensed the frustration of the older sibling in Maryam's family, and Nicky acknowledged the jealousy of her younger daughter, although she found it hard to understand why. Literature would tend to suggest that particularly having a sibling with autism and severe autism as in these instances, this could be an added stressor within the family (Macks & Reeves (2007), Fisman *et al* (2000), Aronson (2009), Ferraoli and Harris (2009), but Sue's elder son appeared to have developed a positive self view, an outcome highlighted by Macks and Reeves (2007) in their study.

The impact of a disabled child was felt most in the adaptation of the relationship between husband and wife. Barbara and her husband found a strength in mutual support through both having had to give up work and in developing a similar parenting style. Sue described her partnership with her husband as being a 'tight' team. Like Barbara and her husband, they had had to make mutual adjustments to their working patterns, in this case, arranging outside help to care for their disabled son so that Sue could continue to work. Simmerman, Blacher and Baker (2001) identified that the participation of the father in child care and the mother's satisfaction with that help contributed to both marital adjustment and the burden of caring. Brageil and Kanoik (2011, 2014) highlighted that fathers were more interested in being involved with the care of their disabled children when there was a willing partnership with their wives. For Nicky, her husband had more difficulties adapting to his new role. Nicky described his initial embarrassment, her father finding it easier to provide the emotional support that she needed. Maryam appeared to be the most isolated and

disappointed of all the mothers interviewed in terms of support from her husband. She appeared to find it difficult to consider that her husband too might also have difficulties adjusting to their unexpected role.

This was a common experience for couples coming to terms with the disability of their child according to Contact a Family research. Reports (2003, 2009) highlighted the strains on relationships in adjusting to new roles, differing expectations and significant emotional adjustment. Different coping styles limited the support parents could give each other, but supportive couples were more able to protect each other from stress and depression. Specifically, 'A parent's guide for Fathers' (2013) highlighted from conversations with fathers, that they usually reached acceptance of their child's disability at a different time to the mother and communication about this subject was difficult and challenging to the partnership. This is evidenced in the difficulties of the husbands of Nicky and Maryam. Even Sue's husband who appeared to be in a supportive relationship with her, only faced up to issues surrounding his son's disability when having to choose a school for his education that would not be mainstream.

Although not as clearly stated as Jo's situation, all of the mothers found that support from their wider family network was lacking and that they were reliant on parents or other very close relatives. For Jo, following the birth of her daughter there appeared to be resentment expressed from her brother and his family. He found the feeling of forced adaption of family circumstances difficult to contemplate. He expressed this discomfort both verbally and by physically removing his presence so that contact became minimal. Ryan and Runswick-Cole (2008) identified that even within close and wider members of the family 'agents of disablism' could undermine the confidence of the parent with the disabled child and they experienced the stigmatization of their children even within the family home.

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5.3.2.1 Cultural considerations

I considered if there were any differing cultural realities expressed in the experience of Maryam. Lawrence (2014) exploring the views of Black African Parents (Maryam was African) found parental acknowledgment of their child's needs was rooted in religious belief systems, and often there was little understanding of disability within the wider community. Heer, Larkin, Burchess and Rose (2012), in a qualitative study that set out to develop culturally sensitive accounts of Sikh and Muslim's experiences of caring for a child with intellectual disabilities, identified that it was only mothers who made any reference to religious explanations for disability. For mothers in the Muslim group the disability was viewed as a 'test' from God. Lawrence (2014) identified that Black African families had a perception that white communities were more open and willing to access services and that within that community the child's need was not viewed as stigmatisation. She found that African families were more prone to isolation because their belief systems could act as inhibitors in understanding, adapting and managing their children's needs. Begum (2007) too identified issues such as' blame' and 'stigma' as common experiences of the Bangladeshi women with whom she worked. In contrast, Krause (2002) described culture as being both inside and outside the person, describing it as a complex interaction of individual stories that were derived from thoughts, feelings, intentions, and motivations from within a social system. She considered the human condition to be culture free and that in all social systems there was a connectedness to be found to each other.

Maryam was the only mother from a different ethnic heritage and culture within the group of mothers that I interviewed. It did not appear from how she responded to the interview that her experience of issues around parenting a child with a disability differed from the other mothers interviewed. Her role as a mother may be more defined, but Nicky defined clear roles in her family too. Her husband may have appeared more distant, but so did Nicky's. The difference for Nicky was that she had her father to support her. Even within the partnership of Barbara and her husband, she viewed the adaptions he had to make as more of a sacrifice than hers. Krause's

(2002) concept of the human condition being 'culture free' is one that seemed to unite these mothers.

5.3.3. Impact of a child needing a special school

- Transitioning into school
- Relationships at an emotional level
- Relationships at a professional level
- Facilitating a new peer group

For some of the some of the participants interviewed, the occasion of their children starting school led to a reassessment of their identity as a mother, and a doubt in their capabilities. Nicky, who found positive support in her role from the multi-agency pre-school Team around the Child team, suddenly found the professional support located in school. Staff from school advised her to 'just be his mum' but this appeared to be something she found difficult to imagine. She talked of wanting to sit outside the school in case 'as a mum' she is needed. For Barbara, there was a lack of surety expressed about what to expect from a professional relationship with school staff, not wanting to be viewed as inadequate. Ytterhus, Wendelborg and Lundeby (2008) explored turning points and transitions that occurred during the life course of children with disabilities and their parents. They identified that when a child reached the age of 8, a major turning point occurred in the family life, describing the transition from 'doing ' to 'being' and a change in the role of parenting. Although describing a stage later on in life, Nicky experienced similar uncertainties during her transitional role as her child started school. Barbara's wariness appeared due to previous engagements with professionals where her input was not valued or seen to be important, feelings highlighted by Lundeby and Tossebro (2008). Jo's reaction to her daughter starting school was completely different. She valued the 'vocational' role of the teachers and saw the transition into school as entering a period of calm. Baxter, Cummins and Pollack (2006) identified

that for some parents, their children starting school was a relief and to be viewed as a positive achievement.

For Nicky, Jo and Barbara the school appeared able to contain their emotional anxieties. As the school received the child in a way that validated their own view of their child, they were able to change, allowing them to become 'just parents'. For Jo the fact that the physical needs of her child were as equally looked after as the emotional needs, again underlined her view of special school teaching as a vocation. The highest accolade that she gave was that she perceived the education that her child was receiving to be as good as mainstream education. For Barbara, in gaining a sense of identity and partnership, she was able to recognise that the teacher spent as much time with her children as she did, accepting that their opinion was equally valid. Even though Maryam's relationship with school appeared to be more distant, and based mostly on information seeking, this was a satisfactory meeting of her particular need. The experience of these parents was in direct contrast to those described by Lundby and Tossebro (2008) who found that their parental knowledge was regarded and treated as subordinate, subsequently resulting in them being deprived of the power to define what they as parents valued and thought important.

Sue expressed a differing opinion which seemed to arise out of a breakdown in communication with the teacher. Following a lack of understanding about a new way of teaching her child that she found difficult to grasp, Sue described her experience of detachment from the process as being in a foreign country, and unable to understand the language used. Lundeby and Tossebro (2008) identify that most disagreement between parents and staff arose when a child developed a problem at school. This concerns was a reminder that in most schools where there was good support for and good relationships with parents at times these relationships could break down.

Experience of the different relationships that the participants had experienced with many professionals was contrasted with those in school. Both Nicky and Jo appeared to have

experienced a 'medical model' understanding of their situation with professionals, where as parents they were put at a disadvantage because of their lack of a specific understanding (Goodley & Runswick-Cole 2009). In contrast at school there was an effort to build confident relationships with parents that enabled them to engage with their rights and responsibilities, and to communicate effectively with professionals in school (Leyser & Brobst Cole 2006). Nicky described engaging with medical professionals who she felt had talked down to her and undervalued her experience, in contrast with the school who she identified as approachable and a willingness to share their expertise. She articulated ongoing dealings with professionals and services outside of school as a daily battle. The most successful pre-school relationship she experienced was with the Team around the Child, who were professionals working in the community, valuing their accessibility. Jo also expressed negative views about the professionals she has encountered outside school. Her perception was that there was no understanding of the basic human qualities of her child. In contrast the school gave validity to her views and worked with her and other professionals as equals when trying to support the behavioural difficulties she had with her daughter.

Four of the participants expressed relief at finding a new peer group, describing the falling away of friends as the disability of their children became more obvious. Nicky articulated feelings of isolation from the 'normal' experiences of motherhood, and Maryam found it too painful to contact her friends because of the contrast in life styles. Barbara felt her friends were embarrassed about the disabilities of her children. In school they found other parents with whom they had a commonality of experience and identity, this opened up new opportunities for socialising and being able to share and offer encouragement from their own experiences. Ryan and Runswick-Cole (2008) described how parents could share the stigmatization of their children and experience the discriminatory practices and attitudes that their disabled children face. They identified the difficulty that parents had in even having everyday conversations about their children without confirming prejudices already widely held. For the participants interviewed, school presented as a safe space where they could develop trusting relationships with their peers.

5.4 Answering the research question: How does having a child with a profound or multiple disability affect the home/ school relationship?

In answering this question, all the aims will be identified and considered individually

5.5 First aim: to explore the impact of having a child with profound or multiple disabilities upon the home/school relationship.

The first aim was to explore impact of having a child with profound or multiple disabilities upon the home/school relationship. In consideration of the superordinate themes that have emerged from the interviews carried out with the participants, a rich picture emerges in terms of the personal experiences that they were willing to share. I have summarised what both school and the home bring to the home/school relationship and the effect on both.

What the home brings to the relationship – from a positive experience	*What the home brings to the relationship – from a negative experience*
Personal development as a mother	On-going effect of having a disabled child in the family
Determination	Pressures of contracted family support
Courage to speak out	Marital pressures
Taking up disability as a cause	Limited input/influence of Father
Reframing life in a positive way that enables one to cope in the present	Pressure on sibling relationships
	Fear of the future
	Identity of mother
	• a mother? / a carer?
	• lack of confidence because of interface with professionals who disregard their experience

	- isolation from peers - ongoing sadness - self-sacrifice of previous aspirations Uncertainties of role when dealing with professionals
What school brings to the relationship	
Normalises the experience of disability Accepts the child for who they are Provides a two way relationship - acknowledges the validity of the parents experience - supports positive relationships with professionals - gives parents confidence to find their voice - provides a new peer group for parents - engenders a sense of 'well-being'	

Table 5.2. Describes the impact of having a child with profound or multiple disabilities upon the home school relationship

It is interesting to note that there are no negative comments regarding the school from the mothers and represents the nurturing role the school plays in containing their emotions and enabling them to participate in school life, giving a validity to their experience and identity as a mother of a disabled child.

5.6 Second aim: to explore parental experience of school support

The second aim was to explore parental experience of school support. Although overall the experience of school support is highlighted in terms of the home/school experience as summarised above some particular positive and negative experiences emerged.

Negative experiences of school support	Positive experiences of school support
Parent's not always being aware of services on offer at school	Joined up working between school and home to support the child
Not enough focus on meeting the emotional needs of parents	Emotional and practical support
Individual personalities of staff can sometimes cause barriers in communication	Immediate access to teachers
No support for the children during the school holidays, although parent's are signposted to other providers	Diaries, home/school books to aid communication

Table 5.3. Negative and positive experiences of school

The last 3 questions of the questionnaire focused on perceptions of school support, but as can be deduced from the spider-diagrams to summarise themes for each participant (see appendix 12, page 178) the mothers placed most of their emphasis on other concerns. One mother who had been given particular emotional support after suffering from post-natal depression wanted similar support to be openly available at school. Support for their children during the holidays was also highlighted. A positive feature was the importance of the home/school diary as it enables parental voice to be heard and is seen as a vital form of communication

Interviews of each mother took place in their homes. If interviews had occurred at school it might have engendered a different perspective and more focus on school specific concerns.

