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DOCTOR OF PHILOSOPHY

The meaning of being a parent: fathers' and mothers' day-to-day lived experiences of caring for and living with their learning disabled child, a phenomenological inquiry

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**THE MEANING OF BEING A PARENT: FATHERS'
AND MOTHERS' DAY-TO-DAY LIVED EXPERIENCES
OF CARING FOR AND LIVING WITH THEIR
LEARNING DISABLED CHILD: A
PHENOMENOLOGICAL INQUIRY**

**A thesis submitted to Bangor University for the Degree of
Doctor of Philosophy in the School of Healthcare Sciences**

January 2010

Chris Catherall
Senior Nurse, Childhood Disabilities



In memory of my loving wife

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ABSTRACT

This study is associated with the exploration and description of the meaning for parents who live with and care for their child/children that have a significant learning disability. A qualitative methodology that reflects Husserlian transcendental phenomenology was used to explicate and illuminate the life-world of the individuals involved in the study. A purposive and criterion sample strategy enabled access to two parents and single parent families, who participated in focused open-ended and semi-structured interviews. The search for meaning revealed the existence of three core themes and clusters of associated sub themes that were commonly shared between these parents. The core themes include: being a parent, living with disability and a career in caring. These meanings are discussed in the context of literature that is pertinent to this study. Recommendations focus on the systems and service provision that will enable parents to positively care for their children without the perceived inevitability of adopting unproductive coping strategies, associated high levels of stress and poor well-being. Recommendations also have pertinence for pre and post-basic training, recruitment, practice and policy development. This should be achieved through a better understanding by education, service commissioners and providers of what it means to be in a long-term carer career and the influence this can have on individual capacity and well-being.

ACKNOWLEDGEMENTS

This thesis has evolved and developed over the past seven years during which I have developed and tested my reasoning and thinking with colleagues to which I owe a huge debt, particularly their patience.

I have also benefited from the very capable scholars who have helped shape my thinking and how this thesis has been presented. Ron Iphofen and Anne Cody have been instrumental in the process. I am particularly indebted to Ron for his guidance and encouragement during supervision and for the belief he has given me in my abilities to achieve this task.

A very special mention to the families who have contributed to this research, their honesty during high emotive times has proved to have been an inspiration and without their strength to continue caring, often during difficult times this research would not have been possible, again many, many thanks for your support.

To Conwy & Denbighshire NHS Trust, in particular Rachel Shaw, Head of Nursing, who has provided me with dedicated time to sit, read and complete this work, and to my family, who have tolerated my demands for quiet and who have provided me with the time to escape and become immersed in this work. Thank you all.

I would like to dedicate this work to my late wife Maureen. She was an inspiration and in spite of her ill health she provided a pillar of support in assisting me reach this target. You will be missed.

ABOUT ME...

Being born the second son to my parents in 1959 I grew up in the suburbs of Manchester. Having experienced several changes of schooling – a direct result of my father's employment as a police officer – one striking and enduring memory being the 'new boy' in class, always seeming to be during mid term! Having survived the earlier moves, schooling all but complete – another move on the horizon - this time to North Wales. New beginnings, new friends and a career in a busy supermarket until a chance opportunity changed my direction and life's work completely. I entered onto a nursing training programme within the field, as it was known then, of caring for the mentally handicapped.

Three years passed, I gained a nursing qualification and had also acquired a wife and a son and another child on the way. As per family tradition we uprooted and moved to Cornwall to seek a new life and new challenges. After five years experience as a community charge nurse and home leader we embarked on a move back to North Wales.

Employment with the now Conwy and Denbighshire NHS Trust has seen my career progress from that of community charge nurse to one of senior nurse manager. During this time I have attained a variety of qualifications, which I consider to be pertinent to my work. One example is the dedicated counselling training I undertook up to Masters level. Throughout my nursing career I have, as a constant, supported parents and their children – this remains true to date, where I retain a clinical caseload in

working directly with parents and their school aged child/children who often engage in significantly challenging behaviours.

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PRESENTATION OF THESIS

Chapter one: Introduction and Research Background

This chapter provides a narrative to my journey as I travelled through the maze of phenomenological literature. It provides a background to the research subject, touching on personal and professional issues. Both of which have shaped the research inquiry and the selection of methodology.

Chapter two: Subject Literature Review

This chapter presents information to the literature search conducted, and an examination to the research that was critiqued. The core findings from this review have been collated into themes relevant to the context of this study.

Chapter three: The Phenomenological Perspective

This chapter provides the reader with a detailed historical perspective on the phenomenological movement and its core ideas that are central to its philosophy. Further to this discussion there will be an in-depth exploration of the themes that underpin transcendental phenomenology, the particular approach adopted within the project reported in this thesis.

Chapter four: Methodology

This chapter for logical reasons moves away from the previous two chapters that have focused primarily on the phenomenological movement, its development and its central tenets. The rationale for direction change is to provide an overview of methodological considerations and processes: from sample selection to ethical

implications. The bulk of this chapter then focuses back to the practical application of conducting a transcendental phenomenological inquiry and how it was applied in answering the research question.

Chapter five: Bracketing

This chapter contains a further exploration of the concept of bracketing within the context of philosophical and research methodology. A framework for bracketing is presented in this chapter, one that provides a clear explanation as to how bracketing was achieved in this study.

Chapter six: Phenomenological processes

This chapter begins with a discussion as to the core elements of the phenomenological data processing. The central theme to this chapter presents Moustakas' (1994) modification of the Stevick-Colaizzi-Keen model for transcendental phenomenological inquiry.

Chapter seven: Research Method

This chapter provides an overview of the research method and steps that were used in managing and conducting this study.

Chapter eight: The Meaning of Being a Parent

This chapter begins within the context of the phenomenological reduction by offering a description of my personal accounts of what it means to be a parent: being a father to two children. A further reflection examines my own beliefs, perceptions and

underlying assumptions about the meaning of being a parent to a child that has a significant learning disability.

Chapter nine: The Meaning of Being a Parent and Caring for a Child with Significant Learning Disabilities.

This Chapter begins by presenting an overview of each co-researcher who was involved in this study and their story. Part two of this chapter detail their experiences in the context of a textural and structural description. Part three provides a composite description of the textural and structural descriptions and concludes in part four by presenting a synthesis of meaning.

Chapter ten: Reflective Account of Implications for Practice and Conclusions

This chapter draws together the findings from this study and discusses the findings in relation to the existing literature. The limitations, transferability and conclusions are also discussed, as are recommendations for practice.

WHICH PARENT WILL I BE?

"I got two A's," the small boy cried.
His voice was filled with glee.
His father very bluntly asked,
"Why didn't you get three?"

"Mom, I've got the dishes done,"
The girl called from the door.
Her mother very calmly said,
"Did you sweep the floor?"

"I've mowed the grass," the tall boy said,
"And put the mower away."
His father asked him with a shrug,
"Did you clean off the clay?"

The children in the house next door
seem happy and content.
The same thing happened over there,
And this is how it went:

"I got two A's,"
the small boy cried,
His voice was filled with glee.
His father very proudly said,
"That's great, I'm glad you belong to me."

Mom, I've got the dishes done,"
The girl called from the door
Her mother smiled and softly said
"Each day I love you more."

"I've mowed the grass," the tall boy said,
"And put the mower away."
His father answered with much joy,
"You've made my day happy."

Children deserve a little praise
For tasks they're asked to do.
If they're to lead a happy life,
So much depends on you.

Author Unknown

CHAPTER ONE: Introduction and Research background

1. Introduction

This thesis describes and explores what it means to be a parent who lives with and cares for their child/children that has a significant learning disability. The term parent refers to both father and mother as two or lone parent families. This chapter begins by proffering a context to this study in terms of Welsh national and local policy, before providing an insight into the topic under investigation in relation to my own experiences as a father and as a practising senior nurse/clinician. This study also describes and follows my development as a phenomenological researcher.

2. The Context of this study.

This study has evolved out of a personal interest to investigate the meaning for parents who care for their learning disabled child. The backdrop against which this study was conceived and subsequently conducted was the rationalisation of local service provision as a way of meeting budgetary constraints. The subsequent reorganisation of services effectively dismantled inter-agency learning disability children's teams. These teams have over the past decade become insular and have developed 'silo' thinking mentality and practices that have undoubtedly impacted on the lives of those that we are here to serve and support. More recently there has been another shift in policy, both nationally and locally, that aims to deliver services to the local population in a coherent joined way.

The National Service Framework for Children, Young People and Maternity Services in Wales (2006) policy document details a ten-year strategy that aims to transform services in Wales. The standards that are contained within it are in line with the principles that are embedded in the Healthcare Standards for Wales (2005) and dovetail with the Welsh Assembly Government Designed for life (2005). As such the National Service Framework (2006: 43) clearly states that: “**Disabled children** and their families need particular support from health, education and social services, including early diagnosis or identification of difficulties and early intervention. They also need support from housing, transport and leisure services.” Service design aims to maximise the development of a disabled child and according to the NSF (2006: 44) should include:

- An assessment of each child’s needs and strengths, including diagnosis, if and when appropriate;
- Prompt delivery of services to meet assessed needs;
- Provision of educational support to maximise cognitive development;
- Encouraging social development through inclusive policies and practices;
- Provision of family support to maximise emotional development;
- Provision of services which respect each child’s view, language and culture.

It further states that services are designed so that support to families of disabled children is available, and will include:

- Clear and accurate information that empowers them to make informed choices, and to gain access to help when they need it;
- Practical support to assist them in caring for their child;
- Access to emotional support when they need it;

- Advice on how to maximise their child's development and offer training, if needed;
- Access to affordable childcare and other services to enable parents to return to work, if they wish;
- Provision of short breaks and additional services to enable the family to participate in the same lifestyle that parents of non-disabled children experience;
- Access to leisure.

The National Service Framework has as a requirement prompted local service providers to measure compliance against the flagged areas with a view to meeting its core aims. Services in Conwy and Denbighshire, as with other local authorities, have produced a local single plan that is in essence a local response to the seven core strategic aims of the National Service Framework that sets out a detailed plan of action. Its main aim is to coordinate a service response in a co-terminus way and produce a three-year plan that is transparent and subject to monitoring and evaluation.

3. On becoming a Phenomenological researcher – the beginning...

Having briefly presented the policies that have influenced service developments the following discussion will describe, by way of personal reflections, further context to this study and its development.

It is essential to have identified an interest in the nature of a particular human experience. Until this task has been completed one cannot form or begin to answer a

true phenomenological question. To engage in phenomenological research, one is to question something phenomenologically: what is something really like, what is the nature of this experience as experienced by someone, be it yourself or another person? This question is central to my own understanding of being a parent and to my understanding of what it must be like to be a parent of a child that has a significant learning disability. The essential question being: what is it to be a parent?

Through my own experiences of being a father to a wonderful son and daughter I can clearly say watching them grow, watching them succeed and watching them fail. To be there to support, to guide, to offer advice and set rules with consequences, to anticipate their achievements, to experience their joy, happiness and sadness as they developed into young adults; these experiences and a multitude of many others constitute, for me, the elements of being a parent: being a father. The father/son relationship still remains more important for me as an individual. This is, of course, not at the expense or detriment to my daughter or our relationship. On reflection this is in all probability as a result of a longing for something I did not experience as a growing child. A father who was not present, primarily as he was engaged and subsequently married to his job: as a police officer.

To be able to play and watch football, to go fishing and cycling, things that I view as important, which through reflection I understand to be my needs, are none the less fundamental and important in the father/son relationship. Whilst my son and I achieved some but not all of these, one of the important milestones of becoming an adult as I see it: going for our first pint together never happened. My son, who was a popular, outgoing young man, as if by a click of a switch, became very insular and

reclusive. He shut himself away from the outside world as his depressive episode deepened. His moods darkened, with frequent episodes of aggression and incidents of self-harming. We were fortunate enough to have had the insight to have sought help from the appropriate services. For my son, this was not welcomed; he reluctantly for the next twelve months attended 'his' appointments, until he decided he had had enough. He then refused all forms of help other than taking his prescribed medication. Taking regular medication has helped to stabilise his aggression and elements of his mood swings, but it has not altered his strong views on humanity: that we are all parasitic!

He still lives at home, occupying his time; of which there is a lot, by helping out on our small holding. The mood swings are a regular feature of his and our lives, as is the loss of our son that was.

It is this very experience of losing something special that has provoked and stimulated an interest in exploring how fathers and mothers, whose child/children have a significant learning disability, experience and manage on a day-to-day basis. Questions such as: What does it actually mean for them? Do they view their lives as being different to families that are not touched by a child's learning disability? Do they view or experience their situation as a loss? These questions have filtered through my conscious mind; they are questions that I cannot readily answer without directly experiencing the phenomenon for myself.

As my interest increased so did my awareness of potential research methodologies, one in particular stood out: phenomenology. As I understood it, back then many years

ago, there was an attraction because it provided a framework that enabled one to understand more about a given phenomenon through another person's lived experience or life-world. It appeared to be an appropriate approach and perfect choice. Now looking back I can only see how immature my thinking was. I was fairly confident, in certain circles, of describing and defending my chosen method; which again on reflection was a naïve view. I had in some respects made a crucial error; I had read accounts of phenomenology from the nursing research literature without going back to original sources. On securing dedicated literature, my confusion spiralled, the language was complicated and spoke in riddles, of which I could make little sense. Spiegelberg's (1982) historical account of the phenomenological movement has proved a valuable resource, yet initially, only to confirm my naivety in understanding the facets of this philosophy.

It was very clear to me at this juncture that the amount, breadth and depth of available literature described a philosophy that had a long-standing history and many differing views and standpoints. I took it upon myself to identify and justify the form of phenomenology that would suit my research inquiry. As such, I have been fairly consistent throughout my research development in advocating the work and philosophy of Edmund Husserl. There have been times when my convictions have been challenged and tested. I alluded earlier to the reading of nursing research that claimed to have used Husserlian ideas as their guiding principle - their interpretation of the philosophy and methods adopted were found wanting. These issues will be discussed in more detail in chapters three, five, and six but for here I would like to offer an example where nurse researchers have misunderstood one of Husserl's main concepts, the concept of bracketing. It is clear from what is described by these writers

(see Baker *et al.*, 1992) that it is far removed from what Husserl had in mind. Unfortunately, as a novice I was drawn somewhat naively and unknowingly into thinking that phenomenology could be conducted as a step-by-step project. I had to go back to the source, to the central and core tenets that underpin this philosophy.

My evolution as a phenomenological researcher had begun; I was developing a clearer understanding of Husserl's and his critics' thinking. This understanding materialised suddenly as if it all made sense: issues relating to the *epoche* and that of the 'phenomenological reduction' or bracketing, as it is commonly known. This concept where one suspends unquestioning acceptance of the prephilosophical or 'taken-for-granted' was also becoming clearer, yet it continued to pose further questions and tensions. One recurrent question being: can one actually suspend all beliefs in the natural world? This debate will be engaged at a later stage within this thesis (see chapter 4). Suffice to say here that I believe there needs to be an openness to this way of thinking. The complicated concepts of intentionality and the noematic and noetic relationship were also beginning to make some sense, with a newfound confidence in being able to apply the principles to everyday experiences.

This deeper understanding of Husserl and his ideas strengthened my belief that I had chosen correctly and that this philosophy and research method would enable the answering of my inquiry. It also served to delineate the difference between that of Husserl's and Heidegger's philosophical differences – which, for present purposes, relate to how they viewed the concept of the 'world'. This new understanding however raised more questions about methodological selection. This questioning stemmed again from the issue of bracketing. Would I be able to set to one side

elements of my own biography, some 28 years of being a nurse (in the field of learning disabilities) and 26 years of being a parent?

There remained an internal conflict, one, of wanting to believe that Husserl's ideas of the epoche and phenomenological reduction are in practice achievable and two, the questioning whether this state of 'suspension' can actually exist. The reading of Husserlian critique magnified this dilemma. Strong tangible argument and debate have questioned Husserl's claims: that one can study the essential structures of the world by engaging in the epoche and subsequent phenomenological reduction. Being open to these criticisms and furthering my own development through the work of Moustakas (1994) I now would argue that one can be transparent to the object in view.

My journey as a phenomenological researcher is by no means complete. My understanding of the core principles is at an early stage. I have grappled with and embraced the basic tenets; as such my understanding of the concepts and terminology has broadened. I feel that I have taken another step forward in my journey of discovery.

The subsequent chapters that make up this thesis will allow the reader further insights into this journey: that of a phenomenological researcher, a father and a nurse, which form and provide the foci for this inquiry: The meaning of being a parent: fathers' and mothers' experiences of caring for and living with their child/children who have a significant learning disability.

CHAPTER TWO: Subject Literature Review

1. Introduction

This Chapter examines the literature about the experiences of fathers' and mothers' that live with and caring for their learning disabled child/children. Electronic and manual searches relevant social science, nursing and psychological databases were conducted (see Appendix nine for full search strategy) to identify relevant literature that meets the following criteria:

- Articles published within the past four decades
- and;
- That investigated fathers' and mothers' experiences of being a parent
- and;
- That was clearly related to children aged 18 years of age and under, which had a recognised diagnosis of learning disability.

Each article was individually critiqued and ordered to reflect issues that sought to address this studies research question. In this regard the prominent headings being:

- Being a parent: the reaction and adaptation to their child/children's learning disability;
- Parental well-being;
- Parental coping;
- Role in family;
- Support systems

2. Terms of reference

Irrespective of the precise meaning of terminology, or the words used in defining learning disability, there are essentially three core criteria for learning disability:

- Significant impairment of intellectual functioning;
- Significant impairment of adaptive and social functioning;
- Age of onset before adulthood.

This definition is consistent with that of ICD – 10 (WHO, 1992) and DSM – IV (APA, 1994). For the purpose of this thesis terms such as: severe learning disability, mental handicap, mental retardation and other related syndromes and diagnoses were covered by this definition.

3. Context of this review

Most children with a learning disability live at home with their families. It is estimated that 90% of these parents are the principal carers (Towers and Swift, 2007). The nature and impact of caring for a child with learning disabilities has in some ways driven the research agenda in attempting to understand the vagaries of parental responses and to inform service design and provision.

It is clear from this review that family based research is rich and varied utilising quantitative, qualitative and mixed method approaches. The purpose of family based research has tended to focus solely on the experiences of the mother, the mother/father dyad, and within the past decade the experiences and needs of the father. A specific range of disabling conditions have been targeted to contrast specific phenotypes on family adaptation and functioning. Likewise families of typically

developing children have also been selected to provide contrasting measures. Research studies have also been selective in the child's age range covering pre, school and school leavers with a view to establishing life course impacts.

4. Being a Parent: the reaction and adaptation to their child/children's learning disability

The birth of a child usually brings about feelings of joy and excitement. Likewise the birth also engenders new challenges and responsibilities for parents as they adjust to the new family member. The birth of a child with a disability can and often leads to new and additional challenges for this group of parents. The process of adjustment and accommodation may be prolonged as parents come to terms with the new demands of caring that generally arise over the years as the child grows (Hanson and Hanline, 1990). Kearney and Griffin (2001) concluded from their study that pain and sorrow were integral to the experience of being a parent of a child that had a significant learning disability. Drotar *et al.* (1976) developed a conceptual framework that identified a sequence of parental reactions, namely: shock, sadness, adaptation and reorganisation. This framework is similar to the 'middle-range' theory as advocated by Eakes *et al.* (1998) that is closely related to that of Olshansky's (1962) chronic sorrow model, where trigger events such as milestone achievements perpetuate feelings of grief and pain.

The reaction to the news of a child's disabling condition may differ between fathers and mothers (Fidalgo and Pimental, 2004). Most research in this area has focused attention on the needs and experiences of the mother and child with the father's needs generally going unnoticed (West, 2000). This is clearly evidenced in Glendinning's (1983, 1986) contributions to our understanding of parental experiences and how

these experiences have impacted on many aspects of their day-to-day life. She clearly neglects the issues of fathers and their needs. In her earlier study she devotes an entire section to the effects on parents, only offering a small section that mentions fathers. It is not surprising that fathers' feelings were under represented when only 18% of the interviews involved fathers directly. In addition to this the findings need to be viewed with caution as mothers in both these studies reported their subjective opinions as to how they thought their partners responded to the demands of living with and caring for their learning disabled child.

Hornby (1991, 1992) reviewed fathers' accounts of their experiences of parenting children with disabilities. Common themes were identified from these accounts, which enabled the development of a model of father adaptation to their child's disability. He suggested that fathers experience emotions that move from shock and denial, through anger, sadness and detachment towards reorganisation and adaptation. Hornby (1992) also suggested that the range of emotions experienced spanned a spectrum of negative to positive feelings about their child and their response to fatherhood. Whilst it is commendable that Hornby focused on fathers, his findings would have been more balanced had mothers also been involved with the research process.

What is clearly evident in the literature is that parent's, irrespective of gender, journey through a variety of common emotions that include shock, denial, numbness, confusion and sorrow (Kearney and Griffin, 2001; Maxwell and Barr, 2003). There is an estimated rate of disturbance within families of between 30 to 35% in contrast to 10 to 15% for families who have a child who is typically developing (Davis, 1993).

This is also reflected in Margalit and Ankonina's (1991) comparative study where parents (couples) of disabled children reported higher levels of negative affect compared to families with typically developing children. This high level of disturbance is attributed to parental difficulties in establishing and maintaining family routines (Redmond & Richardson, 2003). Flaherty and Glidden (2000) in their study took a different slant on parental adjustment and compared parents who knowingly adopted a child with Down syndrome against the birth parents of a child with Down syndrome. This study found both sets of parents to be well adjusted to rearing a child with Down syndrome. This was mirrored in Carr's (2005) follow up study where families over many years have remained resilient and demonstrated an ability to cope.

Young Seideman and Kliene (1995) present a theory of transformed parenting. This qualitative study sought the views from both parents and described the parenting experience as they moved beyond their 'original' envisioned role and expectations to a new form of parenting. Some parents in this study created a mindset, one that enabled them to deal with situational problems that allowed them to hold on to the 'best' possible outcomes. This paper suggests that parents of learning disabled children face and cope with issues that are similar to families of typically developing children, the only difference being the nature and additional challenges that are presented by their child. Young Seideman and Kliene support Olshankey's (1962) definition of chronic sorrow as a natural response to a tragic event that continues over the life span.

Kelly (2005) examined the notion of 'embodiment of impairment' by interviewing mothers who attended an out-patient clinic. Essentially mothers in this study were

caught in a loop of consciously making, unmaking and remaking the taken for granted sense of what it is to be a parent. This enabled the coming to terms and acceptance of the reality as they constructed a parenting identity within the confines of their child's impairment with the possibilities presented. Similarly, Towers and Swift (2007) exclusively interviewed 21 fathers' who experienced changes in their social values and personal attributes in terms of being a parent of a disabled child. Both these studies would have benefited by including both parents, thus giving an equitable balance to their findings.

Woolfson's (2004) paper takes a different perspective when investigating parental adjustment. This study focused on the psychosocial factors of impairment and disability, by examining whether different families experience behaviour problems differently. Woolfson also considered the notion of cognitive reappraisal within an ecological context and argues that negative societal beliefs influence parental engagement as parents. A model is presented that challenges parental attitudes about disability. It is suggested that those parents who engage in cognitive reappraisal about their learning disabled child usually view their child differently and subsequently adopt effective parenting styles that encourages their child's growth into a person who is self-confident and a useful member of society.

Johnson *et al's* (2006) qualitative study used a Grounded Theory perspective to establish mother's experiences of caring for their severely disabled children. 5 main themes were developed that covered: Isolation, conflict, lifestyle limitations, self-blaming and coping on a day to day basis. Mothers in this study employed emotion focused strategies as a means to surviving. Child behavioural problems were viewed

as a direct stressor that had consequential effects on the marital relationship. Families also experienced exclusion from community-based services, often as a direct result of their child's social and emotional difficulties; this is also reflected in (McGill *et al.* 2006) study. Further to this, Herring *et al.* (2006) explored the presentation, development and family impact of behavioural and emotional problems in young children with pervasive developmental delay and those with delay but without a pervasive developmental delay. The findings suggest higher correlate of maternal stress, mental health issues and perceived family dysfunction as a consequence of child emotional behavioural problems rather than the child's diagnosis.

Shearn and Todd (1997) in their paper used qualitative methods to provide an account of daily living. It is unclear as to which parent participated in this study yet the findings provide an illustration of 'parental work'. This encompasses the physical care burden, supervision/safety, their teaching/mentoring role, their engagement with support services and general public, and finally their 'articulation' work. This is where parents balanced parenting work with other general household activities. The findings from this study are similar to that of Waggoner and Wilgosh (1990) who interviewed 8 families in-depth. Parents in this study highlighted their role as teacher and advocate and expressed the relationship difficulties they experienced with education providers. These parents were consumed with concerns as to their children's future and the impact of the emotional and physical demands of caring would have on them.

In terms of employment mothers were more than likely to work part time, they often worked below their capacity, first as a way of maintaining work life balance and

secondly, due to the needs of their learning disabled child (Brehaut *et al.*, 2004). Olsson and Hwang (2006) in their study comparative study of mothers' and fathers' involvement in paid work and child-care activities in families with or without children with intellectual disabilities. The findings from this study mirrored that of Brehaut *et al.* (2004) where mothers from families that include a child with an intellectual disability tended to work part-time, if at all, and take more responsibility for childcare. Likewise, fathers' of intellectual disabled children worked fewer hours than those in the control group and were reported to have the lowest levels of well being. This is attributed to their difficulties in finding successful paid work due to carer overload and low levels of well being.

Father's in Towers and Swift (2007) study found the balance between home and work a logistical nightmare, being caught between the need to earn and provide for family and to be home to support their partners. Further to this they found it easier to remain in the same employment in fear that they would not find the same level of understanding and flexibility from their employer. Parents experienced less social contact; this dynamic existing throughout the life cycle (Seltzer *et al.* 2001), often putting their needs on hold so as to meet the needs of their learning disabled child (Gatford, 1999). This is reflected in Emerson *et al.*'s. (2008) paper where families who supported children with developmental delay experienced income poverty, lived in social housing, relied on the benefit system and were viewed as being generally disadvantaged in contrast to parents of similarly aged children who were typically developing. In Olsson & Hwang's (2003) study it was emphasised how the Swedish Government offered financial assistance to families who have a learning disabled

child. This support aims to redress the imbalance of the impact of costs and loss of income associated with the caring of a learning disabled child.

As evidenced, it is well documented that parents are unprepared for how much their lives will change (Dobson *et al.* 2001), this is in spite of claims that carers should maintain a normal lifestyle outside of their caring responsibility (The Carers Action for Wales, 2007).

5. Parental well-being

Literature reports a spectrum of emotions experienced by parents, who parent a child with learning disability. Kearney and Griffin (2001) for example focused on the experiences of 6 parents (4 mothers and 2 fathers) and highlighted 3 themes: a sense of no hope and despair (sorrow) to hope and defiance (Joy) and the inherent tensions of raising a child with disabilities. Reports like this have a tendency to focus on parental stress and parental coping. Whilst most research in this area identifies parental experiences with stress and the care burden (Kearney and Griffin, 2001) there are a growing number of studies that report parents' positive views of parenting a child with a significant learning disability. For example, some parents in Skinner *et al.* (1999) viewed their learning disabled child to have had a positive effect on family in that it had helped them to re-frame their perspective on life and what really is important. (See also: Hasting *et al.*, 2002; Olsson and Hwang, 2003; Redmond and Richardson, 2003). It is however widely reported and generally accepted that parents of disabled children are placed in a novel situation and as such experience higher levels of stress in comparison to parents of children who are typically developing (Simmerman *et al.*, 2001). Sloper (1999) reviewed a number of research papers that

explored the factors that contribute to parental well being (see also: Knussen and Sloper, 1993; Beresford, 1994b; McConachie, 1994). One of her main observations found families to vary considerably in how they assessed their situation of having a disabled child, with the aetiology of stressors mainly being attributed to the child's level of challenging behaviour, ill health and parental/family sleep deprivation as a result of the child's poor or unestablished sleep settling habits (McConachie, 1994). Warfield's (2005) study concludes that a good predictor of stress level amongst parents relates to the amount of children being cared for within a family.

From these studies it is uncertain whether stress experience is differentiated between fathers and mothers. However, in Esdaile and Greenwood's (2003) study stress levels were reported to be higher for both parents of a child with learning disability in comparison to parents who have a typically developing child. This is evidenced further in Emerson *et al's*. (2006) study where mothers of children with intellectual disabilities reported lower levels of happiness, self-esteem and self-efficacy than the mothers of typically developing children. One factor for the increased risk of poorer well-being may be attributed to the increased likelihood of socio-economic disadvantage, usually as a result of mothers having to terminate employment (Redmond and Richardson, 2003). In Dyson's (1997) comparative study a similar picture was presented: fathers and mothers of learning disabled children were reported to experience greater levels of stress than fathers and mothers of children who were typically developing. Stress was related to a variety of factors that include: age of child, lack of appropriate information about managing children's presenting problems, educational placement issues, support issues such as short breaks and the physical features of the child's disabling condition. Ryan and Runswick Cole (2009) used a

mixed method approach with a fairly equal cohort of mothers and fathers to explore parental stress and coping. The mothers in this study reported statistically higher levels of generalised stress and higher levels of stress and coping in relation to care giving than their partners. The child's inappropriate and unpredictable behaviour, fears about the future and their child's education and learning topped a 12 point hierarchical list.

Some parents are said to experience a range of difficulties that evolve over time. Evidence can be found in Saetersdal's (1997) longitudinal study of families with developmentally delayed children. In this study parents reported a shift in their experiences of exclusion, their desperation, and their fight for recognition, to a new position of being accepted and having rights. Likewise, Beresford *et al.* (2007) reported parents desired outcomes, which encompassed their right to a personal identity, to experience physical and emotional well-being, to be skilled and informed, to have a balance between caring and parenting that maintained family life for all, to have adequate practical, financial resources and positive experiences as a service user. This report also sought the views of children and their desired outcomes. A study conducted by Saloviita *et al.* (2003) of a larger cohort of mothers and fathers found the most important predictor of parental stress was how they reported and defined their situation. Mothers in this study were most likely to relate stress to their learning disabled child's level of challenging behaviour, whilst fathers attributed higher stress levels to their perceptions of social acceptance of their child. Mothers in this study were more likely to seek outside agency support than the fathers, who sought support from their spouses.

It is evident in this review that some studies have reported higher levels of stress in mothers compared to fathers (Hastings *et al.*, 2005) and greater levels of depression (Veisson, 1999). The typology of disability and gender of the disabled child have also been reported to have an impact on the level of stress experienced by either parent (McConachie, 1994). Fathers' levels of stress have also been influenced by their own educational attainment and the personality, age and behaviour of their child (Ricci and Hodapp, 2003). Hastings (2003) in his study examined the inter-relationship between the mental well being of mothers and fathers of children with Autism and behavioural difficulties. There was a clear correlate between the stress in mothers and the problems experienced by other family members. This correlate was not evident for the fathers in this study, which may suggest that fathers are less involved in the direct care giving. However Dale's (1996) study reported fathers, as a direct correlate to exposure to sustained stressors, to experience mental health and low self-esteem issues.

There is evidence to suggest that stress levels are reduced in situations of reciprocal spousal support, particularly in respect to sharing the care (Button *et al.*, 2001), marital satisfaction and good mental health (Trute, 1995). In Simmerman *et al.*'s (2001) study mother's satisfaction with their partner's support was not directly related to the type or amount of care giving provided – suggesting that the father's role was determined by negotiation and or natural evolution within family. According to McConachie (1994) the key to positive parental adaptation is a good level of spousal support. Marital stress has been reported to affect the way fathers interact within the family (Pelchat, *et al.* 2003). Further to this, Kersh *et al.* (2006) focused on the contribution of the marital relationship to the well-being of mothers and fathers of

children with developmental disabilities. It is suggested by these authors that greater marital quality predicts lower parental stress and fewer depressive symptoms above socio-economic status, child characteristics and social supports.

Childcare provision has also been identified as a direct link to parental stress (Warfield 2005). This according to Warfield (2005) has had a direct effect on fathers who have in some respect been pressured to fill shortfalls in childcare provision. Whilst this may have a positive effect on the father-child interaction there is evidence (same author) to suggest that fathers of disabled children contribute less than fathers of children without disabilities. Further to this, increasing fathers' involvement in child-care activities can act to increase their confidence, with the potential to increasing their overall involvement with a subsequent reduction in their general levels of stress (Elder *et al.*, 2003).

6. Parental coping

The majority of families who care for a child with a learning disability develop coping mechanisms that enable them to continue to live their lives; some do not cope so well and experience chronic sorrow. Olshansky (1962) first described this as a parental response to the news of their child's learning disability. It was indicated that parents struggled to cope with the loss of the 'perfect child' as such their lives were punctuated with waves of grief and sadness. Specific times such as birthdays/anniversaries, selection of educational placements and pubertal issues exacerbated the levels of sadness. Parental coping therefore can be defined as the behaviours and cognitions that an individual engages in with a view to evaluate and protect against the effects of living with and raising learning disabled children

(Margalit and Ankonina, 1991). There is a wealth of available research that has explored and conceptualised individual coping styles, for example, Nolan *et al.* (1994) offer four coping typologies and presents a self-efficacy and outcome beliefs model, that consists of 'It will work' to 'It won't work' and 'I can do it' to 'I can't do it' polarities.

Hasting *et al.* (2005) provided tangible evidence that mothers and fathers adopt and use different coping strategies with mothers being more likely than fathers to use 'active avoidance' and 'problem focused' approaches. Latterly, Glidden *et al.* (2006) refer to other coping strategies that parents accommodate. These include both productive and unproductive strategies that include Positive Reappraisal Strategy, Escape Avoidance, Confrontative Coping and Seeking Social Support. These findings are reflected in Gray's (2006) study, in particular the use of Confrontative Coping as a strategy, which contains elements of advocacy. Glidden *et al.*, (2006) discuss unproductive coping strategies in detail, with the use of parental use of escape avoidance, escape avoidance and distancing being prominent. All of these strategies are reported to reinforce the negative effect of the stressor.

In studies such as Carpenter and Herbert (1994) fathers were reported to engage more in 'active avoidance' strategies, where they withdrew from their families, either by immersing themselves in their work or other activities normally outside of family based activities. These factors are evidenced by Grant and Whittell (2000) who interviewed 17 couples and 10 lone parents using a semi-structured format. These parents employed a mixture of problem solving and stress reducing approaches, with mothers relying on their own personal experiences in finding practical solutions

before establishing priorities; fathers on the other hand opting to maintain their own interests as a vehicle to cope. The study concludes by stating that these approaches are differentiated by gender, life stage and family structure with lone parents tending to use cognitive coping as their main stress relieving strategies.

This too is reflected in Gray's (2006) study where parents were found over time to move from 'problem focused' to that of 'emotion focused' coping strategies. The majority of respondents in this study reported their child's symptoms of Autistic Spectrum Disorder having improved over time with a resulting routinisation of family life. As such they experienced lower levels of distress and used fewer coping strategies, or at least, perceived themselves to be doing so. Gray concludes that the use of emotion-focused coping strategies is linked to the aging process. Glidden *et al.* (2006) in their study reported the adoptive and birth parents to use more 'problem-focused' strategies. The personality of the parent, in particular neuroticism, was predictive of the coping strategy employed. In this regard higher levels of positive reappraisal of their situation reflected higher levels of well being, whereas mothers who used higher levels of 'escape-avoidance' tended to experience lower levels of well being.