5.7 Third aim: To support the school in developing a model of support that could be utilized to understand and meet the needs of any family at times of crisis

The third aim identified was to support the school in developing a model of support that could be utilized to understand and support the school in understanding and meeting the needs of any family at times of crisis. This aim could be met by utilizing Rolland's Family Illness System's model and could bring greater understanding for school staff of ongoing changing dynamics and impact upon the family of having a disabled child. This greater understanding could enable the school to target sensitive support at an earlier stage before a crisis emerges.

5.8 Rolland's Family Illness Systems model

The purpose of my research was to consider how a model of systemic thinking called the Family Illness Systems model (Rolland 1994) could be used to help understand the context and stage in which a family might be operating. Rolland suggested a model of the life cycle as a developmental framework. He suggested that there would be times of higher (centripetal) and lower (centrifugal) cohesion.   Rolland felt that if the illness or disability was severe, then a family could become stuck in an overly cohesive cycle with all their energies focusing inwards. I wanted to explore if using the framework that Rolland suggests would give a picture of particular family life and a useful understanding of what pressures a family might be operating with.

I have chosen to consider Jo, who from interpretation of her experience appeared at a centripetal stage of life and then contrasted her experiences with Sue, who from interpretation of her experience appeared at a more centrifugal stage.

I have identified that Jo's family life style fitted a centripetal life stage. Rolland described this centripetal phase as when individual members and the family unit's life structure emphasised

internal family life and external boundaries tightened with internal boundaries loosened to emphasise internal family life. In Jo's situation it appeared that her circumstances of having to move back in with her sister and parents had caused that family to look inwards to meet the needs of her child. Jo identified pressures that I would identify as contributing to the tightening of external boundaries. Jo described these as:

Outside influences

Attitudes towards her child who she feels is perceived as 'inhuman, 'an animal', 'an object'

People's negative attitudes

Mainstream school attitudes

Charley's ongoing behaviour difficulties

Her brother's disgust as being in the same room as Charley

Her brother's attitude that she should give her up

Within her family Jo was supported by elderly parents and her sister who assumed the role of the other carer. Rolland suggested that if the illness or disability coincides with a period of considerable cohesion such as child rearing, then this could cause a family to become stuck. For Jo and her family, her child's disability was such that there was developmental delay added to the caring pressure that the family was under. Jo identified that Charley's behaviour was one of her major concerns. Jo's construction of the outside world appeared to be quite hostile i.e. her experience of interacting with staff in mainstream setting, her perception of the 'worlds' view of her child as not having equal human value human and the reaction of her brother. These all lead to her turning inward to the safe-haven of her close family. Rolland identified that illness or disability might cause a loss of the previous identity of the family resulting in upheaval and a rethinking of previous commitments, and also a sacrifice to commit to a caring role. For Jo, her child became a focus point for family disruption. Jo had to move in with her elderly parents and sister resulting in her brother withdrawing his family from visiting. Her sister partnered her in being

the other main carer and Jo had to give up work. Their lives were changed completely. Jo's family had already gone through a considerable transition.

Rolland stated that if the illness or disability remained at a constant level then a family could enter a less cohesive phase of life. Multi-agency support facilitated by school had targeted behaviour to address the concerns of Jo and support her at home. This support gave Jo hope to move forward to a less cohesive family life style.

In contrast, Sue's family life style appeared to be in a more centrifugal life structure maintaining period with her family. Rolland described this period as one where external family boundaries are loosened and a 'normal distance' between family members was resumed. Sue identified family adaptations that enabled the family to be more outwards looking:

Flexible work pattern
Outside support to enable her to return to work
Joined the Autism working group and facilitated change in an A and E department
Describes her family as a 'tight supportive team'
Good sibling relationships
Flexible family support

Although there was a traumatic transition into becoming a family with a disabled child, in Sue's family, she and her husband were been able to maintain the previous family structure because the caregiving, and family adaption that followed was shared between herself and her husband. They were able to maintain their currant life with some changes such as incorporating an outside agency to provide child care for when .Sue worked, and also had flexible family support who would come at short notice. Sue had been able to develop resiliency through using her experience to join the Autism working party and also to affect change in a local A and E department following her experience of taking her son there. She also used direct payments to

organise child care to fit the family's need. Although Sue described the impact on daily functioning of the family centring everything they do on containing the behavioural needs of her son, she appeared able to maintain a balance within the family that enabled each member to retain some autonomy.

Rolland's Family Illness System's model is a unique contribution in addressing the gaps in understanding what it is that families bring with them to the school context. In my experience although a school may be sympathetic towards a family and their circumstances, an understanding of systemic thinking is lacking. As well as highlighting to schools the pressures that a family might be under, this model also highlights the impact of family resilience over time.

Rolland's Family Illness System's model was used as a post IPA analytic tool as suggested by Fade (2004) in taking IPA a step further. Fade describes how IPA can be used to develop in-depth descriptions of human experience, but can also be taken further to develop theories, models and explanations that help us understand human experience better. By using the Family Illness Systems model as a tool to delve deeper into the experience of two of the mothers it enabled factors to be established that led to a greater understanding of both struggles and developed resiliency. Concepts of centripetal and centrifugal phases as part of the life cycle are illustrated by the experiences of the two mothers.

5.9 Fourth Aim: To explore a potential role for Educational Psychologists based on what is found from families that could enable Educational Psychologists to offer more systemic and family orientated support

Before engaging in this research as an Educational Psychologist, I only had a limited understanding of family systems psychology, being aware of wider environmental issues that

have affected a family and seen the impact upon the child. Participants raised concerns about the quality of professional relationships that they have encountered highlighting relationships facilitated within school as being of the most value. At no point is an Educational Psychologist mentioned specifically, and perhaps reflects that in a school for children with profound and multiple disabilities that we are one of many professionals that parents engage with and that the Educational Psychologists role is not always transparent for families. Through engaging in this research and having had the opportunity to interview mothers who have been open about the pressures that affect them, I feel that using Rolland's Family Illness system's model as a 'lens' has given me an understanding of family systems within the context of having a disabled child and the impact on home school relationships and is an example of what Fade (2004) describes of being able to take IPA a step forward to develop a theory building approach. The fundamental aim and strength of the Educational Psychologist is to support children, young people and their families and facilitate the process of solution finding and problem solving when lives become ensconced in difficulty (Gersch 2004) and I feel that the use of Rolland's model adds understanding to this role and could be used to understand any family who might be in crisis, not just those families who have a profoundly disabled child. I also feel that this model gives way to optimism for families as strengths and abilities can be identified. The two maps developed, one to show centrifugal pressures on a family (5.1, page 115) and the other to show a family with a more optimistic centripetal outlook (5.2, page 116) are a useful visual representation of the model and could be used to develop the understanding of family systems and enable Educational Psychologists to develop school thinking around ways to support individual families. The eliciting of this information from a family by the Educational Psychologist also develops systemic thinking.

5.1 Centripetal Map

Centripetal Map for Jo

A child with disabilities is in-human – an animal rather than a child

Perceived child as an object rather than a person

Brother – disgust/can't stand her "you must give her up"

Mainstream school attitudes

Grandparents

Sister

Mum & Charley

LIVING WITH ELDERLY PARENTS AND SISTER

Outside influences

Overcrowding

Wider family withdraws

Charley's behaviour

Had to give up job

People's negative attitude

5.2 Centrifugal Map

Centrifugal Map for Sue

Partnership of caring with Alan

Flexible support from wider family

Child's day to day behaviour

Sarah

Auntie Sue

Alan, Sue, Freddie, Joshua

"FAMILY AS A UNIT"

Child loves school

"Huge determination"
"Tunnel vision"

Relationship of siblings

Alan's Mum

Care support organised to fit family need

Joined Autism working group

Facilitated a change in A&E practice for children with Autism

5.10 Strengths and limitations of the research

5.10.1 Research aims

IPA is a qualitative approach that is committed to the examination of how people make sense of major life experiences (Smith *et al*, 2009). Its key strength is the recognition of experience (Larkin 2007). It was therefore an appropriate approach for this research as I was interested in gathering rich, detailed experiences about the impact of having a disabled child on family functioning and how this might affect the home/school relationship. My initial questions, which were the basis for the initial conversations with the mothers had been based around utilizing themes from Begum (2007) (see appendix 6, page 156) that have been discussed previously. These included opportunities for descriptions of care, coping with the recognition of disability, coping with blame, but also the acknowledgement of self-value and self-growth. I had hoped that using these themes as a basis for open-ended questions would engender the rich descriptions desired. The research followed the systematic guidelines as outlined by Smith *et a*l (2009) for carrying out an IPA study. The process concluded with the identification of superordinate themes that captured an insight into the world of the participants in relation to the phenomenon being investigated (Willig 2008)

The examples of Jo and Sue show how centripetal and centrifugal pressures could affect family life both negatively and positively. In my experience, although a school may be sympathetic to a family and especially during a time of crisis, an understanding of systemic thinking is lacking. At Ashtree School, I was engaged with other EP colleagues in a three year project that considered mental health issues for children with profound and multiple learning difficulties and how to support staff in stressful situations. A lack of understanding about stress factors that families might be undergoing arising from the project led to this research. Rolland's model contributes to this understanding in highlighting family development over time and identifying the internal and external processes that affect family resilience. This model could give the school a greater

understanding of how these pressure affect their families and to offer more timely and targeted support.

5.10.2 Features of good IPA research

Smith (2010) carried out a systematic review of what constituted good IPA research which I would hope are demonstrated in my research.

He highlighted the following;

- a clear focus on a particular aspect

- the collection of appropriate data

- a demonstration of both patterns of similarity as well as the uniqueness of the individual

- that the analysis should be interpretive and not just descriptive

- should show how participants manifest the same theme in particular and different ways

5.10.3 Interviewees

IPA relies on participants who as Willig noted (2008) are able to be articulate and to express themselves. The mothers who I interviewed were able to engage and participate fully. They were able to reflect on their experiences and were open and honest, articulating not only the impact of having a profoundly disabled child upon themselves, but also the wider family. Some of the emotions expresses were strong and one particular mother was in tears as she told me her story.

5.10.4. Reliability and validity

Qualitative research can never claim to be replicable and so Smith et al (2009) argue that qualitative research should be evaluated in relation to criteria that is recognised as appropriate to it. Smith et al identify four principles as defined by Yardley (2000).

5.10.5 Sensitivity to context/sensitivity to data

A close engagement with the idiographic and the particular and an immersive and disciplined attention the unfolding account: An example of how I carried this out can be seen in the example of Barbara (see appendices 9: page 161, appendix 10: page 165 and appendix 11: page 175). I first coded the transcript according to Smith *et al* (2009) to identify emergent themes. I then sorted the themes under subordinate themes and then identified the superordinate themes.

Verbatim extract: I transcribed quotes for each theme: I then transcribed the superordinate themes into a spider diagram that were colour coded to highlight each superordinate theme (see appendix 12, page 178)

Giving the participants voice/carefully written account: Active listening skills were utilized when listening to the participant's accounts. I then transcribed each interview myself and checked and re checked for accuracy.

5.10.6 Commitment and rigour

Attentiveness to the participant when the data was collected: I visited participants in their homes to ensure that they were at ease when participating and so attempted to address any power balance that might arise. The mothers were aware that I could signpost them to extra support if any of the issues discussed caused them stress.

Thoroughness of the study/analysis conducted thoroughly and systematically with sufficient idiographic engagement: I followed the guidelines for IPA as detailed by Smith *et al* (2009), and Larkin (2007).

5.10.7 Transparency and coherence

The degree of fit between the research done and the underlying theoretical assumptions to the approached being implemented: Following the guidelines of Smith et al (2009) a systematic and rigorous analysis of the data was carried out. Transparency of the results of the analysis was possible because the superordinate themes that emerged could be checked against the original

transcript and the process of coding that occurred to achieve them. I also used a pilot study to practice my interview skills and to consider if the interview schedule needed to be amended.

Creswell (2009) suggests a peer debriefed to enhance the accuracy of the account by asking ongoing questions so that the account will resonate with someone other than the researcher. During supervision at work, I have engaged with my Line Manager who has asked ongoing questions as well as interested colleagues.

5.11 Reflexivity

A failure to be critically aware and know oneself can undermine the validity of research (Bannister, Burman & Polak (1994). IPA acknowledges that any insights or understanding that are gained are interpretive and can only be gained through the researcher's engagement with and interpretation of the participants accounts so that the researcher is implicated in the analysis (Willig 2008). IPA researchers are encouraged to 'bracket' off prior knowledge or assumptions of the phoneme under investigation. This I attempted to do by using a reflective diary. During data gathering I tried to capture the impressions and feelings that I felt and during the data analysis I tried to set aside any experience I might have bought to the first reading. The experiences that I identified and tried to bracket off were those of being an Educational Psychologist working at a PMLD school, including supporting individual families and the experience of having been a Respite and Shared Care Foster Carer for Barnardo's, giving me some understanding of what it was like to care for a disabled child in the short term.

5.12 Sampling

In IPA participants are selected on the basis that they can offer a meaningful perspective so the selection is purposive to be as homogenous as possible (Smith 2011). I was able to recruit 5 participants. All the mothers had children between the age ranges of 4 – 9. One mother was Black African, one was a single mother and one mother had two children at the school. They all shared the experience of parenting a profoundly disabled child.

5.13 Critical review of using IPA

Willig (2008) has noted several conceptual and practical limitations of IPA in that the language used can construct rather than describe reality so that it is impossible to access someone's experience.   She questions the success of participants in actually communicating their experience and counters that IPA describes and documents, but does not explain.   IPA is also idiographic, focusing on the particular, so leading to a restriction with regard to applicability of the findings to a wider population.   However, Willig also acknowledged that while small scale studies are not able to make claims for generalisation, they demonstrate what is available within a society or culture. IPA has a commitment to examining how people make sense of their experiences (Smith *et al* 2009) and IPA's idiographic commitment emphasises the importance of positively engaging with participants in an attempt to understand their sense making. In doing so as Thackeray and Eatough (2015) state, the researcher privileges the experience of individuals in the context of their lives and a strength of this research is that it gives a contextual account of what it is like to be the mother of a disabled child. The findings illuminate the ongoing anxieties of parenting, with families having to make sense of new and unsought situations and uncertainties about the future.

5.14 Limitations of the research

The research undertaken offers only a snap-shot of the experience of the participants. It is a small sample that does not reflect the general population and is limited to those parents who were prepared to engage from a particular school and who have had a particular experience (having had children with a profound or multiple disability). Therefore any conclusions drawn are specific to the particular group of participants and generalisations to the wider population should be treated with caution (Smith *et al,* 2009).

The use of an open ended interview schedule devised by the researcher makes it hard to replicate the research.

The interpretation is bound within the limits of the participants being able to communicate their individual experiences and a source of bias could be the subjectivity of the mothers in wanting to answer the questions posed to please myself as researcher.   A further limitation of the research is that there could be bias introduced through the perceptions of the participants of a power imbalance given some of the articulated experiences of previous interactions with professionals. There could also be bias through the subjective interpretation of the researcher. This leads to an acknowledgement of the results being approached with caution, but the value and strength of this research is that it provides a rich and contextual account of what is like to be the parent of a disabled child with profound or multiple disabilities (Thackeray & Eatough 2015) and emphasises the value of parental voice.   It also allows an insight into the experience of grief and resiliency and an interface with society's view of disability.

5.15 Implications for practice

Rolland's Family Illness System's model brings a better understanding of what families might be experiencing and the pressures that a family might be under. As has been already stated it is an opportunity for Educational Psychologists to develop systemic thinking and a more nuanced support for a family at a particular time. It is also a useful tool to elicit parental voice and to give value to their experience. For many of the mothers interviewed, interactions with professionals were negative experiences, feeling talked down to; their experience not being acknowledged and their children not being valued for who they are. This model allows parental experiences to be valued and placed at the centre of an interaction between themselves and the Educational Psychologist. Through using this model and understanding, the Educational Psychologist can also bring about organisational change, as school develops better targeted support and thinking that reframes views of the value of parental experiences.

Rolland's Family Illness System's model could also be used as a method of consultation with schools and for INSET training, and could contribute to wider understanding around mental health issue

Using an intake questionnaire such as that devised by Begum (2007) (see appendix 6, page156) should also be considered at transition into school to elicit further understanding and give opportunities for mothers to express their feelings about the life journey's that have taken them thus far. Begum uses the questionnaires as opportunities within a group, for mothers to acknowledge the skills, knowledge and stories that each other tell. Educational Psychologists are well placed to facilitate this process. The findings also highlight the positive resource a school can be in containing anxiety and providing a peer group for the mothers, developing advocacy and validating the mother's individual experience. Facilitating a group to develop these skills could also be a role for the Educationalist Psychologist.

I shall be reporting the findings of my research to the Governing body of Ashtree School and the Educational Psychology Service during the next academic year, but initial conversations with the Head Teacher are leading to INSET with staff, the development of a peer support group by parents for new parents and future Action Research around transition into school.

Further research would be useful in capturing the particular views of fathers and the impact of having a disabled child upon them. Their voice is seldom heard in research, and the views of mothers prevails. Fathers go through a similar range of emotions as mothers as is evidenced in their views from Contact a Family research (2013) and their involvement with their families can equally contribute to the family's well-being. Opportunities for their voice to be heard in school time due to work commitments also limits opportunities to capture their input.

Although similar experiences to those that I found to my research question have been highlighted in other research looking at the impact of a child with a disability upon the family, and similar themes have been identified in IPA studies by Heer, Larkin, Burgess and Rose (2012) and Thackery and Eatough (2015), I feel that as an Educational Psychologist working in a school for PMLD and interviewing parents from that school this has added a unique perspective to understanding the impact upon the home school relationship of a disabled child.

5.16 Reflections and Conclusion

Undertaking this research has given me new opportunities and insights. By attending the Tavistock and Portman NHS Foundation Trust to carry out this research, I have had opportunities for new learning that I would not have accessed anywhere else. I have developed skills as a researcher over time and have felt privileged to interview the mothers that I did as part of the research. I have appreciated their openness and willingness to share at times quite difficult things as I have tried to make sense of their experiences. As a Supervisor of trainees from Birmingham University, it was this experience that first spurred me on to consider undertaking research myself and I have enjoyed discussion about research methodologies and exchanging the ups and downs of carrying out research.

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LIST OF APPENDICES

Appendix 1: Ethical Application

Tavistock and Portman NHS Foundation Trust

Research Ethics Committee

Application for Ethical Approval of Research Involving Human Participants

Please read the Notes for Guidance before completing this form. If necessary, please continue your answers on a separate sheet of paper: indicate clearly which question the continuation sheet relates to and ensure that it is securely fastened to the report form.

Applications should be made on this form, and submitted electronically, to your **Course Organising Tutor.** A signed copy of the form should also be submitted to the **relevant course Organising Tutor**. Applications will be assessed by the **Course Organising Tutor** in the first instance, and may then passed to **Trust Head of Quality Assurance and Enhancement**, and then to **The Tavistock and Portman NHS Foundation Trust Ethics Committee**. A copy of your research proposal and any necessary supporting documentation (e.g. consent form, recruiting materials, etc) should also be attached to this form.

A full copy of the signed application will be retained by the **Trust** for 6 years following completion of the project. The signed application form cover sheet (two pages) will be sent to the **Trust Head of Quality Assurance and Enhancement as Secretary of the Trust's Ethics Committee.**

1. | Title of research project:

An exploration of the impact of having a child with profound or multiple disabilities upon the home/school relationship in a multi-cultural Special school for Primary aged children |
   |---|

2. The title of your research project will be published in the minutes of **The Tavistock and Portman NHS Foundation Trust Ethics Committee** . If you object, then a reference number will be used in place of the title.
   Do you object to the title of your project being published?   Yes ☐/ No X☐

3. This research Project is a Student Project X☐

4. Principal researcher (s) (students should also include the name of their supervisor):

Name: Jane Linton	Course: M5 - Professional Doctorate in Educational Psychology
Supervisor: Carol Greenway	

5. If external approval for this research has been given, then only this cover sheet needs to be submitted

   External ethics approval obtained   Yes ☐/ No X ☐

Declaration of Principal Researcher:

The information contained in this application, including any accompanying information, is, to the best of my knowledge, complete and correct. I/we have read *The Tavistock and Portman NHS Foundation Trust Guidelines for Ethical Approval of Research Involving Human Participants* and accept responsibility for the conduct of the procedures set out in this application in accordance with the guidelines, laid down by *The Tavistock and Portman NHS Foundation Trust ethics committee* . I/we have attempted to identify all risks related to the research that may arise in conducting this research and acknowledge my/our obligations and the rights of the participants.

Signature(s): ....……………………………..

Name(s) in block capitals: ....………………………..

Date: 18.02.2013…………………………………………………………………………………….....

Supervisor's recommendation (Student Projects only):

I recommend that this research project should be referred to *The Tavistock and Portman NHS Foundation Trust Ethics Committee* .

Supervisor's signature: ..…………………………………………………………………….………

Outcome:

The Chair of *The Tavistock and Portman NHS Foundation Trust Ethics Committee* has reviewed this project and considers the methodological/technical aspects of the proposal to be appropriate to the tasks proposed. The Chair of *The Tavistock and Portman NHS Foundation Trust Ethics Committee* considers that the Researcher(s) has/have the necessary qualifications, experience and facilities to conduct the research set out in this application, and to deal with any emergencies and contingencies that may arise.

This application is approved on behalf of *The Tavistock and Portman NHS Foundation Trust Research Ethics Committee* .

☐

Signature(s): ....……………………….……………

Name(s) in block capitals: ....….……………………………

Directorate: …………………………………………………………………….…………….………

Date: ……………………………………………………………………………………………..

☐

The application has not been approved by *The Tavistock and Portman NHS Foundation Trust Research Ethics Committee* .

Signature(s): ....……………………………………..

Name(s) in block capitals: …..….……………………….…

Date: …………………………………………………………...…

Details of the Research

1.
Title of research project :
An exploration of the impact of having a child with a profound or multiple disabilities upon the home/school relationship in a multi-cultural Special school for Primary aged children
Name of researcher (s) (including title): Ms Jane Linton
Nature of researcher (student): Yes
Student number: LIN0302539
Email: jane.linton@blueyonder.co.uk
Name of Supervisor: Carol Greenway

2.   Course title: Directorate:
M5 Professional Doctorate in Educational Psychology   **Department of Education and Training**

3.   Level of the Course programme (delete as Appropriate):
(c)   Postgraduate (taught)   **(d)   Postgraduate (research or Professional Doctorate) X**   **(e)   post-doctoral or staff**

4.   Number of:
(a) researchers (approximately): 1
(b) participants (approximately): 4-8

5.   Nature of participants (general characteristics, e.g. social workers, primary school children, etc):
Parents of Primary aged children who have profound or multiple disabilities.

6.   Probable duration of the research:
from (starting date): Spring 2013   to (finishing date): October 2014

. **Aims of the research including any hypothesis to be tested:**

- **To explore the impact of having a child with profound or multiple disabilities upon the home/school relationship**
- **To explore the parent's experience of school support**
- **To support the school in developing a model of support that could be utilised to understand and meet the needs of any family at times of crisis**
- **To explore a potential role for Educational Psychologist's based on what I find out from families that could enable Educational Psychologists to offer more systemic and family orientated support**

My research is set in a primary aged school for children with Profound and Multiple Learning Difficulties.
The school is in the north part of Walsall. Although the school is situated is in a poor socio –economic area, it has a multi-cultural population because parents send their children from all over the authority due to the school's outstanding OFSTED reports.

My research topic has been agreed by the school because it builds on their style of working and will create opportunities for learning how to work with parents at crisis points, an area of practise that the school is keen to develop.

I am using Interpretative Phenomenological Analysis to formulate my research because it has been described as the examination of how people make sense of a major life experience. IPA researchers are especially interested in what happens when everyday life takes on a particular significance. In my research I will be concerned with the parent's personal perception of the impact upon their lives of having a disabled child and how this has affected their relationship with the school. IPA allows a transparency of process, which will give my research validity.