Turnball *et al.* (1986) classified parental coping strategies as being either 'internal' or 'external'. The most commonly used external coping strategies include acquiring social support, be it informal or formal. Activities such as taking up a previous hobby can assist parents in their coping (Taanila *et al.*, 2002). Some parents according to Ray and Ritchie (1993) sought spiritual support – this essentially helped parents

maintain hope. This form of support has according to Turnball *et al.*, (1986) been identified as the most important external coping strategy

7. Role in family

McConachie (1982) conducted her research study into fathers' involvement with their disabled child with an attempt to define more clearly what they actually 'do'. Although dated the issues presented are still relevant today. Firstly, McConachie found that there was a paucity of studies that specifically targeted fathers. She made the point that research is often based on interviews conducted with mothers that asked them to comment about their partners' views and/or roles. Secondly, there was little or no differentiation between parents. In fact when the term 'parent' was used it generally referred to the mother. Thirdly, McConachie argued that services and information were primarily targeted at the mothers, as they were viewed as being the primary carer and that the fathers' involvement was viewed as being secondary. McConachie (1982) also addressed the long held tradition surrounding the needs of the fathers, their abilities and role within family. She argued that the stereotyping of these roles has influenced the way fathers have been viewed in their relationships with their child. She also explored a number of opposing assumptions that have been made about fathers. An illustration of this paradox is the notion that fathers of disabled children will be more involved with their child as a direct consequence of the increased care load. McConachie considered these contradictory assumptions as being one factor that makes research into families problematic. This view is supported by Carpenter and Herbert (1994) support who add that the amount of time fathers spend with their child will inevitably have a direct effect on their responses to their situation. However, fathers who go out to work, leaving the bulk of the child care burden to the

child's mother, will naturally be less involved in all aspects of their child's care and daily life. Thus impacting on their interactions with formal support services and all the accompanying stresses and rewards this will bring. More recently, Schneider *et al.* (2006) interviewed 20 families in-depth. The findings from this study suggest a change in family roles and family relationships, with family time being divided up equally to facilitate an equitable family routine. There is evidence to suggest role division where one parent sees to the learning disabled child's needs whilst the other parent deals with any other children 'in family' and their needs. Families talk of a team approach that acts to protect others from 'too' much involvement, thus creating a balanced home life. Fathers in Dex and Ward's (2007) national survey were of the opinion that they did not spend enough time with their children; this was attributed to their work life patterns. These findings are also mirrored by Ellison *et al.* (2009), here fathers expressed that they wanted to spend more time with their children. Both parents in this survey stated that they wanted to share work and child care equally. It has to be noted that the findings from both these studies reflect the views of the general population.

Another aspect to the parenting role as suggested by Schneider *et al.* (2006) relates to parents awareness and protectiveness to the role of their other children. In this study parents expect them 'not' to assume a caring role; as such parents endeavoured to maintain a semblance of balance between interdependence and dependence. Parents as a consequence often protected by shielding their non-disabled children from a perceived high level of involvement in the care of their learning disabled brother or sister. This protecting strategy was primarily influenced by their belief that the care for their learning disabled child/children was their responsibility.

The reviewed literature suggests that the mother is the planner and organiser 'in family'; this is evidenced in Docherty and Reid (2009) study. Mother's views about the future of their Down syndrome children were sought. They experienced a more dynamic and changing picture to their role as parent. There is reference to their constant awareness and readjustment of their parenting role (not dissimilar to that reported by Kelly, 2005) where they defined and redefined what's next for their child and indeed for them. Mothers in this study were reported to produce change and to be changed. This would suggest that one of the mother's role is to plan, gate keep and facilitate their child's path to adulthood and ultimate independence. Interestingly all of the mothers were active members of the Down syndrome association, which may have acted to influence their thinking, views and beliefs. This study would have benefited by seeking and differentiating fathers views.

8. Support Systems

Baldwin and Carlisle (1994) reviewed the literature and gave an account of how there has been a steady recognition that caring for a severely disabled child at home impacts on the whole family. They quoted the Younghusband report (1970) as highlighting the need for more and better-organised support services. Two significant reports: The Court report (1976) and the Warnock report (1978) also identified the nature of the problems that parents were facing. The Court report made clear distinctions between support services and their design. As such parental problems were not necessarily due to the lack of service provision but as a consequence of poor design and delivery. The Warnock report was amongst the first to identify the format support should take and can be credited for being an early advocator of care co-ordination i.e. that parents needed one person who they can relate to for advice on services available to them.

Other research studies attempted to quantify 'support' as experienced by parents (see Fox, 1974; Armstrong, Race and Race, 1979; Glendinning, 1983). The conclusions of these studies featured a number of common elements, with a high percentage of parents reportedly having infrequent contact with either social workers or health visitors. Most parents much preferring to have had more advice and support. However, parents when in receipt of support found the advice to be passive or routine. The overall emerging picture from the research at this time is that parents felt generally unsupported by services that were primarily set up with the purpose of providing that support.

Supports generally fall within two categories: informal and formal that both generate a range of benefits and costs. Beckman's (1991) earlier work differentiates between these support sources and identified informal support and formal support. Informal support is argued to be an important factor as a potential mediator to stress. She reported fathers not to have reported significantly less informal support than did the mothers. There is however reference in the literature that fathers needs go unmet. This issue has been highlighted by Herbert and Carpenter's (1994) who reported fathers to be classified as 'peripheral parents'. Wing (1975) in her study identified fathers as the source of emotional support for mothers in her research into family and disability. She found that emotional support provided by the husbands was mentioned by nearly one third of her research sample, all of whom were the mothers. Redmond *et al.* (2002) reported that having a child with a learning disability can place a strain on parents' personal relationships. This was attributed to the actual time couples have for each other, outside of the caring role. According to Beckman (1996) a decrease in marital satisfaction evoked feelings of lack of support and isolation This has been well

researched by Glen (2007) who surveyed child and parental relationships. She highlighted mothers who perceived partner support as being inadequate. This often led to partner conflict and subsequent father withdrawal from family life; often resulting in marital breakdown.

Social support from friends and extended family was more likely to promote parental well being and has been reported to be more beneficial than contact with professional services in how parents adapt to their situation. The role of the extended family has been reported (see Hastings *et al.*, 2002) as a source of support but also having the potential to create additional pressure and stress.

Schneider *et al.* (2006) suggests that as families move along the life cycle they experience lower levels of informal support from in and outside of their family i.e. reduced supports from grandparents, siblings moving out of the family home or engaging in activities that excludes other family members. This means that families rely more heavily on supports from formal sources. It is evident that families develop routines that 'fit' best and operate within the boundaries of the life cycle i.e. the phases of their child/children life stages. Whilst parents are able to predict transition points i.e. where their child/children fit in the system at any given time they nonetheless find transitions fraught with uncertainty. These changes may include a change of school, particularly when mainstream education is unable to meet the child's educational, social and behavioural needs. Some families talked of their children not being eligible for short and long term breaks, as a direct consequence of their child's behavioural difficulties. This was evidenced by Schneider *et al.* (2006), who also highlighted that some parents experienced a loss of respite support provision

when their children reached eighteen years of age, simply because they fell outside service age eligibility criteria. Further to this, parents at each service transition had to engage in the discussion regarding the search for placement and enter into the funding bargaining between agencies - thus elevating parental stress and lowering feelings of well-being.

It has been argued that 'support services' can add to the burden of caring. Beresford (1995) in her study identified some families as experiencing negative relationships with professionals. There is considerable evidence to show that parents and professionals have a difference of opinion about the needs of families (see Sloper and Turner, 1991; Balwin and Carlisle, 1994; Hall, 1997). Middleton (1998) in her study addresses the question of the relationship between parental views and those of services providers, in this instance the social worker. She talks about gaining a picture of 'families' views by way of interviewing them. It is not explicit as to whose views she sought, whether the mother, father or both. She does however acknowledge that the views of the disabled child had not been sought. Many families in this study found a discrepancy between the services offered and their wishes, needs and priorities, particularly with regard to the frequency, level and timing of services. In addition to this, service providers tended to offer what was available rather than being creative in what they offered, this often resulted in a service that did not reflect the child's needs i.e. being placed with other children who were either older, younger or of differing ability levels. Further to this, formal support services were prone to being offered at short notice, giving families little time to plan and prepare. Services were subject to change often as a result of budget cuts or rationalisation. Families found themselves having to frequently request services, often resulting in further professional

assessment that again added to parental stress and uncertainty. According to Schneider *et al.* (2006) families who are faced with these external challenges adopt a combination of strategies as a way of maintaining their daily routines. It has been suggested that families given these situations advocate their rights - informally and/or formally. Informal advocacy involves confronting and making known their concerns to professional agencies. Formal advocacy on the other hand involves entering into the statutory appeal processes. Families in Schneider *et al.*'s (2006) study generally co-ordinated multiple services, those who engaged in a co-ordinating role were reported to find it much easier to plan and manage their child's supports. Some parents forfeited desired outcomes held the view that it is their responsibility to continue caring and as such no other alternative exists. Schneider *et al.* (2006) suggest that forfeiting is a last resort option for parents. This option manifests with one or more family members sacrificing a valued family routine in order for them to maintain the care of their disabled child/children. Some parents in this study felt pushed into a corner when they had little opportunity for formal supports, which resulted in them having to consider out-side of home care, such as supported community living.

Potential tensions that can emerge between internal and the external range of family life were highlighted by Schneider *et al.* (2006). The preferred internal management strategies often result in families having to access external services. These services pose a new set of challenges for families as they often do not fit with and match families' needs and wishes. This is also reflected by Beresford's (1994a, 1994b) studies where parents had at least some confrontation with health, education and/or

social services primarily around the professional encounter and dissatisfaction with service provision.

There is a range of explanations given as to why mothers' and fathers' experiences are different. One such explanation is linked to their differential access to support services. Cunningham and Davies (1985) and Marks and McLanahan (1993) in their respective studies make the assertion that services tend to deal with mothers, who in turn would have greater access to appropriate support networks. Carpenter and Herbert (1995) also focussed on this particular issue and state clearly that fathers are disadvantaged as they are not able to access the same support systems as the mothers. This in turn can have a negative impact for the mothers as additional stress is put upon them. Carpenter and Herbert (1995) referred to how services assume that all dialogue can be sustained exclusively through the mother. Beckman (1991) indicated fathers to express greater dissatisfaction with formal support services than mothers do. Men in general are less likely to seek assistance with their health or emotional problems. However, a small cohort of fathers as reported in Dale's (1996) and West's (1998) respective studies attended pilot therapy groups where positive outcomes for fathers were reported. Focused counselling as identified in Prachee's (2004) study can assist fathers to understand their role better. Counselling provided to mothers can also have a beneficial effect for fathers, in that, as the mothers emotional needs are addressed the interactions with child and spouse will undoubtedly improve (Shechtman and Gilat, 2005).

Todd and Shearn (1996) examined some features of parents' lives that act to shape their need for support and their assessment of the adequacy of the support received.

The findings from this study suggest that parents experienced a lack of spontaneity where parents were unable to exercise control over their lives and use of their time. The support needs of this group of parents varied over the life course as a result of changing relationships within their personal support networks and the changing perspectives on their own situations. Further to this, Todd and Shearn (1996) suggest that support services seemed to operate on a narrow understanding of parents needs. This issue, it seems, is to determine whether the departure of people from the parental home is to indicate either the failure or success of support services.

Valuing people (DOH: 2001) clearly highlights the need for better advice and information from services in an integrated way, with easier access to the support services. Literature that has been reviewed implies that the relationship between parents and professional support services is focused on key events: the diagnosis of the child's condition, and the decision making about the child's subsequent support needs. There is evidence that suggests services in some way marginalise fathers, to the extent that services fail to utilise a major resource for the family. Lillie (1993) found fathers more likely to participate in support activities if professionals who had input to the family acknowledged them. Factors such as appointment times, scheduling of other activities i.e. assessments need to reflect both parents' times and demand issues (Turbiville and Marquis, 2001). Fathers in West's (2000) qualitative study found the support from the paediatrician, teaching staff, speech and language therapist, nurse and independent key worker most helpful. Some of these fathers though experienced some health professionals as being unhelpful particularly with regard to comments made and their general attitude towards them as if they were not part of the family unit. Likewise, parents who were interviewed by Shuwa *et al.* (2006) reported

problems such as a lack of key workers, dissatisfaction with the assessment and advice given, not being listened to, lack of information and communication between agencies. Case's (2001) suggests that service providers had taken positive steps in improving parent/professional relationships. However, services continued to remain reactive in their focus, primarily offering counselling and advice. This is in spite of repeated requests from parents for a more proactive supportive service. This study does however draw attention to parental need and their expertise when it comes to their learning disabled child/children. In terms of future planning and service collaboration families interviewed by Knox *et al.* (2000) held positive views about their prospects for the future and that they felt that there was a genuine sharing of decision making with service providers.

9. Summary

It is clear from this review that there is a large body of research available to the field of learning disabilities. This research has investigated a variety of aspects that include how parents adapt and adjust to the news of their child's learning disability and how the child's disabling condition impacts on family life. It is worrying to note, that in spite of the wealth of research conducted there has been a failure to acknowledge and clearly state that parents should, in all instances, refer to father and mother as separate individuals, who experience and hold views independently from each other. In particular their views on what constitutes a parent and their experiences of being a parent.

It is important to reflect on the research studies that have been reviewed. Most of them have adopted quantitative methods to elucidate information – these studies have

used a range of standardised measures and rating scales. More recently there has been an influx of studies that have specifically applied qualitative techniques and/or mixed method approaches. Within the scope of this review I have been unable to locate any pertinent research that has adopted Husserlian phenomenology. In some studies (see: Towers and Swift, 2007) a qualitative approach was adopted but failed to acknowledge methodological and philosophical alignment. Likewise other studies, such as West (2000) failed to report the framework used in analysing the data. .

The next section provides an overview of the phenomenological movement and how Husserlian philosophy as a method can be applied to nursing research.

CHAPTER THREE: Phenomenology

1. Introduction

This chapter provides a brief historical overview of the development of the philosophy of phenomenology. It presents the key contributors to the development of this philosophy in the form of mini biographies. The key core concepts that are central to the phenomenological philosophy are introduced during this discussion. Further to this, the theoretical assumptions that underpin phenomenology and phenomenological research are explored in some detail. The chapter first addresses the question: ‘what is phenomenology?’ before moving on to discuss pure philosophical phenomenology as advanced by Husserl and how this can be applied within the context of nursing research. Real life examples are introduced and interweaved within this text to illustrate how this way of thinking can be utilised to explore and understand the phenomenon of parents’ lived experiences of caring for their learning disabled children.

2. An historical perspective: the development of phenomenology.

Spiegelberg (1982), a historian, presents several volumes that give an authoritative and historical account of the “phenomenological movement”. Structurally he divided the development of phenomenology into three phases: (a) the preparatory phase, (b) the German phase and (c) the French phase. The word ‘movement’ as used by Spiegelberg (1982) reflects the fluidity of the philosophy i.e. that it was ever developing. This can be seen across the movement as different philosophers have left their own mark and indelible imprint on this philosophy.

The Preparatory phase can be credited to the works of Franz Brentano (1838-1917) who is considered the forerunner of this movement during the first half of the nineteenth century and Carl Stumpf (1848-1936), who was the founder of experimental phenomenology (Spiegelberg, 1982). Brentano has been credited with two major contributions. His primary objective was to reform philosophy in the service of humanity in order to provide answers that organised religion could not supply. He also strived to make psychology truly scientific (Cohen, 1987). Descriptive psychology was to be the base of this science. This way of thinking i.e. describing and clarifying before undertaking causal studies was quite innovative at the time (Spiegelberg, 1982).

Brentano was the first to discuss and expand the idea of inner perception, the awareness of our own psychic phenomena and the notion of intentionality. The concept of intentionality was at the core of his thinking, for Brentano this referred directly to the idea that consciousness is always conscious of something. Merleau-Ponty (1956: 67) summaries this thus: "interior perception is impossible without exterior perception, that the world as the connection of phenomena is anticipated in the consciousness of my unity and is the way for me to realise myself in consciousness". Cohen (1987) provides an example that simplifies Brentano's thinking that one does not hear without hearing something or believe without believing in something. Therefore intentionality is the notion that everything that we consider to be physical refers to an object. Brentano's ideas of intentionality have been modified by further philosophical thought. Yet these ideas remain one of the most fundamental assumptions of phenomenology.

Stumpf, Brentano's first prominent student, developed the idea of experimental phenomenology. This is an approach whereby knowledge is derived from the analysis of empirical material. This involves, by experimentation, an analysis of the structural connections between the elements of the (object) material (Cohen, 1987). Stumpf's lasting contribution to the 'movement' was by demonstrating that phenomenology could be studied with the rigour of experimental and scientific techniques. It was indeed Stumpf who designated phenomenology a pre-science – preceding any claims to knowledge (Jones, 2001).

Two prominent scholars essentially dominated the German phase: Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). Husserl was and continues to be regarded as the central figure of the phenomenological movement. There have been attempts to place Husserl's development and thinking into periods. Spiegelberg (1982) outlines three phases, 1) the pre-phenomenology phase 2) the stage of phenomenology and 3) the period of pure phenomenology. Kockelmans (1994) would agree that it is necessary to spend some time pondering and distinguishing the periods of Husserl's development. As such he views the time between 1900 and 1906 as the main transition phase, where Husserl moved from a pure descriptive form of phenomenology to that of a more complete transcendental phenomenology.

For the purpose of clarity I focus here solely on Spiegelberg's three-phased account of Husserl's philosophical development. Firstly, the pre-phenomenology phase (1887-1901) covers the period Husserl spent at the University of Halle. It was during this period Husserl became a 'privatdozent' under Stumpf. His work involved interpreting mathematics by a psychology. After receiving criticism of his third book Husserl

abandoned the psychologism of his earlier writings. To some extent he rejected every form of psychologism in logic. It was during this period that he studied and worked with Brentano; Brentano being best known as Husserl's teacher and mentor (Spiegelberg, 1982).

The second phase, where Husserl spent his first years at Gottingen (1901-1906), saw the development of phenomenology. Husserl placed equal emphasis on the objective and subjective aspects of experience. It was during this time that he accepted a position of 'professor extraordinarius' in philosophy, and following an overruling by the Minister for Education he was offered a 'professor ordinarius' in 1906. Husserl throughout this time worked on increasing his knowledge of philosophical heritage (Smith and Smith, 1995).

His final phase included his later years at Gottingen (1906-1916) and his time in Freiberg. During this time he conceived "pure phenomenology". It was viewed as the universal foundation of philosophy and science. Husserl formulated a new transcendentalism, which he continued to make more radical. Subjectivity was the dominant force of his thinking, and was indeed the source of all objectivity (Cohen, 1987). Husserl, although becoming disillusioned with the scientific position of positivism continued to espouse his ideas of a rigorous science throughout his career. He strongly believed that science needed a philosophy that would strengthen its contact with deeper human concerns. As such, his phenomenology was founded on a critique of the positivists (Cohen, 1987). His radicalism was an important constant in his philosophy. For Husserl this meant going to the roots or beginning of all knowledge. His later phenomenology placed emphasis on essences. As his thinking

developed so too did his radicalism where he moved away from describing actual facts to describing ideal types of logical experience that corresponded to ideal logical laws (Shand, 1994).

One of his terms: 'Anschauung' (intuiting) describes Husserl's thinking: the ultimate test of all knowledge. This concept moves away from the notion of experience as experienced in real individual cases. 'Anschauung' as advanced by Husserl can occur within memory or through imagination (Spiegelberg, 1982). Husserl during this period coined several other terms, in particular, 'Epoche' and 'Phenomenological Reduction'. He viewed these concepts as a vehicle to obtain pure and unadulterated phenomena that are available in the natural attitude - the everyday, unreflected attitude of naïve belief (Hamlyn, 1988).

Husserl's use of the mathematical metaphor for the 'bracketing' of suspended belief as intended has been interpreted and altered – in the research tradition the epoche refers to bracketing out of prejudices and has in many ways been misinterpreted and misused (Cohen, 1987). For example, its application and operationalisation remains vague, and often superficial. Some nurse researchers, who have claimed to use this device, do not provide clear descriptions of how it was achieved (see Oiler, 1982 and Rose *et al.*, 1995).

Towards the end of his career Husserl moved away from pure phenomenology to that of transcendental phenomenology. Husserl never fully explained this term and it remains unclear whether his thinking was fully developed. It was indicated that one was to suspend all transcendent claims, such as assertions about reality other than

consciousness itself (Spiegelberg, 1982). Following his death, unpublished manuscripts yielded yet another concept, that of the 'Lebenswelt' (the life world). Husserl was referring to a world of everyday experiences that is not immediately accessible to us in the natural attitude (Scruton, 1994). He believed that the access to the material world was through consciousness and that all knowledge was derived through experience. Husserl had expanded his ideas of experience that encompassed anything a person may be conscious of, be it a physical object, an abstract concept or a state of mood (Priest, 2001). It is common for us to take for granted what is around us without really noticing it. To see what surrounds us requires a phenomenological study – this is the task that is central to the phenomenological tradition.

The second most noted philosopher of the German phase was Martin Heidegger. Heidegger was an established scholar before becoming, for a brief time, Husserl's assistant. He was primarily concerned with being and time ['being' being essentially temporal]. His interests lay with ontological and temporal issues and how they related to authenticity (Jones, 2001). Heidegger's work in some ways mirrored that of Husserl's. Spiegelberg (1982) claims that it is highly plausible that Heidegger's thinking and work was as a direct consequence of Husserl's ideas. Some of Heidegger's principles, especially the *Epoche* were close to Husserl's ideas, yet he opposed the notion of bracketing. As such, he viewed phenomenology as being important, but not in the Husserlian sense. However, in his later writings the term phenomenology was not used. Spiegelberg (1982) speculated this might have been in deference to Husserl who had disclaimed him. It is reported that the two men lost contact later in Husserl's life (Cohen, Khan and Steeves, 2000). Two aspects account for this, firstly the opposing philosophical differences and secondly, Heidegger's

increased involvement with the Nazi movement. According to Spiegelberg (1982) Heidegger is reported not to have helped Husserl through the tragedies he experienced as a Jew during his retirement. With Heidegger's involvement in Nazism came the end of his connection to 'activism' as well as his trust in human beings. After the war it is perhaps not surprising that he published little, it is also interesting to note that his interests changed drastically. Even though Heidegger was heavily criticised for his involvement with the Nazi regime during the 1930s and 1940s he was never charged with any crimes following the war (Jones, 2001).

Heidegger's greatest contribution to the phenomenological movement may have been the inspiration to the later French phenomenologists as he refined and converged Husserl's phenomenology with existentialism, what is commonly known today as existential phenomenology or philosophical hermeneutics (Jones, 2001). Phenomenology in Germany ended with the Nazi years. Cohen (1987: 33) states that "there is currently some interest in Husserl, but there has been no real revival in his philosophy".

The French phase began after the Nazi takeover. Husserl's papers were transferred to Louvain, Belgium shortly after his death. Following the Second World War, phenomenology has been the foremost philosophy in France. Heidegger's concepts suited the French philosophers' precision in formulating the philosophy and science of existential phenomenology, as such he was better known than Husserl. This could also be said of Max Scheler (one of Husserl's earlier students who was interested in the phenomenology of essences). According to Spiegelberg (1982) the most noted

scholars during this phase were Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961).

Marcel used phenomenology as a beginning to explore the ontological questions of being - one step in metaphysical reflection. Even so he never viewed himself or called himself a phenomenologist. He was a user of phenomenology but never considered or called himself a phenomenologist. According to Cohen (1987) Sartre is credited for reactivating phenomenology, yet like Marcel he too never called himself a phenomenologist. He however reluctantly accepted the label of existentialism and used phenomenology for his ontological existentialism. Like Husserl, Sartre's philosophy developed through phases: a pre-phenomenological period that was influenced by a morbid destructive philosophy. This emerged into the development of a phenomenological psychology. His work during this phase lacked his usual scepticism and was far more scholarly and concrete. His third phase that was influenced by Heidegger's ideas of 'being and time' concentrated on phenomenological ontology (Spiegelberg, 1982). In his final phase, Sartre concentrated his thinking toward phenomenological existentialism. This was attributed to his political involvement and the combining of Marxism into his thinking, particularly the subjective nature of being. His interest focussed on the actual practice of phenomenology rather than its theory. He was a firm believer "that a person's concrete consciousness and concrete behaviour (existence) preceded a person's character (essence) – character being the outcome of free acts" (Cohen, 1987: 34).

Sartre's thinking enabled the problem of dualism to be eliminated, for example how the mind and body communicate with one another. When viewed this way consciousness is in the world and as such is always conscious of something. Continuing with this way of thinking Sartre was of the opinion that the best way to learn about human consciousness is to describe it where it exists.

Sartre's friend and fellow philosopher Merleau-Ponty is credited as being the first French author to publish with the word phenomenology in the title to a work [Phenomenology of Perception, 1962]. It is claimed that Sartre and Merleau-Ponty had differences of opinion between their philosophies (Spiegelberg, 1982). Merleau-Ponty was more concerned with science than Sartre. He strived to demonstrate that a science of human beings was possible, perception being the origin of this science. In his volume 'Phenomenology of Perception' he provided a case for considering the experiences of individuals. By contrasting a phenomenological approach against that of a positivist approach he demonstrated that a phenomenological stance provided additional and valuable insights. As such he fervently opposed the French positivist movement that focussed on the 'objective' at the expense of the experience.

Cohen (1987) states that several important French philosophers continue the phenomenological work. Examples are Paul Ricoeur, Mikel Dufrenne and Raymond Polin. Although there is some interest in phenomenology outside of France, it has not assumed a dominant place in Western philosophy in general (Spiegelberg, 1982).

It is worth noting that during the development of the phenomenological philosophy a parallel development was occurring among therapists (both psychiatrists and

psychologists). According to Cohen (1987) this development has been described by Binswanger (1958), Ellenberger (1958) and May (1958), which later comprised the *Daseinanalyse*, or existential-analytic movement. Its development was primarily motivated by the inability to understand why various therapeutic techniques were able or unable to effect cures as well as the problem of understanding what was happening in the patients' existence. Husserl and Heidegger influenced this movement, which in essence is as complicated as the phenomenological movement. Phenomenological descriptions were used by the therapists to help them begin to "see the patient as he really is, knowing him in his own reality" rather than seeing a projection of our own theories about him (Von Gebattel, 1958: 3, cited in Cohen, 1987).

This view is not far removed from the views of the nurse theorists, who have stressed the importance of understanding the patients' perspective as central to providing nursing care (Cohen, 1987). Examples include Leininger (1978), Parse (1981), and Watson (1979).

The succeeding section provides a comprehensive discussion on the theoretical assumptions that underpin phenomenological research principles.

3. Theoretical Assumptions – A Philosophical Viewpoint

3.1 What is Phenomenology?

Phenomenology is the science of phenomena. It was first expressed by Kant in 1764, the term as a derivative of the Greek '*Phainen*' – meaning 'to appear'. Kant used the term to distinguish the study of objects and events as they appeared in one's experience from objects and events as they are in themselves (Priest, 2001). This term

has been used intermittently by a variety of other philosophers. Hegel expressed phenomenology as the science in which we come to know *mind* as it is in itself through the way in which it appears to us. For Husserl, who is considered the founding father of phenomenology, it became a descriptive method as well as a human science that was based on modes of reflection at the heart of philosophic and human science thought. He was determined to find a scientific method that would find and guarantee the essential structure of consciousness, where it would be possible to set aside mere appearances and deal directly with the reality as it is in itself. Husserlian phenomenology is therefore a discipline that aims to describe how the world is constituted and experienced through conscious acts. According to Priest (2001: 51) its aim “is to produce a description of a phenomenon of everyday experience, in order to understand its essential structure”. In this sense phenomenology differs from that of ontological inquiry, which studies the existence of being – which is in essence interpretative in nature (Jones, 2001). The phenomenologist describes what is presented to them in the immediate experience without the obstruction of pre-conceptions and theoretical notions. Husserl during his working life advanced transcendental phenomenology – which is central to and underpins the basis of this research.

Schutz (1970: 320) defines the central purpose of phenomenology as “the lived experience of everyday life. The “total” sphere of experiences of an individual which is circumscribed by the objects, persons, and events encountered in the pursuit of the pragmatic objectives of living”.

It is called phenomenology because it espouses subjectivity and the discovery of the essences of experiences. It also provides the philosopher/researcher with a method that is disciplined and systematic. Husserl makes two clear distinctions regarding his own conceptions of phenomenology. Firstly, that his method is descriptive and, secondly, that it suspends all judgments by the bracketing of all empirical beliefs that one holds about the world (Rosen, 1998). As a method it only uses the data that is available to consciousness – the appearances of objects. In action the subjective experiences of others, in this instance that of the co-researchers will be brought to the attention of my consciousness by way of listening to their stories and re-reading the verbatim transcribed account. This enabled the processing of the subjective accounts by the Epoche and the subsequent transcendental reduction. This process will be discussed and clarified later in chapter 4.

Husserl in his last major work formulated the idea of the *Lebenswelt*, the life world (Van Manen, 1990). This relates to the every day world in which we live. This notion has become programmatic in the development of an existentially oriented phenomenology. This approach aims to describe how a phenomenon presents itself in the lived human experience.

Phenomenology differs from other human science approaches such as ethnography and grounded theory in that phenomenology makes a clear distinction between appearance and essences: it is primarily the study of essences. This means that phenomenology as a constant asks the question of what is the meaning or nature of something and asks us to look at the world as we meet it in the 'here and now' immediate experience. It also asks of us to seize the meaning of the world as that

meaning comes into being. Phenomenology therefore does not produce empirical or theoretical accounts it offers accounts of experiences as we live them (Moustakas, 1994).

The notion of the 'lifeworld' (Lebenswelt), as described by Husserl is the 'world of immediate experience' the world as already there, pregiven. Husserl makes a clear distinction between our theoretical attitude to life and our natural pre-theoretical attitude to life, upon which, according to Husserl, all theorising is based and ultimately derived (Scruton, 1994).

Modern phenomenology aims (in parallel to Husserl's thinking) to understand the world and gather information about it. This though is not evidenced within some nursing research, it is far removed from what Husserl intended. According to Paley (1997) this is in all probability due to a misunderstanding and misinterpretation of Husserl's work.

It can be achieved by engaging in a variety of activities, such as:

- Suspending belief in the world of phenomena and investigate further 'the experience'. This can be related to what Husserl called 'bracketing' (epoche) or as it is more commonly known 'the phenomenological reduction'.
- Analysing by reflection and introspection.
- Intuiting: The ability to be able to experience the experience as though it was one's own.
- Describing, as outlined by Lemon and Taylor (1997) is the final stage of the process where the researcher pulls together insights and tests them against the

information from the informants' quotes. This process can be likened to 'telling a story', the tale that tells the story of a given human experience.

There are seven accepted assertions of the phenomenological approach:

1. phenomenologists generally oppose the acceptance of unobservable matters and grand systems that are erected in speculative thinking;
2. phenomenologists generally oppose positivism that is a worldview that has grown from modern natural science;
3. phenomenologists generally justify cognition with reference to Husserl and what he termed "evidenz";
4. phenomenologists generally believe that not only objects in the natural world, but ideal objects such as numbers, and even conscious life itself can be made evident and known;
5. phenomenologists generally hold that enquiry should focus upon what might be called "encountering";
6. phenomenologists generally recognise the role of description as a priori or eidetic terms;
7. phenomenologists generally debate as to whether or not the transcendental epoch and reduction as coined by Husserl is useful or even possible.

Taken and adapted from: Center for Advanced Research in Phenomenology (1997).

Husserl acknowledged that the transcendental phenomenological approach is not the only approach in seeking knowledge of human experience. As a science it is carried out with systematic concreteness (Moustakas, 1994).

Husserl's philosophy brought with it a host of terms that for him held very different meanings. The remainder of this chapter explores the key concepts of Husserl's work, which will include his thinking on intentionality, the noematic and noetic relationship, his epoche and phenomenological reduction.

3.2 Intentionality

The term intentionality is central to Husserl's thinking. His reasoning: the intertwining of subjective and objective thinking was influenced significantly by Descartes (Moustakas, 1994). This has been widely agreed by most of his critics and interpreters. In its most mature form it provides a strong debate on the thought and language issue. Husserl developed his theory that made intentionality the vehicle of all objective reference. As such he had a greater interest in epistemological matters rather than psychologism. He subordinated the contingent features of mental acts and their associates – for example, their date, duration, location or intensity – to their logical and referential function (Shand, 1994). As a theory it indicates the inseparable connectedness of the human being to the world. Husserl argued that the fundamental structure of consciousness is intentional (Spiegelberg, 1982) and that every conscious experience is bi-polar: that there is an object that presents itself to a subject or ego. This means simply that all thinking is always thinking about something – one does not think about nothing! The same can be said for actions: touching is touching something; hearing is hearing something. All human activity is oriented activity, directed by that which orients it. It is in this way we discover a person's world (landscape). For Husserl, this meant that all consciousness has an object or content.

Husserl understood intentionality in terms of the object-referring ('objectifying') function of mental acts. He made the important distinction between two senses of 'intentional object', namely, between the object that is intended and the object as it is intended. As such, for Husserl intentionality is no longer a relationship of a mental act to its 'intramental' object, but the vehicle of objective reference.

The task of philosophy can therefore no longer consist in installing itself between the subject and the object in the critical attitude in order to try to find out whether and in what sense the subject attains the world as it is in itself. All that manifests in transcendental experience is to be described just as it appears according to the principle of pure evidence. Further to this the phenomenologist has to realise that intentionality of consciousness has two other essential qualities, one 'static' and the other 'dynamic', that call for two related yet different forms of description (Moustakas, 1994). The static description tries to determine all that is found in every lived experience in a concrete way. The dynamic description attempts to describe intentionality in its origin and evolution. It is the latter that is deemed phenomenologically more important. Its greatest problem lies in the constitution of the objects of consciousness. From these writings we can see that phenomenology wants to establish all knowledge on incontestable evidence immediately rooted in intuition.

On closer examination it becomes obvious that, in the transcendental sphere, the different objects are not found in the thoughts as are 'matches in a box', but are composed in different forms of synthesis. An example of this is given by Kockelman (1994), who refers to a cube as being an objective unit (this cube), the cube can

appear in a multiplicity of modes (noemata). What appears in consciousness is an absolute reality, while what appears in the world is a product of learning – the cube, as we know it in the ‘real world’ is known by a product of learning. Therefore there is a relationship that exists between what exists in conscious awareness and what exists in the world. Husserl advanced the notion of the noematic and noetic acts to describe the process of concept/precept.

3.3 The noematic and noetic relationship

Husserl’s philosophy used a host of terms that can be confusing and misleading, no more so than his concept of the ‘noema’ and ‘noesis’. The noemea (noematic [*pI*]) denotes that to which we orient ourselves: it is the object referent of noesis, the noetic act. The noesis is the interpretive act directed to an intentional object, the noema (or the noematic object) (Moustakas, 1994).

The term ‘essence’ originates from the Greek ‘ousia’, which means the inner essential nature of a thing, the true being of a thing. Essence makes a thing ‘what it is’ and without which it would cease to be what it is. Husserl used Plato’s Eidos – a term for idea or form – to designate universal essences. Husserl often referred to essence as the ‘whatness’ of things as opposed to the ‘thatness’. It is said that some phenomenologists make a distinction between the basic or fundamental essence (Grundwesen) and empirical science (Empirisches Wesen). Within Husserlian phenomenology essences, whether they are basic or ideal, are said to be accessible to phenomenological intuiting (Moustakas, 1994).

I offer a working example that is personal to me one that can only add to my and the reader's understanding of this difficult concept.

An act of consciousness...

Here today, sitting outside typing. The sky is clear blue with the odd white cloud passing by. The sun is making it difficult to see the laptop screen. I pause and look out to the fields directly in front of me and to the rolling hills beyond. What a beautiful view, one that fills me with a feeling of calm and warmth. The view of the fields and rolling hills is the matter – the object of the intentional act; its perception is in my consciousness. The 'objectifying' quality is the fields and rolling hills that are present to me – the noesis. The 'non-objectifying' quality is the feeling of calm and warmth that has been evoked by the view of fields and hills that are in my view – the noema.

The noema is not the real object but the phenomenon – not the fields and rolling hills but the manifestation of them.