As a reflection tool, I will be using a model of systemic thinking called the Family illness systems model (Roland 1994). It could be used to help understand the context and life stage in which a family might be operating, informing how the school might more appropriately foster the home/school relationship. Roland suggests a model of the life cycle as a developmental framework. He suggests that there will be times of higher (centripetal) and lower (centrifugal) cohesion. Roland feels that if the illness or disability is severe, then a family can become stuck in an overly cohesive cycle with all their energies focusing inwards. This can then affect how they interact with the outside world.

I want to consider how the concept of family being 'stuck' in a centripetal phase or at a more fluid lower cohesive phase might impact upon the home/school relationship enabling the school to gain a greater understanding of the stress that a family might be. I would hope that the research would lead to the school having more understanding as to why the home/school relationship might be difficult as that time. I would hope that the research will lead to the school developing earlier interventions with a family rather than being reactive to a more difficult situation where support can less effective for the family. Although this model applies to families with a disabled child, I would hope that as a result of this research that it could be utilised to understand and support any family at a time if crisis.

I will be utilising themes from Begum's Intake Questionnaire (2007 Appendix 2) to develop semi- structured interviews as this will enable me to reflect the multi-cultural nature of the school population and help me to make sense of what might be happening.
Following the SEN Green paper (2011) consultation process, which considered the ongoing role of the Educational psychologist, it was highlighted that respondents wanted

there to be more face to face contact, more frequent home visits and work with families. I would hope that from my research there might emerge a potential role for Educational Psychologist's based on what I find out from families that could enable Educational Psychologists to offer more systemic and family orientated support.

8.   Description of the procedures to be used (give sufficient detail for the Committee to be clear about what is involved in the research). Please append to the application form copies of any instructional leaflets, letters, questionnaires, forms or other documents which will be   issued to participants:

I will be inviting parents to participate who have already shown interest in an ongoing two year project that I and two colleagues have been involved in with the school. The project has been around the area of the emotional and well-being needs of the pupils who attend the school. They have identified themselves by participating in an earlier questionnaire sent to all parents of the school. I will send the parents/carers a letter of introduction and an information sheet. Once parents have shown an interest, I will meet with them to explain the research further.

If they decide to participate, I will ensure that they understand that the research will be shared with the school and Educational Psychology Service.   Parents will be told that they will remain anonymous at all stages and that no information will be contained within the research that will allow them or anyone that they refer to be identified. They will be reminded that at any time during the research they have the right to withdraw. I will ask the parents to sign an informed consent form indicating that they understand this.

I will be using semi-structured interviews with parents.   All the interviews will be conducted face to face and will take place either in their own homes or in a location of their own choice.

I intend to utilise themes from the intake questionnaire developed by Begum (2007 to develop the semi- structured interviews. She considers the areas of:
- A history of care
- Currents acts of care: physically, emotionally, other people's care, history of skills
- Responding to blame and stigma

The interviews will be audio taped and then transcribed.

- Appendix 3: Sample Letter
- Appendix 4: Information sheet for Parents
- Appendix 5: Informed consent form

9. **Are there potential hazards to the participant(s) in these procedures?**
YES

If yes: (a) what is the nature of the hazard(s)?

The main ethical consideration of the research will arise from talking to potentially vulnerable participants about their experiences of raising a disabled child and the impact that this may have had on the family. This has the potential to re-ignite feelings of grief or loss.

(b) what precautions will be taken?

I will ensure that I am mindful of this and do not ask questions or pass comments that might alter their perceptions. If a participant should become distressed, I will follow up our conversation with a phone call to monitor their response and then signpost them to a relevant agency that might be able to provide further support. There is a named Clinical Psychologist attached to the school to whom I could also refer participants for support.

10. **Is medical care or after care necessary?** **NO**

If yes, what provision has been made for this?

11. **May these procedures cause discomfort or distress?** **NO**

If yes, give details including likely duration:

12. **(a)** **Will there be administration of drugs (including alcohol)?** **NO**

If yes, give details:

(b) **Where the procedures involve potential hazards and/or discomfort or distress, please state what previous experience you have had in conducting this type of research:**

13. **(a)** **How will the participants' consent be obtained?**

A clear outline of the research will given to the potential participants to ensure that they are aware of the purpose of the research, who the results will be shared with and their right to withdraw both initially and once they have agreed. This will be presented in both written from and verbally to account for any literacy difficulties.

(b) **What will the participants be told as to the nature of the research?**

The participants will be told that the research is exploratory and that I am interested in hearing their experiences of having a disabled child in the family and considering how the home/ school relationship could be strengthened to support them.

14.   **(a)**   **Will the participants be paid?**   **NO**   **(b)**   **If yes, please give the amount:**   **£**   **(c)**   **If yes, please give full details of the reason for the payment and how the amount given in 16 (b) above has been calculated (i.e. what expenses and time lost is it intended to cover):**

15.   **(a)**   **Where will the research take place?**
 	
 The research will take place in the participant's home or at a location of their choice. If the research by the participant's choice should be at school I will ensure that a private space is located to ensure confidentially.
 	
          (b)   **What equipment (if any) will be used?**
 	
 Data will be kept on a Dictaphone and transcribed personally.
 Data will be kept on an encrypted memory stick.
 	
          (c)   **If equipment is being used is there any risk of accident or injury? NO**
 	
                  If yes, what precautions are being taken to ensure that should any untoward event happen adequate aid can be given:

16.   **Are personal data to be obtained from any of the participants?**   **NO**
 	
          If yes, (a)   give details:
 	
 During the semi-structured interviews, participants will be asked about their experiences of having a disabled child and the impact on the family. This may result in personal details about themselves and their child.
 	
 Participants will be reminded that anything that they talk about during the research process will be confidential unless they share something that might indicate that they (or those around them) are at risk of harm. In that case I would follow the procedure s set out by my employer.
 	
                  (b)   **state what steps will be taken to protect the confidentiality of the data?**
 	
 Data will be kept and stored in accordance with the Data Protection Act (1998). Data will only be used for the purpose for which it was originally intended. Data will be kept on a Dictaphone and transcribed personally so that only I have access to the data in its raw form. Data will be kept on an encrypted memory stick. All written transcriptions will be stored electronically and password protected. The data will not be stored against the participant's name at any stage.   Interviews will be recorded and transcribed. Any information that is given that could enable identification of the participants will be

anonymised and deleted where necessary. It will be locked away in a secure filing cabinet to which I am the key holder. It is possible that as the parents are known to the

Educational Psychology Service that their details will be on the data base, but there will not be any way of knowing they participated in the research.

      (c) state what will happen to the data once the research has been completed and the results written-up. If the data is to be destroyed how will this be done? How will you ensure that the data will be disposed of in such a way that there is no risk of its confidentiality being compromised?

All electronic data will be deleted by myself as I will ensure that only I have access to the data in its raw form.

Written transcriptions will be shredded and removed by a Secure Disposal Unit. This will occur a year after the research has been completed.

17.   **Will any part of the research take place in premises outside**   **YES** *The Tavistock and Portman NHS Foundation Trust*?

    Will any members of the research team be external e.g. a research assistant to the *The Tavistock and Portman NHS Foundation Trust*?   **NO**

    If yes, to either of the questions above please give full details of the extent to which the participating institution will indemnify the researchers against the consequences of any untoward event:

This research is not a requirement of the Employer and so is undertaken at my own risk. I have professional indemnity through being a member of the Association of Educational Psychologists. Permission has been given for the research by the Assistant Managing Director of Walsall Children's Services SERCO.

18.   **Are there any other matters or details which you consider relevant to the consideration of this proposal? If so, please elaborate below:**

21.   **If your research involves contact with children or vulnerable adults, either direct or indirect (including observational), please confirm that you have the relevant clearance from the Criminal Records Bureau prior to the commencement of the study and the clearance number noted.**

    YES CRB: 00-1265589293

22.   **DECLARATION**

    I undertake to abide by accepted ethical principles and appropriate code(s) of practice in carrying out this research.

    Personal data will be treated in the strictest confidence and not passed on to others without the written consent of the subject.

The nature of the research and any possible risks will be fully explained to intending participants, and they will be informed that:

    (a)   **they are in no way obliged to volunteer if there is any personal reason (which they are under no obligation to divulge) why they should not participate in the research; and**

    (b)   **they may withdraw from the research at any time, without disadvantage to themselves and without being obliged to give any reason.**

NAME OF APPLICANT: **Signed:** _____
(Person responsible)

_____   **Date:** _____

NAME OF DEAN OF TRAINING: **Signed:** _____

_____   **Date:** _____

ethics.app
[October 2010]

Appendix 2: Research papers considered for further scrutiny using CASP

Author, year and country	Sample	Method of data analysis	Methodology	Theoretical perspective	Why chosen?
Down (2010) UK	4 families, 4 doctors, 4 nurses	Constant comparison, axial coding, and theoretical sampling	Grounded theory	Systemic and social constructionist	Confirms the usefulness of focusing on relationships between parents and medical professionals and to look beyond the family as the sole locus when difficulties arise
Lalvani (2015) USA	32 parents 30 teachers	Inductive analysis	Narrative inquiry	Disability as a socially constructed phenomenon	Explores the perspectives of parents and teachers in regard to the meanings and implications of disability in the context of raising and schooling a child with disability. The findings highlight conceptual differences between the two groups
Lundeby & Tossebro (2008) Norway	Parents of 31 children	Issue-focused procedures using matrices to categorise different themes	Mixed methods		Considers that in parent/professional relationships the underlying problem as viewed by parents is that their knowledge is not valued. The findings suggest the necessity of negotiation between parents and professionals and a more humble approach
Heer, Larkin, Burchess & Rose (2012) UK	9 Sikh and Muslim parents	Analysis of data set identified 3 master themes	IPA		Provides an insight into how culture can shape the ways in which disabilities are understood

Appendix 3: Letter to parents

Dear Parents/Carers

I am writing to ask you to take part in research into the impact that having a child with multiple or profound disabilities has on your family and how this might affect your relationship with the school.

I enclose further information that I hope you will be able to discuss with your family. I will be very happy to discuss any questions that you might have.

If you are interested in sharing your experience with me could you return the slip below in the envelope provided. I will arrange to meet with you to explain the research further.

Yours sincerely

Jane Linton

Educational Psychologist

Yes, I would like to participate   _____

No, I would not like to participate _____

Name……………………………………………………….

Appendix 4: Information Sheet for Parents

A study into how does having a child with profound or multiple disability affect the home/school relationship

I am inviting you to take part in a research study. Before you decide if you might want to take part, I want to explain why the research is being done and what it will involve. I am undertaking the research as part of completing a doctorate.

As Educational Psychologist for the school, I have been involved with colleagues running a project in the school. We have been helping staff to consider how they could meet the emotional health and wellbeing needs of pupils who attend the school. I am looking to explore how you feel that having a disabled child has affected you and your family, and in what ways the school could better support you. I am interested purely in you experience.

I am writing to you because you recently participated in a questionnaire as part of the school project and I would like to discuss you experiences more fully.

If you take part you will be asked to sign a consent form. If you change your mind at any time, you will be free to withdraw. If you agree to take part, you will be offered an interview at a place where it will be convenient for you.

Once the interviews have been completed, I will feed back the result to you to check that you are happy with what I have written and so that you were aware of what the outcomes are. The research will be shared with the school to help inform their support for parents and also to the Educational Psychology Service to help us understand and support parents better and to improve our practise.

- At no point in the research will you be identified by name or will any in formation be stored against your name
- I will be aware that you have participated in this research, but other than this you will remain anonymous

- Everything you talk about in the research will remain confidential unless you share something that that might indicate that you or those around you are at risk of harm. Then it is my duty to follow procedures set out by my employer

- Should the interview raise any difficult issues, I will sign post you to other agencies who might be able to give you support

- Any interviews will be recorded, but the recordings will be kept in a safe space and destroyed once they have been transcribed

- I will be carrying out the transcriptions to make sure that no-one else has access to the data

Contact details: Jane Linton Educational Psychologist 01922 686 375

Appendix 5: Informed consent for parents

Informed consent form

I have read and understood the information that I have been provided with	
I have had time to think about the information	
I understand that the views I give will be shared, but that no information will be attributed to me	
I understand that my participation in this research is entirely voluntary and that I can withdraw at any point. If I decide to withdraw, I can ask for my data to be withdrawn from the research	
I understand that the interview will be recorded	
I agree to take part in the study	

………………………………………………………………….