The 'object' that appears in perception varies in terms of when it is perceived, for example, time/temporal variations, orientation/angle, with what feelings, wishes or judgements. These variations are always from the point of a perceiving individual. If I viewed the fields and rolling hills in front of me following a disagreement with my wife, or at night, or when it was blowing a gale, the fields and rolling hills will still be presented to me. The synthesis of my perception will always inform me – through experience – that the fields and rolling hills are those in front of our cottage. Wherever I view it from, day or night, whatever the season or my frame of mind, the

fields and rolling hills are present in time and space, whilst the perception of the fields and rolling hills are in my consciousness.

As Moustakas (1994: 29) states “Regardless of when or how, regardless of which components or what perception, memory, wish or judgement, the synthesis of noemata (perceived meanings) enable the experiencing person to continue...” In the example presented above ... seeing the fields and rolling hills from the cottage as no other.

Husserl (1931: 260, cited in Moustakas, 1994) sums up:

“What is the ‘perceived as such’? What essential phases does it harbour in itself in its capacity as a noema? We will reply to our question as we wait, in pure surrender, on what is essentially given. We can then describe ‘that which appears as such’ faithfully and in the light of perfect self-evidence”.

The ‘perceived as such’ is the noema and the ‘perfect self-evidence’ is the noesis. Their relationship constitutes the intentionality of consciousness. The noema and noesis is a relationship, you cannot have one without the other – they are linked. The noema is the textural component whilst the noesis is the structural component of a phenomenon. The subsequent arrival of meaning is the essential function of intentionality.

Brand (1967: 198, as cited in Kockelmans, 1994) explored the notion of functional intentionality, he observed:

“in each experience intentionality functions simultaneously as implicit pro-ject (vorwurf) and as retro-spect (ruck-schau). In the beginning, functioning intentionality is completely anonymous, it is concealed; “its quiddities are still wrapped up, not yet unfolded”

In the phenomenological attempt to seize the meaning of experience, we are engaging in the functioning of intentionality process. The meaning of the phenomena is unveiled; it is delivered from anonymity of the natural attitude and moved towards an all-inclusive totality of consciousness.

Moustakas (1994: 31) provides a summary of the challenges of intentionality:

- “1. Explicating the sense in which our experiences are directed.
2. Discerning the features of consciousness is essential for the individuation of objects (real or imaginary) that are before us in consciousness (noema).
3. Explicating how beliefs about such objects (real or imaginary) may be acquired, how it is that we are experiencing what we are experiencing (noesis) and
4. Integrating the noematic and noetic correlates of intentionality into meaning and essences of experiences.”

In his writings – ‘investigations’ and ‘Ideas’, Husserl stressed the similarities in the structures between perceptual acts (relational account) and linguistic acts (adverbial account). This problem has been long debated with Husserl presenting a new solution to these issues. In his earlier works he treats the problem of intentionality in a relational fashion “as a special problem of ontology” (Smith & Smith, 1995: 15). In his later work Husserl adopted an adverbial theory to deal with this problem. Husserl

argued that there is a clear difference, not merely in function, but also in the structure between 'signitive' intentions and perceptual fulfilment. This assertion opened a way to contrast between the signitive intention and the perceptual acts. This resulted in Husserl demonstrating the maintenance of identity of 'sensation' (*empfinden*) and 'sense-data' (*empfundene*), leading to an integration of the sense data and the noematic appearances of the object (Welton, 1977). According to Smith & Smith (1995) Husserl's work, when viewed as a whole, provides an account that enables the joining of the two sides of intentionality together.

3.4 Intuition

After the reduction, eidetic intuition is in some ways Husserl's second most celebrated methodological technique. For Husserl it was the return to the things themselves. Intuition is therefore the starting point, the place from where to derive knowledge of human experience, free from everyday sense and its impressions and the natural attitude (world). According to Moustakas (1994), all becomes clearer and evident when viewed through an intuitive – reflexive process. This is a process of stripping away the layers, by abstaining from the natural world, the everyday knowledge and knowing of things - by considering something in its nakedness – as it truly is.

Husserl did not advocate the use of deduction, unlike Descartes, in his transcendental philosophy. He asserted the sole use of intuition. Intuition therefore is crucial in describing accurately what presents itself and whatever is actually given. For Husserl, intuition is the presence of something (an essence) to consciousness, with all that it implies by necessity and universal validity (Lauer, 1958, cited in Kockelmans, 1994).

Husserl (1931, cited in Moustakas, 1994: 33) identified a priori knowledge with the intuition of pure essences. Every experience:

...however far it extends, leaves open the possibility that what is given, despite the persistent consciousness of its bodily self-presence, does not exist... *existence in the form of a thing is never demanded as necessary by virtue of its givenness... the further course of experience will compel us to abandon what has already been set down and justified in the light of empirical canons of rightness... the thesis of my pure ego and its personal life, which is "necessary" and plainly indubitable, this stands opposed to the thesis of the world.*

Intuition is an 'eidetic' comprehension or in other words an accurate interpretation of what is meant in the description of the phenomenon in question. As a process the researcher varies the data by way of imagination – it is a solitary activity – to such an extent that a common phenomenon emerges. Through this imaginative process the researcher will begin to wonder about the phenomenon in question and will seek to investigate the relationships between the various descriptions. An example of this in action in the current project is the immersion in the rich data generated by the face-to-face parent interviews. Listening to each tape recording over and over, exploring all possibilities, until a relationship emerges against the informants' descriptions and the essences.

Lothar Eley has been credited by Patocka (1977) for providing an explanation of and uniting Husserl's thoughts, particularly regarding the transcendental motives. For

example, intuition that discloses essences and reduction that discloses the consciousness that constitutes the factual world.

3.5 Epoche

Within the epoche, the everyday awareness and judgements are set to one side. The phenomena are re-examined, freshly in a naïve manner, with eyes open wide to it and from the vantage point of a pure transcendental ego. According to Moustakas (1994) the epoche is a necessary first step before moving on to the transcendental reduction. Transcendental in this instance because it moves beyond that of everyday life and experience, but to that of pure ego. Phenomenological because it transforms the world and what it constitutes to mere phenomenon. Reduction because it enables one to travel back to the source of meaning and the existence of the experienced world.

For Husserl (1975: 8, cited in Moustakas, 1994: 45) “the world is nothing other than what I am aware of and what appears valid in my *cognitions*... I cannot live, experience, think, value, and act in any world which is not in some sense in me, and derives its meaning and truth from me”.

3.6 Transcendental Reduction

Husserl borrowed the term ‘bracketing’ (reduction) from his mathematician background (Hamlyn, 1988). He used the terms: bracketing, eidetic reduction, and epoche interchangeably. Irrespective of the term used they all describe the necessary change in attitude for philosophical inquiry (Priest, 2001). As such, it is a process where one engages in an act of suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world. Merleau-Ponty

(1962) describes this 'reduction' as a phenomenological device that enables us to discover the 'spontaneous surge of the life world'. In order for one to understand the essential structures of something one needs to reflect on it by practicing a certain reduction.

Several levels of reduction can be distinguished. Firstly, there is an awakening of a sense of wonder and amazement at the 'mysteriousness of the belief in the world'. This leads to a questioning of the meaning of the experience of the world. Secondly, there is a need to overcome one's own subjective and private thoughts/feelings, preferences, inclinations, and/or expectations that would prevent one from coming to terms with a phenomenon as it is lived. Thirdly, in the reduction process one strips away the theories and/or scientific conceptions and any thematisations that may overlay the phenomenon of study, and which may prevent one from seeing the phenomenon in a non-abstracting way. Finally, in the eidetic reduction one needs to see past or through the particularity of lived experience toward the universal, essence of eidos that lies on the other side of concreteness of lived meaning. The reduction is the ambition to make reflection emulate the unreflective life of consciousness.

Reduction is essentially a search for an absolute foundation of knowledge. It is necessary therefore to engage in a ground clearing that will enable a clear focus on what is the issue (not 'what the issue is' as this is purely an assumption). This is by common consent by far Husserl's most obscure feature of his work (Rosen, 1998). The subject matter of phenomenology is the 'object' in the manner of its 'givenness'. To attend to this 'givenness' requires one to examine our thoughts without paying reference to either the state of the world or to the psychological attitude of the thinker

who thinks them (Rosen, 1998). So in practice it is a requirement to suspend (bracket) those aspects of our thoughts that involve commitments regarding the nature of the empirical reality. It is through the purging that the essential aspects of the thoughts in question will emerge in response to the phenomenologist's investigation.

We can see from this that the transcendental reduction leads one from the things in the world to the transcendental ego, which epistemologically precedes all objective reality. It does not make sense to use the "I think" as an apodictically evident premise for deductive arguments, quite the reverse, the phenomenological reduction enables an infinite realm of being of a new kind, that is the sphere of transcendental experience. It is important to understand that the transcendental reduction in no way changes the experience as experiences are experiences of something, and that all consciousness is and remains consciousness of something.

There have been a number of criticisms levelled at this process. Rosen (1998) believes it is possible to suspend beliefs about the natural attitude. However, Husserl requires all beliefs to be suspended, whilst at the same time maintaining the contents of our thoughts. Rosen (1998) argues that there are very strong reasons to suspect that this is an impossible task. Likewise, Taylor (1995) echoes these doubts as to being able to 'bracket' oneself in any human-to-human situation. She adds that one has to be open to this possibility. Hintikka (1995) also posits that if one is to concentrate one's attention exclusively on 'noemata' too much will be bracketed. Hintikka adds that such a concentration will inevitably bracket, not just the objects, but also the relationship of the noemata to the objects. As such "you can not be aware of the relations holding between two terms if you are not aware of the two terms" (Hintikka,

1995: 80). If in the phenomenological reduction the entire object is bracketed it will be all but impossible for the phenomenologist to explain the relation of a noema to its object.

Rosen (1998) offers a plausible argument here in stating that many of our thoughts depend entirely on our beliefs about the world. If we were then to suspend these beliefs, then the content of these thoughts would be altered. In his argument Rosen presented an illustration, this I have amended to bring it to my world of experiencing: When I drive to into a car park I see a dark blue Volkswagen Polo, it carries a W plate. I attach a meaning to the appearance of the car – that it is my wife’s car. I just don’t have a mental picture of the car, it being made of metal, plastic, rubber and cloth. It has seats a steering wheel, one that I have sat behind and driven. These are the beliefs about the world that contribute to my understanding of my wife’s car. If I bracket out those beliefs how can I go on seeing the car in the way I do? Rosen (1998) states that the only way for that to be possible would be if I were to make a distinction and say “these beliefs are not ‘part of’ what I see, but are beliefs ‘about’ what I see. But then what would remain? The answer seems to be that it would be some kind of perceptual image, without all the judgements and pre-conceptions associated with it. Rosen (1998) argues that this view cannot be that as Husserl intended as it would return phenomenology to the empiricist picture of the mind: one that he strongly rejected – the idea that what is given to us in experience is a series of bare sensible particulars.

It is possible Husserl identified this problem as he wrote, “the thesis is experienced as lived, but we make no use of it (that is, our beliefs about the reality that we

experience)” (Rosen, 1998: 693). This appears to be more of an assertion – one which again is deemed implausible (Rosen, 1998), as it would be wrong to say that when I see the blue Volkswagen all that I see is a blue Volkswagen – I am said to be making no use of my beliefs and that what is in front of me is my wife’s blue Volkswagen Polo. I would counter this in true Husserlian tradition, that in seeing the blue Volkswagen Polo I am doing so without the presuppositions of it belonging to my wife and the car that I have also driven.

As an acknowledgement Rosen (1998) feels it is not right to dwell on the objectionable features of Husserl’s work, his phenomenology. His importance ought to be assessed on his influence on the tradition of continental philosophy, as this has been much broader.

3.7 Imaginative variation

Imagination figures importantly in Husserl’s phenomenology, yet according to Elliston and McCormick (1977) Husserl’s notion of imagination is rarely discussed in his writings. When imagination has been discussed it is of secondary importance to that of perception. Irrespective of its related importance to perception, Casey (1977) is of the opinion that imagination is most crucial, particularly in the preparatory stages of varying the terms of reference when viewing the phenomena. As such, imagination is necessary in enabling the exclusion of causal factors from the phenomena whilst aiming to discriminate essential from non-essential features. Giorgi (1985) and Moustakas (1994) both refer to imaginative variation (intuiting) as a strategy in achieving the transcendence from the natural to the phenomenological attitude. This involves asking questions of the phenomenon in order to remove or peel away non-

essential features thus allowing an unshackled exploration of all possible meanings of the data presented. Processing in this manner allows the phenomenological researcher to see what is needed to change in order to make the phenomenon under scrutiny a different one. Intuition and reflection are intrinsic to this process, and in doing so allow the opening up of meaning to the experience.

According to Elliston and McCormick (1977: 7) the variable nature of imagination is paradoxical: "...on the one hand imagination is a liability because it is merely variable; on the other, it is a resource because, as variable, it gives the philosopher another approach to truths".

The examples that relate to a given phenomenon constitute the starting point for free variation proper. Casey (1977) refers to the phenomenologist who is unable to find any examples that relate to the phenomenon in question, be it within past or present experience. In situation such as these it is according to Casey (1977) legitimate for the phenomenologist to invent an example "as a point of departure in an eidetic analysis". These examples, be they fact or fiction, are then subjected to a systematic variation of imagination. The use of imagination enables the examples to be varied until the essential structures of the phenomena are more visible.

Casey (1977) lists three complementary procedures that can be used independently or together:

- 1) All significant traits are removed from the examples by varying terms of references and looking at the phenomena from different perspectives.

- 2) Newly identified traits are used to substitute old traits. This procedural step enables the phenomenologist to look at existing examples and replace them with traits that best fit the phenomena. The phenomenologist is able to determine whether traits are essential to the phenomena when they are unable to replace traits with new ones or when they cannot remove them as in step one. If the phenomenologist is able to remove or replace a trait then they are viewed as being contingent to the phenomena.
- 3) 'Productive imagination' is seen as the third and final procedural step. Additional traits that played no part in the initial 'variation' and have not been replaced are seen to 'fill out' examples that are deemed incomplete. These traits do not represent a definitive essential structure – but act as an aid in determining the essential character of the phenomenon.

“The employment of imagination (as method) to describe imagination (as phenomenon) draws on imagination’s intrinsic powers of variation” (Casey, 1977: 79). The principal aim of imaginative variation is to arrive at structural descriptions of an experience – what underlies and what precipitating factors account for what is being experienced (Moustakas, 1994). It is the describing of the essential structures that determine the task of imaginative variation. It is in essence a “free play of fancy” (Moustakas, 1994: 98) – the making of the invisible visible. The process is reflective where all possibilities are examined giving a ‘fullness’ to the search for essences.

Moustakas (1994: 99), like Casey (1977), offers the phenomenologist a four-step procedure that can assist them in the imaginative variation process:

1. Systematic varying of the possible meanings that underlie the textural meanings;
2. Recognizing the underlying themes or contents that account for the emergence of the phenomenon;
3. Considering the universal structures that precipitate feelings and thoughts with reference to the phenomenon, such as the structure of time, space, bodily concerns, materiality, causality, relation to self, or relation to others;
4. Searching for exemplifications that vividly illustrate the invariant structural themes and facilitate the development of a structural description of the phenomenon.

Through imaginative variation there is given an insight into the general features that are shared by practical things. This makes it possible to compare and classify them.

3.8 Tensions in Husserlian phenomenology

Husserl focused on individual personal experience from the perspective that ‘self’ is the only thing to exist (solipsism). The phenomenology of Husserl “is a first person exercise, each of us must explore our own experience, and not the experience of others, for no one can take that step ‘back to the things themselves’ on our behalf” (Crotty, 1996: 82). Within the tradition of this phenomenology Husserl did not explore how others might have experienced a similar phenomenon. This presents a tension if justifying research strictly to Husserlian principles i.e. if one is to adopt strict Husserlian phenomenological principles and apply them to a range of

participants, like in this project, the parents who live with and care for their learning disabled child/children. Further to this, there remains the issue of describing 'essences' – this can be problematic when searching for the essence of many diverse experiences. Paley (1997) argued in his paper that it may be legitimate to describe a range of experiences of a phenomenon, but it is extremely doubtful whether the purest form of essence can be described. Moustakas (1994) in some way addresses these issues in his adaptation of Van Kaam's method. He incorporates an additional stage to his analysis; this involves the development of a composite description of the meanings and essences of the experiences that represents the group as a whole. I would express a caveat here, as it is not the real intention of phenomenological research to seek out shared, common meanings, **unless** they are held common with others. On considering this statement further McNamara (2005) would posit that it would be proper to present phenomenological research as one or more rich and comprehensive narrative accounts of each individuals' experiences of a particular phenomenon.

These positions have been challenged. For example, Swanwick and Barlow (1994, cited in Priest, 2001) claim that the analysis of several persons' meanings can lead to a greater understanding of the phenomenon under investigation. With regard to the concept of 'essence', Watson (1985, cited in Priest, 2001: 53) claimed that this does not necessarily "...need not mean absolute or definite but more pragmatically represents the deepest understanding available, established on the basis of inter-subjective agreement of a given context".

Some nurse researchers have been criticised for assuming that Husserlian and Heideggerian phenomenology were one and the same (Koch 1994). Further to this

others have misused phenomenology, concerning themselves with the person's experience of a phenomenon rather than the phenomenon itself (Crotty, 1996); hence the development of phenomenography in education circles (Dall'Alba and Hasselgren, 1996). Yegdich (1999) adds to these criticisms, in particular nurse phenomenologists, who were said to be acting as though Husserlian phenomenology concerned itself with subjective experience, rather than, as its primary intention is, with the essence of phenomena 'unclouded by subjective opinion'. Porter (1998) cited in McNamara (2005) accuses nurses of having done phenomenology without actually knowing phenomenology. McNamara (2005: 697) illustrates this by insisting that some nurse researchers have a tendency to "unsettle Husserl's 'noetic-noematic correlation' by misconstruing the fundamental interdependence between that which appears and is experienced (noema) and the mental apparatus of the experiencing, meaning constituting subject (noesis) to which it appears". As such, nursing phenomenology does not always get behind the mundane and banal that in many respects covers the object of pre-reflective experience. Nursing research is therefore deemed impoverished as it lacks both the "note of objectivity" and the "exercise in critique" (Crotty, 1996: 82). Walters (1995) argues that some nurse researchers equate the technique of bracketing with all phenomenology, irrespective of fit with the philosophical framework.

It is clear from this that there are in fact two types of phenomenology being used by nurse researchers, one that linked directly to that of Husserlian tradition and the other that is directly influenced by humanistic psychology. According to Crotty (1996) both of these approaches are valid, but the researcher must be clear in identifying which approach they have adopted, as they cannot be used interchangeably.

The tensions discussed in this text have presented many difficulties for me, I have struggled to conceptualise Husserlian thinking in its purest form. This has been primarily due to reading source material that is third and fourth hand, as such this has created methodological conflict, particularly in how I remain true to Husserlian principles. Despite these difficulties I have not been discouraged in using this approach; on the contrary it has bolstered a keen interest in this subject. I have over the years learnt to accept and adjust to the philosophical and methodological tensions in my personal pursuit of completing this thesis that reflects Husserlian thinking. This has been achieved essentially by reading and re-reading a wide range of critiques and opinions that are closer to the original sources (see for example: Olafason (1977), Kockelmans, (1994)' Paley (2005). These volumes (and others) have in some way helped shape and form my own views. Evidence of my thinking can be found in Chapter four where further deliberation to the issue bracketing is presented. Within this discussion tensions that have been generated for nurse phenomenological researchers like myself will be debated.

CHAPTER FOUR: Bracketing

1. Introduction

This chapter begins with a further exploration of the concept of bracketing and the philosophical and methodological issues that are presented to the phenomenological researcher. A framework for bracketing is presented to the reader, one that provides a description on how bracketing was achieved in this project.

2. Bracketing – a concept

Merleau-Ponty (1962) argued that the phenomenological reduction allows one to enter the life-world of another. For Husserl, this was a vital and necessary step to putting on hold every assumption that is normally made in the ‘natural attitude’ – this includes common sense beliefs about the nature and existence of things in the ‘outer world’ (Paley, 1997). He used the terms phenomenological reduction, epoche and bracketing interchangeably to describe a change in attitude that is necessary for philosophical inquiry. According to LeVasseur (2003: 49) bracketing has been described as “an attempt to hold prior knowledge or belief about the phenomenon under study in suspension in order to perceive it more clearly”. It is in all sense and purposes a reflective process by which opinions and prejudices are suspended to a point that allows a focus of attention on what is essential in the given phenomena. With this in mind, it is the intention of the succeeding narrative to discuss the activity of ‘bracketing out’ presuppositions, when the life-world of parents who live with and care for their significantly learning disabled child/children is being considered. The beliefs I had long held as an experienced practitioner, the family systems and

behavioural theories that have guided me in my practice had now to be unshackled, lest they encumbered me further in my journey of discovery.

Beech (1999) asserts that if one is to remain steadfast to the notion of bracketing and its importance to phenomenological research, it is important to determine what may be bracketed and what must be assumed. Bracketing experience is not supposed to alter or change it, but to leave it perfectly as it was. This process is supposed to enhance and focus its structure of meaning, resulting in a purge of assumptions that relate to a range of things in the world. This is in some ways very similar to the Buddhist enlightenment, where “the logical end of Husserl’s bracketing was an arrival at the ‘transcendental ego’, the consciousness necessary for the apprehension of pure phenomenal experience devoid of any assumptions about personal history or location in space and time” (LeVasseur, 2003: 413).

We assume, naturally, the existence of the person to be interviewed (intentionality). To bracket out their existence would negate the research activity. We must also consider the parents’ intentionality – in this regard we need to consider two meanings of intentionality. On a common sense standpoint intentionality refers to the parents’ motives for action. For example a parent may construct such an elaborate story for the purpose of the interview – the motives for doing so could be plentiful. This according to Beech (1999) if experienced during a positivist inquiry would be deemed an invalid piece of self-reporting. However, if presented in a phenomenological inquiry such an incident would indicate a ‘truth story’ that an informant wants to convey – therefore it cannot be classified as being invalid. According to Beech (1999: 41) ‘The value of a

story lies in the access it gives to the person's experiences and not in its relationship to any claims to an objective truth'.

In a phenomenological sense it is expected that a parent will have an intentionality towards the phenomenon being investigated – in other words the parent is conscious of the phenomenon – living with and caring for their learning disabled child/children, and will be able to reach out and discuss their experiences. The phenomenon though must be intuited and grasped, and then described by the co-researcher, not by the researcher (McNamara, 2005).

Within this discussion of bracketing, we therefore cannot bracket out the existence of the parent, nor any intentions towards the thing under investigation. As part of this discussion, attention needs to be drawn to the intentionality of the researcher – again in the common sense usage of the term, here our intentional act refers to our purpose: the carrying out of our research, to fulfil the requirements of the PhD programme. This research is therefore about finding out something about the parents I work with in order to add to current knowledge about the meaning (or essential structures) of caring and also to achieve the award of a Degree of Doctorate of Philosophy. The whole process would be meaningless without such direction and purpose – as such this cannot be suspended completely.

With regard to the research focus there is, in the phenomenological meaning, an intentionality towards it – a consciousness of the thing being studied – the phenomenon of parental experiences of living with and caring for their learning disabled child/children. It is therefore important that one remains attuned to it, it is

also important that we require to suspend in parenthesis our previous experiences and knowledge of it.

In my own experiences – upward of thirty years of working with parents, offering direct support in often highly emotive and challenging situations – my thoughts, beliefs, attitudes, assumptions and judgements towards this group of people have been firmly embedded. These thoughts, beliefs, attitudes, assumptions and judgements of the external world must be bracketed. This dynamic can be considered the tension to which Kvale (1993) describes. This is where there is an ‘essential tension’ between bracketing and the recognition and incorporation of foreknowledge about the phenomenon.

Beech (1999, cites Giorgi, 1985), who discusses further problems for the phenomenological researcher. If the researcher is attempting to adopt a presuppositionless position to what extent can the phenomenological method itself be bracketed? In response to this question, the phenomenological researcher should in their general approach be phenomenological. This according to Giorgi (1985) means that general phenomenological approaches to data are adopted: for example, bracketing, imaginative variation and the intuition of structures.

Beech (1999) asserts that there is a need to be presuppositionless to method and that one does not apply a rigid prescriptive approach, as this can be seen to bind the researcher. The phenomenological researcher must also bear in mind that there is a possibility that the thing being researched may have no relevance to the life-world of

the interviewee – or that meaning between one person's life-world to that of another person may be totally different.

There is a claim from the philosophical and psychological standpoint to be carrying out an activity, the activity of bracketing. As the term was coined by Husserl is there an argument for psychology to re-name what they do? Or are the differences purely semantic here? Beech (1999) suggests that as long as the phenomenological researcher remains totally explicit about the process of bracketing, and that the explicitness enables others to understand the context of what has taken place, the researcher, if following these rules, can legitimately use the word. Paley (1997) argues otherwise, he asserts that nurse researchers betray the fundamental tenets of Husserlian phenomenology and with it misconstrue its key concepts. As such, nurse researchers cannot achieve what they have alleged to have achieved, and should therefore detach themselves from Husserl's philosophy, his ideas and terminology that is used to justify their claims.

Confusion about the bracketing activity may occur in situations where the phenomenological researcher assumes that there is a shared meaning between the philosopher and the psychologist – it is imperative that a common understanding should not be assumed. It is also important to avoid the assumption that as interviewer we know about the life-world of the interviewee. Part of the bracketing activity is to 'unknow' our own interpretations and assumptions of similar or parallel experiences. In my case, I will need to 'unknow' my own biography of being an experienced community nurse, my experiences of twenty-something years of relationships with parents over that time and the amassed knowledge. Further to this I will have to set

aside and ‘unknow’ my own experiences of being a father and parent. According to Beech (1999: 45) ‘unknowing involves something other than merely forgetting – there is a need to remain mindful of the phenomenon while unknowing experiences of it’.

Carpenter (1995) suggests that one should refrain from conducting a prior literature search in an attempt to remain presuppositionless. I would concur with Beech (1995) here that our own personal and professional life experiences have significant influences on our attitudes and beliefs. However, these influences will not have been reflected on in a purposeful way, nor will they have been cancelled out from the natural attitude – to be unknown. In my situation a prior literature review was conducted and is updated continuously – any findings have been reflected upon and noted.

3. Bracketing In and On action

It has to be acknowledged that researchers are subject to human frailties, which will naturally bring into the research arena their own personal experiences, preconceptions and attitudes. It is these very aspects that the phenomenological researcher, who has adopted a Husserlian stance, strives to expose and hold in abeyance. In doing so the phenomenon of study is presented from the co-researcher to the researcher’s consciousness in a clear and unadulterated way, exactly as experienced, before it is exposed to the researcher’s biography of experiences, attitudes and bias. This is the hub of phenomenological research: aiming to reflect a true image of an experience as experienced from a co-researcher’s point of view.

The process of returning to this state of awareness is termed 'phenomenological reduction'. Husserl, whose earlier experiences were within the world of mathematics coined the term 'bracketing'. This reflects a position where everyday assumptions are contained or held within a field of imaginary brackets, such as the brackets that contain mathematical formulations. It is important to understand that this philosophical process as advanced by Husserl is not a process that occurs in a step-by-step manner. It is also important to understand that it is not a research method, nor a technique: it is a philosophical device which, must be 'interpreted' for pragmatic research purposes.

For the novice researcher contemplating such a process evokes many questions that cannot be answered easily. For example, how does one attempt to bracket? When does the process begin and end? Several academics have attempted to answer these questions. Giorgi (1997) states that it is the researcher who engages in the bracketing, as it is the co-researcher's natural attitude that is being sought and understood. Paterson and Zderad's (1988) assert that the phenomenological researcher has to be open in order to break through one's tunnel vision of routine. Paley (1997) and Yegdich (1999) argue that many nurse researchers use of phenomenological method is questionable because there is a clear failure in how they have understood Husserl's meaning of bracketing. Further to this, Paley (1997) illuminated a variety of nursing studies that failed to provide clear descriptions as to how bracketing was achieved. He also holds the opinion that nurse researchers often misunderstand and misinterpret the concept of phenomenological reduction that often results in an unintelligible and incoherent project. Whilst these nurse researchers provide reference to their own attempts to suspend their own preconceptions, there is no mention of the co-

researchers' naïve assumptions. There is a tendency to focus entirely on these naïve subjective assumptions. It is this very misunderstanding of the idea of bracketing that renders the natural attitude to be 'bracketed in' in order for them to remain faithful to their co-researchers' experiences and not to the phenomena or the things themselves (McNamara, 2005).

My own personal experiences have also taught me that there are no set methods, or step-by-step stages to follow in undertaking this activity, it is a philosophical and psychological orientation towards oneself. It is intrinsically solipsistic, one where all judgements that concern spatio-temporal existence are suspended. As such, it is a first person, reflexive process that involves a turn from the naïve understanding of the object itself, as it is presented to consciousness in an original and direct fashion (McNamara, 2005). This includes making judgements about people and events, thus enabling the 'natural attitude' to be cancelled out before embarking on the phenomenological enquiry.

Wall *et al.* (2004) developed a framework that was influenced by the works of Schon (1987) and Johns (1994). This framework relates closely to the concepts of reflecting 'on' and 'in' action and 'learning'. These ideas were adapted and used by Wall *et al.* (2004) to develop a reflective framework for the reductive process.

A reflective diary similar to that as advocated by Wall *et al.* (2004) was used in this project as a way of 'opening up perspectives' in a self-aware and meaningful manner (Appendix six). This diary has been instrumental in enabling me to develop my bracketing skills and allowing me to demonstrate that I have remained faithful to the

tenets of Husserlian phenomenology. Further to this I am able to provide to the reader a descriptive account of how I achieved bracketing.

The diary consisted of four key areas these are:

Pre-reflective preparation: It was essential to take time to prepare mentally, thus bringing into awareness possible issues and personal beliefs that may require bracketing. This was of particular importance as the main source of data collection was by way of face-to-face interviewing. Chapter seven provides a detailed examination of my own beliefs, ideas and attitude to the meaning of being a parent and what my perceptions of what it means to be a parent of a child that has a significant learning disability.

Reflection: This aspect of the diary provided time to reflect on the specifics of the interviews and gave opportunity for reflections to be made about the progression of this study. Reflections of this nature were described in detail, as was the influence they had on the situation. In addition to this I engaged in a critical analysis as to the extent to which bracketing was achieved.

Learning: It was important to identify what new learning had taken place as a consequence of reflection. This learning uncovered new insight on the bracketing process, for example, what actions to take in the event when bracketing did not occur. The following exemplar describes such an event: when listening to a mother talk of her other children and how they have been affected I found myself immediately linking the content of what was being said to previously conducted parent interviews and to my own set of beliefs. A theme - 'window of opportunity'- came to mind as this mother spoke about family life. If I had put to one side my thoughts and listened, I would have understood that what she was saying wasn't what I had initially thought.

Her son really enjoyed being with his sister [referring to her daughter who has a significant learning disability]. I had wrongly assumed, through my own set of beliefs and through other co-researchers' experiences that she was about to speak of how difficult it is for her son to bring friends home when her sister is home – hence the 'window of opportunity'. From this experience I had learned to open my mind to my own thoughts, but to place them to one side and not to link them immediately to what is being said.

Action from learning: According to Wall *et al.* (2004) learning from reflection enabled change to occur, in particular, how learning could be employed within other situations. For example, during subsequent interviews I used other co-researchers experiences as a way of illustrating and clarifying what was being said. Wall *et al.* (2004: 23) also used learning as a way of transferring "...learning into the methodological decision-making process as the study progresses".

Three other aspects were also considered as being central to enable bracketing: Bracketing 'pre'-action, bracketing 'in'-action and bracketing 'on'-action.

Bracketing 'pre'-action: A period of time was spent reflecting on my own personal experiences – one, of being a parent, and two, as an experienced practitioner. This time was spent documenting my own thoughts, feelings and attitudes, with the goal to developing a plan in how to manage issues so that they did not interfere with the interview process. Wall *et al.* (2004) describes visual imagery to guide discovered issues and to place them within brackets – to the point of them being visually being put aside, on hold psychologically. With practice this visual imagery is possible, for example, reflecting on what it is like to be a parent of a child with significant learning disabilities, unearthed statements that were mainly negative in nature i.e. "life is determined with fewer opportunities..." These negativities, in some way, reflected my

working experiences, supporting parents who cared for a child that presented with complex behavioural difficulties. As I was about to meet parents, some known and some unknown to me, with a research question, it was imperative to put to one side these thoughts. The placing of these thoughts within imaginary brackets helped me to hold them prior to and during the interviews.

Bracketing ‘in’-action: As issues emerged during the interviewing process I adopted what Wall *et al.* (2004) coin bracketing ‘in’-action. Wall *et al.* (2004) gave an account where one interviewee stated that they would feel more comfortable being interviewed with their partner. This was not anticipated in practice or during methodological development. Like Wall *et al.* (2004), for methodological purposes co-researchers were interviewed separately. The rationale for this was based primarily on the research purpose and my own personal views that some individuals are not able to express themselves openly and honestly in the company of their partner. This demonstrated that through my own personal bias and attitudes there is a danger of being closed to the possibility that some couples are comfortable sharing inner thoughts with each other.

In situations, where issues are presented ‘in’ action it is important to make a conscious effort to be open to these changes: for what it is rather than for what it is thought to be. As such there has to be an acceptance that unplanned issues will occur – any such issues will need to be dealt with by way of bracketing so that they do not interfere with the emerging phenomenon.

Bracketing ‘on’-action: Wall *et al.* (2004) describe a position where the study is reviewed methodologically. Like Wall *et al.* semi-structured interviews were the main method of data collection. There is a taken for granted position that parents’ can or

indeed want to describe their experiences as set out in the interview structure. Wall *et al.* (2004) reflected on the process and found that most participants wanted to tell their stories, without interruption. As her interviewing skills grew she became less worried about the structure and allowed the participants to tell their stories before refocusing them by asking specific questions. Wall *et al.* felt this was a more effective way of eliciting information as it gave more depth and meaning to their accounts. Wall *et al.* advocate the use of unstructured interviews as, in their study, richer in-depth information was yielded.

4. Interview process and issues of bracketing

Beech (1999) advocates the use of a diary as a means of quieting the mind prior to conducting research interviews. This allowed detailed recordings about significant issues arising from each of the interviews and any personal feelings and reflections on the interview and its process. This information is reflected on, and where necessary is incorporated in to the bracketing activity. Beech (1999: 46) is also of the opinion that it is important to distance the timing between interviews – as this will prevent blurring “so that unconsidered data is allowed to become present to the interviewer, so allowing it to be bracketed”.

5. Interviewee issues

Beech (1999) is of the opinion that it is not a requirement for the co-researcher to bracket out any preconceptions prior to and during the interviews. This opinion is based on the acknowledgement that these very preconceptions make up the co-researcher’s life-world as it relates to the phenomenon in question. Beech’s view here is purely from the phenomenological perspective – he strongly believes that research

participants need to be pre-informed about the nature of the study and what is expected from them. He adds that from a phenomenological stance there is no requirement for the researcher to inform the interviewee of the proposed nature of the interview. These points can be considered contentious and have been criticised. Crotty's (1996) viewpoint is the antithesis of Beech's (1999) and argues that both the interviewer and interviewee should bracket on the phenomenon. I am of the opinion in this regard that co-researchers should nonetheless 'be up to the task', that they have the ability and the determination to engage in a process of inquiry of their own experiences of the phenomenon, thus elucidating the essential elements of the meaning of being a parent to a child that has a learning disability. In addition to this I need to draw attention back to the purpose of a Husserlian phenomenological inquiry: that it is crucially a first-person exercise. The nurse phenomenologist must, by employing techniques of questioning, facilitate an in-depth exploration of the phenomenon by those that have experienced it: "This mandates that co-researchership be a genuine feature of the process for it to be phenomenological research if at all" (Crotty, 1996: 71).

6. Ethical considerations

Beech (1999) refers to the research ethic and the respect for the person being interviewed. Ethically there is a requirement, for reasons of good practice to identify potential hazards, costs and benefits. This also involves the development of a research protocol, with appropriate research participant consent forms and participant information fact sheets. As a consequence of the legality of the ethics of conducting research co-researchers will have a prior understanding of the research aims, which could have an influence on their account during interview.

7. Co-researcher respect

There is a pre-requirement to demonstrate absolute respect for the co-researcher. Information giving is central to this – this position though can be argued against. For example, too much information may act to bias the interviewee as they will have time to reflect on their experiences, develop and rehearse their story prior to the interview (Beech, 1999). However, the researcher's position here is crucial. One such position is that of facilitator that encourages a deeper probing of the co-researchers experiences. During this process the researcher brings the co-researcher back time and again to re-look at the phenomenon with a view to assisting them to move from descriptive accounts of their experiences to a position of what is being experienced.

This chapter has discussed in some detail the issue of phenomenological reduction (bracketing) and how this impacts on the phenomenological researcher and co-researcher. A framework that enabled bracketing was presented as a model of good practice, one that was used within this project. Chapter five presents an overview of the qualitative methodology as a process.

CHAPTER FIVE: Phenomenological Method in Action

1. Introduction

This chapter departs from the discussion of the previous two chapters that focused on the phenomenological movement, its development and its central themes. The rationale for such a move has a logic that allows an exploration of the processes involved in conducting a phenomenological inquiry. Significant broader issues that sit within the sphere of qualitative research will be discussed: issues such as sample size, sample management, sample typologies, methods of data collection, issues relating to research credibility and, finally, ethical considerations.

2. Qualitative method - 'In Action'

Qualitative research is viewed as an appropriate way of answering a specific research question. Questions such as: 'What is it like for...?' or 'How do parents manage on a day to day basis?' and 'Who does what in relation to childcare?' It is essentially an approach to inquiry that focuses on the way human beings interpret and make sense of their experiences and the world in which they live. Morse and Field (1996: 15) describe this as providing "...a window into the worlds of others, providing empathic understanding of the world."

Qualitative research has a complex history that accounts for differing frameworks that are guided by their own set of underlying principles and evaluation criteria (Deatrick and Ledlie, 2000). Creswell (1998) presents five traditions to qualitative inquiry: biography, phenomenology, grounded theory, ethnography and case study. It is apparent from his writings that it is evident and legitimate for researchers to integrate

elements from each of the above-mentioned traditions into one single study. It is also widely agreed that qualitative research is conducted in the natural setting (Creswell, 1998) for example in a parent's home. In doing so the researcher becomes an integral instrument enabling the collection of data, and its subsequent analysis.

It is through my own prior knowledge of the five traditions as explicated by Creswell (1998) that I am able to provide a justification for choosing phenomenology. This project has adopted transcendental phenomenology as advanced by Husserl; as such it is an appropriate method to explore the meaning of lived experiences of parents that live with and care for their child/children who have a significant learning disability.

As described in previous chapters phenomenology is firstly a philosophy and, secondly, a research methodology that has become increasingly popular within nursing research over the past decade (Omery, 1983). Its intention, as discussed previously, is not to generate theory, but to describe and understand the essence of an experience. As our lives tell a story, so too do our stories tell about our lives. By listening to the stories of our co-researchers we can gain an 'inside' view of their world, a place of privilege, where the essence of these experiences come together in a synthesis of shared experience (Baker and Dickelmann, 1994).

Possible tensions that exist for phenomenological researchers that espouse Husserlian phenomenology have been mentioned previously in chapter three, one such tension being: the investigation of a phenomenon from multiple co-researchers. We need to be mindful here that Husserl always intended his phenomenology to be solipsistic. However, Priest (2001) suggests that her approach has remained faithful to the ideas

of Husserl, whilst at the same time attempted to provide a strategy for dealing with multiple co-researchers and multiple data sources. She adds that by adopting Moustakas's (1994) and de Rivera's (1981) recommendations of engaging in a period of reflection and intuiting as a way of producing an initial phenomenological account the issues and tensions that relate to bracketing were managed and overcome. Priest (2001) at the outset made it very clear and transparent as to her chosen methodology, thus sensitising the researcher to the phenomenon and to preliminary ideas, presuppositions, assumptions and biases. These issues will be discussed separately and more thoroughly in chapter six.

2.1 Sampling management and typologies

Within the qualitative paradigm sampling strategies such as random sampling are deemed of little use, given that the aims of qualitative research limit the potential to generalise. The employment of a sampling frame will inevitably result in the recruitment of co-researchers who may have little or no knowledge of the research topic. Sampling frames are therefore considered ineffective to the intended aims of the qualitative research; use of such techniques may also lead to the research being deemed invalid. It is of importance to reiterate the purpose of qualitative research here, which is to discover and uncover meaning, **not** to provide measures of representativeness within a population (Morse, 1989). Generalising therefore is not an immediate goal when considering or undertaking this form of study.

Morse (1989) in her writings identifies four common typologies of sampling. Miles and Huberman (1994) likewise advance sixteen typologies. According to Creswell (1998) there is to hand a small range of sampling strategies available to the

phenomenological researcher. Of these, two were utilised in meeting the specific interests and focus of this project: 'exploring the meaning of fathers' and mothers' experiences of living with and caring for their learning disabled son or daughter'.

A 'volunteer' sample as termed by Morse (1989) recruits co-researchers by advertising in local or national newspapers/journals. This approach is considered appropriate for soliciting co-researchers when there are no known or immediately available co-researchers. In Imeson and McMurray's (1996) study six couples were interviewed by the researchers following an advertisement being placed in a local newspaper. This approach was rejected in light of prior research of this nature that failed to attract, in particular, fathers' participation. For example in Orr *et al.* (1991) fathers either declined to participate and/or responded poorly to the request. Using this approach would have presented a real danger of lowering the response rate from fathers and mothers.

It is of necessity that all of the co-researchers approached have experience of the phenomenon being studied. Sweeney and Olivieri (1981) echo this view by suggesting that the qualitative researcher may need a sample that incorporates co-researchers who have been selected due to their prior knowledge and experiences that relate directly to that of the research study. A good example of this is Patricia's experiences of being childless in 'We laughed a little, we cried a little' (Munhall, 1994). Patricia's experiences of not being able to be a 'natural' parent would be considered invaluable as a co-researcher.

Adopting a purposive sample can, according to Sweeney and Olivieri (1981), present the researcher with a range of difficulties. One example relates to how co-researchers are approached. Co-researchers who are known to the researcher may agree to participate in the research process not because they want to, but because they feel obliged to do so. Taylor and Bogdan (1984) have also criticised volunteer and purposive sampling typologies for similar reasons. They are of the opinion that there is a danger for sampling biases to occur when considering and co-opting co-researchers.

In Summary, sample selection involves choosing a group of co-researchers who are able to shed light on the phenomenon under investigation. The selection of participants is a crucial and key decision in any qualitative study (Creswell, 1998). For the purpose of this present study, a purposive 'criterion' sampling strategy was adopted. All birth parents (co-habiting and single parents) that currently live with and care for a child that has a significant learning disability were considered.

2.2 Sampling size

The size of sample is an important aspect to consider prior to research commencement. Robson (1993) states that the larger the sample the lower the likelihood of error in generalising the research findings. This statement proves problematic for the qualitative researcher, particularly if having to justify their sampling criteria to those from a quantitative arena. Furthermore, due to the nature of qualitative research it would be physically impossible to manage a large sample when you bear in mind the process of collecting and analysing large sets of data. Robson (1993) acknowledges that research studies that utilise small samples are generally

well received and are indeed viable when there is no intention to make statistical generalisations.

Polkinghorne (1989) suggests that a number of participants ranging from five to twenty-five are adequate for phenomenological research purposes. Dukes (1984), cited in Creswell (1998) recommends studying between 3 and 10 subjects. Creswell (1998) provides examples from other studies of co-researchers that range from one up to three hundred and twenty five. Strauss and Corbin (1998: 292) provide an alternative slant to this question by providing guidelines as to how many interviews/observations should be conducted. They advocate that one should stop interviewing and collecting data once “theoretical saturation” takes place. Given these recommendations a decision was taken to recruit co-researchers within these parameters. This would allow for an acceptable amount of data from which analysis can take place, even in the event of co-researcher attrition.

2.3 Data collection method: Interviewing and process

Having considered the process and issues of sampling I will now explore methods for data collection. According to Cormack (1996) the researcher has a range of methods available to them. It is therefore a requirement for the researcher to assess these methods in order to ascertain the best method for the research to be undertaken. According to Porter (1996: 118) the ‘most common qualitative method used in nursing research is in-depth interviewing’. Porter (1996) suggests that the phenomenological researcher tends to avoid using questionnaires or well-structured interview schedules. The rationale for such is that the phenomenological researcher is concerned with discovering knowledge that is related to specific phenomena, such as

parents' experiences of caring for their disabled child. They do not attempt to explain, predict or generate theory, but attempt to understand shared meanings by drawing from the informants' lived experience (Sorrell and Redmond, 1995).

Face-to-face interviews are deemed to offer the greatest possibility for modifying one's line of enquiry (Lemon and Taylor, 1997). Generally there are two types of face-to-face interview: the unstructured and semi-structured, both having many advantages (see table one). Jerrett's (1994) study provides an illustration that higher response rates are achievable by inviting co-researchers to participate in a face-to-face unstructured interview as opposed to sending out a postal questionnaire. In Jerrett's (1994) study, all bar one co-researcher agreed to participate.

Gillham's (2000) Table of verbal data dimension						
Unstructured				Semi-structured		
Listening to other people's conversation; a kind of verbal observation	Using natural conversation to ask research questions	Open ended' interviews; just a few key open questions, e.g. 'elite interviewing'	Semi structured interviews i.e. open and closed questions	Recording schedules: in effect, verbally administered questionnaires	Semi-structured questionnaires: multiple choice and open questions	Structured questionnaires: simple, specific, closed questions

Table One: Verbal data dimension (Gillham, 2000)

According to Creswell (1998: see table two) interviewing can be viewed as a set of steps in a procedure:

1. Identify co-researchers by way of utilising a purposive sampling frame, such as advanced by Miles & Huberman (1994).

2. Determine the type of interview. Assess the variations, such as, face-to-face (one-to-one), telephone or focus groups with a view to determining their effectiveness and the amount of information they will elicit.
3. Provide effective and reliable recording equipment, for example microphones that are sensitive to the room's acoustics.
4. Construct a developed interview protocol
5. Determine where the interviews will take place
6. Explore consent issues and decide upon procedures for gaining informed consent
7. Profile interviewer characteristics – a good listener and/or a talker??

The purpose of the interview is to derive meaning by drawing on the experiences of the co-researchers to generate a vivid picture of their lived experiences. The principal aim of phenomenological interviewing is to discover knowledge related to specific phenomena (Sorrell & Redmond, 1995).

DATA COLLECTION ACTIVITIES	
Data Collection Activity	Phenomenology
What is traditionally studied?	Multiple individuals who have experienced the phenomenon
What are the typical access and rapport issues?	Finding people who have experienced the phenomenon
How does one select sites or individuals to study?	Finding individuals who have experienced the phenomenon - a "criterion" sample
What type of information typically is collected?	Interviews with up to 10 people
How is information recorded?	Long interview protocol
What are common data collection issues?	Bracketing one's experiences, logistics of interviewing
How is information typically stored?	Transcriptions, computer files

Table Two: Data Collection Activities. Taken from Creswell (1998, pg 112-113)

A research design adopting a phenomenological approach requires the collection of descriptions, whilst preserving the spontaneity of the co-researchers experiences (Priest 2001). In addition to this the people who are living their reality can provide legitimate sources of data pertinent to the phenomenon. The most usual data collection source is the verbatim transcripts of audio taped interviews. Other data sources can be used, for example, group discussions, written accounts and personal reflections in the form of a diary.

It goes without saying that in-depth interviews should always leave room to uncover unexpected unknowns. Gerson and Horowitz (2002: 204) claim that this is more easily “accomplished by choosing a theoretically focused sample and developing an incisive and probing interview schedule”.

2.4 Characteristics of interviewer style

The relationship and the interaction between the researcher (interviewer) and the co-researcher (interviewee) can affect the quality and the amount of information obtained at interview. According to Coolican (1999) factors such as the class, sex, culture and age of both interviewer and interviewee may affect the interview situation and may act to limit or distort the information obtained. King (1996) discusses in her article the merits of trust within the interview situation and views such as being central to the interviewer/interviewee relationship. She adds that trust has to be earned and is more likely to be achieved by interviewing the informants on several different occasions.

King's (1996) comments are reflected within this project. Most, if not all co-researchers were known to me and as a consequence were comfortable in my

presence. The interviewer/interviewee research encounter, as a consequence of 'knowing each other' changed to what Fontana (2002) describes as a 'reciprocal personal relationship'. This is also reflected in Lemon and Taylor's (1997) study where emphasis was placed on conducting the interview as a conversation. This helped the co-researchers to focus their thoughts and allowed them to express their experiences in their own words. This, according to Sorrell and Redmond (1995) shifts the emphasis of the interview in that the interview is not being conducted but being participated in by both. This is also reflected in Melia's (1982) study where open-ended questions were used. This allowed the student nurses to expand on their own experiences, thus a wealth of detailed information was obtained.

In Quine and Phal's (1991) and Bruce *et al's* (1996) studies, structured interviews were used to collect data. Such an approach ensured that each co-researcher would be asked the same questions in the same order (Carter, 1996). I am of the opinion that this form of interviewing is too rigid and can interfere with the flow of the interview as the research becomes task-orientated as it has a fixed set of questions that "must" be answered.

In this project I made use of myself: of being a good communicator, by utilising my interpersonal skills and my willingness to rephrase and reorder the questions whenever necessary. This enabled the interviews to be conducted as a conversation.

Non-verbal behaviour during the interview process can also be observed and recorded. As such, most if not all information from the face-to-face interviews

was of value and was used. Responses can be elicited from a wide range of subjects. Questionnaires and surveys would prove ineffective in the situations as just described.

These examples clearly reflect the major advantages of adopting qualitative methods for this type of project. They essentially allow the researcher the opportunity to gain a holistic understanding of the experience that forms an important part of the co-researcher's day-to-day existence (Sorrell and Redmond, 1995).

There are of course disadvantages to the interview process (Burns and Grove, 1987; Polit and Hungler, 1991). Interviews are deemed costly and time consuming in relation to both travelling to and from the interview site and to the actual time taken to conduct the interviews. An example of this can be found in Imeson and McMurray's (1996) study where each interview lasted for up to two hours. Robson (1993) in his writings explores the demands that can be placed on the co-researcher. Imeson and McMurray (1996) could be viewed as placing unreasonable demands on their sample group by interviewing them for long periods of time.

The quality of the data could also be placed under scrutiny. This according to Guba and Lincoln (1981) refers to and reflects the individual nature and expertise of the researcher. If the researcher possesses good interpersonal and analytical skills there is a stronger likelihood that good quality will be gained. However, if the researcher on the other hand possesses none of these prerequisites, the resulting data could be flawed and be open to criticism (Guba and Lincoln, 1981).

Following on from this the interviewer according to Robson (1993) requires considerable skill and experience if they are to succeed in their research. It is essential that rapport between the interviewer and the interviewee is established; failure to do so may result in the interviewer inadvertently dominating the sessions by asking leading questions (Rose, 1994). King (1996) outlines a list of activities that resemble that of a counselling situation: the giving of yourself, being sensitive and unassuming, whilst defining boundaries. Although King (1996: 182) would not advocate that a research interview constitutes a counselling session per se, yet states "...some of the aims of counselling may often be applicable in the research interview..." The semantics of this debate illustrate the skills of the counselor and how useful they can be when conducting a research interview. Barker (1996) in his writings offers a similar suggestion; he talks of the interviewer needing to be attentive and having the ability to adopt a position of being open. Personal factors such as age, sex, culture and race are said to have a bearing on the interview and the subsequently collected data. He continues by stating that the interviewer should ideally be aged between the ages twenty-five to forty-five and should preferably be the same sex as the informants. These claims are based on the premise that very young interviewers may lack the tact and the necessary interpersonal skills that are a prerequisite for interviewing. He also suggests that older co-researchers may also view them as being inexperienced. Further to this Barker (1996) cites Topf (1988), who states that younger informants may respond to the older interviewer in one or two ways: being either subservient or rebellious.

Barker's criteria may have some merits, but by examining and reflecting against this project and my experiences as a clinical practitioner I would contest some of his claims. Firstly, my own empirical knowledge of working with families, mainly

mothers, over the past twenty years has never produced meaningless or biased information. This claim may appear anecdotal and opinionated, but I can if there is a requirement back up these claims by providing examples of a routinely administered parent questionnaire (Aman *et al.*, 1995). This questionnaire is a recognized and validated assessment in the learning disability arena. Further to this, Barker's claims of informants being either subservient or rebellious when interviewed by an older person can also be dismissed in light of my own personal experiences, again working with a range of parents younger than myself over the years. These influences as described by Barker have, in my opinion, not affected the nature of the information collected as part of this project. Secondly, Barker's statements in their entirety could be considered as being discriminatory in the sense of ageism and gender'ism (Thompson, 1993).

Haven taken all of the aforementioned aspects into consideration this project engaged in initial exploratory first interviews. They were wide ranging, yet focused on the thesis topic, and, as according to Jerrett (1994), allowed the discovery of the co-researchers stories, experiences and meaning of caring for their learning disabled child. The use of exploratory interviews is a common in qualitative research (Jerrett, 1994). In this project they were used as a pilot study, which helped to eradicate any potential errors in the style and layout of subsequent semi-structured interviews (Oppenheim, 1992). Proceeding in this way also enabled the familiarization with the audio tape-recording equipment used, prior to conducting the second interviews.

Interviews on topics such as this are regarded as being best conducted in the co-researcher's own home. This, as in Tishelman's (1997) study allows the co-researcher

to be more relaxed and at ease. It is however important to be aware of potential disturbances and interruptions. For example, from other family members, television sets, music being played and telephone calls. These issues were discussed with the co-researchers prior to conducting the interviews. Any television set or music systems were with agreement switched off. Telephones' volumes were lowered prior to and during the time of interview. Seating arrangements were also discussed with the co-researchers prior to the commencement of the interviews. It was essential to maintain good eye contact throughout the interview process, otherwise subtle non-verbal responses such as: body posture and movement may have been lost and gone unrecorded.

During the interviews there were often pauses, sometimes a seemingly endless pause. As a trained counsellor and practitioner I am used to situations where language isn't present, be it due to a pause in the conversation or as a result of stillness of reflection (Van Manen 1990), a fulfilled silence (Bollnow 1982, cited in Clarke and Iphofen, 2006), an uncomfortable silence or a silence due to not understanding the question or inability to voice a response. The latter two aspects when recognised warranted an interjection from myself, this maintained the flow of the conversation. It was not necessary to offer any intervention when the co-researcher paused to reflect, on the contrary they required the time, with no disturbances to reflect.

The interviews from the vista of my own personal experiences: one of a seasoned practitioner, a trained counsellor and a parent, mirrored and reflected that of a therapeutic counselling session. In spite of King's (1996) statement that the research interview does not constitute a counselling session 'per se', parents were nonetheless

received with warmth and understanding, by way of unconditional positive regard. As such they were enabled to explore their situation in an unjudgemental way. One father expressed his thanks following the second interview – thanks for allowing him the time to discuss openly issues that he had never shared before.

The first interviews, which were low structured but highly focused, allowed the co-researchers to tell their story, in their own words with little or no prompting from myself (see interview schedule one: Appendix one). The second interviews, semi-structured in design, maintained this informal, yet focused approach (see interview schedule two: Appendix two). The semi-structured approach provided a guide of outline topics that were discussed during the interview. The questions were arranged in no formal order, which enabled the questions to be presented according to the situation. Questions were re-phrased in a ‘free style’, an advantage of conducting the interviews in this way allowed a natural conversation to develop, rather than conducting a rigid schedule of questions. This allowed flexibility to further explore unpredicted issues or avenues of thought that arose during the interviews.

2.5 Preparedness

Any study that involves interviewing requires substantial forethought and advance planning. According to Gerson and Horowitz (2002) this may appear easy, to choose people at one’s own convenience and engage with them in an unstructured and semi-structured conversation. However, one needs to think about the careful selection of the targeted sample, a sample that is suited to illuminate the phenomenon under analysis. This strategy must be able to provide an efficient way of asking and answering questions to a relatively small group of people. An effective interview

design needs to be able to guide the co-researcher skilfully through their life experiences in a semi-ordered manner, within a limited period of time. It is therefore crucial to decide which areas of 'reality' are important in answering the research question without prejudicing the research.

The introduction of any equipment can have an effect on the interview process. On one occasion I was very aware that the co-researcher was talking directly at the tape recorder. Following this I was keenly aware that the tape recorder, although vital in capturing the interviews, should be placed in a position out of view of the co-researcher. To counter issues of recording quality a lapel microphone was purchased. This was offered to parents before the interviews commenced; in addition to this a small microphone with an extension cable was placed close to the co-researcher being interviewed.

2.6 Quality standards and research verification

This brief discussion focuses on issues that relate directly to phenomenological quality standards and research verification: in this regard what steps can a phenomenological researcher take in ensuring that they have "got it right".

According to Creswell (1998) the empirical and transcendental phenomenologist does not place real emphasis on verifying their research as they deem their own perspective on the research to be adequate. With this regard, I, like Dukes (1994, cited in Creswell, 1998) believe that there is a requirement for procedures that will enable the phenomenological research to be transparent and open to scrutiny from outside reviewers.

Stratton (1997) discusses the authenticity of research and states that the criterion of assessment requires redefining, as most criteria are derived from the quantitative paradigm. Clarke (1995) posits a different position whereby all researchers irrespective of epistemological and methodological differences should be judged using the same evaluative process. Brink (1991) argues that the issues in research are the same but the route to achieving reliability and validity [credibility and truthfulness] in qualitative research should be modified. Further to this Smith (1996: 192) states that 'qualitative research should not be evaluated in terms of the canons of validity that have evolved for the assessment of quantitative research, since they have different epistemological priorities and commitments.'

Pidgeon (1996) suggests that there is a need for the qualitative researcher to develop criteria of evaluation that reflects its own philosophy and one where it is accepted on its own merit. Pidgeon and Henwood (1997) claim that a number of good practices have been suggested that act to guide the qualitative researcher throughout the entire process of their study. For example, Leininger (1994) presented a six-point set of evaluation criteria that is claimed to be applicable to all qualitative methods. This approach has been criticised, as it appears to be too subtle and difficult to differentiate one aspect of the criteria from another (Nolan and Behi, 1995a, 1995b). Sandelowski (1995) in her writings advocates the assessment of rigour in terms of assessing credibility, consistency and congruence, which in essence places emphasis on the values of the phenomenological methodology.

Moustakas explicates the establishment of truth that begins in the first instance with the researcher: on a perceptual level. In other words the phenomenologist must reflect

on the meaning of the experience before seeking validity from those who contributed to the research: the co-researchers.

It is clear from this discussion that phenomenological research requires to be judged, but which standards should it be judged against? Creswell (1998: 208, cites Polkinghorne, 1989) who discussed the meaning of validity. He queried: "Does the general structural description provide an accurate portrait of the common features and structural connections that are manifest in the examples collected?" In addition to this question he advanced five further questions that a phenomenological researcher may wish to ask:

"1. Did the interviewer influence the contents of the subjects' descriptions in such a way that the descriptions do not truly reflect the subject's actual experience?

2. Is the transcription accurate, and does it convey the meaning of the oral presentation in the interview?

3. In the analysis of the transcription, were there conclusions other than those offered by the researcher that could have been derived?

Has the researcher identified these alternatives?

4. Is it possible to go from the general structural description to the transcriptions and to account for the specific contents and connections in the original examples of the experiences?

5. Is the structural description situation specific, or does it hold in general for the experience in other situations?"

This brief discussion can, for now, only present these questions to the reader. Chapter Ten will provide a full response to these questions, thus illuminating further the research process and how this project ensured quality standards and research verification.

2.7 Ethical considerations

As research inevitably involves some contact with people be it direct or indirect it can be viewed as being invasive. It is therefore prudent to consider here the ethical aspects that are a necessary and important facet of the research process. In Tishelman's (1997) study consent from the ethics committee was sought. This was the same for this project. Following ethical approval verbal and then written consent was sought from the proposed sample group. In Imeson and McMurray's (1996) study participants were given assurance that they would remain anonymous. I am of the opinion that it is vital to offer total anonymity and confidentiality to any prospective co-researcher. Morse (1989) however, suggests that confidentiality may not be assured in qualitative research as actual quotations may be used in the publications and presentations.

In an attempt to preserve anonymity and confidentiality this project utilized specific coding that were allocated at random to each taped interview and subsequent transcription. This prevented any of the co-researchers from being directly identified. Imeson and McMurray (1996) employed a similar approach in their research. They also offered the participants the opportunity to retain the tape recording once data analysis was completed. This project, as a formal request from the ethics committee, had to destroy the cassettes as it was thought that the content of the interviews could have the potential to cause other parties, namely partners, distress. Appendix three

provides evidence of ethics approval.

Having discussed qualitative methods the next chapter places these concepts within the realm of the phenomenological perspective.

CHAPTER SIX: Phenomenological processes: In action

1. Introduction

This chapter presents a discussion as to data processing within the context of this phenomenological study. Discussion also focuses on the models as advanced by a cohort of phenomenologists before presenting Moustakas' (1994) modification of the **STEVICK-COLAIZZI-KEEN** model for transcendental phenomenological inquiry.

2. Phenomenological processes

As has been stated before Phenomenology is widely viewed as a method that is rigorous, critical and systematic in its investigation of a phenomenon. Its main purpose is to draw out the structure of lived experience, in doing so there is a search for the unity of meaning by identifying the essences of a given phenomenon that provides accurate descriptions of the everyday experience as it is experienced. There are a variety of procedural interpretations available that can act as a guide to using this approach to research. Spiegelberg (1982) identified core central elements to phenomenological investigation. These are described as: descriptive phenomenology, phenomenology of essences, phenomenology of appearances, constitutive phenomenology, reductive phenomenology and hermeneutic phenomenology. In a later revised edition he presented a method that consists of seven steps: "1) investigating a particular phenomenon, 2) investigating general essences, 3) apprehending essential relationships among essences, 4) watching modes of appearing, 5) watching the constitution of phenomenon in consciousness, 6) suspending belief in the existence of the phenomena, and 7) interpreting the meaning of phenomena" (Spiegelberg, 1982: 682). Spiegelberg (1982) refers essentially to a

three stage first step that comprises: the intuitive grasp, the analytic examination and the subsequent description – collectively known and referred to as the ‘phenomenological description’. It is of concern to Spiegelberg that the reader distinguishes between each of these stages and steps, even though they interrelate and belong close together.

There is, for some phenomenologists, a reluctance to use a series of steps in the generation and processing of data. This according to Priest (2001) is as a result of them being at potential risk of being ‘reified’ by those from the natural sciences. For others, systematic methods have been developed to assist in this process. Moustakas (1994) for example provides a framework for conducting transcendental phenomenology. A feature of this framework involves the division of text into specific units and the transformation of these units into meanings that are expressed as phenomenological concepts before being synthesised into a unified statement of the experiences of the phenomenon as a whole.

Other phenomenologists such as Van Kaam (1969), Colaizzi (1978), Hycner (1985) and more recently Priest (2001) have provided models that present a series of steps that aid the generation and processing of phenomenological data (see Appendix seven). A feature that is common to Husserlian-influenced researchers and which is notable to Moustakas’ (1994) framework is the notion of horizontalisation: where all aspects of the textural data are valued equally.

Priest (2001) claims that for one to be able to produce an initial descriptive account there is a requirement to engage in a period of quiet reflection. The focus of this

contemplation can be personal and professional experience and a sound knowledge of relevant literature; in this instance, twenty something years experience working directly with families and their learning disabled child/children coupled with my own personal experiences of being a parent. This process, as I view it, is in some way an opportunity to identify and set aside any prejudgements or biases prior to immersing oneself into the rich textural nature of the parent's personal accounts. Priest (2001) claims that by engaging in this process researchers place themselves in a position where they become a legitimate participant in the research process. To immerse oneself into the rich textural world of the parents involves an intensive engagement with the data. Spiegelberg (1982) suggests that this undertaking requires supreme concentration; it is also a highly demanding activity. For this study it meant that I had to listen to the audiotape recordings repeatedly and read and re-read the verbatim transcripts and any other written accounts, in this instance the reflexive diary. This enabled me to look at the parental experiences with 'wide-open eyes', with previous knowledge, facts and theories held at bay (Oiler, 1982; Lemon and Taylor, 1997).

I have considered and reviewed this literature and have chosen to adopt Moustakas' (1994: 122) modification of the Stevick-Colaizzi-Keen method. It has offered me the opportunity to remain as true as I possibly can to Husserlian principles, whilst providing a clear structure that has enabled me to complete this project.

The remaining part of this chapter presents Moustakas' model and how I have interpreted and utilised it to explore the meaning of being a parent of child that has a significant learning disability.

The first step in using this phenomenological approach, was to obtain a full description of my own experiences of the phenomenon, in this instance I explored my own perceptions, ideas that make up my own biography that relate to being a parent and what it may be like to be a parent of a child that has a significant learning disability (see chapter seven). During this process I set time aside to think about my role as a parent and what it meant for me, this exercise was repeated when I explored the phenomenon of inquiry. Each statement was recorded as they came into consciousness and from these the specific horizons of the experience were listed and clustered into themes. The next step was to provide a textural description of these experiences, this involved studying and reflecting on the meaning of the statements and teasing out the texture, the 'what' – a description of what I have experienced. A further reflection of this description enabled me to work and manipulate through an imaginative process to construct a 'structure' of the experience, the 'how' – a description of how I have experienced what I have experienced. The end stage of this process was to construct a composite textural – structural description that illustrated the essence and meaning of my experiences of being a parent and what I imagine it to be like for parents who live with and care for their child/children who have a significant learning disability.

Following collection of interview data the verbatim transcripts of the experiences of each of the co-researchers were subjected to the processes as described above. In practice, this meant that the transcendental process followed the phases of Horizontalisation, where I was open and receptive to every statement of each co-researcher's experiences. Each statement was treated equally and with the same importance. I was particularly drawn to experiences that stood out; this is what

Moustakas' terms the 'Invariant Horizons' - the unique quality of any given experience. As a result of this activity I was able to reduce these experiences into core horizons and invariant meanings before developing a thematic portrayal. From the themes and delimited horizons of each person's experience, a textural description was constructed. The thoughts, feelings and ideas were used to illustrate the textural nature of the phenomenon – what it looked like. I then provided a vivid account of the underlying dynamic of the 'actual experience'. The themes and qualities that account for the "how" thoughts and feelings connect to the experience and which conditions evoke these thoughts and experiences. The structures of experience were brought into my awareness, I moved beyond the 'actual-ness' of the appearance, and into the real meaning or 'essence' of these experiences.

Moustakas' model enabled the individual textural-structural descriptions to be collated and constructed into a composite textural-structural description of the meanings and essences of the experience. This involved the integration of all textural-structural descriptions into a universal description that utilised key words and phrases that were common to all co-researchers that represented the group as a whole. In doing so, an understanding of **how** the co-researchers, as a group, experience **what** they experience. Thus bringing to life the character and dynamic account of what it is like to live with and care for a child that has a significant learning disability.

3. Computerised software – advantages and disadvantages

In this study NUD*IST NVIVO (2000) was used to assist in the essential clerical and data management task. It also benefited the analytical process by providing a comprehensive system for the indexing, coding, searching and enabling retrieval of

large sets of rich textural data (appendix eight provides examples of coding stripes, node listings and document coding reports).

Davis *et al.* (1997) claim that there are several advantages to using this type of computer software, the most significant being that they facilitate researchers to be creative in their analysis. Some software packages, however, limit the user as they are forced in some respects to conform to procedures, protocols and structures as set by the parameters of program design. Other systems demand that documents are formatted in a specific way before they can be imported to the system. This can be costly in terms of time, but also critical with regard to the coding and retrieval process (Woods and Roberts, 2000).

In actual use I found NUD*IST NVIVO (2000) to be a practical system in enabling me to manage large amounts of rich text. I was able to freely navigate and browse individual and multiple co-researcher interviews when searching for similarities. I also found the facility for quick coding, node generation and modelling a very useful attribute to this system – without this capability I would no doubt have had to resort to a timely paper exercise. My only criticism of this software was the difficulties I experienced in importing other word documents – if they were not correctly formatted the system did not recognise them, which resulted on two occasions having to re-type the interviews directly into the system.

The next chapter presents an overview of the research method and steps taken in conducting this study.

CHAPTER SEVEN – Research Method

1. Introduction

The aim of this study was to explore and describe what it means to be a parent who lives with and cares for their child/children that has a significant learning disability. In order to explore the parental ‘life-world’ a transcendental phenomenological approach has been adopted, with the ‘in-depth interview’ being the most appropriate data collection method. A purposive sample, as described in chapter 5 enabled the selection of co-researchers who had a son or daughter with a learning disability who were of an age relevant for the research purpose. The co-researchers, in this instance, fathers and mothers were considered to have knowledge and experience that was essential for this research. They were either known to health and care services and therefore could be approached directly by the researcher or known to colleagues of the researcher. This chapter provides an overview of the research method and steps used to undertake this study.

2. Process

The first phase of this project consisted of seven couples, who were the birth parents of the disabled children being cared for. The inclusion criterion determined that they were co-habiting and had child/children with significant learning disabilities aged between fourteen and nineteen years. The fourteen co-researchers in this study were interviewed individually on two separate occasions. Taking account of the sample size and the time given to interviewing: up to two hours per co-researcher, this sample size would meet Polkinghorne’s (1989) recommendations (see Chapter 5).

The second interview, which was offered to all participants, was loosely based on a semi-structured thematic interview, and was used as the main vehicle for collecting further data. Its composition as described by Astedt-Kurki and Heikkinen (1994) allowed the exploration of issues that related directly to the object of study: the meaning of caring. The use of a more focused interview technique like this permitted the targeting of specific issues that related to the parental experience. Adopting a dual interview approach like this allowed the interviews to flow and be less rigid.

The second phase consisted of two single parents and two couples, who, again, were the birth parents of their children and had a child/children with significant learning disabilities aged between two and thirteen years. Parents from this cohort were interviewed on one occasion using the same semi-structure interview style and format as used in phase one.

This project's principal data collection method involved in-depth face-to-face interviews. They were highly focused, using open phenomenologically based questioning. The interviews were audiotape recorded. Personal reflections on the interviews were recorded in a diary post interview.

As has been stated previously, the aim of this inquiry was to explore and discover the meaning for fathers and mothers that live with and care for their child/children that has a significant learning disability. The sample population therefore is this group of parents who make up the cohort of co-researchers. Based upon the needs of this inquiry parents who are currently experiencing living and caring for their learning-

disabled child/children need to be accessed. As such a criterion purposive sample strategy was employed to provide the framework for co-researcher selection. Further to this an inclusion criteria were developed to aid selection. Table three provides an explanation of the inclusion criteria.

Research requirements	Rationale
Birth parents	To capture the experiences of both parents as individuals in the context of caring.
Child with significant learning disability	The foci of the inquiry – adding a different perspective to the existing knowledge base within the field learning disability.
Parents including child/children to be intact as a family	To explore and uncover meaning as it is lived within the context of family.
Child with significant learning disability to be aged between 14 – 19 years of age.	To capture the experiences of parents during their child's pubertal and transitional years.
Child with significant learning disability to be aged between 2 – 13 years of age.	To capture the experiences of parents during their child's early development.

Table Three: Research Inclusion Criteria

The co-researchers for time and organisational factors were selected from within the boundaries of a NHS Trust, who were supporting this study following approval from the local ethics committee (see Appendix Three).

The process of sampling management, from selection to recruitment is detailed below. This detail will enable the reader to track any decisions made, which in turn provides transparency and an audit trail.