(Full name)

………………………………………………………………..   …………

(Please sign your name)   (date)

Thank you for completing this form

Appendix 6: Talking with Mothers and children - An intake questionnaire. Developed by David Denborough (Dulwich Centre Institute of Community Practice) in conjunction with Maksuda Begum (Bangladesh Protibondhi Foundation) 2007

A history of care

- When did you first come to think that your child was different from other children?

- How did to respond to this knowledge?

- What steps have you taken before coming here?

- Why did you take these steps?

- Were there any difficulties along the way?

- If so, what assisted you to keep persisting, to keep seeking help? Why was this important to you?

- What do you think it says about you that you have taken all these steps?

- What does it say about your commitment to your child?

- Who would be the least surprised to know that you have this commitment to your child?

- If they were here now, what might they say about this history of care?

Current acts of care

Physically

- Are there ways in which you care/support/assist your child physically? Including food, shelter, warmth etc?

Emotionally

- Are there ways in which you are/support/assist your child emotionally?

- When he/she is upset, how do you respond?

Relationships with others

- Are there ways in which you care/support/assist your child with relationships with others (brothers/sisters/friends/other family members)?

Others people's care

- Are there other people who assist in caring for your child?

- If so, who are these people?

- Why do you think they assist in this caring?

- What do they value and appreciate about your child?

History of skills

- It seems that you care for your child in many different ways; how did you learn to care for your child in these ways?

- Who taught you these skills? Who did you learn your caring from?

- What would they say about the ways in which you use these skills to care for your child?

Responding to blame and stigma

Responding to blame

- Is 'Blame' part of your life?

- What effects does 'Blame' have on your life and what you think about yourself?

- What effects does 'Blame' have on your relationships with other family members?

- What effects does 'Blame' have on your relationship with your child?

- What effects does 'Blame' have on your child's life?

- When is 'Blame' most powerful?

- When does it do the most harm?

- Are there times when 'Blame' is not so powerful?

- Are there people, friends, family members who do not support 'Blame'?

- Who is the most supportive? Why do you think they are supportive? What do they value about you? Why do they care about you?

- Are there ways in which you have found to cope with 'Blame'? When 'Blame' is present are there any ways in which you protect yourself?

Responding to Stigma

- Is 'Stigma' a part of your life?

- What effects does 'Stigma' have on your life and what you think about yourself?

- What effect does 'Stigma' have on your relationship with other family members

- What effects does 'Stigma' have on your relationship with your child?

- When is 'Stigma' most powerful?

- When does it do most harm?

- Are there times when 'Stigma' is not so powerful?

- Are there people, friends, family members who do not support 'Stigma'?

- Who is most supportive? Why do you think that they are supportive? What do they value about you? Why do they care about you and your child?

- Are there ways in which you have found to cope with 'Stigma'? When 'Stigma' is present are there any ways in which you protect yourself and your child?

Appendix 7: Questionnaire for parents

Questions for Parents

HISTORY OF CARE

- Can you tell me about your family? (*Family Map*)

- Can you describe the ways you and your family care for..........?

- Can you describe how you first came to think that you child was different from other children? *Prompt: how did you feel? How did you cope?*

-

EFFECT ON CARER AND WIDER FAMILY

- Can you describe the impact that having ....has had on your family?   *Prompt: coping with blame*

- Have you changed in the way that you see yourself over this time?   *Prompt: How would you describe yourself as a person? What do others value in you?*

- Can you tell me about who has been the most supportive in your family? *Prompt: What do they value about you? What do they value about your child?*

RELATIONSHIPS WITH PROFESSIONALS

- Can you describe the most helpful support you have had from outside the family?

- Can you describe what sort of support you feel the school gives you?

- Can you tell me about a time when you found the support from the school the most useful?

- Can you describe the support you would like the school to give you as your child gets older?

Appendix 8: Family Map for Nicky
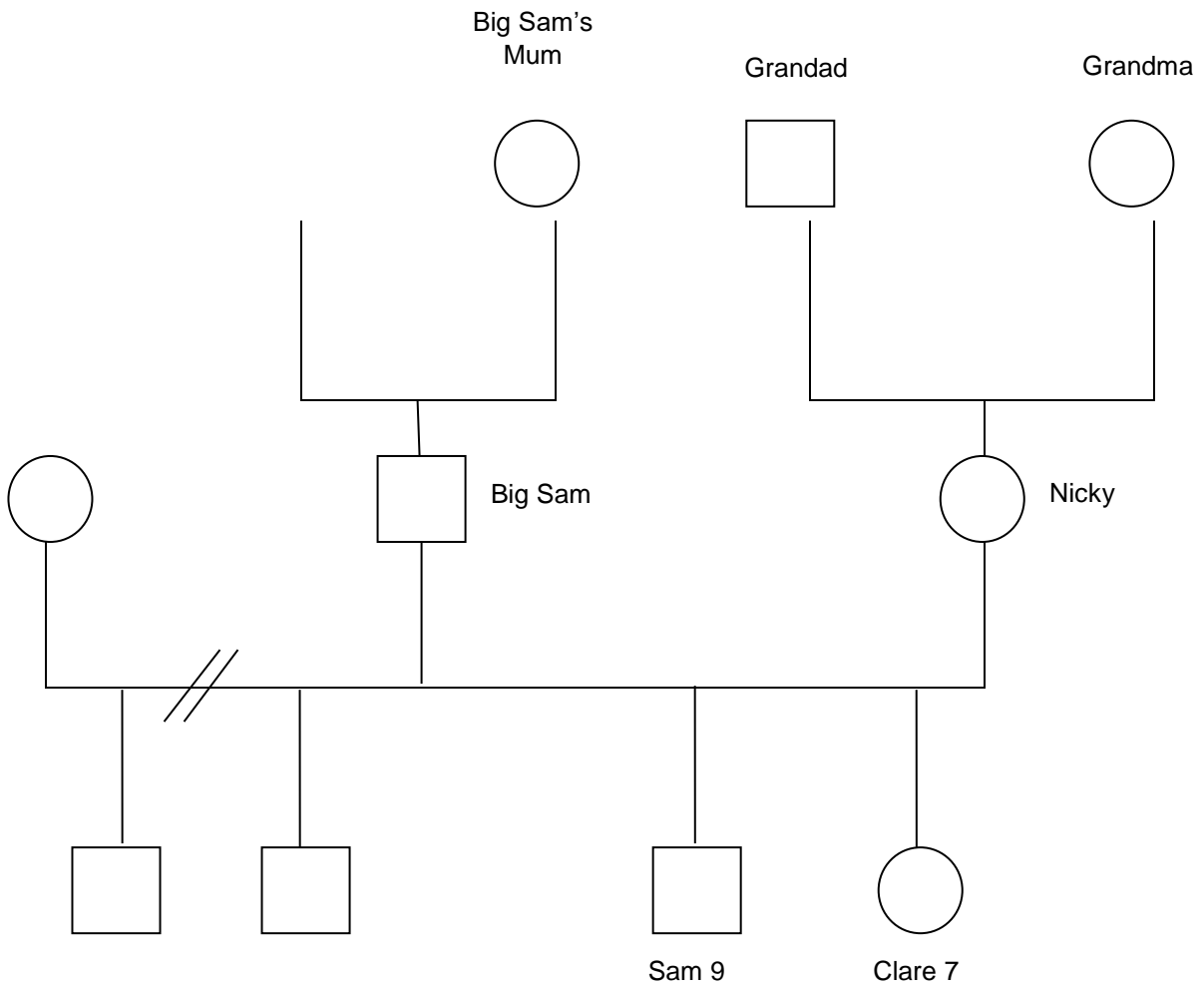
Appendix 9 – Step 2 for Barbara - initial noting

Descriptive
(blue ink in) conceptual comments

Emergent themes		transcript	Exploratory comments
	1	Ok. What I am going to do first is to draw	
	2	something called a family map. It looks at family	
	3	relationships. So the first question is - Can you tell	
	4	me about your family? – And I'll try and draw it.	
	5		
	6	P. This family?	
	7	I. Yes, whatever you consider your family to be.	
	8	P. Um, basically, probably on my side, there's my	
	9	mum and dad and I've got a nanny still alive on that	is mce a sux of indignation that the
	10	side, my mum's mum. It's quite an extended family	extended family, but will support
Family relationships as	11	around my mum, but we don't really have an awful	are lots of family history dont help
un supportive-problem are	12	lot to do with them. I've got one sister, but we don't	from? inconsispecity of being isolated
	13	really have a lot to do with her either. Then Luke	
	14	has, um, Luke's mum is still with us and then he has	
	15	two sisters that we have quite a lot to do with, and	
	16	they have kids as well so, um.	
	17	I. And how old are the children?	
	18	P. Colin, actually, right this very month they are	
	19	both four, but Colin will be five in the first week in	
	20	September, and Caitlin turned four about two	
	21	weeks ago so. There's, um, just 10 months between	
	22	them, so there's this strange thing where once a	
	23	year, they're both the same age.	'nearly twine'
	24		
	25	**Right, so then, the first question is can you describe**	
	26	**the ways that you and I suppose Luke really as well**	
	27	**– how you and Luke and your family care for Caitlin**	
	28	**and Colin?**	
	29		
	30	P. Basically when we received the diagnosis, um, I	hesitancy
	31	was already ready, um, sort of given up work	
	32	because I had just gone through maternity, I'd had	on going maternity- impate I
	33	about two or three years of maternity. Obviously	was before is big the

1

162

the grandnots has actively back compromised	34	having the kids back to back and I wasn't very well,
	35	um, with a post natal illness with the pregnancies
	36	and whatever, so I hadn't gone back to work, um,
	37	but Luke had to give up work to help me care for the
	38	kids, because it was pretty impossible. Both my
Lack of supportive network	39	parent's worked and Luke's mum was out, and so
	40	there wasn't really any sort of support networks. So
	41	in terms of sort of caring for the children 24/7, you
A giving up-lots of future aspirations / expectations? what was everybody else done?	42	know, we've really had to sacrifice quite a lot to
	43	make sure that they was ok. Um, and then my mum
	44	and dad, they obviously sort of help when they can,
	45	but physically, they're not able to keep up with the
are family support only reaches physical need	46	kids quite so much. So they can care for them in the
	47	house, but pretty much outside it would be, um, too
	48	much for them really. Um, and Luke's mums the
	49	same, she, um, Luke's mum tends to focus on
	50	helping us care for the house, keeping the house in
	51	order while we're looking after the kids. So, um, we
	52	have, you know, we do have a support network, but
overstated expectations of family support more widely core-emotional needs not met	53	it, it's probably not as, you know, as wide reaching
	54	as we would have hoped. Um, you know me and
	55	Luke have you know, pretty much had to say, well,
	56	you know, there's no time for ourselves, it's for the
	57	kids at the moment. Um, my mum and dad bought a
maternal sacrifices of others (parents) not highly valued	58	caravan for the kids, um, to go to the beach and that
	59	sort of stuff, so in terms of respite, we kind of, we go
	60	away to the caravan probably every weekend. Um,
	61	that gives us a bit of down time because the kids are
	62	quite happy there, and you know we find that the
	63	smaller space work easily for us and they get to be
	64	outside and run off some energy so, um, that kind of
	65	helps as well. Um, again it doesn't give us any time
	66	away, but it does give us down time and my mum

having the grandkids & close together post natal illness - impact. What has already effected their life? Dad & also a lot what was it like was impossible?

lack of support network

sacrifice + a giving up what was she a worry when?

limited of support - physical not emotional - practical

everyone has a role.