Phase one:

Step one: families were identified using the disability register. This register lists the names of children and their families; it provides details of the children's name, age, area residing, contact address, disabling condition and school attending. As the register is voluntary it does not capture all children and their families who live in the catchment area. In addition to this search, the local special schools were approached with a request to provide a list of the school roll.

Step two: the disability register and school's roll on receipt were cross-referenced to select children who met the age thresholds and who were classified as having a significant learning disability. The disability register or school roll did not provide information on family status i.e. whether or not the birth parents and the child/children were still co-habiting. To seek answers to this significant question assistance from his immediate health colleagues was sought, by requesting that they checked and cross-referenced their records as to knowledge about child and family. A similar dialogue was had with colleagues from Social Services Disabilities teams and colleagues from the Local Education Authority.

Step three: this search yielded 20 families (40 parents) who met with the inclusion criteria, of these three families were known personally to me through my employment as a community nurse. A letter that explained the intention of the research was sent to the 40 parents asking whether they would be interested in participating in the process. A return slip and stamped addressed envelope was included with this letter (Appendix Four). A follow-up reminder letter was sent out to those parents who did not respond two weeks after sending out the invite letter.

Step four: the response rate produced a sample of 16 co-researchers. Two of the respondents' partners did not return their reply slip and as a result of this were

eliminated from the inquiry; they were informed of this decision by telephone conversation and thanked for their interest and support. The remaining 14 co-researchers were contacted by telephone. The purpose of contact was firstly as an introduction, even to the three families who were known to me, and to discuss the research process. During this discussion further interview dates were agreed. Times, dates and venue (all interviews were conducted in the parent's home, this being each co-researcher's preference) were balanced out against the co-researchers daily living commitments and my own work commitments. The initial interviews averaged out at 2 per week.

Step five: the consent form and information sheet (that had already been previously developed and agreed by the local central ethics committee (Appendix Four) were posted to all co-researchers prior to the interviews. This gave them the opportunity to check the information in a non-pressured situation and to have opportunity to think about and formulate any questions prior to the interviews.

Step six: following each interview a diary entry was recorded. The content of this diary contained my thoughts on the interviews and any 'stand out' issues. Appendix Five provides an exemplar of entries following interviews with all co-researchers.

Step seven: each interview was subjected to an initial detailed analysis. This process is described in Chapter six. Following this analytical process a semi-structured interview schedule was developed (Appendix two) and taken back to the 14 co-researchers, who had agreed to participate in a further interview. The second interview essentially followed on from the first interview and provided an opportunity to explore further any issues that may have arisen as an account from the first interview. It also enabled the exploration and uncovering of meaning from areas not previously touched on.

Phase two:

Step one: As I was aiming to change the research protocol I had to gain an amended ethical approval (Appendix three), following this;

Step two: families were identified from specialist childhood disabilities community nursing active caseloads.

Step three: this search yielded eight lone parents and six couples who met with the inclusion criteria. A letter that explained the intention of the research was sent to the eight parents asking whether they would be interested in participating in the process. A return slip and stamped addressed envelope was included with this letter. A follow-up reminder letter was sent out to those parents who did not respond two weeks after sending out the invite letter.

Step four: the response rate produced a sample of six co-researchers (two lone parents and two couples). The six co-researchers were subsequently contacted by telephone. The purpose of contact was firstly as an introduction and to discuss the research process. During this discussion interview dates were agreed. Times, dates and venue (all interviews were conducted in the parents home) were balanced out against the co-researchers' daily living commitments and my own work commitments.

Step five: the consent form and information sheet (that had already been previously developed and agreed by the local central ethics committee, (Appendix four) were posted to all co-researchers prior to the interviews. This gave them the opportunity to check the information in a non-pressured situation and to have opportunity to think about and formulate any questions prior to the interviews.

Step six: following each interview a diary entry was recorded. The content of this diary contained my thoughts on the interviews and any ‘stand out’ issues. Appendix Five provides an exemplar of entries following interviews with all co-researchers.

The next two Chapters detail the processes, as described in Chapter 6, which enabled the synthesis of the textural and structural descriptions to that of general essences: the meaning of being a parent that lives with and cares for their child/children that has a significant learning disability.

CHAPTER EIGHT: The Meaning of Being a Parent: A personal reflection.

1. Introduction

This chapter describes within the context of the epoche and phenomenological reduction a personal reflection on and a search for the meaning of what it is to be a parent: being a father to two children. A further reflection explored and uncovered thoughts, perceptions, beliefs and assumptions about the meaning of being a parent of a child that has a significant learning disability.

2. The Epoche

Evidence from phenomenological research is gained from the first person experience. As such, knowledge is sought and arrived at through descriptions that make it possible to gain an understanding of the meaning and essence of an experience. The phenomenological researcher has to adopt a position that prepares them to receive the descriptions unadulterated. As has been discussed previously Husserl used the term *Epoche* to describe a position where one is free from suppositions. It is in this position that we set aside any prejudgements and ideas about the thing we are looking at. It is important to reiterate that the phenomenological Epoche does, and cannot eliminate everything, it does not deny the reality of everything, nor does it doubt everything: only the natural attitude (Moustakas 1994).

In practice, the *Epoche* as perceived enabled me to prepare for the activity of looking at a new phenomenon: the meaning of being a parent living with and caring for their learning disabled child/children. Irrespective of what appeared to me in my consciousness it was approached with openness - seeing it for what it is.

This presented me with a challenge: Could I be transparent to myself? Could I view something as if seen for the very first time, in a naïve and open way? If this position is achieved then one does indeed become transparent in the viewing of things and transparent to ourselves.

This way of being dictates the way that one can look, become aware, without imposing our own thoughts and beliefs on what we see, think or feel. Everything that we see, think or feel is viewed with equal value – nothing is determined in advance.

In action the *Epoche* required that everything in the natural attitude be set to one side, to be placed within the imaginary brackets that I had conjured in my mind. To achieve this I had to engage in quiet solitude, where I was able to concentrate on the phenomenon in question – I explored what sits in my memory and what perceptions, judgements and personal experiences I hold. Everything became available for self-reflection. In some respects this process is like a ‘reflective-meditation’ (Moustakas 1994) where any preconceptions and prejudgements are allowed to filter through and leave consciousness. Any preconceptions and prejudgements that did appear to me were recorded in written format thus aiding further reflection.

Throughout the entirety of this project I have found myself immersed in quiet solitude, thinking clearly about my own experiences as a parent, in particular of what it means to be a father. Many of these moments or ‘appearances’ were unplanned they arrived as ‘out of no where’, as though my mind allowed me an inward look. Further to this, additional time was also spent reflecting on my thoughts of what it may be like for parents who live with and care for their child/children who have a significant

learning disability. Whilst in this position I have managed to become aware of my thoughts and feelings, thus explicating my own prejudgements and preconceptions that have been formed and informed over twenty something years of working with families and their children. This has been ‘done’ to a point where the attention has focused on what is essential in the phenomena – to the things themselves.

3. Phenomenological reduction

The filtering out of preconceptions and prejudgements enabled me to be prepared, to be open and ready for the phenomenological reduction. This reduction, has allowed me to look and describe; to look again and to re-describe, thus providing clear descriptions of my own experiences in relation to the questions I have asked myself.

The following text provides a textural description of my thoughts and my experiences that have contributed to the ‘natural history’ of this project and its relationship to my biography.

4. My thoughts, experiences on and being a parent:

“It is the most important thing that I will ever undertake as a person – to bring a new being, a life – a child into this world. The state of being committed to this task, the responsibility”

“With this comes a plethora of emotions. What you first see when you see your first born being delivered, when your child looks up to you with total trust, unconditional love and trust”

“The mixture of feelings when your child becomes unwell is hurt or is in danger. These feelings are out of your control, as you would do about anything to protect your child”

“It is a very difficult task, there are no books to guide you, but you want to do your utmost best for your child. This will include ‘letting go’, almost pushing them to become independent so that they can survive and be ‘good’ people even when you are no longer there for them”

“Learning to stand back and ‘allow/watch’ your child/children to make mistakes and to learn from them (as I have done). But with the proviso of being there when they need you”

“To be able to enjoy your children is one of the most rewarding aspects of being a parent. Wanting to spend time with them whether they are three years of age or thirty three years of age and that they too want to spend time with you”

“To be there to nurture and encourage. To watch them grow and develop as individuals and that they are happy and rounded as adults”

“Hoping that they will follow the life cycle, meeting new friends, experiencing new experiences, themselves leaving home and becoming parents themselves”

“To enjoy them, being silly with them. Taking part in a range of recreational activities, as individuals and as a family”

“Providing a framework of security, love, openness and honesty – whatever the cost”

“Being the bank of dad”

“Being the father, the motivator, the friend”

5. My thoughts, feelings and experiences on the meaning of being a parent to a child with significant learning disabilities.

“The difficulties of daily living, the stress of the situation and how this may affect the relationship between husband, wife, other children, maternal and paternal grandparents extended family and friends”

“The constancy of feeling torn between the time required to be a ‘good parent’ for the child with disability alongside balancing being a parent to any other children in the family”.

“Being normal (whatever this is!) – usual family life just getting on with it. Attempting to remain positive and accepting that this is the way it is – this is my family”

“Hoping that other children, their and my friends accept the child with disability as being equal, for who she/he is”

“That life is governed by routines that contribute and create additional stress”

“Having to deal with and manage interactions with organisations that you would not normally have recourse to do business with”

“Life is determined with less opportunities – this is variable and dependant on the type and level of disability. The more significant the disability the more likely it is that opportunities will be reduced”

“Wanting your child to experience ‘normal’ things, schooling, friendships - social/recreational activities. These aspirations can be affected by societal and socio-economic factors”

“The frequent discussions and frustrations in securing adequate support services i.e. short and long term breaks”

“Partner, if full time carer, unable to fulfil own career pathway if it is a want. Unless there is a role change. Would this be a financial decision based on potential earnings or one of sharing the care burden?”

“Often dealing with significant behavioural challenges that affect the fabric of the house, the levels of stress – leading to family dispute”

“A feeling that we have been chosen for this role – to have a ‘special person’ to care for.

6. My thoughts, experiences on and being a father – a textural/structural context

“Being a father is something you should not undertake without thought. It is an emotive business that one usually enters into totally ill equipped. It is a life-changing event. It is a role of responsibility, where the child’s needs are, and should be, greater than your own. You have to be the nurturing adult in this relationship, the one who encourages, motivates, to be selfless and to be there to protect, whatever the circumstance. Finally, it is a role where one should enjoy being with your child/children throughout the life cycle.”

By engaging in this process I was very aware that there are endless possibilities, ones that emerge, that have a connection with the essences and meanings of an experience.

7. Thoughts, feelings and experiences on the meaning of being a parent to a child with significant learning disabilities – a textural/structural context

“Managing and juggling a range of emotions whilst coming to terms and accepting your child’s disabilities – a disability that was never expected or planned. Adjusting yet trying to resume a level of normality with family and friends. Coping, or not coping, with the daily demands and the subsequent raised levels of stress. Not wanting, but having to have contact with services providers, the discussions – endless discussions with subsequent frustrations – that leave you with a sense of ‘what is it all about’. Work, career and social opportunities are significantly impaired for one or both parents”

Further reflections: "...this structural context is evidently skewed towards my professional background – where I have worked with parents and their children over twenty eight years. The families that I usually have contact with are in receipt of health-based services as a result of their child presenting with significant complex behavioural difficulties, usually resulting in high levels of expressed parental stress.

8. Being a father: Synthesis of meaning and essences

An immense feeling of joy and happiness at the moment of birth coupled with a tinge of worry hoping that all is going to be okay with your newborn and your wife. As time passes by there is a sense of being totally unprepared for the responsibility that awaits you – a responsibility that is a life-changing event where your own personal needs will be put on hold, at least for a few years. There is an expected shift in role where you become the provider, nurturer, protector, advisor and friend to your child/children. There are inevitable costs to having a child both on a financial and personal level. On both counts there is a necessary reduction on individual pursuits as funds and energies are re-directed in pursuance of your child/children's growth and family well being.

The synthesis of meaning and the essence of being a parent to their child are presented in Chapter eight: part four. Part one of this chapter introduces the co-researchers – the parents who live with and care for their significantly learning-disabled child/children - and their life-world.

CHAPTER NINE: PART ONE. The Meaning of being a parent and caring for a child with significant learning disabilities: Horizontalization

1. Introduction

This chapter begins with a brief overview of each of the co-researchers; it details family characteristics and employment status of each parent. This overview will also provide information as to the nature of their child/children's learning disability.

It need not be said but each and every statement from the interviews have been viewed with equal importance, however due to the restrictive nature of the word length of this thesis I am unable to present the transcripts and each statement in their entirety. This decision is based purely on the wordage of the verbatim transcripts, which exceed 500,000 words. This chapter therefore will present significant statements and passages of conversation that I have selected. Each statement and passage of conversation has been carefully chosen, as described in chapters three and five, with a view to illuminate the conversation that was held with each parent. I have chosen, as in true Husserlian tradition, to present each co-researcher's story individually, this may appear lengthy and unwieldy but it will assist the reader to immerse him or herself into the world of the parent without the unnecessary flitting from one co-researcher's response to a question to the next. Part two follows a similar pattern in that it presents the textural and structural descriptions of each co-researcher individually. Parts three and four provide a composite account of the textural and structural descriptions and latterly the synthesis of the textural and structural descriptions that presents the essence that account for the meaning of being a parent that lives with and cares for a child/children with significant learning disabilities.

2. Co-researcher characteristics.

Features that act to identify individual members, such as names, places and particular use of language have been altered so as to protect the anonymity of each co-researcher. The following text will be presented as family one (meaning couple one) and so on. The order and selection of how the families are presented are totally random. Whilst each parent experienced the same question format I used additional questions to further illuminate or clarify a given response. This is reflected during each interview. Appendices one and two outline the unstructured and semi-structured interview format used in this study.

3. Individual accounts: Invariant horizons

Family one

Jane lives in a rented house with her two young children. Jane separated from her husband twelve months ago; she is unemployed and relies on benefits to 'make ends meet'. Her two children, Zoe aged seven and Jessie aged five are of school age. Her eldest daughter Zoe has a profound learning disability, which has impacted on her mobility and her language development. Zoe attends a special needs school as a day pupil.

Jane's story

Can you describe your role as a parent as you see it?

...as a single parent I am here, I do the lot, from looking after the children to seeing to the household things, you know, paying the bills, cutting the grass, cleaning and painting the windows... those kind of things...

Is being a parent more than this?

Yes, that answer was a bit crass, I am essentially here for my children, that is what it is all about... to protect them from harm, to encourage them to be independent from me, to love and to cherish them come what may...

What is it about this role that makes you say that?

...that is how I see it, that is what a parent is, isn't it? I suppose though if my ex was still here, things may be different in that I wouldn't be expected to do 'everything', but as it is he isn't so I have to do it all... ...in relation to Zoe things are a bit different aren't they, she needs much more than say another child of the same age, most seven year olds can see to themselves, to an extent anyhow, but Zoe can't I have to do it for her... and probably will have to for years to come, so in relation to this aspect of being a parent Zoe's disability has shaped, or should I say maintained this role...

The role of actively caring for an older child?

Yes.

If your role is made up of certain elements how essential are these elements?

... cleaning and painting windows isn't really essential is it [laugh] when it comes to being a parent. It is essential to want to have children and to be there for them when they need you... the needing you, Zoe does need me more than Jess, even though Jess is five years old... she needs me to see to her daily needs, you know from wiping her bum, to dressing her, to feeding her, the whole works, as you said the caring for an older child. If I did not do these things well Zoe would be filthy and unkempt and I would be in trouble with the social...

Would you still be a parent if one or more of these elements were missing?

I would be classed as a bad parent [laugh] if I did not look after Zoe or Jess properly wouldn't I, so I suppose if I didn't care for Zoe as she needs it I would still be a parent to them, but I wouldn't be a good one...

What is it about your role that makes it matter?

...being there for them both, come what may, irrespective of whatever is happening in my life Zoe and Jess will always come first whenever they need me. That's what makes it matter...

To what extent do you think your role has been influenced by ideas from elsewhere?

...I come from a big family [Jane has moved to this area and has infrequent contact with her parents and siblings], my parents are extremely happy together and had what you could describe as a traditional marriage.

Meaning?

Dad went out to work, kept the garden and the house maintained and played with us of a weekend and when we had family holidays. Mum kept home, did the washing the cooking and looked after us... kept us safe, being there for us when we needed her most. So my role has obviously been shaped by my own upbringing... my role is

different to theirs, that's only because I am a single parent now. ... that's how it was for me and that is how it should have been for Zoe and Jess, me doing the caring, the rearing of them and my ex doing the manly things, you know going out to work to provide for us...

How does your role make a difference to your family?

As a single parent it is important to get a balance between being a parent and being an individual, that is sometimes really hard because you are a parent first, you have to put your needs to one side and deal with whatever is going on. So I think by being there for them, come what may, providing a stable home life... as you know when me and my ex were together it wasn't very good, the fighting and all that... that wasn't good for them then...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

...cleaning and painting windows [laugh], when I notice that they are dirty and in need of touching up. When I stand there and gaze at them it suddenly strikes home that I am alone here, it is me, Zoe and Jess against the world, just three of us, not four as it used to be...

If you were to sum up your situation in one or two sentences what would you say?

...that life has many twists and turns, when we were together I felt strong and supported, but now I am alone and have two children, one who has very special needs, who really needs me to be strong as she needs an awful lot of help throughout the day, but I always do not have the strength. One where you put your life on hold, waiting for one day when you can pick it back up. But also knowing that in all probability that day will never come.

Is this for you the essence of being a parent?

I guess this is what it is all about right now...

What effect does Zoe's disability have on you?

...my friends they don't understand how you are feeling, um, they don't take into account what you are going through, so because of that I have lost contact with most of my friends now. They don't bother with me, so I have become much more isolated, even though I live in a town.

Is this as a direct result of having Zoe?

In many ways it is, I have really struggled coming to terms with Zoe and her disability and because of this I have drifted apart from my friends and at a time when I most need them. My parents don't live locally, I have split from my husband, so having a group of friends would be of great help and support...those friends that I do have, I find that I am too busy, that I don't have the time. When I do have the time, say when Zoe is in school I am too tired to go anywhere, I just clean up, sit down and watch the telly, and then get ready for her to come home from school.

How would you describe your levels of stress – high or low relative to past experiences?

...at the moment they aren't too bad this is because Zoe is in full time school. When she is unwell and home more than she is at school well that is a different story. I am usually up the wall, I find it really hard to cope with her...

Is this picture repeated during the longer school holidays?

Yes, that's when I am at my worst.

Can you describe this and how you manage?

...my head is all messed up, can't think straight and I usually end up doing nothing just sitting there watching her... as I have said I get no real support from the social, have no real friends and my family don't live close, so I am on my own. I have listened to J's [referring to community nurse] advice and take myself out of the room when I am really stressed out – that helps me to calm down and take stock. I have a glass of wine and a fair few fags – that tends to help me... I have no one to talk to, except for J, but she is only here for an hour or so, every other week so having a drink, fags and a moan and taking myself out of the situation is how I manage...

What other strategies might help?

Well if I had time and support being able to go out, just simple things like going for a walk, going to the gym or a club where I could meet friends, you know, someone who I could talk to, confide in, that would really help me...

Have you ever experienced private thoughts about your child/children?

...I do have private thoughts some good and some bad, nothing horrid here. I sometimes find myself looking at Zoe and Jess when they are playing and I am so proud of the fact that I have these two beautiful girls. There are other times when I find myself wanting to really shout at them, you know when they are being really bad for me. When Zoe has a full nappy and she gets her hands in it and it goes all over the place... on the floor, over her face and in her hair, then I really don't like her...

When you have these thoughts, good and bad ones, how do you deal with them?

...a good thought makes you feel good you know, but bad ones makes you feel bad, as I have said as if I am a really bad parent. But like the good ones they come and go and they don't hurt anyone... so I think they are quite normal to have...

Family two

Rob and Christine own their own property, they are both unemployed. They have four boys Barry aged eighteen, Michael age sixteen, Jason aged fourteen and William aged six. Michael has a significant learning disability and epilepsy that has been resistant to medication intervention. Michael requires full assistance to meet his day living needs and a higher level of supervision both day and night due to his uncontrollable

epilepsy. Michael engages in a range of difficult and complex behaviours that include: Pica (eating inedible items), regurgitation and faecal smearing.

Rob's story

Can you describe your role as a parent as you see it?

Your whole life is run by him in a sense, you... you cannot plan anything without him being the first thing you think about, before making any other plans. You have to think about how Michael fits into the scheme of things... he will be and always is the priority. I play a big part in overseeing all of his needs. This is from the food he eats to the clothes he wears. Ensuring that he is happy, healthy, loved and cuddled... ...I tend to do the physical things with Michael him being a lad. It is more difficult for Christine now that he has grown so much, she finds it really hard work. He is still a baby really, he wears pads and needs changing, cleaning and all that... ...it is better that I do it now, much more appropriate for him. So my role obviously is to see to his physical needs on a daily basis when he is at home. I also make sure that he is safe and that no harm can come to him... ...this means that I will also go and check on him when he is wandering about the house or when he is in his bedroom. I make sure that he has enough drinks and that he is fed. I think he enjoys it when we sit down and have a cuddle and a bit of a play fight.

What is it about this role that makes you say that?

...the physical side to his care, well this is really because Christine finds it hard to do. She has done it for years and has suffered from a bad back as a result. So it is my turn now. It's also better for Michael as well; he is a young man now so it is better for him that another male sees to his needs. ...as you know Michael has quite a severe disability and has bad fits so we need to keep an eye on him at all times, so our roles have developed and shaped by Michael's needs.

If your role is made up of certain elements how essential are these elements?

...as you know I do most if not all of Michael's personal care, so they are very important for him. If I didn't do it there would be no one else in this house... it would not be fair to ask his brothers' to do it and as I have said Christine finds it really hard now, she struggles with his size and weight and suffers badly afterwards with her back. So the elements of providing Michael's personal care is essential without me doing it he would smell, be covered in poo, generally he would not be properly cared for...

Would you still be a parent if one or more of these elements were missing?

Erm, of course I would still be a parent if I did not see to Michael's personal care, if he did not have his problems we would not be having to see to them, would we? I, we, would still be his parents we would still care for him, want the best for him, all those kind of things. It would be that I would not have to bathe him, clean his teeth, and feed him, those kinds of things...

What is it about your role that makes it matter?

...being there for them all, being a brick for Christine, we are in it together the two of us. If we did not work as a team life would be difficult for both of us. With regard to what I do I think me seeing to Michael really helps Christine.

To what extent do you think your role has been influenced by ideas from elsewhere?

The way I was raised by my parents has had an impact on how I think a parent should be. My dad was a really hands on person, he cooked helped out in the house... that is really unusual for his day and age but that is what he did. I think I have taken his lead here, I don't think it is unusual for a man to help in the house; in fact I am a better cook than Christine [laugh].

How does your role make a difference to your family?

As I have said before Chris seeing to Michael's needs really helps Christine these days, she struggles with him now, as you know he is a big tall lad and it is a real effort for her to care for him, you know, changing his pads all that kind of stuff. So me being here for that very purpose makes a real difference.

If you weren't here what would that mean?

Quite simply Christine would not be able to do it. It would mean Michael being cared for by someone else, either in this house or elsewhere. That's how important my role is nowadays.

And what about your other children?

Well I am the one who takes them to football practice, fishing, motor biking. Don't get me wrong Christine takes part in these things but I take the lead, so the boys see that and talk about it with me more than Christine.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

I feel it when the boys ask if they can go fishing, like, 'dad it's a good tide today can we go fishing'. I can't say yes straight off as it depends on Michael and how he is, if he is going through a bad spell of fitting then it is a clear no no. The boys are really disappointed I get frustrated and begin to question how unfair it is...

If you were to sum up your situation in one or two sentences what would you say?

It's like being a single man, even though you know that you are married and have children. You never really get the chance to do things together as a couple, which we should be doing now that they [children] have grown up. Michael's disability and his level of need prevent us from experiencing things like this, you know simple things like going out for a meal...

Is this for you the essence of being a parent?

No not strictly, it is a part of what it is like to be a parent to Michael and his disability. You expect to give up a whole lot of yourself for your children, but in Michael's case you give much, much more of yourself. This is just one element of being a parent.

What effect does Michael's disability have on you?

I think Michael has had quite a bad impact on his brothers. Barry's mates would not come to the house. I think they were frightened of Michael... not that he would hurt them, but more because of the way he is, you know, he will come right up to your face and stare at you... if he is, you know, er, holding sick in his mouth and dribbling it over you it is not very nice. So that was a real off-putter for Barry's friends and Barry himself as he missed out on having his mates around to play, to hang around.

Whilst I will go anywhere with him and be seen with him anywhere it is difficult. Life can be restricted when with Michael you can't go to café' or things like that as he won't sit still... he has a tendency to regurgitate his food so that can be, is, a problem in public places, so much so that we never do that kind of thing when Michael is with us.

It is a real burden, more so for the other boys [referring to brothers] we shouldn't have to put on them. There needs to be somebody who can look after him so that as a family we can experience normal things, you know, being able to go to the football, go bike riding or even fishing... these are things that we have not been able to do on a regular basis.

How would you describe your levels of stress – high or low relative to past experiences?

I do get stressed but it is situational, like when Michael is having a really bad fit and no one is in the house but me. There is no one to get help for you, so I guess I panic and my stress levels soar, or when the boys are fighting, squabbling over trivial things.

How do you manage your stress levels?

We go out once a week to our local pub, meet our friends take part in the quiz, have a few beers and a bite to eat. That gives me something to aim for each week. Also when we get the chance I take the boys to football practice, take them fishing. That gives me a chance to blow the cobwebs away.

Have you ever experienced private thoughts about your child/children?

...I said before that sometimes I get frustrated with it all, the not being able to do things spontaneously as a family. I never blame Michael it is not his fault, I think his brother do, they resent him sometimes. ...they have said so to me on more than one occasion, but we can't change our situation we have to make the best of what we have got, that's all there is to it...

Christine's story

Can you describe your role as a parent as you see it?

Being there to ensure that all of his needs are met, either by myself or by Rob. I tend to be the one to orchestrate what is happening throughout the day. I make sure that all his things are ready for him, you know, his clothing, that his bag is packed and his medication is ready for when he is in hostel. To attend all the planning meetings and essentially to make the final decision about any plans. I discuss and agree this with Rob but when in a meeting I will make the decisions then and there and discuss later with Rob. To fight every fight that comes his, our way. To fight on his behalf, Michael is totally dependant on us for that. To make sure that he gets what he needs in terms of daily care. To make sure that school are doing their part... that his one to one is there for Michael and no one else, and that they remain totally vigilant because the capacity for accidents with Michael is huge and that is my main worry keeping him safe and well and looking to the future all of the time. Rob tends to do the changing of the nappies, giving the baths and bits like that whereas I seem to do the planning and the worrying.

What is it about this role that makes you say that?

It is what I do, that is what is expected of me... when you have a child you are there to provide for them, that is what it is to be a mother...

Is that different when considering Michael?

Not really, granted he is a young man now and he still needs a high level of support and supervision, but he is still my son... I will continue to offer him the support whilst he lives here for as long as he needs it...

If your role is made up of certain elements how essential are these elements?

As I have said my main role other than being the mum to my children, nurturing them, helping them to acquire new skills, you know daily living skills... being able to look after themselves, that kind of thing, in particular to Michael is to plan and organise for him on a daily basis... from ordering his medication, his nappies, completing his home school diary, keeping his 'fit' chart [referring to epileptic seizure record chart] updated, attending school meeting, meeting with social services and health. If I didn't do it who would? Rob I suppose would have to do it, if I wasn't here. Our roles have developed over the years and that is what I do... this is who I am, the planner the organiser...

Is this role the same for your other children?

In some ways it is, but in others no, as they have grown up they take charge of their own responsibilities, that's a given isn't it?

Can you give an example?

Well, yes in relation to Jason, he looks after his diabetes, his menu planning and taking his medication... he only requires a gentle reminder now and then, but as he has grown with it [diabetes] he has learnt to manage it, without me having to do it for him... when he was younger then yes, I had to plan his medication and his menus, to make sure that he was well... I suppose if Michael did not have his difficulties... lets say he had his epilepsy but no other problems, then he would be like Barry by now, looking after his own health needs...

So from what you are saying your role is determined to some extent by Michael's learning disabilities and his needs?

When you put it like that then yes the features of my role have been shaped and determined by Michael's needs and they are essential because M is not able to do these things for himself, by no means can he do these things for himself. He needs somebody, me, to be there to do for him, to make sure that he is looked out for... school, health and social services would not do that for him... well maybe they would if he was in care, but he is not in care, I do that for him... so what I do on a daily basis is very important to ensuring Michael is well cared for and that his immediate and future needs are planned and catered for...

Would you still be a parent if one or more of these elements were missing?

Um, that's an interesting question. Any or all of the elements would in many respects not constitute being a parent. If you are a businessman, or should I say a businessperson, you would plan, chase people and organise, er... a businessperson is not a parent.

What is it about your role that makes it matter?

To be there, come what may. Irrespective of whatever Michael has done, you know, smeared poo all over the place or worse still spit out regurgitated food at you. To keep on going even when it gets really tough... when you are at your wits end and above all to still love him and want the best for him... even if that means caring for him at home.

To what extent do you think your role has been influenced by ideas from elsewhere?

Well you see it on television and films, particularly soppy films, you know, when it involves a mum and dad and children. When they are all together, sitting around the dinner table, sharing hugs and kisses, talking together... being a family. When you see things like that, not even on television... when I go to my friends or my sisters house and see how they are as a family... you begin to question, is that how I am supposed to be with Michael and his brothers? I guess my own upbringing has also influenced how I view what a parent should be... so yes there is a preconceived idea put about, erm, by the media and whatever else you come into contact with that does have an influence over what you think you should be like as a parent. For me it has a knock on effect, a bad one though...

Can you explain this?

Well, as I have said I have this image of what it is supposed to be like, you know, all nicey nice, sitting at the table discussing, you know, having a family conference, all getting on well together and enjoying each other's company. It is not like that here, it can be more of a battle ground... if it is not Michael having a fit, or smearing his poo or his brothers' having a squabble or a major fight. When I reflect on it all I then start to think that it must be me... that I must be the bad parent, that I have got it all wrong... like I said when I go to my friends it is not like it is here, it is calm their children are polite and do as they are told, there seems to be respect...that respect though is mutual.

How does your role make a difference to your family?

... I would like to think that my contribution to the running and planning of the household has made a big difference to Rob and the kids. Rob has his hands full with Michael, as you know, seeing to him and all that. As I have said I tend to busy myself with the organising, the running of the house if I did not do this it would be even more chaotic than it can be...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

There has been many a time when you think about your life and question what it is all about... I bet most parents do that... all parents must question sometimes, it is not an easy job. The best time is when they are babies, when they are totally and utterly dependent on you for everything... that doesn't last long as they grow up... they don't need you quite the same... but saying that they need you for other things. So what is it all about?... for me it is about bringing someone in to this world, to help them grow and develop and to watch them leave and make a life for themselves.

Is this the same for Michael?

I would dearly love it to be, but as you know he has a significant disability and he will never be able to make it on his own Michael he will always need someone to look after and care for him, to protect and keep him safe... We, I have watched him grow to a young man, but he still needs us as much as he did when he was a baby... you know, to see to all his needs. So I see it as my, our lot to have to carry on looking after him... I would not be able to let him go, I would not be able to trust the level of care out there.

Is there a reason for this?

Well, yes there is. We were persuaded to have some sessional support, but rather than someone coming to take Michael out for a few hours they [social services] agreed for someone to sit in the house and play with him, giving us the chance to go out and do things as a couple or with our other children. Well Chris it was a nightmare, this young lad, must have been in his early twenties was introduced and after a couple of meetings it was agreed that he could have his first session with Michael. I was really nervous about this but Rob reassured me that we must do it, it would be for the better. Well, we were only gone an hour and when we got back home there was pandemonium... Michael had gone to his room, the support worker remained in the lounge, when he went to see what Michael was up to, he said he only left him for a few minutes... Michael had emptied his nappy all over the place, including himself, it was everywhere. I sent the support worker packing. Rob and I then had to begin clearing the mess. So in the end it wasn't helpful to us and I made up my mind... never again. So that is why it is our lot, we will for as long as we can continue to look after Michael.

If you were to sum up your situation in one or two sentences what would you say?

That it is a role that you can never be prepared for; there are no books or courses that you can study that will prepare you for it. It is a role that is at times full of despair and anger. On saying that it is a role that I would not change now, but this is probably due to having sixteen years of it... it is all we, I know now. It is a massive juggling act,

trying to make sure that they [referring to all family members] are all viewed equally. That no one gets left out or that Michael does not get extra at the expense of others.

Is this for you the essence of being a parent?

The juggling act is certainly one essence of being a parent, yes.

What effect does Michael's disability have on you?

The older I get, the bigger he gets... it is getting much harder to care for him. It's more about the physical strain on me really, having to move and lift him... my back is not what it used to be. If he was normal... I mean not having this profound disability, he would in all probability be getting ready to go to university or maybe have a job somewhere or just be bumming about with his mates, going to the pub or whatever. You know, I would never see him, but back to earth, here I am still cleaning his bum. ...It is hard work, don't get me wrong we love him to bits; the main thing is how tired we all are. A physiotherapist asked me to talk to other professionals, do you know why, because I sound so weary! I get really fed up of making endless phone calls and people putting me off, stalling me... that doesn't help me, it created further weariness.

How would you describe your levels of stress – high or low relative to past experiences?

At the moment they are fairly high, this is because we are meeting with social services and education to discuss Michael's future. We want him to go to a small local college, somewhere he can be looked after properly during the day but it is a real fight trying to get what we feel Michael needs, it's all about the cost at the end of the day, not about what is best for him. So I'm feeling really stressed about it at the moment

How do you manage your stress, irrespective of its level?

I'm lucky 'cos I've got Rob, someone to talk to, to bounce off. I'm also able to go out, Rob and I both go out together once a week, just to the local pub, play a quiz game, that really helps, just having something to aim for. We are able to be a couple then.

Who is caring for Michael?

My mother sits in, and we are only down the road if she needs us.

Have you ever experienced private thoughts about your child/children?

I do experience feelings of not liking what Michael is or has done, you know when he has a mouth full of regurgitated food... it repulses me, that is when I shout Rob and ask him to clean him up. It is the same when he has a fit I just look at him and pity him, I then do think what if he doesn't come out of this one? And then I think what it would mean for us as a family if that did happen, but as quickly as they come they go again and I carry on doing what I was doing, you know, giving him his rescue medication...

When you have these thoughts do you dwell on them later?

No not really, as I said they come and go... they don't make me a bad mother, I'm never going to harm Michael. I just think that they are normal things to experience; I would guess that most parents/carers have them, but they don't talk about them... ...after this way of thinking I feel awful. I must be a bad parent to think about Michael like that. But then... when Barry or Jason bad mouth me, I say to myself 'I

hate you for speaking to me like that'. In situations like this my feelings disappear as quickly as they appeared. With Michael though I do feel resentment towards him, but also I dislike myself for thinking that way.

Family three

Drew and Marian own their own house. Drew works for the family business and Marian views herself as an employed 'housewife'. They have two children, Brian aged seventeen and Jasmine aged twelve. Brian has a formal diagnosis of autism with a severe learning disability; he attends a school that specialises in the education of children with autistic spectrum disorder. He spends two nights per week at the residential facility. Brian developed epilepsy when he was thirteen years old. Brian communicates by using gestures and can become extremely frustrated when he is unable to convey to others his wants/needs. This generally results in significant physical outbursts where he can harm himself, those close to him and property.

Drew's story

Can you describe your role as a parent as you see it?

Whilst I provide the income I also see my role as that of house maintainer. I like to make things, to make things nice. Um, how can I put it... without too deeply into my own background and upbringing, um, I was raised in many respects by my fathers mother, my grandmother, who taught me quite simply that at the end of the day your responsibilities don't stop, your children are always going to be your children irrespective of their age or their physical presence, or whatever they have, or have not achieved in their life... they will always be your children and the responsibility for them will always be there until the day you die. ...In an old fashioned way I was raised quite simply. I am the major breadwinner, it is my job, as I say because of my family background my job is to provide all the normal things that a father should provide, the standard things, the food, the home, the clothing ... all those kind of things. It is also my responsibility to set the moral tone within the home, to raise your children to the best of your abilities, the best you know how. To do so according to the laws... the laws of the land and by your own standards. This also applies to Brian although he will not understand these fully, but he should behave in a way that is acceptable to us and to the general public.

What is it about this role that makes you say that?

Before Brian was born I was secretly hoping for a son so that I could do things er, you know, like going fishing and playing football. When he was born he developed normally until about eighteen months of age, then he went into himself... closed him off from the world. It was at that point that I had to re-evaluate what I had envisioned for us, you know, the father son things... out doing outdoor things, like I said going fishing, camping... the real outdoor type of activities that sort of thing. We weren't able to do those sort of things so my role of being the teacher, you know, how to put up a tent, how to tie a fishing knot, to be patient and sit still and wait for the fish to bite changed to that of trying to teach Brian how to control himself, how to behave in public places. Other simple things like how to tie a shoelace. These are things that fathers do... amongst other things...

For example?

There is a clear distinction, at least in this family, and this must be the same for other families, regarding what a mother or what a father does. Marian and myself both care for Brian just as much as we care for Jasmine we want the best for them, for them to have a good life, with or without us. What is different is what we do on a daily basis, it is in some way like an unspoken agreement, and maybe it is something that evolves over time as you adjust and grow into the role of being a parent. For me, I am the earner; I provide the material aspects to this family. It is my unique role to teach Brian new things, like I said, not the things I was hoping to teach him, but still passing on to him things that I know, my experiences of how to do things...

If your role is made up of certain elements how essential are these elements?

erm, well if I wasn't here how would Marian cope, that's a question and a half isn't it Chris. I suppose, as I have said before, I am here to be the punch bag [laugh], to take the physical knocks, to be the strong one in this family... this is about my physicality I guess... so if I wasn't this strong person, the physical and emotional strength, then who would do that, Marian isn't physically strong, nor is Jasmine... they would not be able to cope with Brian and him being physical towards them, they would just not be able to cope with that, I'm one hundred percent sure about that... so the element of being able to cope with Brian's physical nature is extremely essential when caring for and looking after a young man like Brian. If this element was missing then this family would be in a right old position, you know, w we would function...

From what you are saying one of the important elements of being a father to Brian is your emotional and physical strength, how do you see the future, if we say Brian continues to present behavioural challenges and your physical strength with age reduces?

God, Chris, you know I have thought about that recently, it really does frighten me, what if Brian gets the better than me... He already towers above me and he is heavier than me, what he lacks is co-ordination so it is relatively easy to escape his swings, he might get a lucky punch in, but as you say when I am much older, I am not going to be as fast or as strong... I'm afraid that Brian will hurt me, not intentionally, 'cos he is just in a temper... he is not meaning to harm or hurt you in a malicious way. He will probably start to connect more, the punches and slaps will hit the target... how do I, we cope with that, because then I wont be as useful in those situations...

Would you still be a parent if one or more of these elements were missing?

Yes, of course I would, as we have discussed I might not, in the future, be able to manage Brian in a physical way, but he is always going to be my son, I will always be there for him, I will always do my best for him, to fight his corner, to make sure that he is well cared for...

Well cared for?

Well Marian has always insisted that Brian will, when he becomes a man, leave home, to be cared for, like in a specialist college, a village type of thing... I am not that convinced, but it is Marian who is the main carer for Brian so I have to respect her on this one... anyhow when and if he goes to residential college or leaves home I will always be making sure that he is okay and well looked after, that he is happy... so even though I am not doing it, you know, the hands on bit of being Brian's dad I will always be there for him... always, until the day I die... That is the same for J as well, god help me, if anyone hurt either of them I would kill them...

What is it about your role that makes it matter?

You would still be carer, you would still possibly be there for those in your charge erm, say you were looking after children... like a foster carer. But on an emotional level it would not be the same, surely? Foster carers have children and then watch them move on elsewhere in the world, when it is your own child... the one you watched being born, taking their first steps, saying "dada" for the first time, learning to use the toilet [referring to Brian who learnt this skill at thirteen years of age], it's emotional, you are there, you are attached no matter what. Even when Brian is residential [staying at the hostel] I find myself thinking "I wonder what he is doing?" and "I hope no one is hurting him?" You can't switch off this for me is one of the essential elements of being a parent.

...There are things that I do that Marian isn't able to do... well not anymore. Brian is a big strong lad now, and as I have said he can be very physical, you know, pushing you around to the point that he hurts you in the process.

Is Brian's 'physicality' a constant or it is specific to certain times or events?

Yes, when it is... say time for bed, or time for a shave, haircut, and toe nail clipping, specific personal care things. That's when Brian really kicks off... good style. It becomes a real battle, but once you have started you have to finish particularly when it comes to shaving or hair cutting... that's why he has a grade three... he would look mightily silly with half a hair cut, or half a shave even [laugh]. As I said this aspect to my role is unique to me within this household, no one else can do it. Marian or Jasmine being women, no disrespect here, but they are not strong enough physically to manage Brian, one, when it comes to holding him while cutting his hair or shaving him and two, when you have to deal with and manage the fallout... when he starts to have a go at you.

To what extent do you think your role has been influenced by ideas from elsewhere?

I immediately think about my own upbringing... a man's job was to go out, to seek work and to provide for the families basic needs, you know, put food on the table, clothes on our backs and of course a roof over our heads. Other things on top of that

are extras. So my ideas of what my perception as a parent, a father is naturally influenced by how I was raised, parented as a child.

How does your role make a difference to your family?

If I wasn't here, and I must say Chris that it really galls me when Marian tells me that such and such a person have split up because he can't cope with his disabled child... it really gets to me. I know families break up and that, it happens, but I think what would it be like for Marian, Brian and Jasmine if I wasn't here, if I had buggered off elsewhere because I couldn't cope, there lives would be a misery. Being together, being there and supporting each other, often through some difficult times has helped us. We have grown up together, been strong together and because of this we do have friends.

Are these friends new to you?

Relatively new, we moved into this area so we had to make new friends...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

There is one incident that really says it all, you know about the amount of time, preparation and thinking it takes when taking Brian out... about how important it is to get it right... otherwise disaster. Brian was, last year this was, linked with a new support worker, a young lass, she took him to the local park, for a walk, an ice cream, so she thought... Brian had other ideas, the park for him means that he is going swimming, if you drive down that road Brian is going swimming, that is how he sees it, he is literal in his thinking... so on that day he decided to go swimming, he broke away from his support worker somehow managed to get into the swimming pool area, strip off his clothes, he was stark b*****s naked and jumped into the pool, the place was really busy. Brian was having the time of his life in the water, the poor lass was beside herself, jut didn't know what to do... they got him out in the end and away from the park... So here it tells me that you need to have your wits about you at all times, you need to think very carefully about what you are about to do when with Brian, you have to consider everything, you can't play things by chance alone...

If you were to sum up your situation in one or two sentences what would you say?

I am a father of two children...that I have a son who has autism and also has a severe learning disability. That my role now that Brian has grown into a big strapping lad is to help prepare him for adult life... to transfer what I consider right and proper and instil that... to both of them, that is Brian and Jasmine. To be a punch bag [laugh]. To go out there and provide for my family. God Chris I would say that life is bloody tough, that you are given massive knocks, you pick yourself up, adjust and try to carry on. Brian has been the biggest knock having to come to terms with his disability and all that it brings, and you know it doesn't get easier as the years pass you by, I still love him the same, that has never changed, but life is tough living with him being Brian's dad.

Is this for you the essence of being a parent?

In many respects it is... yes it is.

What effect does Brian's disability have on you?

Marian will call me a hard bastard because there is very little in life that gets to me, except for Brian, he is the only bugger who can make me cry. The other night we had an incident where Jasmine was playing with him quite happily; all of a sudden he turned and became very aggressive, very punchy... he caught Jasmine on her back making her cry. The only way I was able to stop it was to literally have a physical fight with him, to the point where I had to punch him harder than he could punch me. Brian broke into tears... it stopped the situation fine, it doesn't make you feel good in any way at all, don't get me wrong, but, it still, um, has to be done. It may sound horrific, for some totally hard and inappropriate, but on these occasions it is the only way you can stop him from really hurting someone, even himself. But I must tell you Chris after these events I cry, god do I cry. You should never have to fight with your own son; I never fought with my father, respected him too much for that...

How would you describe your levels of stress – high or low relative to past experiences?

I do get stressed out, sometimes more than others. When Brian is performing and Marian is screaming about the place God do I get stressed. It hits you like a ton of bricks, I feel weary, really tired, my mind is a constant whirl and I cannot seem to settle down to do anything. At other times I am usually quite relaxed.

When are these times?

...when Brian is in hostel, that's when I am less stressed, that's when the family as a whole are less stressed...

What strategies do you use to reduce your stress?

Having a cigar, sitting down here [kitchen] in the small hours on my own thinking about our situation, looking forward to going on our annual holiday, planning this with Marian and Jasmine [note: Brian never goes on the family holiday] and enjoying the moments when Brian is in hostel that really helps me, us as a family.

Have you ever experienced private thoughts about your child/children?

As I have said before Chris, when I sit at the table, a cigar in one hand and a glass of milk in the other. I sit there for hours, it was early in the morning and I could not get to sleep. Brian was at the hostel Marian was in bed, as was Jasmine. It was about two in the morning. So I just sat there thinking about our life and the meaning if it. Was it God's wish that we had Brian or was it bad luck, you know Chris one of those things, rotten bad luck. Don't get me wrong here, I'm thinking of Brian here, he has no life, he is not going to have a girlfriend, drive a car, have a job, you know, those kind of things... things that any normal eighteen year old would want... but not Brian. So you get to thinking Chris, about what it is all about... I have thought long and hard... there is no greater being that is dealing shit out here and there, it is all by coincidence, genetics, lifestyles... bad luck even... some get touched, some don't and we have been, that is all there is to it, we have been touched and we have to get on with it. So I got to thinking about ending it all, taking a pillow to Brian and suffocating him and then doing away with myself. At least then Marian and Jasmine would not have the responsibility for Brian, but I would never be able to do it. I, we can't change our situation, we can't send Brian back, we have to adapt to it... we have adapted to it,

but when you think about it deeply, blimey it really does hurt, but you have to keep your chin held high and get on with it and plan each day and deal with it as it comes.

Marian's story

Can you describe your role as a parent as you see it?

...I'm the mother, the one who has carried Brian and Jasmine and given birth to them. I have nurtured them, given them life. Have been there to comfort them when they needed comforting. I am there to support them in all that they do... irrespective of who they are and what they achieve in life. ...life with Brian is not as it should be, he is seventeen now and still needs looking after, simple things like running a bath for him, sorting out his clothes, even wiping his bum, but this is because he has autism and a severe learning disability...

What is it about this role that makes you say that?

Because that is what being a mum is about, don't get me wrong Chris living with Brian can be pretty tough, you know, when he is home you are not able to go out, to do normal things, but I am his mum, I am the one who brought him into this world and I will be the one who will continue to look after him, at least until he goes to residential college [laugh]...

If your role is made up of certain elements how essential are these elements?

...being able to drive [laugh] that is so important, if I wasn't, or even if I didn't have access to a car, my life would be hell. We would be stuck in the house all the time and he would be at me constantly...

Would you still be a parent if one or more of these elements were missing?

I would still be a parent without a car or if I weren't able to drive – not having these things would not stop me being a parent to Brian. I am and will continue to be his mum, the one who looks after him.

What is it about your role that makes it matter?

...knowing that I have done my best for him, having the responsibility the rewards and the disappointments that's what makes it matter for me.

To what extent do you think your role has been influenced by ideas from elsewhere?

That's a tough one, er, when you consider my role as a parent to Brian and Jasmine, I am a friend and companion more so for Jasmine. For Brian that is slightly different I am his carer, because of his autism I am unable to be his friend or companion like I am with Jasmine. But it is I suppose a question of how you define friend, carer and companion or other such descriptions. A parent is a parent first and foremost whereas

a carer, friend and companion can be independent to that of a parent. They can be totally unrelated... in the biological sense to a person, yet they can be a good friend and companion, or be a paid carer... someone who is paid to do a task.

How does your role make a difference to your family?

...it's about being there, for Brian and Jasmine and there for Drew to support each other that is so important. We live far from our families so we don't see them that often and we don't have friends to speak of.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

...when Brian is in full flow you know screaming and banging around the place. Like when his video player breaks and he is constantly pulling, dragging you to his room. You do take stock sometimes and you think what the hell have I done to deserve this?

If you were to sum up your situation in one or two sentences what would you say?

...one of having to make adjustments as a constant, we, I have been doing this since we were told about his autism. Life since then has not been easy by any means, having to attend meetings, people visiting our home offering advice but no practical help in managing him.

Is this for you the essence of being a parent?

...yes it is constantly adjusting to the ever-changing demands as your children grow up...

What effect does Brian's disability have on you?

...you have to be totally organised, you have to organise your life, you can't sort of just think "oh, I'll do that, er, if it is a typical week when he's at school it isn't too bad because he goes to school on a Monday morning and sleeps in for two nights, so he doesn't come home until Wednesday afternoon. So on those days you can be a bit more flexible, but it is always on your mind, what if he gets ill? What if he has a bad fit? So you need to be available, just in case, you can never switch off totally. Times when he is away from home like when he is in the hostel does give you time to do things which you can never do when he is home.

You have to come to terms with your situation and you have try to make life as normal as you can, from the simplest of things like going to the shops with Brian to going to a café. If we had not done these kinds of things when he was younger we would not be able to do so now. Otherwise he would be controlling our lives... totally. It still is hard when we go out to a café, even though Brian will sit and eat his food... as soon as he has finished he wants to go, even though we may still be eating... but at least we can take him to places like that, so our persistence all those years ago has really paid off for us as a family.

How would you describe your levels of stress – high or low relative to past experiences?

... these change dependent on what is happening in our lives. When Brian is at his worst behaviourally or when he started fitting then my stress is up, in the rafters. When he is in his room being quiet or when he is at the hostel then they are relatively low. ... Wine is my saviour a good slurp or two of wine really helps me to unwind, as does planning our holidays.

How do you manage with Brian during these times?

As you know he does not come with us, he goes to the hostel. We have to plan our holidays during school term otherwise we wouldn't be able to go. It does cause some anxiety, it isn't normal to leave your son in the care of someone else, but we need a break from each other, I don't think we would cope otherwise...

Have you ever experienced private thoughts about your child/children?

...oh, I have many there are days when I would wish Brian had never been born and there are days when I think really positively about him, you know when he sits there in his room and I look at him and say 'you are such a handsome chap' well he is isn't he [laugh].

How do you deal with the negative thoughts?

I don't really pay much attention to them really, they come and they go, it is all dependent on what is happening you know when Brian is having a go at me physically or demanding mentally... they are just normal, for me anyhow...

Family four

Tony and Glenda live in their own house. Tony is unemployed due to ill health, Glenda works part time. They have three children, Mark aged nineteen, Morgan aged seventeen and Christine aged fourteen. Christine has cerebral palsy and an associated learning disability. She attends a special needs school as a day pupil. Christine is an active young lady who can be highly demanding during her waking hours.

Tony's story

Can you describe your role as a parent as you see it?

Christine always needs help to do things... like getting dressed, washed, cleaning her bum after a bowel movement. It has been my job to see to these things... that's what I do. I have a set routine; it is my role to see to her, to get her ready. I get up first... I have my alarm set so that I don't oversleep in the week... when she is going to school. Once I am up I get her out of bed, come down stairs and get a brew on. I then go back up stairs and have to literally drag her back out of bed. I get her washed and

dressed, teeth cleaned and hair brushed. Then we go down stairs, I put the telly on for her whilst I go and get her breakfast. It has been the same routine now for years... so it is well drilled. I then get her medication ready and give it to her and then wait for the taxi to arrive. Then she is off to school...before she goes she tells me what she is going to do when she comes home, like doing her flags or something like that. ...When she has gone I will tidy up and then get her flags or whatever it is she has asked for out and ready for her return home from school...

What is it about this role that makes you say that?

I see it as my role to see to her needs, everything I do for her. As I have been ill things are the other way round. My wife goes out to work and I stay home and look after Christine. Usually the child would run to its mother, the father thinking that is her job and sits back and watches her deal with whatever. Whereas here it has been reversed, Glenda [referring to wife] sits back and watches me do it ... it is my job.

If your role is made up of certain elements how essential are these elements?

Christine cannot look after herself, so if I did not do it who would? She needs to be cared for even though she is a teenager. Glenda cannot do it, I suppose her brothers could, but that would not be right, them seeing to her personal care.

Would you still be a parent if one or more of these elements were missing?

...if Christine did not have her level of disability and could look after herself then I would not have to do what I do on a daily basis. If this was the case I would still be Christine's dad, it is not just about doing the caring things it is about looking out for her, wanting her to grow up to be independent, all those kinds of things.

What is it about your role that makes it matter?

Even though Christine is fast becoming a young lady I still see to her. Glenda has never really done this, it has been my responsibility since she was a baby and still is. So I get her up, give her a bath or shower, help her to dry herself, you know, do all that is needed so that she is ready to go to school. Glenda has always found it hard to see to Christine's needs, this is because she doesn't cope well with Christine's physical deformities, erm, you know, to her spine. My role of father to Christine is to help her get ready, to see to her physical needs. Glenda will sit for hours playing and entertaining Christine. I suppose when you look at it we have reversed our roles, me being the main carer and Glenda being the entertainer... but this works for us.

To what extent do you think your role has been influenced by ideas from elsewhere?

Well what I do is very different to what my father did, so I have not been influenced in that way, otherwise I would be off to the pub of a Friday. I'm like a paid carer in some ways, where I am tasked to look after someone's personal care needs, my daughter. My mother would have taken on this role if she had had a child like Christine.

How does your role make a difference to your family?

...Christine would not be looked after, as I have said Glenda finds looking after Christine in this way very difficult. So my role as the caregiver has a beneficial effect for both Glenda and Christine.

What about you?

Well, it is the way it is, it's what I have always done and will continue to do. I am finding it harder now that Christine is developing you know cleaning her private parts when she has her periods. I think it would be better if Glenda saw to Christine's very personal needs, but she can't so what do we do as a family?

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

... as though I have been chosen to look after a very special child, a role that I didn't ask for but have been given. That's about it really; I've been given this special role...

If you were to sum up your situation in one or two sentences what would you say?

It's like being on a massive roller coaster ride, the roller coaster ride of emotions, with the constant physical pressure of having to care for and provide for a very demanding young person who would otherwise be out and about with her friends.

Is this for you the essence of being a parent?

That is what being a parent is about for us anyhow we know no difference...

What effect does Christine's disability have on you?

At the end of the day she has done brilliantly, when you think of the problems she had at birth and along the years. She has made really good progress, when you think back... we were told that she would never walk or talk. She can walk to a fashion... albeit not very far but she can get around and boy can she talk, never shuts up. It is repetitive but at least she can make her needs known.

She is always telling me what she wants. Like when I am getting her dressed in the morning she is telling me what she wants to do when she comes home from school. So, um, even before she gets out of the taxi when she comes home from school she it is like we have not had a break... it is exactly where we left it that morning... every day is the same that is the size of it...

How would you describe your levels of stress – high or low relative to past experiences?

I get really stressed with her ...when she plans my day, my evening, it is as if I don't have any say, she controls my life... I find myself getting uneasy around three o'clock, coming home from school time, it's an odd feeling, a dread, like a heavy cloud over me. So I would say that my stress levels are fairly high and as a result of Christine.

What do I do to manage my stress? What works for me? Not a lot really I get the chance to potter in the garden and the garage when Christine is in school, that helps

me to keep chilled, but I can't always do that, particularly when Christine is home at weekends and during the school holidays...

Have you ever experienced private thoughts about your child/children?

Erm, if it is a particular situation like when she is emptying the toilet pan water over the floor, I will blow up at her, really tell her off and tell her that I don't like her and what she has done, in fact I will shout "I hate you for what you have done and that I'm not going to talk to you, go to your room" I will send her to her room and then clean up the mess she has caused, when I start to calm down I then start to feel guilty about what I have said. I will then go up to her room and talk to her and try to explain how wrong it is, and that as she is a big girl she should not do what she does. This makes me feel better because I am not shouting at her and not excluding her, which somehow balances out all the negatives because I am now being positive with her. So I suppose it is like a big rush of emotion, I explode; say some nasty things it all subsides more rational thinking comes in to play and you sort it all out... until the next time.

Glenda's Story

Can you describe your role as a parent as you see it?

I am mum first and foremost to all of my children; I am there to protect them to provide a home that equips them with the skills to live independently as adults. They are older now and are on their way.

Is this the same for Christine?

I hope the same for Christine as I expect for the boys, yet things are different for her she needs quite a lot of personal care, care that I can't give I find it really hard to see to her personal needs so Tony does all of that, I know that it isn't right for him a man to be changing his teenager daughter, but I just can't do it. I tend to do the creative things, painting and drawing, entertaining her and settling her to sleep at night.

What is it about this role that makes you say that?

As I have said I find it hard to do the personal care stuff, I, I find it repulsive. I think it relates to the fact that Christine is a teenager and should be doing it herself. I used to do it years ago, when she was much younger, but I can't do it now. So I see my role as Christine's mum as one of planning her entertainment, seeing to it that she and the rest of the family are fed well and live in a clean house and have clean clothes to wear.

If your role is made up of certain elements how essential are these elements?

The usual mundane things like cooking and cleaning are very much the things that I do, Tony can't or won't cook [laugh] the boys just expect it of me, this is the same with the cleaning and ironing...

Would you still be a parent if one or more of these elements were missing?

Of course I would still be a parent, it is not just about the physical side of doing for your children it is about the love you give, the time you put to one side to give them. I could employ someone to do the cooking and cleaning; they would not be Christine's mum...

What is it about your role that makes it matter?

I think what I contribute is very important Tony sees to Christine's physical care and I see to her entertainment. When I am doing that Tony is having a break and when he is seeing to her I am having a break. We share the caring...

To what extent do you think your role has been influenced by ideas from elsewhere?

I am a carer to Christine, but it is much much, more than just being a carer. She is my daughter at the end of the day. A carer can come and do a job a bit like a home help, come clean a house a bum or two [laugh]. Being a mum is more than that, with Christine I am her friend, a companion to her and her carer, well at times at least. It goes deeper than that...

In what way?

Well how I experienced my own childhood that certainly has influenced how I am as a parent. I remember back then with dad, he was a strong man who laid down the law, it was not uncommon for him to get out his belt to us when we had been naughty. I said to myself that I would never do that with my own children; maybe that is why children of today have no respect.

So from what you are saying you own experiences as a child can influence or change how you act as a parent?

Yes I think so.

How does your role make a difference to your family?

I know I don't do an awful lot of dealing with Christine, when she needs the toilet, bathing and I know that Tony has that to do. But I do entertain Christine that gives Tony a break and it gives Christine and I some nice time together...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

Christine and her constant demanding from the moment she wakes to the moment she goes to bed, it never seems to end. We seem to be here just for her, we have very little time for ourselves either as individuals or as a couple, the focus is always on Christine. Even to the point that when we do ever manage to go out we find our conversation always gravitating to Christine...

What do you talk about?

Well it is always about her usually something topical erm, like 'wonder what she is doing', 'hope she is behaving' to talking about her school placement, her health and even her future.

If you were to sum up your situation in one or two sentences what would you say?

Trying to juggle the needs of all the family without singling one out as being more special than the other... so that is what I am a juggler and I have become very good at it.

Is this for you the essence of being a parent?

In some respects yes being a parent is about juggling the needs of the family whilst not forgetting your own needs, with Christine though this is not always achievable.

What effect does Christine's disability have on you?

I find it hard to have any time to myself, I know Tony sees to Christine's needs, you know, getting her ready for school and bed, but still it would be nice to be able to have just some time... I have even found myself getting up early in the morning, tip toeing around the house, trying not to wake her up, but there I am sitting down looking at a magazine and there she is, she has heard me and followed me into the lounge... peace and quiet shattered and I find myself having to sit with her and entertain her... again, until Tony wakes up. ...On the whole she is really very good, but, she is very demanding once she is awake in the morning until the moment she is in bed at night our lives revolve around her. She constantly wants something, be it a sticker book, her painting. She finds it hard to stick to one activity always flitting. The days are very tiring, even when she is at school, because you know what is going to happen when she arrives home. That is why I am in bed for 9.00pm... I am just so tired all of the time. ...When I do a couple of days together... I mean entertaining Christine I am absolutely shattered. I just cannot cope I have no energy left... that is the worst part.

How would you describe your levels of stress – high or low relative to past experiences?

My stress levels these days always seem to be high, I am finding it harder and harder to cope with Christine and her demanding as soon as she comes in from school and I hear her voice my chest gets tighter and I just feel like shouting 'shut up'. It's all about Christine and what she wants.

Are your stress levels just associated to Christine?

No not always, I get stressed at the best of times, silly things really, but Christine tends to set me off...

How do you manage your stress?

My main way of coping is to do my sewing, that really helps me keep calm and it helps me relax and sleep at night. I don't do any keep fit, smoke or drink, I am not in to walking, sewing is my thing, it really helps me.

What about talking to other people?

I don't think that would help me I am a very private person so talking about my life would not be an option...

Have you ever experienced private thoughts about your child/children?

I experience a range of thoughts about all of my children, my husband, some of them are private and have never been shared with anyone, others thoughts have been voiced. I think it is natural that as a parent, as humans that we do so... for me they help me to cope, to deal with situations, to make sense of what is happening to me.

Can you give any examples of these thoughts?

Well, on a superficial level when things don't go so well, erm, when Christine is constantly demanding, when she is at you all of the time, or when Tony gives in to Christine and lets her have what she wants, or when my eldest son makes a mess in the kitchen, well I will voice my anger at them, tell them what I think and feel about them... it is an outpouring, a catharsis... out it pops and then we all carry on as though nothing has happened.

What about the deeper level of thoughts?

Um, well as I have said these have not been aired within the family, but for here, er, I feel slightly uncomfortable... but what the heck... if it helps your research... When Christine is really playing up [referring to learning disabled daughter], you know, when she is constantly demanding this, that and the other, and if I don't give in to her she will start this high pitch screaming... this is when Tony gives in, I have told him that he is teaching her bad habits, but I suppose he can't cope with the high pitched noise... it can go on and on, it is like torture... well after some time, er, I can cope with it for fifteen to twenty minutes, you can walk out of the room, go to the kitchen put the kettle on, play some music to try and drown it out, but when it goes on for half an hour or longer, I think to myself 'If you don't stop now I will bloody well make you stop', I have an urge to go up to her and swipe her very hard across her face... I can see myself actually doing it, as though it is about to happen... but it doesn't, I have never done it, but felt like doing it... it is as though she takes you to a point where rational thought disappears, where you really want to hurt her, to make her stop, to make her go away... you get really tired of it all, she is sixteen years old now, she should be doing her own things and not relying on Tony and me to do for her, she would be getting ready to do her A-levels or going to college, have a group of friends. We don't get any peace and quiet it is all about Christine, our lives revolve around Christine...

When you experience these thoughts and feelings towards Christine how do you deal with them?

As I have said I have never spoken to Tony about them, I have wondered whether he thinks the same, but I have not discussed with him, because how would he feel about me if he didn't feel this way? So when I have these feelings and thoughts about Christine I keep them very much to myself. I do think about what I have thought about doing, you know, going up to her and swiping her very hard across her head... to make her stop... to go away... As I have said I think to some extent these thoughts are natural, a coping mechanism, a way of dealing with extremely difficult situations, even though on saying that, when I do have these thoughts I feel awful afterwards, as though I am a really horrible person, not fit to be a mother, a parent to Christine. But those thought quickly dissipate as I move on to the next situation.

Are these deeper thoughts exclusive to Christine?

No, I remember when Tony was ill, I remember after several weeks of hospital visiting thinking 'I wish he would just go', you know, wishing that he would die, that sounds awful doesn't it, but that is how I felt at that moment in time. So these thoughts are not just about Christine... I must be a wicked person [laugh]... The only

difference between these thoughts is the frequency, with Tony I can count on one hand, they are infrequent, even after all these years of marriage [laugh], with Christine though they are frequent, not every day, sometimes not weekly, but they do occur much more frequently, as I have said it all depends on what is happening... how Christine is behaving, or not behaving and how I am feeling at the time, whether I am feeling a bit more pressured or my stress levels are higher...

Family five

Peter and Noella own their own house. Peter is self-employed and Noella is a full time student, studying a three-year degree course at University. They have two children; Daniel aged twenty and Malcolm aged seventeen. Malcolm has Down's syndrome and a significant learning disability. Malcolm typifies the Down's syndrome behaviour phenotype with behaviour rigidity and stubbornness. Malcolm attends a special needs school as a day pupil.

Peter's story

Can you describe your role as a parent as you see it?

...I'm there as the dad, the one who goes out to work, to provide for my family. I am the one who does the telling off, Noella doesn't do that [laugh], it is my job.

Is this the same for Malcolm?

Yes, but slightly different, he needs much more help with getting himself ready all that kind of stuff. So now that he is a young man I help him.

Can you give an example of the help you offer?

I get him up in the morning, give him a wash, help him to get dressed, take him to the loo all that kind of stuff.

Have you always done this?

Not always, since he has grown up I have done it. Noella finds it harder to do now, and it makes more sense that I do it given his age.

What is it about your role that makes you say that?

...if Malcolm did not have his learning problems then I would not have to do what I have to do with him. I would probably be doing different things with him you know going fishing, taking him with me when I work, that kind of thing, but, as it is he needs a lot of looking after and I think that is right given his age.

If your role is made up of certain elements how essential are these elements?

...being the provider to my family is very essential, if I did not go out to work then we would not have the things that we have, that is important to me and to Noella. Being able to have the physical strength to manage Malcolm is also essential, if I did not have this strength I would not be able to manage him, so where would he be I wasn't able to do what I do?

Where do you think he would be?

Erm, he would be in a home somewhere, Noella would never allow that I know but if I wasn't here or if I wasn't able to deal with him, the physical side of things then she would have to accept this, wouldn't she?

Would you still be a parent if one or more of these elements were missing?

Not being able to work or being unable to manage Malcolm would not stop me from being a parent. These things are the physical and the material. I would still want to do my best for him, to support him those kind of things... the things that make the difference from being a parent to not being a parent.

What is it about your role that makes it matter?

Well, if I wasn't home, all of the care would be Noella's responsibility. Malcolm is a young man it has become my responsibility to see to his personal care... it has been this way for a few years now... I see to his needs. It starts first thing each morning. I will get up and go to his room, tell him it is time to get up. I usually come back after a few minutes and take him to the toilet, give him a shower. He needs one every morning as he is still wetting the bed. Clean his teeth, which can be a fight, comb his hair, dry him and get him dressed. Noella will get his clothes ready for me. If I weren't home, for whatever reason, N would have to do this. It would be a real struggle for her as Malcolm towers above her and she would never be able to manage him, particularly when he doesn't want his teeth brushing or hair combing. So my job as the male, the physically stronger person is essential when it comes to seeing to Malcolm's personal care needs.

To what extent do you think your role has been influenced by ideas from elsewhere?

You can't take the parent out of me, I am the father of my children. I suppose my role has been defined by how I was raised by my parents and by what I think a parent should be as a result of my own experiences...

How does your role make a difference to your family?

As I have said for Noella me being here to manage Malcolm, the physical side of looking after him. That makes a huge difference to her. I suppose for Daniel he sees very little of me, as I work and then look after Malcolm, so I am very much a part time dad for him, and you know that hurts because I am unable to do the things I would have liked to have done with them both.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

When I do my thing [referring to preferred leisure activity] I find myself just sitting there, I am totally oblivious to what is happening to me, our lives. When I come to the surface it is the stark reality of it all that hits me, I'm back to this, the caring for my son, the not being able to go out. It really is a reality check and it is not a pleasant one.

If you were to sum up your situation in one or two sentences what would you say?

Having our lives divided into little boxes, where one goes one way and the other going another way, sometimes where we don't meet in the middle, like passing ships in the night. This is what living with Malcolm means for me.

Is this for you the essence of being a parent?

That's what it is like for me, this is what it is like to be the father of a child with a learning disability.

What effect does Malcolm's disability have on you?

...it hasn't been easy, because sometimes you know that you have been a bit resentful towards him, in sense, er, when for example friends ask you out and you can't go or when friends have been here for a meal and the whole thing has been a disaster because we have not been able to get Malcolm to bed, you know, he is not settled and also any changes in his routine or in his environment, such as meals at different times to normal, this throws him and he starts to get agitated... then our friends end up leaving early probably to save our blushes... so it isn't always easy.

...I don't look forward to anything as such... you tend to sometimes, as long as it carries on as it is, it is fine. That is until something drastic happens, um. I try not to think about the whole thing, if I do it really freaks me out. I don't know if I get in to it such deeply, you know, thinking about Malcolm. I often find myself getting really upset and I don't like that. I get really emotional, particularly when I have a bad day with. It all gets a bit too much for me and I have to escape for my own sanity.

How would you describe your levels of stress – high or low relative to past experiences?

They fluctuate each day, if for example I am doing a big job and need to be out earlier or need to be working later in the afternoon and I can't because Malcolm needs me to be home then they are very high. I find myself pacing around unable to settle, my mind racing, it affects everything my mood, my eating and how I sleep...

What do you do to cope?

I try to get out of the house when I can, go for a walk, plan a trip with the club [referring to preferred leisure activity]. If I can't do these things then I will have a pint or two...

Have you ever experienced private thoughts about your child/children?

...I experience a range of thoughts and feelings that are not specific to Malcolm, they relate to me, Noella and the rest of the family. When I have a row with Noella, can be a row about something or nothing really, then I will say things to her and sometimes just think horrible things about her. I then regret it, but they are only thoughts... I get frustrated sometimes with Malcolm you know when he is taking forever to get out of bed in the morning, particularly when you have a deadline, that really gets me going. I begin to shout at him and I have thoughts...

Like?

I just wish he would go, leave this house you know go to school and not come back...

How do you deal with these thoughts?

I feel bad, really bad but as I have said they are only thoughts, you get caught up in the moment of it all, up goes your stress levels and bingo you have a thought. I guess most people if they were honest and in stressful situations like this would have them...

Noella's story

Can you describe your role as a parent as you see it?

I'm the organiser, the planner, the one who keeps things together. Yeah, I am certainly the decision maker in this family. Um, that sounds rather negative, but it, it's the kind of personality I have. Peter may say something different. Mind you he would most likely agree and say "she's the boss", but actually Peter is not very good at making decisions so he allows me to make the decisions. Equally though, because I make the decisions he may have become lousy at making them – it kind of works both ways.

What is it about this role that makes you say that?

Well. Peter has always said that I've always known Malcolm's needs, better understood him and always seemed to be able to know what is best for him. So I suppose he has always gone along with me and my decision-making, so in some ways that makes my role as the decision maker.

If your role is made up of certain elements how essential are these elements?

If I did not plan, chase and organise Malcolm's day nothing would get done. So I suppose the elements of planning, chasing and organising are very important... I would say they are intrinsic to my role.

Would you still be a parent if one or more of these elements were missing?

Anyone can plan, Peter could even do it, if I gave him the chance [laugh], seriously though if I didn't have to plan for the boys and for Peter I would still be their mum and wife. It is more to do with the nurturing, the love and the longing for them. I feel empty when they, the boys that is, are not around me, if though things can get pretty

difficult, they are part of me a big part of me. I would find it hard not to have those elements; they are for me the essential bits of being a parent.