limited support - is there a disappointment that the wider family haven't rallied more? lack of time - down time in the kids

why not the grandkids / parents a caravan not committed? - respite nearly as wind from parents

respite is giving money / parent / kids diverted in a bit of down time

down time

patient

67	and dad come there and they help us with that, but,
68	so, um, it is a kind of all hands on thing, um, but you
69	know, it's probably not the sort of village life as we
70	would have hoped for, but at least we do have
71	support. We know we're not looking about for
72	friends.
73	
74	**So can you describe how you first came to think**
75	**that Colin and Caitlin were different from other**
76	**children?**
77	
78	P. Yeah, um, Colin's was quite, um, very obvious. In
79	fact as he was developing, um, really nicely really,
80	you know, perhaps a little bit ahead of what other
81	kids might have done. He was doing animal noises;
82	he was learning, you know, a few words of TV
83	characters, that kind of thing. Um, he was bringing
84	us books to read. He knew all the actions to twinkle,
85	twinkle, little star. He was very comfortable with
86	our mum and dad, that kind of thing. And then he
87	just literally, a couple of weeks after his second
88	birthday. He just woke up and everything had gone.
89	All the words had gone. He was very frightened. He
90	was very angry. He was very upset. Um, his speech
91	had developed, but had regressed back into
92	grunting. Um, he would scream if anybody come
93	near him other than me and Luke. Um, so we, we
94	knew pretty instantly. Looking back now, there was
95	probably a few signs. Um, he was quite introverted.
96	He would like to spend time on his own. He would
97	line things up. He would toe walk. Um, all of this,
98	obviously we didn't know at the time, but looking
99	back, you know, it probably wasn't as instant as we

Left margin handwritten notes:
- Access to the 'ideal' community derived living thy second born
- High expectations of normal development
- The overnight change ... ng his ... continues. Appraisal of development.
- The questioning ref

Right margin handwritten notes:
- all hands 'needed', can't be done on one's own
- village life - a romantic view?
- imagined - the ideal community
- but she envisic busy but of a wide community and is disappointed?
- isolation!
- obvious - made sense in hindsight
- something that was obvious, but was...
- development was a head
- comfortable relating with grandparents diff era
- woke up - it was gone - as if occurred... single incidents you're x
- fast + anger - just any to describe reg?
- does he use / hurt any to describe reg?
- her feelings? Everyday changed?
- most instantly knowing was wrong
- missed sign - guilt?
- hindsight
- does she wish she had had prior knowledge?

100	thought it was. There was probably the signs leading
101	up to it, but it was literally overnight the, you know,
102	the dramatic change. Um, and we, yeah, took him
103	to the Consultant, um, who referred him for an
104	assessment. But obviously at that time, I had a lot of
105	involvement, um, from therapists for me through
106	the post natal illness. Um, so they were kind of
107	helpful and valuable in being able to help us rather
108	quickly. Um, and because we was watching Colin,
109	and they obviously was watching Caitlin as well and
110	we knew Caitlin didn't develop anywhere near the
111	likes of Colin, and so even now it's still babble,
112	there's no words. Um, but again she wasn't very
113	sort of um, you know the books and toys and things
114	like that didn't interest her. So, um, almost just as
115	soon as Colin was finishing his assessment, Caitlin
116	started hers. Um, so we was very lucky that at the
117	time because of what was happening to me. It
118	meant that there was lots of people on hand to sort
119	of say look we need to get this sorted as well, so, so,
120	yeah.
121	
123	**Can you describe the impact on you of having these**
124	**children on your life?**
125	
126	Life changing, life changing. Um, at first and
127	probably for about and probably up until about six
128	months ago, um, the impact was quite traumatic,
129	very, very, upsetting. Um, you sort of, um, all the
130	dreams that you had for your kids and for yourself
131	and for you as a family just disappear. You know
132	Luke and I had visions of taking, you know we was
133	both quite, well I guess you would call us hippies

4

Appendix 10

STEP THREE

Conversation 2:   Clustering of themes and subordinate themes leading to identified superordinate themes

Theme	Quote	Page/line number
Making sense of life changing events		
An dramatic change		
• The nightmare continues	'he just woke up and everything had gone'	3.88
	'it was literally overnight you know, the dramatic change'	4.101-102
• Time stands still	'um and because we was watching Colin, and they was obviously watching Caitlin as well, and we knew Caitlin didn't develop anywhere near the likes of Colin	4.108-111
• Diagnosis transforms everything	'life changing, life changing'	4.126
• A severe blow	'the impact was quite traumatic, very, very upsetting'	4.128-129
• Financial burdens	'I mean what are we going to do? In the future are we going to be able to go back to work? If not, how do we support the family?	6.175-177
• Mourning and grief for expected family life	'and life we saw ourselves having has gone, and it's a bereavement you know, it's a bereavement'	16.501-503
Loss of expected future		
• A giving up/loss of aspirations	'you know, we've really had to sacrifice quite a lot to make sure that they was ok'	2.42-43
• The future evaporates	'um, all the dreams that you had for your kids and for yourself	4.129-131

and for your family disappear'

• Ideal future is to fragile/ ethereal/disappears	'and you know, you have visions of what what your children was going to be like, and the dreams you have for the kids, you know walking them down the aisle and what job they will get. And all of that disappears overnight'	5.140-145
• Future can't be defined – a void	'um, we went through a very, very, dark period when we sort of thought, you know they're going to end up in a care home, and we're not going to have any grandkids and what's the future for them'	5.147-151
• Peering into uncertainty	'But you know, that, that feeling of darkness perhaps doesn't leave you. It just gets less, you know, and those dreams that you have don't sort of leave you, but they just become less'	6.167-171
• Fear of isolation	'Um, and it's a very, very lonely journey. You know, um, your social life disappears and your friends you had before disappear'	15.471-474
An alternative lifestyle		
• Access to preferred community denied	'it's probably not the sort of village life as we would have hoped for'	3.69-70
• Loss of ideal role – part of the ideal community	'well, I guess you would call us hippies really, you know we both loved the idea of touring the world with the kids going. I've done quite a lot of backpacking and stuff and I wanted to do that with the kids'	4.133-137
• An alternative life style construed	'well, ok we've had to give up on those dreams. But what dreams	5.162-166

How families change		Quote	Ref
The changing substance of being a parent		'can we have. You know, um, the next best thing to Thailand is a beach in Barmouth. And we've got that'	
• The questioning self		'um, all of this we obviously didn't know at the time'	3.97-98
• Questioning of core values		'We, we were very confused as to our role. Were we parents? Were we carers? Could we have that relationship with our kids that other people have? We were very jealous of other, other families'	5.151-155
• Questioning of purpose		'so, um there's a sort of questioning of identity if you like'	6.173-175
• One's inner core is fragile		'I think we've found that the emotional side of it has been the hardest to kind of deal with'	6.193-195
• Bearing the diagnosis of your child		'You know we've had a lot of cases when people that we had a lot to do with, um, before the children got their diagnosis disappeared pretty soon after'	15.474-477
• Internalising of hurts		'and these are the sort of things that you can't deal with on your own'	15.480-482

	Quote	Reference
Paternal role diminished		
• Father's self-denial is of more value	'Um, you know he's sacrificed far more than me'	8.251-252
	'as the man, he's the bread winner, and things like that you know, and he's had to, he's had to put his family first, before you know, before that sort of manly image if you like'	8.253-257
Loss of expected child development		
• A sudden reversal	'He just woke up and everything had gone. All the words had gone. He was very frightened. He was very angry'	3.88-90
	'His speech had developed, but had regresses back into grunting'	3.90-92
	'but it was literally overnight, the, you know, the dramatic change'	4.101-102
• Loss of expected outcomes	'when they first got their diagnosis, it was the not knowing what was going to happen, and where they was going to be and what they were going to do'	12.391-394
Limitations of family support		
• Family relationships as unsupportive	'It's quite an extended family around my mum, but we don't really have a lot to do with them'	1.10-12
• Disappointed expectations	'Both my parent's worked and Luke's mum was out, and so there wasn't really any sort of support networks'	2.38-40
	'but physically they're not much able to keep up with the kids quite so much. So they care for them in the house, but pretty much outside it would be, um, too much for them really'	2.45-48

	'So um, we have, you know, we do have a support network, but it's, it's probably not, you know, as wide reaching as we would have hoped'	2.51-54
• Material sacrifices of others not recognised	'Um, my mum and dad bought a caravan for the kids, um to go to the beach, and that sort of stuff'	2.57-59
• Uncertainty about future support	'And obviously you know, you have to think, um, how long this support system we've got in place will last'	6.186-188
	'you know, you sort of think, what, who can we rely on in the future and will be there'	6.190-191
Relationships facilitated by school As mother of her children • A defined role	'um, you know, we very much want to be a part of whatever's happening in the school'	11.354-356
• Validates the self	'I think it helps as well because it gives you a sense of identity and it gives you a sense of community'	11.356-358
• School seen as a 'safe base'	Um, it's just a sense of as well of, of not being alone'	12.384-384
	You know everybody there knows us, they know our families, they know our names, they know our kids'	12.385-387
	'I know they are going to be there for the next ten years, so there is a sense of comfort there'	12.396-397
• It requires a full engagement	Obviously I know what's available to me because I've, you know I've sort of thrown myself into it'	12.379-381

As a generic 'parent' • Some issues seen as insignificant	'You know, you don't always feel that you can bother the school for some silly things you know. Things that allow your day to tick over, but perhaps aren't problems as such, but just something you need to deal with on that particular day'	10.310-315
	'I think that you kind of feel like that perhaps there's kind of stuff that you can't go to them for you know. If it's not a huge problem then maybe you should look somewhere else'	11.335-337
Not being seen in a diminished role	'You know you don't want to bother them. You know you don't want to be seen as a nuisance and you don't want to be seen that you're not coping'	11.338-341
Important to be seen as self-sufficient	'but there are certain things that the school will know that I wouldn't go to them for, do you know what I mean, because I wouldn't want to take up their time'	11.344-347
Role of parents/teachers of equal value	'You know I do feel like the teachers, um, are probably the second people that know your kids as well as you do, you know'	11.364-367
	'But I know, that that the school, you know are there as and when you need them'	13.416-418
Professionals validate her view	'Um, there aren't many people in terms of professionals that you can say, well you know, I know they spend as much time with the kids as I do. So I know they're going to have seen what I've seen and will, you know, have an equal sort of opinion'	12.367-372
Parents have needs too	'so yeah, you know, I would say to any services, not just the school, you know, try to think about the parents as well and help them, because it's not just all about kids'	15.497-500

As a conduit to other professionals		
• Access to specialist knowledge for the children	'um, you know like I said, if you need to see a Consultant, you can get that through the school and that kind of thing'	12.375-377
	'And it's just being able to, um, in particular at the moment, you know, it's contacting the Consultant through the school, and that sort of thing'	13.411-414
• Parent experience of professional support	'We had the meeting with the Speech and Language about how we could help the kids. Um, so you know we've accessed quite a few agencies, that perhaps we didn't know were available to us'	13.427-431
• Parental need for professional support not acknowledged	Um, and that's not just at school, I find that support rough across all of the services'	14.466-467
• The unacknowledged impact of emotional hurting	'I think one of the things that, um, you know that we would perhaps would benefitted with and probably will benefit in the future is some form of sort of counselling for, for the parents'	14.440-444
	'But I think it's, it's the sort of professional support for the emotions that parents are feeling that I would like, um, sort of put in place'	14.447-500
	'I think it's about having a, a, professional that I can go and sort of pour my heart out to and receive support that way'	14.455-457
	'And these are the sort of things that you can't deal with on your own. Whereas really you need, you want somebody to be able to say to "look that's really hurt me, that's really upset me and perhaps listen rather than... Um I think it's the emotional support that we needed'	15.481-486

• Seeking a guide to point out the way	'you know there's a lot of focus on the children, and a lot of focus upon the family, but there's not a lot of focus on the parents' 'somebody right at the beginning who could have said this is what this means for you, and perhaps we could have had some hope at the beginning'	15.469-471 15.488-492
• Professional services as distant to real need	'So yeah, you know, I would say to any services, not just at school, you know, to try to think about the parents as well and help them, because it's not just all about kids'	15.497-500
Parental solidarity through shared experience Companionship for the journey • Enlightenment	'And meeting other parent's, um, not just sort of in advice terms. They kind of opened our eyes. You know everybody's at a very different level'	9.297-300
	'And also having you know, um, other families that we can sort of say 'well, do you want to go here? Do you want to go there together? So you start to build up a little bit of a social life you know'	10.316-320
• Reciprocity	'at least you are with people who all understand, you know'	10.321-322
	'it's that kind of thing we've been able to perhaps offer that supports other parents. So that makes you feel, you know, that sort of thing, it makes you feel like normal because you do lose your identity, you do sort of think, well who am I?	10.325-330
	'You know what can I offer? What sort of thing can I do that will make a difference you know, to my kid's life and perhaps somebody else's life?'	10.330-333

• Understanding Isolation	'I know I have support, but should I go through another dark period other than turning to other parents who may also have experiences of problems themselves'	14.452-455
	'As I've said at the moment, a lot of parents don't have that, don't feel they can speak out to other people'	14.458-460
• Mutual encouragement	'you find a way through that by meeting and talking to other parents that have been where you are and they can offer the next step if you like. You can see the next step'	5.156-159
	'and they are a lot further along, so they can offer a lot more insight than, than where we are'	10.302-304
	'Um, I think we'd be very, very, stuck if we wasn't, you know if we didn't have that support. Who would we turn to just for simple things like you know what's the number for the nappy service?'	10.306-310
Hope for the future Mutual support • The ideal companion	'I know that there's you know, lots of mothers do this journey on their own, um, and I am so grateful that I haven't had to'	8.249-251
	'without doubt, I wouldn't you know have got anywhere near through this journey without him and hopefully he would say the same of us'	8.259-262
• A proactive partnership	'I think it helps that we both, we both very much parent in the same style and that really helps. And there's no compromise, no conflict between the two of us'	8.262-266

Development of personal qualities • Self-control	'in terms of myself, me and the person that I was, I'm perhaps, er, an awful lot more patient, er, a lot more understanding. A lot less judgemental'	7. 204-207
	So, you know it's changed me hugely and Luke, for very much for the better you know. Little practical things that we've changed in our life, you know. We don't drink anymore and things like that'	7. 232-236
• A nurturing role	'um, but yeah, you know, I've found that I often think that if they didn't have the special needs that they have, I probably wouldn't be the parent that I am now'	7. 215-218
	Um, you know, we have spent a lot more time observing them, watching our kids and taking joy in the little things that they do, um, than perhaps other parents	7. 226-229
	'I wouldn't have the patience and the understanding of the kids that I have now'	8. 238-240
	'And I've always got this one stuck to me, haven't I (points to daughter) I know mummy disappeared, but she's back now, you've found me'	8. 240-243
New horizons • Adjusted expectations	'but I think in the end, it's up to you how you view that change. You know, you either view it as a trial or try and find the positive in it'	6. 196-198
	'um, so we've had to make a lot of compromises in our life, but I feel we're coming out that period now and we've started to think, well, ok, we, we've had to give up those dreams, but what dreams can we have'	5. 160-164
	'We didn't have any hope, you know and that's only starting now'	15. 492-493

Appendix 11

STEPS FOUR and FIVE

THEME	SUBORDINATE THEME	SUPERORDINATE THEME
• Adjusted experiences	New horizons	HOPES FOR THE FUTURE
• The ideal companion • A proactive companion •	Mutual support	
• Self control • A nurturing role	Development of personal qualities	
• Enlightenment	Companionships for the journey	PARENTAL SOLIDARITY THROUGH SHARED EXPERIENCE
• Reciprocity • Understanding isolation • Mutual encouragement		
• Access to specialist knowledge for the children	A conduit to other professionals	RELATIONSHIPS FACILIATED BY SCHOOL
• Parental experience of professional support		
• Parental need for professional support not acknowledged		
• The unacknowledged impact of emotional hurting		
• Seeking a guide to point out the way		
• Professional services as distant to real need		
• Some issues seen as insignificant	As a generic parent	
• Not being seen in a diminished role		
• Important to be seen as self-sufficient		
• Role of parents/teachers of equal value		

Main theme	Sub-theme	Items
RELATIONSHIPS FACILIATED BY SCHOOL	As a generic parent	• Professionals validate her role • Parents have need too
	As a mother of her children	• A defined role • Validated the self • School seen as a safe 'base' • It requires a full engagement
MAKING SENSE OF LIFE CHANGING EVENTS	A dramatic change	• The nightmare continues • Time stands still • Diagnosis transforms everything • A severe blow • Financial burdens • Mourning and grief for expected family life
	Loss of expected future	• A giving up/loss of aspirations • The future evaporates • Ideal future is too fragile/ethereal/disappears • Future can't be defined – a void • Peering into uncertainty • Fear of isolation
	An alternative lifestyle	• Access to preferred community denied • Loss of ideal role – a part of the ideal community • An alternative life style construed
HOW FAMILIES CHANGE	Loss of expected child development	• A sudden reversal • Loss of expected outcomes • The questioning self • Questioning of core values • Questioning of purpose

	Loss of expected child development	HOW FAMILIES CHANGE
• One's inner core is fragile		
• Bearing the diagnosis of your child		
• Internalising of hurts		
• Family relationships as unresponsive	Limitations of Family support	
• Disappointed expectations		
• Material sacrifices of other not recognised		
• Uncertain about future support		
• Father's self-denial is of more value	Paternal role enhanced	

Appendix 12: Spider diagrams for Nicky, Jo, Barbara, Sue and Maryam

Clustering of themes, subordinate and superordinate themes

Male/female stereotyping

- Roles delineated

Maternal parental relationship intensifies

- Close maternal family support
- Father/daughter bond strengthened
- Mother/ daughter relationship validates her achievement
- Quality of child/grandparental bond validates her achievement
- Child/grandmother bond reaps reward
- Parental pride in what she has achieved

Maternal Father's role enhanced

- Granddad has pivotal role
- Comparison of Granddad/Dad availability
- Child adds value to Granddad's life

Husband/wife drift

- Husband/wife detachment
- Husband couldn't adjust his expectations
- Already proven as a father
- Parallel paths to coping

Forced to prioritise her children

- Impact on daughter acknowledged
- How to attend to each child?
- Disabled child is cherished
- Shared attention means sisters loss
- Son's health has to have priority
- Unhealthy diet impacts on daughter

Feeling she is being fair?

- Child v child
- Struggles to understand daughter's feelings
- Compares physical to intellectual need

Child's limitations limit family spontaneity

- Lack of facilities
- Over planning

Child s impact on family functioning

- Long term burden of disability

Initial grief

- Traumatic birth event
- Cushioning herself against reality
- Reasoning can be easily overwhelmed

Previous life seen as naïve

- Former life is idealistic

Can only contain her own fears and emotions

- Factors outside her control have impact
- Earlier engagement too much to bear
- Own need eclipses others

Fears about how the future will unfold

- Reality unleashes fears for the future
- Long term anxieties intrude that need answering
- Floundering in the new reality

Exclusion from her own peer group

- Friends accessible when disability is hidden
- Embarrassment of delayed development
- Exclusion from 'normality'

Gradual 'gathering of herself'

- A more reasoned view tried to prevail
- Daily existence suffices
- Gradual understanding of her new status
- Confidence and self-esteem develop over time
- Regret she lacked strength in the past
- Acknowledges her 'given' identity now

Family Dynamics impacted by disability

Life's journey unfolds

Conversation 1 Nicky

Interactions with professional services

School as an encompassing community

Misfit of Expert/Parent dialogue

- Specialist support seen as distant
- Misfit between Specialised advice and parental need
- Motherly instinct not acknowledged
- Medical support seen as aloof and unwilling
- concern regarding 'unsuitable' professionals

Being perceived as weak

- Lack of understanding breeds anxiety
- Lack of understanding leads to vulnerability
- Loss of ability to articulate fears
- Floundering in lack of expertise
- Feeling belittled and deskilled by systems
- Effort outstrips value of commodity
- Feeling belittled and deskilled by education system

Confrontation is expected

- Default experience is to do battle
- Lack of choice as a parent of a disabled child

Personalised support is effective

- Specific specialised support is valued
- Specialised service contains her anxiety
- Specialised support is flexible
- Specialised support is trustworthy
- Specialised support facilitates access to further help/peer group
- Specialised support facilitates peer group for mother and child

Transition process into school throws up anxieties

- Personal services subsumed into school
- Feeling de-skilled
- Relinquishing role is difficult
- Future transition stirs old worries

School engages with her emotional need

- School contains her anxiety
- Immediacy of access lessens anxiety
- Validity given to her concerns

School as a resource

- Facilitates communication with her child
- Readily shares expertise
- Can map out the future
- Facilitates specialist access that works

School facilitates contact with peer group

- PSA provides a timely friendship group
- PSA opens the door to a new community
- Communality of language and experience
- PSA contact prepares the way for the future

Clustering of themes, subordinate and superordinate themes

New horizons

- Adjusted expectations

Mutual support

- The ideal companion
- A proactive partnership

Development of personal qualities

- Self-control
- A nurturing role

Companionship for the journey

- Enlightenment
- Reciprocity
- Understanding Isolation
- Mutual encouragement

A conduit to other professionals

- Access to specialist knowledge for the children
- Parent experience of professional support
- Parental need for professional support not acknowledged
- The unacknowledged impact of emotional hurting
- Seeking a guide to point out the way
- Professional services as distant to real need

As a generic 'parent'

- Some issues seen as insignificant
- Not being seen in a diminished role
- Important to be seen as self-sufficient
- Role of parents/ teachers of equal value
- Professionals validate her view
- Parents have needs too

As mother of her children

- A defined role
- Validates the self
- School seen as a 'safe base'
- It requires a full engagement

Hopes for the future

Parental solidarity through shared experience

Relationships facilitated by school

Conversation 2 Barbara

A dramatic change

- The nightmare continues
- Time stands still
- Diagnosis transforms everything
- A severe blow
- Financial burdens
- Mourning and grief for expected family life

Loss of expected future

- A giving up/loss of aspirations
- The future evaporates
- Ideal future is to fragile/ ethereal/disappears
- Future can't be defined – a void
- Peering into uncertainty
- Fear of isolation

An alternative lifestyle

- Access to preferred community denied
- Loss of ideal role – part of the ideal community
- An alternative life style construed

Making sense of life changing events

How families change

Loss of expected child development

- A sudden reversal
- Loss of expected outcomes

The changing substance of being a parent

- The questioning self
- Questioning of core values
- Questioning of purpose
- One's inner core is fragile
- Bearing the diagnosis of your child
- Internalising of hurts

Limitations of family support

- Family relationships as unsupportive
- Disappointed expectations
- Material sacrifices of others not recognised
- Uncertainty about future support

Paternal role diminished

- Father's self-denial is of more value

Clustering of themes, subordinate and superordinate-themes

Grief for what might have been
- Growing realisation of difference

Child valued for her own sake/who she is
- Daughter's uniqueness appreciated
- Child as catalyst to her well being
- Mother/daughter bond

Child's humanity denied
- Growing realisation of difference
- Child perceived as 'other' not human
- Anxiety over how the child might be perceived

The precious child

Developing resiliency
- Inner strength is what counts
- Fight for the right to be heard
- A protective detachment
- Feeling judged
- Emotions could easily overwhelm
- Life trajectory is now set
- Life is narrowed to a point

Fear for the future
- Fear she is perceived as an inadequate mother
- Seeking a diagnosis to exonerate her

Requires total emotional commitment

Professional attitudes
- Lack of professional care
- Labelled by professionals
- Professionals should know better
- Professional interaction seen as impersonal
- Lack of feedback feels like lack of care

Who are they to comment?
- Outside/alien world

Indifference of a wider world

Conversation 3 Jo

Acceptance without stigma
- Special school is a special place

School contains her anxiety
- School is perceived as a 'safe base'
- Approach to personal need shows integrity
- Care of school is evidenced in feedback
- Educational process is normalised

School validates her role as parent
- School relationship on an equal basis
- Joint contribution to the long term

School as a resource to be utilised
- A wish for open ended support
- To advocate on her behalf
- Facilitator of support groups
- As potential facilitator for parent support groups

School is pivotal

The family defined
- Cross generational family
- Supportive family unit
- Child's recognition of family gives value
- Family unit as a 'safe base'