What is it about your role that makes it matter?

The planning and the organising as I have said Peter is hopeless as are the boys. I do think that they rely on me far too much though, my own fault I suppose...

Do you really think so?

Well whilst I continue to do for them all, I even cook, freeze and label food for Peter, so that he and the boys don't go hungry. He's a grown man, he could manage to throw together something, but I think I have made them totally dependant on me, it is something about me. So I have made a difference, I have made them totally reliant on me.

To what extent do you think your role has been influenced by ideas from elsewhere?

My mum did everything for dad and for us all. I was the only daughter and I remember from being a small girl helping her in the kitchen making cakes, cleaning up that kind of thing. So think that I was being well and truly modelled and programmed to become the housewife and you know what I have been haven't I. For me that is what it is to be mum, to cook, to do for others, a very traditional role one that has been shaped over many, many years...

How does your role make a difference to your family?

Well on thinking about it now I think I have not helped them, I have made them so reliant on me. What would happen if I became ill or worse? They would have to cope wouldn't they? So my planning and organising and doing for them has made a difference to them all, but not how I would have first thought...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

There have been many over the years, in respect of Malcolm and Daniel.

Does this make a difference?

Yes, Daniel has and is a real easy going young man, he, makes no real demands it's just as well really. Malcolm has made his life hard and he never really complains about it, he just gets on with it. Simple things being able to go out to the pictures with us both. He never has, just one of us and you do question it all and I often think about Daniel and what he will be like in few years time, will he want anything to do with Malcolm?

If you were to sum up your situation in one or two sentences what would you say?

I have two children and that I am a housewife, who makes home. Life though is a mixture of great happiness... like when Malcolm achieved something and great sadness knowing that he will always need caring for and that he will never live independently or experience things that his brother has and will do.

Is this for you the essence of being a parent?

In respect of Malcolm it is because I want him to have as normal a life as possible, but he will not experience things truly like his brother, he will never aspire to wanting to have children, to drive a car these kind of things...

What effect does Malcolm's disability have on you?

I feel for Daniel, god he has a real right to feel total resentment towards Malcolm. He should be shouting from the rafters "God why don't I get any attention, Malcolm is getting it all". All I have ever wanted is him to be able to say Malcolm is a real pain, but he hasn't it is as though he has instinctively understood Malcolm's difficulties and in some way accepted it. It has not always been like that he has demonstrated his frustrations, you know, when he can't go somewhere because of his brother, he would ask "I want mum and dad to come with me" and we would have to say "you can't have both of us, just one of us because one of us has to stay home with Malcolm", that was difficult for him then.

...as a family we have become er, isolated, rather we have isolated ourselves, in some way this has been a reciprocal thing, we have, they have isolated each other. I mean my mum; I'm referring to my mum here. When Malcolm was born she was very fearful of the effects he would have on us, you know, as a family and suggested that we would never cope with him and that we would have to have him put into care... have him adopted or something like that. She did not want us to take on that kind of responsibility. Whilst she never voiced it at the time I think it was due to her own experiences of her sister who had a learning disability. From talking with her years later she experienced negative experiences when growing up with her sister and felt that keeping Malcolm was going to have terrible consequences for us as a family. She still is quite anxious and in some ways it is like she is kind of waiting for us, you know, waiting for us to break up. For mum she is quite anxious about it all, she is not at ease with Malcolm and she's never um, never really helped out in a practical sense. At times I wished that she would be there for me, but I have analysed that and thought, well, I can understand the difficulties for her, so that is why it is easier to be isolated.

Is this the same for Peter's parents?

Yes, Peter's father died some ten years ago. His mother lives close by, she is very close geographically but lives a very independent life, um, she used to get involved with practical things, like washing the dishes, keeping an eye on Malcolm. That doesn't happen now, has not for several years. More so because of her age... also as Malcolm has grown bigger and stronger it has been a gradual thing I suppose... becoming more isolated.

How would you describe your levels of stress – high or low relative to past experiences?

Thinking about Malcolm's future is causing me concerns. I try not to think about it... I keep putting it off. I have plans to go and have a look at a couple of potential future placements... but I avoid thinking about it.

Is your avoidance a coping strategy?

yeah, but it is not a very positive one, is it? But it actually works for me... I avoid things for a time, I do this as there are many daily stressors and I cannot deal with them all at once – so I have to prioritise. I put them in compartments... in pigeonholes and I say, “I’ll deal with that later”. You know there is not a rush for that one. If I wasn’t able to do this I would be totally overwhelmed and would be rendered useless... unable to do anything at all then. So I have to use avoidance in a way to keep me sane. I avoid dealing with things at a particular time because I have other things to do... other things that are on my mind. ...I do a lot of re-framing – I’m talking psychologically now, yeah, but it has helped me a great deal. To be able to positively re-frame things. I try to do it all of the time now, I do so because otherwise things would be awful for me, you know, if you think about how much there is to cope with...

It is a useful technique?

Absolutely, it works for me and helps me out things in perspective. To this I suppose I am a bit religious as well. I don’t go to church or anything like that, but I think from my background with my parents, they were very religious. I always thank God for what I have got out of life – I actually thank him for allowing me to have Malcolm, because on the whole that has been a positive experience, I mean I would not have done all the training I have done if it wasn’t for him.

So how has having Malcolm encouraged you to seek further training?

I wanted to know, to understand the psychology of it, you know, how I think and react to certain situations and attempting to grasp and understand why Malcolm does the things he does... that has driven me over the years... wanting to understand...

Have you ever experienced private thoughts about your child/children?

I can remember as if only yesterday when he was born, you know holding him in the hospital and at that time, the first two weeks of his life, I wasn’t sure I wanted to bring him home with me. It wasn’t about negative feelings, it was because I had already been through it with my eldest son and I thought to myself “I can’t do this again”. I can remember holding him and, you know, there was a bonding and I really loved this boy and I remember looking at him and saying, “this isn’t your fault, but I don’t think I ‘m going to be the best person to look after you”, but that really hurt me and I remember feeling very guilty afterwards and then thinking what right I had to say what I had said. Those two weeks I was very confused, I didn’t know whether I wanted him or not, as it was, I left him in hospital... I was advised to go home and get myself physically and emotionally well. It was really good advice as it gave me the chance to think about things and to make a decision about our future, the family’s future. I was never pushed in to making a decision, but I did decide, as you know, to bring Malcolm home... so when things are really bad with him I think back to then and say to myself I made my decision.

Family six

Jackie lives in a housing association property. She is currently unemployed but studying at a local college. She has three children; Katrin aged sixteen, Martin aged

ten and Louis aged four. Martin has an unknown aetiology but has been recently assessed and is being treated for Attention Deficit Hyperactivity Disorder (ADHD). Martin attends a special needs school as a day pupil; he can be extremely difficult at home, often engaging in aggressive and violent acts. This is compounded further by his limited requirement for sleep.

Jackie's story

Can you describe your role as a parent as you see it?

I do it all; there is no one else to help out. I look after all of my children from seeing to all of their needs, making sure that they are clean, well fed and happy. It has been like this for several years now so I am well used to it.

For you is it just about making sure that they are fed, clean and happy?

Being a parent is more than that but that is what you see on a day-to-day basis. If any one of them was in trouble no matter what it was I would be there to protect them as best I could. Martin more so, he needs much more support than the other two; he is always getting into scrapes with the neighbours. I more often than not will have a row with one of them over something he has done, even though I know Martin will have instigated it I will protect him and then when I get him home I will give him what for...

What is it about this role that makes you say that?

...it is just the way it is, I am on my own and it is my job to do it as best as I can...

If your role is made up of certain elements how essential are these elements?

As I have said I am a single parent, I have no support from their father; he sees Martin some weekends. My mother is too old to help so I am on my own trying my best to see to their needs. I do everything in the house that is what life is like for me. So if I did not do the things that I do the kids would go hungry, would not have clean clothes, so what I do is pretty essential otherwise I would have the social knocking on my door.

Would you still be a parent if one or more of these elements were missing?

Being a parent is more than just making sure that your children are fed and have clean clothing that sounds really sterile. It is the meaning behind it; that you want to do it... All of them still need me to do for them I don't think it would be fair on Katrin if I asked her to do more in the house. You could take the physical side of caring away and I would still be their mother, I would still look out for them and want them to have a happy life, with or without me.

What is it about your role that makes it matter?

Well if I wasn't here to look after them who would? I think being a single parent puts a very different perspective on things and as such everything I do is important to me and I hope my children. When the children are happy I am very happy...

To what extent do you think your role has been influenced by ideas from elsewhere?

I always thought I would have three children and be in a loving relationship, one out of two isn't so bad [laugh]. That is how I expected it to be, to be the housewife the one who sees to the needs of my children and my husband, traditional I know, but that is how I expected my life to pan out.

What has influenced these expectations?

My own upbringing to some extent and my friends. My parents were exceptionally happy and did an awful lot of things together as a couple, some of my friends likewise.

So you have always seen yourself as the housewife and nothing else?

Well yes, but only when the children are growing up, once they leave home then it will be my time to do things I want to...

Like going to college?

Precisely, I see it as being the right time to start looking towards the future...

How does your role make a difference to your family?

As a single parent my role has quite a difference to my ex. He is not here, he has very little to do with the children. Although Martin does see him on the odd weekend, it doesn't really affect him at all. In fact his role as father, or should I say lack of role has a big impact on me. When Martin does see his father he will come home and say, "I don't have to do this, that or the other, dad says so". That then creates another row, but to be fair Martin doesn't really understand, that is what makes it hard, you would think his dad would know better... so I have to put up with another row, another temper and his running off, because I have to put my foot down that little bit harder to reassert myself over him.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

With Martin life can be complicated what with his tempers and his sleep problems. It is very common for me to be up half the night with him, it is much better than it was, but at three and four in the morning when he is kicking a ball about or trying to get outside and you have not had any proper sleep you think 'what the hell I have done to deserve this'

If you were to sum up your situation in one or two sentences what would you say?

That life as a single parent is not an easy one as you don't have the physical or emotional support from your partner, in fact it can cause more difficulties as the kids can and do play you against each other. Life is much more stressful in many ways with money worries being high on my list...

Is this for you the essence of being a parent?

It captures what my life with the children is like, I have also said before that being a parent is made up of lots of things from giving the actual care to the emotional tie that you have with your children.

What effect does Martin's disability have on you?

Martin is not an easy child he thinks he knows best and will argue with you and if he can't get his own way he will be quite nasty to me, Katrin and Louis. When he runs out of the house I am at my wits end, I have had to call the police on several occasions. He causes me an awful lot of worry. I have already mentioned his sleeping problems they are much better than they were but he still has his moments when he wakes around five in the morning. He just expects the whole household to be up. So I find myself getting up with him and trying to keep him quiet, I just get so tired and then find it hard to concentrate when I have to go to college. But as I have said things have improved over the past year...

How would you describe your levels of stress – high or low relative to past experiences?

Oh, definitely, they are pretty high, not always I would like to add.

Is there anything in particular that causes these stressors?

Fighting between Martin and me and fighting between Martin and Katrin. Martin even for a small boy has a lot of force behind him; he has a lot of venom and really packs a punch... so he really hurts his sister when he hits her and that causes a lot of stress for me...

So Martin's behavioural difficulties causes you higher levels of stress?

Yes, if he is in one of those moods, when he is just not listening to you, no matter what you do, or what you might say he is still not having any of it... that's when the stress levels hit the roof, no go through the roof...

Is this constant throughout the day?

No, I find myself at about half past three I'm looking at the clock and thinking he is going to be home in quarter of an hour or so and I start to think about what is he going to be like when he gets home, what if he is wound up. If he went to school in the morning wound up, what kind of day will he have had and is he going to bring his bad mood home with him... Is he going to carry on where he left it in the morning?

So you are physically watching the clock?

Yes, and as each minute passes I find myself getting more and more uptight...

What do you mean by this?

My chest gets tighter, I can even feel my heart beating, up to the point when you hear the taxi driver peep his horn, hear the door slam and the bang of the door as he arrives home, that is when I get most frightened... how will he be...and then he walks in says "Hi Mum, what's for tea... then I know he will be okay tonight, at least for a while...

And how do you cope with this level of stress?

Drinking lots of coffee and having a fag [laugh], I have been doing this for nine years now... so that helps...

How?

It is what you get used to, you go through a period of anticipation, get yourself wound up in the process and as it is only me, I have to deal with whatever he throws at me, so

with that, a good cup of strong coffee and a few fags that's how I cope and manage day after day.

Have you ever experienced private thoughts about your child/children?

I have never talked to anyone about some of my thoughts... When Martin has been really naughty, when he has not come home at 8.00pm as agreed and I have had to go out looking for him, or when he has hit me when he has had one on him. I start to think how horrid he is and how much I don't like him...

Are these feelings constant for you?

No, not at all they all relate to situations where he has done something bad, either to me or to his brother or sister. Then my feelings do intensify sometimes to the point where I hate him and dread him coming home from school... it is as though you are guessing what state of mind he will be in, has he had a good day or has he had a bad day, on a bad day he brings it right home and takes it out on us... so I dread home times, it's the not knowing.

What do you do with these thoughts?

Like I said I have not told anyone about them before now. I think afterwards that I must be a really bad parent for having these thoughts, but then I think that maybe it is normal to have them, as it is a way of dealing with a difficult situation... it is far better than hitting out at him.

So having these thoughts, for you, is a safety valve?

Yes, when you think it through it, and I will think even more about it after you have gone... but having these thoughts act as a filter, one that can prevent you from losing it. Maybe those parents who harm their children don't have these filters, or maybe that they have just become totally overwhelmed by their situation.

Family seven

Doug and Mildred live in their own house. Doug is a businessperson and is often away from home for weeks at a time. Mildred is a housewife. They have two children; Carry aged twenty-one and Dean aged seventeen. Dean has a significant learning disability and requires total assistance throughout the day and some assistance during the night time as he experiences sleep disturbances. Dean attends a special needs school as a day pupil.

Doug's story

Can you describe your role as a parent as you see it?

Being there, to support and to listen. I suppose being a brick, the foundation stone of this family.

What is it about this role that makes you say that?

That's how our roles have been defined over the years, Mildred has done this and I have done that, it has never been by formalised agreement, it has just simply evolved over the years... I suppose things may be different if I wasn't going out to work. Let's say Mildred was the bigger earner then I would probably be the one to stay at home and do the bulk of the caring, the planning, the organising, but it isn't like that so my role has been defined in some ways by who earns the most...

If your role is made up of certain elements how essential are these elements?

I spend more time away from the home that I am here due to my work commitments my role is solely as provider. I do occasionally sit and play with him, well listen to his music with him. Bringing in a decent wage is the essential part of what I do, it gives us a lifestyle that we all enjoy.

Would you still be a parent if one or more of these elements were missing?

Well let's say if I didn't earn the amount I do... I am a grafter so I would seek work, always have done, never been out of work. Our life would be different but as a family we would still be together, I would still be Dean and Carry's dad and I would still care for them and want the best for them, it's just that things are different I go out there to earn for my family...

What is it about your role that makes it matter?

As I am away from home a lot my main contribution is the financial support that I provide, the stability and bedrock for Mildred and the children. Being able to earn as I do allows Mildred and the kids to live a life without financial worries. Mildred is able to buy in additional help, as she needs it, so this helps enormously with Dean's care. It gives her a chance to have a break from it all. Likewise when I am home we can, when we want, arrange for someone to sit in and watch Dean when we go out, I know of other families who rely on services [referring to social services] who can not always get someone so they never get the chance to do normal things...

To what extent do you think your role has been influenced by ideas from elsewhere?

...my father and his father before him went to work and provided some level of security for their families. I see this as my role whether this has been indoctrinated through my own experiences as a child who knows, but that is how I see it.

From what you are saying you have, as a child, witnessed your father and your grandfather going out to work and providing for their respective families, do you think this has shaped your role?

When you put it like that yes [laugh], it is all I have known for many a year so it has bound to have an effect on me, in some ways a bit like a silent driver...

How does your role make a difference to your family?

By giving them a lifestyle one that they don't have to ask for anything...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

...in the early days when things were tight for us as a family, Carry was born everything was fine, then along came Dean we new immediately when he was born that things weren't right. As a family we really struggled with it for years I secretly prayed that he would die he was such an ill baby, but he pulled through... to some extent we just got on with it. My business grew and that started to take me away on trips and I must say that they really helped me, but there were times when I was alone in a hotel room far away from home it has such an impact on you, you know my son I will never be able to do the things I hoped for like taking him sailing, trekking across the mountains, but that is how it is, we can't change it...

If you were to sum up your situation in one or two sentences what would you say?

That my situation, it is one of work, work and more work that takes me away from the family home for periods of time... but I am very aware that Mildred is home looking after Dean, so there are elements of feeling guilty for not being there... I just get on with it... don't really think about it. I suppose I am lucky in that I work away, so I don't have to see to his needs. My wife does that, it has and I suppose will always be her role.

Is this for you the essence of being a parent?

No not really all it does it describe my life and how that affects Mildred and Dean, Carry is not affected, she is in University and is busily getting on with her own life. We will always be parents to Dean and Carry for as long as we are here, I see it as my job to make sure that they are well catered for now that they are adults.

What effect does Dean's disability have on you?

On a personal, er, physical level not a lot really, as I have said I am not home that much so I don't get too much involved in his daily care. But I do miss out on not being able to do the things that I would have like to have done, like I said before going trekking, that is when it affects me, but can't change the way it is...

How would you describe your levels of stress – high or low relative to past experiences?

As I have said I am lucky because I can get away go on my trips. My stress levels have nothing to do with Dean because all I do is sit and talk with him, listen to his music with him, have a cuddle, Mildred sees to the other bits. I do get stressed but that is about my work and something totally different.

Have you ever experienced private thoughts about your child/children?

I sometimes wonder what life would be like without Dean. We would be off the two of us, to somewhere warm, that's what we should be doing but we can't Mildred won't leave Dean for long periods, she still mothers him...

What would life be like without Dean?

Our lives would be totally different, Mildred would come on my trips rather than staying here, life would be so much better for the both of us...

Mildred's story

Can you describe your role as a parent as you see it?

With Dean it is more about keeping him fed, watered and dry. He doesn't do an awful lot for himself... he can just about feed himself, well to a fashion. So my role, as a parent... um, making sure that his daily needs are met, you know, the usual things, keeping him warm, fed, watered, with some entertainment thrown in to break his day. He enjoys listening to his music, so he spends most of his time lying down and listening to his Walkman. I have to check that the batteries are charged and that the tapes are changed, otherwise he would just lie there and do nothing. ...On a superficial line being a parent to Dean is about seeing to his everyday needs, making sure that he is clean, dressed, fed and watered and has things to occupy him throughout the day. If you go a bit deeper than that, below that superficial surface being a parent to Dean is no different to being a parent to his Carry. For me, as a parent I am there to provide a roof, the comforts of a home... materialistic things I suppose, but important ones nonetheless. I also offer support and guidance, for Dean this is different to his sister.

Such as?

Well support for Dean comes in the shape of helping him to do things, to get from A to B, to getting dressed or undressed at night...that's the guidance I suppose. The support comes in the form of fighting his corner, getting the best services for him, making sure that his needs are going to be met when we are not here to over see this...

What is it about this role that makes you say that?

Well if Dean didn't have his difficulties I suppose my role would be very different now that he has grown up. Dean would not need the level of help he does would he? But he does so I am there as is Doug to see to his needs, but as Doug works from home I am here most of the time, it is how it is...

If your role is made up of certain elements how essential are these elements?

I do most things for Dean, he can't see to his own needs. I can and do pay for private care; I suppose I am privileged in that way. But even then I am overseeing his care from a distance it has to be right, of a very high standard... that aspect of my role is very important, essential as you say...

Would you still be a parent if one or more of these elements were missing?

I will always do my best for both of my children; they are my flesh and blood. Carry is fine she is totally independent now. Dean though still needs me on a daily basis from the moment I get him up in the morning to when he goes to bed. If he did not need me in this way I would still want him to be happy and would do my best to support him...

Support?

I would support him financially; emotionally whatever he needed that is what being a parent is about, for me at least.

What is it about your role that makes it matter?

Having your children close by, I can always remember my mother saying that when we visit her she hates it when we have to leave, even though we are in our forties she would say 'Mildred I love you'. I always thought she was being daft, but I can now see where she is coming from...

To what extent do you think your role has been influenced by ideas from elsewhere?

As I have said that is my role, I am mum, my mum was mum to me and my gran before that and so on. That is what I experienced as a child... being brought up in a very caring and warm house, where we enjoyed good home cooked food, sitting at the table, good family based things, so that is what I do, that is what is expected from me... so from my own upbringing I expect from myself to provide similar kinds of experiences for my children...

How does your role make a difference to your family?

For Doug he knows that the house and the children are going to be looked after when he is away from home. He works hard and it is nice when he comes home to have the house clean and tidy, so I think Doug appreciates my efforts as I appreciate his.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

I have always tried my best for Dean, making sure that he gets the best services available. I have had many an argument with professionals from all walks of life fighting for Dean. I have won some and lost some.

Can you give an example?

I am fighting to get the best local day placement for him, I don't want him to go into a residential college, that would be such a joke I just want him to be well cared for

locally. There is a local placement that is able to provide Dean with what he needs during the daytime; it's like school but for adults. I know he will be happy there. But social services want him to go to a college, come on lets get real here what will Dean get out of going to college? Absolutely nothing he will be one of many and he will be forgotten about, plonk him down and that's it for the day. I can tell you that is not going to happen it is going to be another bloody fight and no doubt they will go on about the funding, but if we have to we will fund it for him, I can tell you Chris he will be going there...

If you were to sum up your situation in one or two sentences what would you say?

Wanting to be normal as a family but knowing that being normal is not going to be easily achieved... It's just like having a great big baby. He still in nappies, I still have to feed him. It's just as if he is still one year old... but in a young man's body. ...that life is hard and cruel but you have to just pick yourself up from the knocks and just get on with it.

Is this for you the essence of being a parent?

That is what life is like with Dean. As his parent I still want the best for him, I would hate to see him unhappy that is why I fight tooth and nail for him.

Is that the same for Carry?

In many respects yes, but she can fight her own corner now, she is an adult, but I am still her mother and I will always be there when she needs me.

What effect does Dean's disability have on you?

I get very tired with the day-to-day caring, nothing changes, nothing alters from one day to the next, that is how it is with Dean. I do get fed up with it but what else could I do, put him into care?

How would you describe your levels of stress – high or low relative to past experiences?

They are very high at the moment; I really need a proper break from looking after Dean. A friend of mine brought it home to me when we were talking about Dean's future. He is supposed to leave school in two years time. My friend pointed it out that if a day placement cannot be found for him that I will be his full time carer, the thought of that and with me having to look after my mother, who is elderly, really freaked me... it has made me think very carefully about the future and about my needs... it has caused me an awful lot of stress. My mother can't come and live with us, because she is frailer and as this gets worse it will end up my responsibility. That sounds selfish, but I just cannot do it... look after two very dependent people.

Have you ever experienced private thoughts about your child/children?

Oh, this is a tricky one, if I am to be brutally honest then there are times when I am with Dean and let's say Doug is on one of his trips to a hot climate well I feel it then...

What do you feel?

Mainly resentfulness at Dean, it is because of him that I can't be with Doug. If Dean was normal than at our time of life we would be doing things together, but as it is Dean's level of disability means that he needs full care and that is down to me. So the bottom line is that I can't do the things we should now be doing and I resent him for that.

What do you think about these thoughts?

I don't like myself for having them, but when you think about it I am caught up in a situation that nobody really wants to be in. There is no way out of it so I have my thoughts; I have my rants and just get on with it...

Family eight

Terry and Katie live in their own house. Terry is employed with a national company and Katie is a housewife. They have two children; Gwenda aged fourteen and Roy aged five. Gwenda has a significant learning disability as a result of brain trauma; she requires high levels of assistance to meet her daily living activities. Gwenda attends a special needs school as a day pupil.

Terry's story

Can you describe your role as a parent as you see it?

On the whole I see myself as the provider; this has many facets though. I provide the financial security for the family, the means for us to live as we do... you know, being able to go on holiday that kind of thing. I also provide the warmth, the love and the laughter in this house. The house is usually full of love and warmth it is so important to me.

Do you help out with Gwenda's care?

I help out every day, I certainly don't do as much as Kate does but I will dress her, give her a bath, feed her and see to her when she has a fit.

What is it about this role that makes you say that?

It is important to me that we live a reasonable lifestyle and enjoy life to the full. It is difficult with Gwenda as she needs so much help everyday. It can get you down but I firmly believe that by spreading happiness throughout the house helps us cope.

If your role is made up of certain elements how essential are these elements?

Providing a good income and a good lifestyle I think is essential to this family and it certainly contributes to how we cope as a family. I help out with Roy and Gwenda

looking after them, seeing to their needs, even doing some of the housework of a weekend that helps Kate and gives her a bit of a break.

Would you still be a parent if one or more of these elements were missing?

Being able to earn a decent wage and engaging in some childcare and housework does not mean you are a parent. We could get a cleaner for example, or even a nanny. It goes deeper than that...

Meaning?

Erm, a cleaner or a nanny would not have the same emotional ties as I do. If Gwenda or Roy hurt themselves I, we are there to make sure that they are safe again and not in a danger of further harm, we are there to comfort, it would be different for another person who was just caring for a child, they would be able to comfort but the emotional pain of seeing your own child in distress is so very different.

What is it about your role that makes it matter?

Being dad, being able to go out with Gwenda and Roy just to mess around on the lawn and kick a ball around, have a game of catch that's what makes it matter for me seeing them happy.

To what extent do you think your role has been influenced by ideas from elsewhere?

As I have said I see my role to be the one who provides for the family, I know a bit old fashioned but that is how it is. I think it is also about making sure that everyone is happy and feels important.

What makes you say this?

As a child life was so much fun, I grew up on a big farm, we did such great things as kids, playing in the hay barn, messing about by the stream. Even though it was a big farm mum and dad had so much time for us all, we were a really happy family; that is all I want in life to have a happy stress free time.

Your own experiences of childhood have shaped your perception of what it is to be a parent?

I suppose they have. I remember Kate and I talking and planning having children, things like what would you do if you had a son or a daughter. I had very clear ideas about wanting to play football, take him to stay and help on the farm, Roy can do that if he wants, but Gwenda well she isn't able to because she needs looking after almost constantly throughout the day. So yes it has been a big influence on how I view parenting.

How does your role make a difference to your family?

I think by just being together, as a couple, that makes a huge difference... the difference between us coping or not coping, it is as simple as that...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

There is one when we were out with Gwenda and Roy, it was really embarrassing Chris. We were in a café having our lunch. Gwenda isn't the best of eaters so had got bored with her food and decided to throw her doll, not at us but at another person, a woman, it hit her full on her nose which bled immediately. Kate asked me to deal with the lady whilst she and the kids made a sharp exit. It could have gone so badly but the lady was very understanding and accepted my apologies. I was so angry afterwards I could not understand why Gwenda had done what she had and said to Kate that I will never go with Gwenda to a café or other similar place in future, it makes you take stock of your situation particularly that going out as a family is getting more limited.

Is this because of the potential for difficult situations to occur?

Yes, but when we are out I am very conscious of other people staring at Gwenda and when she starts to burp and make her noises that's bad enough, but things like hurting other people I can't do that...

If you were to sum up your situation in one or two sentences what would you say?

Sheer bloody hard work, with little or no time to do normal family orientated things, that seems really negative and is aimed at Gwenda, but that is the reality of it.

Is this for you the essence of being a parent?

It is the essence of living with Gwenda and how her disability affects the whole family but it doesn't capture being a parent, I think though that this has already been said [laugh].

What effect does Gwenda's disability have on you?

I love having her around most times; she is rather quite comical in her own way. I feel very sorry for her in that she is never going to have the things that ordinary girls will have and that does make me sad, more for her though. I sometimes get very frustrated with our situation, the not being able to go places that we would otherwise go to...

Is this because of Gwenda's disability or the way she behaves?

Both really, the way she looks and the way other people look at you, that really makes me cringe...

How would you describe your levels of stress – high or low relative to past experiences?

They are very fluid up one minute and down the next it depends really on what is happening in the house, how Kate is coping with Gwenda and how Kate and I are getting on with each other, as you know Chris things can get a bit heated with one thing and another.

When things are heated how do you cope?

How do I cope, erm, well I don't do conflict that well, that gets Kate really mad at me as I tend to just sit there and stare that really gets her going. So I end up going to the shed [referring to office] and sitting there, do some work or just generally mess about

in there for a while. That gives Kate a chance to calm down and for me to think about what she has been going on about.

Do you go to the 'shed' when things are difficult with Gwenda and Roy?

On most occasions I do, usually when Gwenda has done something and Kate is going off on one. I just need to get out so off I go to the shed.

Do you use any other form of coping strategies?

Work is my only way of distressing, I will have the odd pint but that is always in the house, that helps but it doesn't take me away from the what is causing the stress in the first place. We do go out as a family sometime to café's and to our local pub on a Sunday but that can cause more stress...

Have you ever experienced private thoughts about your child/children?

To be totally honest I do think about what life would be like without Gwenda, or what life would be like if Gwenda did not have her problems...

What would life be like?

It would be so different Gwenda would be a normal girl, doing normal things with us and her friends. Roy would have a proper sister someone to look up to, he really struggles having to put up with her tempers and silly behaviour, and it really affects him.

When you think like this do you discuss it with Kate?

I have never discussed this with anyone what would she think of me?

But you are discussing it with me?

I know but it feels okay to do so, it feels safe to do so...

So do you have any other thoughts?

Not really I do get preoccupied with what life could have been like but I can't change the way things are I, we will just have to get on with it...

Kate's story

Can you describe your role as a parent as you see it?

I tend to do the doing, you know, I always get her up in the morning, bring her down stairs and take her to the toilet to change her nappy and clean her up. We then come into the front room and I get her dressed. She gives no help whatsoever, so it is all done for her. I sit her down put on her shoes and callipers. I get her breakfast and we [referring to husband] make up her morning and school medication before I feed her... So getting back to the question [laugh] my role as parent to Gwenda, is one of carer, overseeing and providing for her physical and emotional needs. Fighting with services to get what is needed for her, you know, simple things like enough nappies for the day.

What is it about this role that makes you say that?

It is just the way it is. If Gwenda did not have her disability then we would not have to do as much as we do. Roy at five years of age can do more than Gwenda, he gets himself ready for school, he just needs some supervision and reminding to do this and the other but he has already overtaken Gwenda in all areas...

If your role is made up of certain elements how essential are these elements?

I don't think it is so much to do with elements they are just part of the caring role, as I have said if Gwenda was without her disability we would not be providing the same level of physical care. We would still be supporting Gwenda you know on an emotional level, being there for her, giving her the encouragement to do her schoolwork, to join clubs and do girly things.

So from what you are saying if you did not have to provide the physical care and also having to plan and organise Gwenda's day your role as a parent would not alter that much?

Very much so, yes.

Would you still be a parent if one or more of these elements were missing?

Yes I think so it is not just about the amount of time and effort it takes in making sure that she is up, dressed, washed and fed before the taxi arrives. We wouldn't have to do this for her now, it is all about her disability...

What is it about your role that makes it matter?

Being here for Terry, Gwenda and Roy, even though for most of the time I am at my wits end. There are times Chris when things are really happy, Terry tries his best to inject humour and during those times when I sit back and watch them all on the floor I do think how wonderful it is to have such a lovely family...

To what extent do you think your role has been influenced by ideas from elsewhere?

I think parenting is a perception isn't it what you think you should be like as a parent? It is what has influenced you in your thoughts and beliefs.

What are your thoughts and beliefs and where have these come from?

I think a parent should be there for their children and to provide as best they can for them, and that your children should always come first. These beliefs are in some ways hand me downs from my own childhood experiences, my own parents and their parents, going way back. I think also that what you read and see can also have an influence...

For example?

Well when I was a child we went out playing all day, not a care in the world. I wouldn't let Gwenda or Roy out of my sight it is not safe anymore. But you get some parents who just let their children wander off and some never return.

How does your role make a difference to your family?

I think we are a team, Terry and I, it does make a difference... I know I have an awful temper....and that I make Terry's life more than difficult, but that is the way I am. I still love him as I do Gwenda and Roy that is the difference.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

I'm quite fearful of Gwenda's impending puberty. Terry says that he will not be able to see to her private care needs when she starts her periods, which is fair enough... but it is going to be left to me, who is going to give me some extra bloody help? Weekends with Gwenda are horrible... it is a long day with her. When she is at school she has someone with her to help her do things, whereas I want to things and Terry wants to do things of a weekend and Gwenda wants one or both of us to do things with her. So it is always really stressful here at weekends... if Gwenda did not have her disability she is of an age where she would be off and out with her friends or wanting to go girly things with me... so we, I, would be able to my things... it is not a lot to ask, but something we don't seem able to have... We feel very sad about it, Gwenda isn't sad about the way she is, because she doesn't know the way she is, as far as we know. There was one time when she was, you know, seeing other children playing, doing things that she wasn't able to do, but she just got on with whatever she was doing... it didn't seem to bother her. She drives us to distraction though; it is always a battle doing things with her.

If you were to sum up your situation in one or two sentences what would you say?

Wanting all of your children to develop in to fine young people who lead their owns lives, but knowing that one of them will never manage that and that you will end up providing care until you are no longer able to, because it is your duty as a parent to do so...

Is this for you the essence of being a parent?

For me I think it is, that's what it is like with living with Gwenda...

What effect does Gwenda's disability have on you?

She has a significant effect on me and I think the family as a whole. I feel trapped, as I have to think about her needs all the time, there is no let off from it all, it is constant. If I could change anything in this world it would be Gwenda's disability it would be so good to have a daughter...

You have a daughter?

Yes, that is correct, but I mean a daughter that does not have learning and physical disabilities, a daughter who I can do normal things with, things that I expected to be able to do...

How would you describe your levels of stress – high or low relative to past experiences?

It has made me want to get away – just anywhere – I can't do this long term [referring to caring]. I often find myself thinking about what it would be like without her. I would be totally stress free... I think. Well, I mean my stress levels are so high at the moment; I cannot seem to shake this feeling. I am so tired; I just want a long break from caring for her. I am totally burnt out and have very little to give at the moment... If social services came to my door and said that they had a carer for her I would grab

their hand off and let her go... I always said that she would go nowhere else but home. It is just so difficult now, what with her behaviour and having to see to her every need, you just get worn down to the point that you can't carry on anymore...

What do you do to give yourself you time?

I just don't seem to be able to get any 'me' time. I keep saying when she is in school I will go for a walk, join a gym... I know these things will help me, be a chance to meet other people, who knows... but I don't have the energy to do that, when she goes to school I just clean up, make a cuppa and sit and watch telly, until she comes home from school and then it all starts again... the never ending cycle, here we go again, this my difficulty I just don't seem to have the energy any more...

Have you ever experienced private thoughts about your child/children?

There are times when I just look at her and think to myself, "look at her, look at the state of her, she is so deformed", I then feel pity for her and then a sense of shame for thinking such thoughts, but that is how Gwenda is, she can't help it, it isn't her fault she is the way she is, it isn't her fault they made mistakes during my labour.

How often do you have these thoughts?

Not as often as I used to, they would be nearly every day, but as Gwenda has grown up, so have I, I have adapted to her disability, but there are times when I feel really low... it is then that I just look at her and pity her...

Family nine

Mike and Jenni live in their own property. Mike is employed with the local authority and Jenni has a part time job. They have two children, Deborah (Deb's) aged sixteen and Jade aged thirteen. Deborah has a formal diagnosis of Tuberous Sclerosis with associated epilepsy and significant learning disability. Deborah requires high levels of supervision and help throughout the day and frequent assistance at night due to poor sleep settling routines. Deborah can be highly complex behaviourally engaging in self-harming behaviours i.e. biting herself, hitting out at others and elements of property damage. Deborah attends a special needs school and is in receipt of two nights per week residential provision.

Mike's story

Can you describe your role as a parent as you see it?