Close family ties
- Mother and sister's involvement valued
- Mother and sister as close supportive unit
- Relationship with her mother sustains
- Mother/daughter – parallel affect
- Mother validates her development
- Mother contains her emotions
- Sister a valued supporter
- Generational differences
- Male/female adjusting

Impact of her behaviour
- Child's behaviour validates the home
- Child as catalyst for family dynamics
- A reason for anxiety

Disability causes wider family division
- A lasting impact

Family relationships change

Clustering of themes, subordinate and superordinate themes

Disconnect between parent/Specialist expectations

- Unintended consequences

Paid carers

- Mixed feelings about paid carers
- Show less commitment
- Have a lack of empathy

Intrusion of professional influences into family life

Child's needs have priority

- Child is central to how family functions
- Child's individual need is paramount

Affect on older sibling

- Older sibling 'hot-housed'
- Positive affect
- Imposed responsibilities acknowledged

Sympathetic wider family network

- Particular family loyalty
- Family support helps and hinders

Husband and wife find a way through

- Negative pressures on marital partnership

Family pulls together

Initial impressions set the tone

- Personal relationships valued
- Relationships with Special schools are different
- Relationships make the school
- Personal experience of school allays concerns

Child feels safe

- School is a safe base
- Extra-curricular experiences give confidence

Lack of reciprocity can lead to alienation

- Relationships with school can feel alien
- Feeling in a place of weakness

Holding specialist knowledge

- Seeking support and sharing of knowledge
- Seeking expert advice

Seeking to understand her child

- Less clarity as the child gets older
- Seeking help with communication
- Open communication is vital
- Lack of communication hinders mother/son understanding

Feeling in a position of weakness

- Lacking understanding of ways of learning
- School should be on your side

School is holder of key to a supportive relationship

Conversation 4 Sue

Life changing events and consequences

Pre-birth trauma and affect

- Pre-birth trauma
- Feelings of responsibility
- Sudden awareness dawns

Initial child rearing gives no clue

- Some initial concerns regarding older child
- Initial experience of child rearing clouds expectations

Having to bear bad news

- Lone responsibility at a vulnerable point
- Natural hopes and longing dashed
- Husband found acceptance difficult

Ongoing material impact

- Ongoing financial impact
- Financial consequences

Trying to maintain daily control

- Futile attempts to comfort as a baby
- Futile attempts to maintain order
- Constant vigilance to keep control
- Loss of control difficult to contemplate

Role of mother amplified

- Uncertain day to day functioning
- Facing a lack of understanding

Developing new characteristics

- Developing a sixth sense
- Developing a thick skin
- Total focus on the task

Seeking to make a difference

- Rearrangement of her work life balance
- Will seek to right perceived wrongs
- Will make the system fits her needs
- Gains a position of influence

Clustering of themes, subordinate and superordinate themes

Impact of diagnosis

- Shock – a moment in time
- Feelings of loss and being overwhelmed
- The impact immobilizers her
- Social isolation

Consequences of life changing events

- The self in a diminished role
- The monotony of daily existence
- Loss of personal choice
- A denial of self
- Loss of self-worth

Responsibility is all hers

- Everything comes back to her
- Burdened by responsibility
- Burden can't be shared

Future hopes dashed

- Fear for the future is always there
- Aspirational future was planned
- Uninvited life events
- Juggling her two desires
- Disappointed outcomes
- Aspirations are unachievable
- Compromising her dreams for her family

Seeking a way forward

- Grasping at an alternative narrative
- Glimmers of hope
- The long view brings its own rewards
- Acceptance
- Jettisoning her dream for a new perceived reality

Out of school support is pivotal

- Child can't be contained at home
- Structured hours are vital
- Consistency of support for the child is needed
- The unfamiliar has no value
- Managed time equals more order and control

Professionals as partners

- Specialist support is valued
- Specialist support gives her a role
- Specialist support is personalised
- Specialist support gives direction
- Charities are more effective
- Impact of familiar professionals

Impact on her core identity

Fear of unorganised time

Conversation 5 Maryam

Provides personal support

- School acts as advocate
- School is a secure base for her child
- School contains her worries

Provides the link to other services

- Facilitation of holiday care

Facilitates shared parental experience

- Parent group widens her knowledge
- Shared commonality of experience amongst parents

School as a provider of specific support

Desire to be a mother

- Feeling diminished as a mother
- Parental role constricted
- Role of mother is all consuming

Feeling de-skilled

- Professionals take over

Intergenerational affect

- Developing relationships

Mother/daughter bond

- Relationship with mother sustains
- Mother provides companionable support

How a family functions

Equality of need and attention

- Torn between both sons
- How to prioritise need?
- Needs of both children can be overwhelming

Diagnosis defines the child

- Child viewed as different/isolated
- Unlocking potential

An uncertain future

- Fear for her child's future
- Motherly instinct is to protect
- Seeking a secure base

Impact of disability on the marital relationship

- Differing parental roles
- Impact on married life
- Feeling let down
- Husband has little empathy
- Husband lacks understanding
- Husband hasn't adjusted his expectations

Appendix 13 A Summary List of Superordinate and subordinate themes from Parent Interviews

Code: Bold Heading = Superordinate theme   *heading in italic = subordinate theme*

	Quote	Page number
SUPERORDINATE THEME 1: **Making sense of life changing events:**		
Feelings of loss		
Nicky	I was perhaps in a totally big bubble where everything was quite nice and flowers and daisies and skipping along and then you just feel like a 'oomph' - car crash, sort of 'wow!'	8.234-239
Barbara	And life we saw ourselves having has gone, and it's a bereavement, you know, it is a bereavement. But the whole idea of having a disabled child is massive – too big to bear	16.499-501
Jo	When we gave birth to Joshua we'd sort of like had the celebration of a birth and a death as well. We had a funeral as well as a christening. So we'd already had a lot	12.339-341
Sue	I don't want to be in that place any more. I think I wasn't feeling, things got too much then. I lost all	5.137-140
Maryam	sense of feeling	3.88-90
Future hopes reframed		
Nicky	Even though you think you knew, so you were, sort of, quite prepared, there was still, sort of, I know it's real, what does it mean?	4.108-110
Barbara	And the dreams you that you have for the kids, you know walking them down the aisle and what job will they get. All of that sort of disappears literally overnight	5.142-145
Jo	My biggest fear is that I won't be able to handle her as she gets bigger and stronger and I don't want her to end up in care	18.521-524
Sue	My biggest fear is what would happen to Joshua if I die. You think, 'god, you know is there things in place for that?'	8.245.247
Maryam	So it's giving me a whole perspective to life and what life should be. Is it about happiness? Is it about family? Is it about money? Is it about dreams? And honestly now I would settle for just normal happiness	10.359-363
Personal affect		
Nicky	I think I've changed a lot, to be honest, um, (pause) and I sort of look back and perhaps envy myself slightly before Sam In terms of myself, me and the person that I was, I'm perhaps, er, an awful lot more patient, er, a lot	7.229-231

Barbara	more understanding, a lot less judgmental	7.204-207
Jo	I, feel that, um, it's highlighted my strengths and character that must have been there all along because otherwise I'd have just crumbled	10.276-279
Sue	My strengths? I. Yeah. P. Um. Pure determination. Because if something's not right with the system, I'm not one of these that will moan about it	9.262-266
Maryam	I can't go out, I can't do anything, um, (pause). I have to stop working, um, I have to, (pause) at the moment let go of my dreams and aspirations	4.131-134
Glimmers of hope		
Nicky	You think, no actually, what's happening today or tomorrow. Let's do that first and then deal with those	4.129-131
Barbara	But what dreams can we have. You know, um, the next best thing to Thailand is a beach in Barmouth. And we've got that you know	5.163-166
Jo	I've got a friend who's got a child with Downs Syndrome who's also got other profound difficulties. I see how she copes and then I look at myself and I think 'well, you know, you're lot isn't so bad	12.342-346
SUPERORDINATE THEME 2: Impact on family dynamic		
Adaptation of immediate family circumstances		
Nicky	Obviously my parents are very active in our life	1.18-19
Barbara	Luke had to give up work to help me care for the kids, because it was pretty impossible	2.37-38
Jo	Um, at the moment, I'm living with my parents, my mum and my dad. They're both in their eighties,	1.3-5
Sue	early eighties)	
	I think of us as a family unit. I don't think of things from outside. Both family members have been very supportive.	10.308-310
Maryam	My mum. I mean she's been very supportive of me, I mean, she's helped me a lot with Osman and with both the children	11.400-402
Changing role of being a parents and its impact		
Nicky	I think he found it quite difficult to cope with sort of, we going to have a, well, we've got a disabled child, and there was no sort of warning that we were going to	11.365-368
Barbara	I think it helps that as parents we both, we both pretty much parent in the same style and that really helps. And there's no compromise, no conflict between the two of us	8.262-266

Jo	She hasn't got a father, so my sister was my birthing partner; she's been there all along. So she plays the part of the second carer	2.56-60
Sue	I think, Alan and I together really, we're a team against the world and it feels very isolated, just your little group	10.321-324
Maryam	Honestly I don't have a lot of faith in my husband to take care of him because, um, it is quite difficult because he has his something going on, and I'm stuck with the children, and he doesn't understand him	6.202-206
Unsettling of wider family relationships		
Barbara	It's quite an extended family around my mum, but we don't really have an awful lot to do with them	1.10-12
Jo	The impact on the family has been profound to be honest	7.201-205
Sue	There's been some – Auntie Sue, she's been really good; um, she doesn't understand him though, but she means well	10.310-313
SUPERORDINATE THEME 3: Impact of a child needing a special school		
Transitioning into school		
Nicky	Everybody's in school, and all sort of, what do I do? They were like 'you're just his mum', and that sort of hit me a little bit. Whoa, how do I be his mum?	15.470-473
Barbara	You know you don't want to bother them. You know you don't want to be seen as a nuisance and you don't want to be seen that you're not coping	11.339-342
Jo	The second she got to school ... she was cleared to go to special school, everything just changed, it calmed down. I felt frantic before then	14.389-392
Relationships at an emotional level		
Nicky	Nothing's too much trouble. They are always wanting to make your life as easy as possible and the communications fab	11.339-342
Barbara	We very much want to be a part of whatever's happening in the school and I think that helps as well because it gives you a sense of identity and it gives you a sense of community	11.355-359
Jo	But in Ashtree, I've never felt like that. I've never felt like that. I mean if she does a nappy on her, they're used to it. And that helps me, that has helped me a lot and Charlie has come on in leaps and bounds since she's been there	14.417.422
Sue	I think where ever you go, if you went to a foreign country you wouldn't know how to ask for something.	12.369-372

	Quote	Reference
Maryam	I just feel that sometimes it's a bit like that, I don't know what to ask them. If they can't help me they they use the words 'we don't know anyone who can come, but contact this organization, they might be able to help'. So honestly, I mean, Ashtree is, they are very supportive for the children, personally that how I see it	13.475-481
Relationships at a Professional level		
Nicky	And a lot of this you know you do sort of probably as a parent of a disabled child. Personally I feel I get up most mornings ready to go into battle and I've got to fight again	18.581-585
Jo	She does feel, she does hurt, and what has annoyed me along the way, services even, social, social workers etc., they treat them like an object rather that a person	7.186-189
Sue	So when someone says you can't do this, I'm like, well...I'll just get on with it.	10.299-301
Maryam	Honestly if it was the Disability team, you wouldn't get anywhere. There are so many offices and so many people, they forget. But with the school, and you know some of the charities, you get where you want to go. It is much easier	12.461-465
Facilitating a new peer group		
Nicky	I'm sort of 'and mine – and mine' (laughs) and it was just so although every child is different with different needs, it was just such a relief to have people sort of, you know, talking about wee, poo and nappies	17.540-544
Barbara	Meeting the other parents was a huge step for us. Um, it's sort of made our journey a lot more positive	9.293-295
Maryam	And then we got these meetings and you realize that most of them have the same problems, especially the ones with Autism. Autistic children, they have the same problems as you and your worries are the same as their worries	17.619-624