Me hunter, me bring food [laugh]... seriously though I am essentially the provider, I go out to work to provide the income that allows us to live here [in this house] and to enjoy an annual holiday. I also have a secondary role as carer for Debs. Although Debs is a teenager I still provide some care for her. If you decide to have children, then you should behave in a responsible way and to be there to guide and teach them to behave in a way that is acceptable, and if they can't... or won't then they should be made accountable and should accept the consequences of their actions. For me that is what life is all about and as such this is one of my roles as father to my two children.

How would you describe this care?

If there is a clash between us... I mean Jenni and I tend to share the load so to speak. If Jenni has to go out then I will take charge of Deb's care. This generally involves making sure that she is supervised and kept safe. I will prepare her meals and ensure that she is well fed. If I have to I will see to her personal care needs... yeah, I still take her to bed and help her wash her face and her hands, brush her teeth and comb her hair. The more personal stuff er, like, you know, bathing, changing her sanitary pads I will shy away from now, that's more for Deborah's sake as she is a woman. ...it gets quite upsetting sometimes you know, if Jade is on a bit of a downer and she is talking about how she is feeling and what Deborah has been doing to her, you know, pulling her hair or scratching her, I'll talk to her – I'll even open up and tell her about how I'm feeling and well, we, um, have a cry together.

What is it about this role that makes you say that?

It is how it has evolved over the years; we have adjusted to Deborah's needs and how we meet them as a couple.

If your role is made up of certain elements how essential are these elements?

Being able to go to work and earn a living is important for me, my sanity and for Jenni and the girls. Having to help Deborah with her daily needs and to deal with her tantrums is a part of every day life, it's what I do, it is what Jenni does. This is who we are.

Would you still be a parent if one or more of these elements were missing?

Deborah would not need any help now if she was okay, you know not having her TS. We would be dealing with a different situation, but we would still be Deborah's parents, I would still be her dad and would, like I am with Jade be very mindful of the lads sniffing around [laugh]. So I would still be caring for her but in a different way.

What is it about your role that makes it matter?

There are things that I used to do on a regular basis with Deborah ... like seeing to her personal care needs, you know, washing her, cleaning her and the house after she had shit all over the place. Seeing to her now, is a bit more difficult as she is a young woman, it is not right for her that her dad does those kind of things... even though she

probably couldn't give a damn if I or the next door neighbour did it for her, but as I have said it is not right, got to respect that she is a young woman now... so I used to do these things and now it is left to Jenni to do, so that becomes a bit of a strain for her... Deborah is a big girl for her age; she is carrying too much weight so it is harder for Jenni. So while there has been a change in who does what I have had to do things differently, I still want to help out with Deborah's care... that is important to me, to be visible, to help out so I sat down with Jenni and we discussed what else I could do to make things more even. Jenni wasn't having any of it, as she said, "you have to go out to work", but for me that is not fair, Jenni otherwise would be completely lumbered with all aspects of Deborah's care. So for me that is what matters, being there and being observant to what is happening is important.

What was the outcome of these discussions?

They lasted for sometime, what I mean here is that we did not agree things straight away, it went on for some time, Jenni just kept dismissing it, but eventually, as if by mutual evolvement I started to take more of an active role in preparing things for Deborah...

Like?

Running the bath, getting her clothes ready, clean towels, that kind of thing. So it is a change from actual doing to organising and preparing...

To what extent do you think your role has been influenced by ideas from elsewhere?

I think how you parent very much depends on how you were raised as a child. A friend of mine, going way back now had such a bad time with his dad fighting and all that. He said that if he ever has children he would never raise a hand to them. When I met him a few years ago he was married and had three children he had such a loving relationship with them.

So your experiences can determine or let's say, help you make choices about how you are going to behave?

Yes, I think so.

What about being a parent, for you?

My role has been influenced by my own upbringing, not like my mate, I had a good childhood so I didn't or don't want to change anything, well I do lose it with Deborah, but I think anyone would when you have the constant pressure each day...

How does your role make a difference to your family?

Like I have said before without us both being in it together, come what may, no matter what is thrown at us, if we are there for each other, as a family then we can get through it. So me being able to take the occasional knocks from Deborah, to help her get over her tantrums is really important to Jenni and Jade, indeed to Jenni's parents when they visit us, they are not getting any younger [laugh]. Being able to manage Deborah helps us all to have a good life, don't get me wrong Chris, it can be bloody tough when she is in full flow, but we do things as a family, so it really helps...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

Far too many incidents to even remember...

Any most recent events, situations?

She is such a bad sleeper; it is always a real effort every night to get her to go to bed. Even though we have very strict routines it must be about 10 o'clock before we finally get her into her bed. It sometimes is real hard particularly trying to keep cool with her. What we see is other people having a normal life, ours is on hold to some extent, that is... except for when Deborah is in respite for the weekend. The three of us then can go out. We can go for a meal in a restaurant, er, we can go to the cinema and we will not be wondering whether Deborah has peed on the seat or if she is suddenly going to start screaming or jump up and dance in the middle of a packed cinema when it is completely inappropriate. I, we used to get really embarrassed by the things she did. Jade when she got to an age... I think around 7 or 8 years old started to refuse to come out with us if Deborah was coming. She was, and still is to some extent very fearful of what Deborah can get up to when out of the house. I still get very uneasy when taking her out, because she can be extremely unpredictable, although I don't get embarrassed like I used to and she isn't aware of all the people staring at her I feel for her, because of the stares, the tut tutting and sometimes you can here people saying nasty things, you know erm, "she should be put in a home" things like that. Jade when out with her sister still gets extremely embarrassed, as I have said, she mainly refuses to come out with Deborah, but there are times when she has to come out with us. She is only thirteen, so yeah, you know it is hard for her to see her sister behaving like that and to hear other people making nasty comments. J often says that it is not fair and that other people have it easy. I suppose she is at an age where she is starting to question what it is all about.

If you were to sum up your situation in one or two sentences what would you say?

Being there for Deborah, to support her, to assist her to develop and enable her to live an independent life outside of this family home...

Is this for you the essence of being a parent?

In a nutshell yes that is what it is like to be a parent to a young person like Deborah.

Would this be the same for Jade?

To support and assist, yes much the same...

What effect does Deborah's disability have on you?

On a physical level she has quite an effect, the constant tussles with her, I wouldn't have that normally, not with your daughter.

Meaning?

Well I don't do the same with Jade, I don't have to physically fight with her do I? ...so you would expect the same for Deborah. ...emotionally it is really hard you get tired of it all, you can never see an end to it, if you know what I mean. Each day becomes one it all merges...

How would you describe your levels of stress – high or low relative to past experiences?

Stress is a constant for me, but on a scale that changes from day to day. I never used to be like that, I used to be so laid back, you know, not a care in the world, but not now.

What do you attribute this change to?

Life in general, but this has been compounded by Deborah and how she behaves. On a good day, that is when Deborah is not challenging us, me, er, when she is settled and well-behaved my stress levels are generally low, but when Deborah is at her worst, you know, screeching, pinching, taking her clothes off, those kinds of things, and it is really in your face then my stress levels are really high. I find myself easily losing it, beginning to shout at her. This then causes a row with Jenni and then further stress.

How do you manage your stress levels?

Well, as I have said I shout an awful lot, that helps in the short term, but it also causes more bad feeling and additional stress. My biggest release is going to play golf, I do that every week, just being away from Deborah and the rest of the family for a few hours gives me the chance to recharge, think about things and the like...

What kind of things do you think about?

Some days I try to think what our life would be like without Deborah, you know, not having to plan everything that you do, just so that Deborah has someone to look after her... what life would be like for us not having to plan things

But doesn't life in general have an element of planning?

Yes it does I suppose but I'm talking of simple things in life, say popping to the shop for a newspaper, a loaf of bread or a carton of milk for drink to make something for dinner. If you are alone with Deborah it's just not a case of 'oh, Deborah put your shoes on we are going to the shop'. It involves an awful lot of effort getting her ready presentable, then it is the walk or should I say the refusal to walk or the tantrum in the shop. You can't leave her home alone as you don't know what you would be coming back home to, plus she would harm herself. So something so simple is a major effort. But we can't change anything, we have just got to get on with it... otherwise you would just go mad.

Have you ever experienced private thoughts about your child/children?

We were experiencing a difficult period with Deborah's behaviour... she was smearing pooh all over the place, not sleeping at night and being aggressive towards us all. It just didn't go on for days, it went on for weeks on end, I got to such a low point that I contemplated the ultimate solution [referring to taking his daughters life, this is made evident in subsequent comments], which wasn't a solution at all because if I had done what I thought of, the repercussions are vast, but in those darkest moments I really would have done it. I never actually planned it as such, but I thought about what might happen if I did do it, but I never really saw the big picture until one day when I discussed it with my wife. Her response was "what about us" I thought that they would be all right, but she said "you would be in prison, what would we do without you?" You know in your darkest hour you do not think things through, your thought patterns are not clear or rational, you are responding to the event, to the situation. An irrational thought such as taking your child's life at the time seems quite sane at the time. It is not until you have questioned your thoughts and identified the

flaws in your thinking, particularly how it affects those that you love, those you are supposedly helping. That you realise just how mad it is.

...dealing with these thoughts hasn't been easy; I don't think I have ever dealt with them to be honest. They have just faded away in to the ether. Being able to be honest and discuss them with my wife I suppose has helped as I have realised how mad my thinking was then. I continue to experience negative thoughts about Deborah, but certainly not to that extent of madness. I still question things about Deborah's level of skills and often find myself saying to her "you are fifteen years old, why are you doing this, God I hate you" But you know in your own head that you do not hate Deborah herself, it's the situation, she is only doing what she has always done, she's not being deliberately naughty, she's just... it's something that she does. You hate what she is doing, but because she is doing it at you, you begin to hate her for what she is doing and then you start to dislike yourself for having such thoughts.

Jenni's story

Can you describe your role as a parent as you see it?

It's not my job nor is it Mike's job; it is whoever is around at the time [referring to care needs]. Whoever is up first in the morning sees to her, you know, takes her to the toilet, sometimes it is me and at other times it is Mike. We tend to share the care load when it comes to looking after Deborah. I tend to be the person who does the housework, that kind of thing, whilst Mike goes out to work. So as a parent my role is to be there for Deborah and to see that her needs as well as the needs of the rest of the family are met. ...to protect my children from whatever may act to harm them, to provide a loving caring home that nurtures them. To provide the care that they need, you know, as babies and toddlers they need an awful lot of looking after, making sure that they are fed, kept warm, I suppose it is about seeing that their basic needs are met consistently until they can do it themselves, that is look after themselves, so my role as parent is then as a teacher as well.

Is your role as parent to Deborah different then?

No not really, er, it is with regard to the looking after because that bit of being a parent hasn't stopped. Even though Deborah is fifteen years old we are still looking after her, making sure that she is safe from harm, that she is fed and that she is kept clean and tidy. But in relation to providing the love and nurturing home that is no different really... except she can be a real handful and she can make life hard...

What is it about this role that makes you say that?

Deborah needs constant care and supervision throughout the day. She wouldn't care if she didn't get dressed, washed, have her teeth brushed, her hair combed, er, her bum wiped or even her sanitary towels changed... these things are not important to her, they are meaningless. The only thing of importance is food and drink... she will search and scrounge for food and has even taken the water from the toilet pan to have a drink. So without me being home throughout the day Deborah would not be safe nor would her needs be met.

...As I have said I see it as my duty to be there to protect, to hurt when they hurt, to be happy when they are happy... that is what being a parent is about, for me at least. I

remember when I was carrying Deborah we were both so excited about having a child together, that was still the same when she was born... nothing was wrong then, that didn't happen until she was two and a half years old. We were there for her, we doted on her, when she fell, we were there to console her, to wipe away the tears. When she took her first steps we were there to watch to encourage, to laugh and show how proud we were when she did something new. When she uttered her first words. That is what being a parent is about it is to be there, to share in the joy, to love, to protect.

Did this change for you when Deborah had her diagnosis?

At first no, we were both devastated, we couldn't believe it... our cute little Deborah, something wrong with her, was it something we had done... we were in shock when you look back... in a state of numbness. But when she fell and hurt herself, she was still our little Deborah; she still needed us to protect her, to love her... so those feelings never have changed... just new ones have emerged...

Can you explain?

Whilst I still love Deborah and would protect her from harm. I have become harder I suppose, more worn down over the years. that hasn't helped at all having to keep on doing the things for her that you did when she was a toddler... as if time hasn't moved on for her... but for me it has, I have grown older and more weary with it all... so feelings of wishing that she would reach an age where she can leave this home to go to a residential college... that kind of thing.

If your role is made up of certain elements how essential are these elements?

Having to look after Deborah is really important to me, she has to be well dressed and clean, nothing else will do, Mike knows that too, I am very particular, so it is very important, or essential as you say for Deborah to be presentable...

Would you still be a parent if one or more of these elements were missing?

Being a parent is made up of many different facets, when you have a child like Deborah she is always going to need someone to look after her, that is my job at the moment, that is what I do every single day when she is home. When she goes to school that care is transferred to them, they do it, it might not be to the same standard, as I would do, but it is done, Deborah is looked after and kept safe. So the difference here is the emotional angle, school or any other form of help, being paid or otherwise will not have the emotional attachment that I and Mike have for Deborah. She is our daughter at the end of the day, she is made from us, she is our flesh and blood...so for me it is important that her care is of the highest standard... So getting back to your question, yes I would still be a parent, a mother even if I wasn't able to see to Deborah's immediate needs, you know feed and wash her... I would still be there in the background hovering around making sure that these things are done for her... I don't think that those feelings of love for your children ever go away, no matter what they do or bring to your door, you can hate or not like them for what they have done, but you will always be there to protect and help them... that is my duty as a parent.

What is it about your role that makes it matter?

Being part of a unit, being together as a husband and wife team, being friends and sharing together the care load, the meetings. Without each other I don't think we would be able to manage it alone, so my role as wife and mother is very important to

this family, I am part of the machine that helps to make it work for us... Mike is a real support, as I have said we have grown together and learnt how to cope together. So me being there for him and for the children really matters. If I wasn't here or even if Mike wasn't here for whatever reason this family would not be able to cope, it would break down.

What do you mean by this?

If I or Mike were single parents living and coping with Deborah on a day to day basis, I don't think either one of us would cope... Deborah would end up in care somewhere. As a couple we have gotten used to supporting each other, you know, where one breaks off and the other comes in... it is a partnership and without this partnership things would go bad...

To what extent do you think your role has been influenced by ideas from elsewhere?

This might sound a bit crass and stupid but I have, well, as a teenager always wanted to get married to the most handsome bloke and have his children and live forever happily [laugh]... This is probably because my mum and dad divorced when I was a teenager and I wanted to prove to myself that it can be done...

And can it?

I think so, life isn't a bed of roses I know that now, life is hard and it comes with many knocks, but I have Mike and Jade has come out of all this...

So from what you are saying your experiences of your parents divorce has made you more resolute to succeed where they failed?

Definitely.

How does your role make a difference to your family?

I think it makes a huge difference to Mike and Jade, Deborah probably doesn't care, it could be the milkman as long as she is fed and watered. It wouldn't bother her if she never had a wash, cleaned her teeth... By being part of a team, Mike and me that's what matters and by us being and doing together, well most of the time, it has an effect on Jade...

In what way?

She is quite together as a person, very understanding of our situation and I really do believe it is down to how Mike and I are.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

Sometimes it is a great pleasure... most of the time it is a pleasure... there are other times when we want to get hold of her and strangle her. I often tell her to sit there [pointing to a chair] and tell her not to move, to stop pinching me... just to stop. ...You are given these things in life and you just get on with it. So it's no use belly aching about it. Just have to get on with it... it is all that I, we have known for the past sixteen years.

If you were to sum up your situation in one or two sentences what would you say?

A constant longing of wanting... wanting to be able to do things in a spontaneous way, without thinking about it, without having to plan... just being able to do it...

Is this for you the essence of being a parent?

It gives an idea as to what it is like to live with Deborah, that we are in many ways prisoners to her. I love her to bits and I'm sure Mike does, nor would I just abandon her no matter how hard it gets...

What effect does Deborah's disability have on you?

Living with Deborah is really hard, there are good times don't get me wrong, but there are an awful lot of bad times when you feel really low and have no energy to carry on; that's how I am affected...

How would you describe your levels of stress – high or low relative to past experiences?

At the moment I would say my stress levels are fairly low, the highs tend to come around any school holiday when Deborah is home for more than three days. Deborah needs assistance throughout the day and night, when she is having a bad spell with her sleeping we all get very stressed. One of us has to get up through the night putting her back into her bed, making her stay in her room, switching the lights off at two, three, four, five and six o'clock in the morning. You can't have a lie in to recover from a what is like a night shift, you have to be up no later than 9 o'clock because Mike has been up since 7 o'clock dealing with her, you know, making sure that she is safe from the point of her getting out of bed for the day. So any school holiday puts more stress on us as a family.

Have you ever experienced private thoughts about your child/children?

Oh... [long pause] I don't know how to answer this, er, there are times, mostly when she is being badly behaved. I have felt, said to myself, God I wish you would have died when you were younger, I can't stand you I hate you for what you have done to us. There are times when I think to myself, and I mean to myself, 'what the hell have we done to deserve this?' You know we are not bad people, we have never harmed anyone, caused anyone any pain or trouble. But we find ourselves in this state of perpetual stagnation...

What do you mean by this?

As a family we have remained stuck, have not moved on and I can't see us ever moving on, not unless Deborah leaves home... but that is a point of contention, I'm fearful of this, I have a sister who has a learning disability and to be honest she did not fair well in an institution, so I am reluctant for Deborah to go anywhere other than staying at home; this causes arguments between Mike and me...

What effect will this have on you?

As I have said we remain stuck, not able to do normal things, you know, just put our coats on and go out for a meal. Not asking for major life things here, just things that other normal families do. For us it is a real effort that involves a lot of planning, er, arranging someone to sit in for us, which is not easy as Deborah can be very difficult.

So I do keep asking that question why us? Why me? If it wasn't for Deborah and her disability things would be so different... it is her disability that I don't want or like it has had such an effect on us all. It is not Deborah's fault, she can't help that but I project that blame onto her, as though it is her fault, so at times I really hate her for what she brought to my family.

How do you deal with these feelings as you said that you 'think these things to yourself'?

I do keep these thoughts to myself, I'm sure Mike would think me a horrible person if he could hear my thoughts... I don't think I am a horrid nasty person I am responding to the situation. My feelings towards Deborah are of hate and detest but not always, they come and go, you know, they are brought to the fore when either, er, like for example, recently we were invited to a family wedding, we couldn't arrange for anyone to look after Deborah, I said that I would stay home as the wedding was on Mike's side of the family. He would have none of that, if we both couldn't go then we wouldn't go... so that was it... because of the way Deborah is we often lose out on being able to do normal things.

So these feelings towards Deborah are transient?

Yes they come and go depending on what is happening, be it her difficult behaviour or if we are not able to do something.

Family ten

Shaun and Joan live in a rented local council house. Shaun works away from home during the week returning for the weekends. Joan has a part time job during the school terms. They have five children; David aged twenty, Robin aged nineteen, Edward aged sixteen, Chris aged fourteen and Imelda aged ten. Robin has a formal diagnosis of autism with a significant learning disability. Robin has no formal language and uses signs to communicate his immediate needs. Robin engages in behaviours that can severely challenge, he can be very physical towards his carers and has on occasions caused injury. Robin has poor sleep settling and sleep disturbance that has been resistant to intervention. He attends a special needs school and is non residential.

Shaun's story

Can you describe your role as a parent as you see it?

Well Chris as you know I work away from home during the week and have been doing so for many years, urm, it's about nine years now. I come home every weekend and am home when on holidays. We have gotten used to it, J and me... as well as the kids. So I am a real dad to them when I am home... I speak to them on the mobile

every now and then... except Robin... he doesn't do phones [laugh]. So when I am home I do any building work, cut the grass things like that

So your role is one of maintenance man?

Not quite, it's a bit more than that... I find that when I am home I give Joan a break when it comes to Robin, she has him, looks after him all week, has to put up with his tantrums and all that, so I see it as my turn... as I said it gives her a break. So I usually end up, me and Robin, sometimes Imelda comes along, and we go for a long drive... we go into the country, we don't stop anywhere or do anything else... I point the car and drive for hours, Robin really enjoys it, keeps him quiet and out of Joan's hair for a while... when we get home he just follows me around, I think he wants me to put his coat on and to take him out in the car again... I don't do anything else really I will play with the lads, you know on the gaming machines and go to the pub with David, have a few pints and a bit of a laugh.

What is it about this role that makes you say that?

Well it is just the way it is, it has developed that way over the years. I'm only home at weekends and when I have a holiday. So I am in all respects a part time father. It is Joan who does it all, the looking after, the shopping, and the cooking everything. All I do is take Robin out in the car for a bit of time, do a bit of house repair...

What about other contributions?

Oh, I suppose that I provide the finances, I put my wage packet on the table every weekend, so yes... I am the provider for the family... I provide the money to pay for the bills and I also entertain the kids when I am home, especially Robin...

If your role is made up of certain elements how essential are these elements?

Well, providing the finances to keep our head above water is an element of my role, without me going out to work, without me bringin in a decent wage each week... well I suppose without it we'd be on benefits and life would be tough for us all. Being able to drive and to have a car is also essential, without this I would not be able to take Robin out and give Joan a break of a weekend.

Would you not be able to take Robin out without a car?

Um, well yes I would, but it would be bloody hard work 'cos he won't walk with you, he runs ahead of you and he has no sense of danger... so it would be bloody hard work... so having the car and being able to drive makes life a lot easier for me, for Robin, for Joan and the rest of the kids. ...To be a parent is to be there for your child irrespective of whatever has happened, er, say they have got into trouble at school, been in a fight, police knocking on the door. So one of the essential features of being a parent is to be available to them when they need you... Robin a year ago when out with his project worker ran into the sea fully clothed. His project worker was a slip of a girl and really freaked by what he had done, she phoned us on our mobile, we were out shopping; in fact we were in a café having a bite to eat. We just got up, got to the car and raced to the promenade, collected a very wet Robin and took him home... he needed us and we were there for him, we were also there for the project worker as she was so distraught and upset as to what had happened.

How did you feel when the phoned rang?

We were both quite alarmed and worried at first, thinking "has he attacked her" or something like that. When that poor girl told us what he had done and once we were certain that she and Robin were safe, yes I got a bit cross thinking "we can't even

have some bloody time to ourselves without something happening". But isn't that what being a parent is, dropping everything when they need you most.

Would you still be a parent if one or more of these elements were missing?

Um, yes I think so, not being in a position to drive a car or being able to afford a car... or even earning a weekly wage, don't get me wrong they are important for me as a person... but they would not stop me being a parent to my kids. Not having these things would not change the way I feel about them, you know, wanting them to be happy, to grow up and live their own lives, to help them when they need help. So yes I would still be a parent...

What is it about your role that makes it matter?

Well I am the head of the family; I am the one who goes away to work... to provide for Joan and the kids. As head of the family, Joan though would argue this [laugh] I am expect to be listened to, you know, by the kids.

How easy is this when you are away from home during the week?

In some respects it is made easier as Joan will give me a run down of who has done what and to whom. When I get home I will deal with it... it is as though I have the final say...

Does that help Joan in the long run?

I don't know really, I suppose it can make her job harder as they [referring to children] may play her up more knowing that I'm away and not home until late Friday, but Joan has never complained...

To what extent do you think your role has been influenced by ideas from elsewhere?

Well, that's what dad's do isn't it? They provide for their family, that's what I do, that's what my dad and his dad do. All my mates on site, that's what they do... they work from home, have a bit of a laugh but at the end of the day put the wage packet on the table for your wife to keep house.

Is that how you experienced your father as a child?

Yes it was, that's how it has been for years. He went to work and provided for his family. He did very little with us, we were told to be quiet when he came in from work so that he could have a rest. He sat down and read a story to us now and then, but on the whole he wasn't home that much... always at work.

Would you say that your life style has been shaped by your own childhood experiences?

In some respects it has in others it hasn't. Times have changed a bit since then. I do more in the house when I'm home, I do more with the kids... like I said I try to give Joan a break when I am home... my dad never did that, and there was seven of us, in all...

Was this a conscious effort on you part to do more in the house?

No, not really it is something that dads do nowadays; you see it wherever you go. Dads in the playground on a Sunday morning with their kids, kicking a ball around, being there I suppose...

So are you saying that the role of being a father has changed?

Yes, it has I think dads have been actively encouraged [by the government] to be part of their children's growing up... to be active...

How does your role make a difference to your family?

I don't think that my role has made any difference basically because I am not at home during the week, as I have said Joan has her routines now and when I am home I feel sometimes that I am in the way. My only real contribution is to take Robin out of a weekend, you know, driving him around the countryside.

So by taking Robin out for hours on end this makes a difference?

I suppose when you put it like that, it gives Joan and the other kids a chance to do things without Robin...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

It really is about how restrictive life is for all of us when Robin is home. Every door in the house has a lock on it, even the toilet. So when you need to go and you haven't got a key it's a made search or beings boys we run outside and relieve ourselves by the hedge. We shouldn't have to live like this, but if we did not lock the doors Robin would create chaos...

If you were to sum up your situation in one or two sentences what would you say?

That I am the proud father of five children, my second eldest has autism and that I have been privileged to have been given the role of being his dad... and that it comes with a huge responsibility, that there are many challenges some that make you come close to a break down where you feel like running off into the sunset...

Is this for you the essence of being a parent?

Yes this describes what it is like for me having a child with autism...

What effect does Robin's disability have on you?

...I have five children four of them are fine, they are normal, it creases me when I see Robin, he is in a world of his own. It is so unfair that he has to be like that? I often ask myself why does he have to be like that, he has done nothing to hurt anyone, but he will never do normal things in life, not like his brother's or sister, that really gets to me...

How would you describe your levels of stress – high or low relative to past experiences?

When I am at work my stress levels are relatively low, I'm not caught up with the turmoil of what's happening at home. When I am home then I do feel it, not just because of Robin it's more about being home the noise levels, the demands on me from all of the kids.

How do you manage this?

I sneak off to the pub [laugh]. I take Robin out for a ride in the car, that makes it easier for me because it is only me and him, no other demands. He loves riding in the car so I have no problems with him...

Have you ever experienced private thoughts about your child/children?

It is a balance of extremes... but there are times when you think any more of this and I will snap and possibly do some damage... that does frighten me. Robin can be very aggressive towards Joan, she has taken many a beating from him over the years, he always targets her, but I suppose he will as she is the one who is here all the time. But recently Robin caught me a real cracker, a direct punch on the nose, bloody hell it hurt. It took all my effort not to hit him back, I really wanted to. I was so angry with him I really hated him.

Are these thoughts and feelings usually as a result of an event like this?

On the whole yes, but there are times when I do think to myself, you know times when we [referring to himself and Joan] can't just pop down the road together like when you fancy going for a pint. We can leave the other kids for a while but we can never leave Robin. So I have feelings of resentment towards him, life would be so different for us otherwise...

Can you explain this?

We would be able to be a couple again, doing things together, you know we have not been on a family holiday for eight years now, that's not fair on the other kids they are missing out as well... we can't be normal.

Joan's Story

Can you describe your role as a parent as you see it?

Irrespective of Robin's disability I am here to look after him, to make sure that he is safe and free from any harm. Yes... I know that he is almost an adult and that he still requires a lot of caring for and needs loads of supervision throughout the day, you know, he needs to be washed, dressed fed and all that. If he did not have his learning disability he would be doing all those things for himself, but as his mother I would, and am, still there... to protect him from harm, to look out for him, as I am for his brothers and sister. There is no difference in that respect; if anyone laid a finger on any of them I would go ballistic, so my love for them has not been altered in that regard.

What is it about this role that makes you say that?

That is my job, I have always wanted children and I have five of them. I am here to look after them to the best of my ability, to provide as stable a home life as possible for them all. Robin needs much more care and help than his brothers and sister, but that is the way it is.

If your role is made up of certain elements how essential are these elements?

Shaun works away from home coming home on a Friday. So it is down to me most of the time. So I have a good routine the kids follow it well, they know what is expected now they are getting older, even Robin. So I organise, plan and do everything that

needs to be done to get them ready for school, to any activity they go to, so what I do is really important...

Would you still be a parent if one or more of these elements were missing?

If Shaun was home and we shared things out I would not do half what I do now. If these things were missing from my role I would still be a parent, you can't take away the love you have for your children, I cannot ever see me not thinking about them and what they are doing wherever they are. So if I am not directly looking after any of them I will always be their mum.

What is it about your role that makes it matter?

Being here that's what makes it matter, being home when they arrive home from school, being there to listen to them...

To what extent do you think your role has been influenced by ideas from elsewhere?

I come from a large family, where we kept animals. We were always taking in sick animals, looking after and caring for them and each other. It was a loving home one where I have fond memories. It is these memories and these experiences that I think have influenced how I am, come on Chris you have known me for years, you know what I am like with the kids and all the waifs and strays that I bring in to this house, that's what I have been used all my life and it is what I am like.

Your own upbringing has influenced your perception?

I suppose so, that's what I like, am like, even when watching telly, I will watch animal programmes and family based films, it is how I see family.

How do you see it?

A house full of love, it should not be about possessions and belongings and how clean and tidy the house is. For me it is about providing the love and warmth and letting your children be free to experience the wonders of this world that we live in.

How does your role make a difference to your family?

I am the foundation stone of this family, without me it would not work. Shaun is a help of a weekend but he is away more than he is here. So I am this family...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

Yes, many times I have found myself thinking what is it all about, you do question life and what life has given you, is it fatalistic or just pure luck, or bad luck [laugh]. Don't get me wrong here I love my children to bits, but there are times when you sit down and think...

Can you give an example of this?

Well last week I was on the phone with my friend, you know the one I work for. She was asking if I wanted to go out for a few bevs and a bit of a laugh. Nothing major here, just going out for a few drinks, but with Shaun working away from home and having no support from social services I had to say no. She said "can't Edward sit in?" But he can't, I wouldn't let him anyhow, he is frightened of Robin and Robin

knows that. So something as simple of putting on your coat and going out for a few drinks, or even going for a walk to the shops, I can't do that so you do get to thinking why are we trapped in this situation. The trouble is how do you get out of it, put Robin into care?

If you were to sum up your situation in one or two sentences what would you say?

A life that is punctuated with large amounts of stress... stressors that are not easily remedied, that is unless you put your child into permanent care. Life with Robin is not easy what with his aggressiveness, his obsessions and routines

Is this for you the essence of being a parent?

It doesn't describe what being a parent is as such, but is certainly captures what it is like to live with Robin...

What effect does Robin's disability have on you?

He is my son and I love him to bits and would do anything to protect him from any harm. Living with Robin though is not easy, you end up taking lots of knocks and sometimes he will really have a go at me, you know, attacking me. That's when I find it hard, that's when I question what it is all about.

What is it all about?

If I could answer that I would be very rich [laugh]...I don't know if there is a god then he is a sick b*****d...

How would you describe your levels of stress – high or low relative to past experiences?

At the moment they are pretty high, this is due to planning a college for Robin, There are no local colleges for him to go to, so we have to look further a field. That worries me because of the distance, what if anything happens to him...

When your stress levels are high how do you recognise this?

My mind is constantly on the go, I can't sleep properly, I smoke and drink much more and my blood pressure is higher, I know that now because I have been having blinding headaches and pains in my eyes.

And management of your stress?

Smoking and drinking and talking to you [laugh]. I can moan at my mum when she visits, but she really doesn't understand. I have now got a part time job, that really helps me, Shaun said it would make matters worse but it has really helped me, it's a release from this madness [laugh]...

Have you ever experienced private thoughts about your child/children?

I often find myself thinking of what it will be like when Robin is living in a residential college that thought really frightens me, having to let him go. But just being able to do a simple thing, like putting my coat on and going for a walk. Going to the shops and not having to rush back before 3.30pm – I have to be home for when he gets home from school.

To be able to go out for a meal of a weekend when we feel like it – not having to plan it like a military exercise. When I have these thoughts I begin to resent him for giving

us a life like this and then start to wish for the day when he turns nineteen and can leave this house.

Isn't that normal expecting your children to leave home?

In some ways yes, but not wishing for it because you want to get on with your own life, that sounds so selfish, but it isn't. Living with Robin is really hard.

How do you deal with these thoughts?

They just come and go depending on what has happened. When he has had a real go at me and he has hurt me that's when I think about him leaving home. I suppose they are just a reaction to a situation...

So having these thoughts is normal?

Yes, yes I think so.

Family eleven

Peter and Tania live in a property they jointly own with someone else. They are both unemployed and rely on benefits. They have three children, Wendy aged 26, Phillip aged eighteen and Ricky aged fifteen. Wendy has left the family home. Phillip and Ricky both have varying degrees of learning disability. Phillip has a recognisable syndrome with associated learning disability and mental health issues. This is manifested in psychotic type episodes. Ricky has a formal diagnosis of autism and with this a severe learning disability. Ricky like his brother can engage in extremely challenging behaviours with high levels of property damage, injury to those who care for him and some incidences of self-injurious behaviours.

Peter's story

Can you describe your role as a parent as you see it?

I do some of the cooking when I'm home. I even do some of the ironing when Tania lets me [laughter], she doesn't like the way I do the ironing. I will do some of the cleaning like the Hoovering. Nowadays I spend an awful lot of my time with the boys in the playroom. I keep them entertained when they are home, playing games on the computer, watching films, building Lego monsters for Ricky. I also help out with usual routine things like helping them get ready in the morning, having a bath of a night. I also deal with the outbursts; Tania usually runs the other way [laugh].

Has this changed over the years?

Yes, when they were much younger I would help Tania much more as she had her hands full with three young children, so when I got home from work it would be hands to the pump, bathing, hair washing.

Who sees to the boy's personal care now that they are teenagers?

Both of us, it is a joint task, if Ricky is in the bath one of us is with Phillip. So it is a family affair.

What is it about this role that makes you say that?

It's just how it has developed over the years; both Ricky and Phillip can have their moments. Ricky tends to go for objects and Phillip for you and as they have got bigger it is much harder for Tania to deal with it, so it is down to me... I find it really hard sometimes, if it goes on and on, I get tired quickly...

If your role is made up of certain elements how essential are these elements?

Apart from doing a bit around the house I tend to spend more time with the boys, sitting in the television room either reading a book for Ricky or playing a computer game with Phillip. This gives Tania a break from being with them. So how essential is my role? Very I think, you would have to ask Tania [laugh]. Spending time with them, if I didn't then Tania would have to we can't leave them, Ricky more so he would be out of the window and be off down the road. So someone has to keep an eye on them both and that is my job.

Would you still be a parent if one or more of these elements were missing?

There is a duality here; well I think there is. One that requires you to do the doing and the other is to do the emotional stuff. Anyone with the right frame of mind can do the actual physical caring when it comes to Phillip and Ricky, because that is all it is, doing something. It is the meaning behind it that matters, so if the element of doing the actual hands on day to day caring was missing then that would not stop you being a parent, you would just stop doing the 'actual' caring, if though you stopped caring in an emotional sense, in that you were completely detached from Phillip and Ricky then those missing elements would in my opinion stop you from being a parent.

What is it about your role that makes it matter?

Having the physical presence to be able to manage most situations and being usually calm in situations where all hell is breaking out.

To what extent do you think your role has been influenced by ideas from elsewhere?

Being the breadwinner to this family, it is a traditional thing... on being a man, that is what being a man is all about isn't it? [laugh]. To take your son's camping, to sit him down when he is of age and talk about the 'birds and the bees', to do the son father things, like I said to go camping, to go fishing, go shooting...

Are these types of activities you did with your father?

Not at all, my dad wasn't in to anything like that, all he could muster was to sit and watch football on the telly... he would either just sit there or get quite animated by what he was watching... so no we never did anything like that.

So can you tell me where you have got these ideas from?

Er, one of my school mates used to come to school and talk of what he had done over the weekend, you know, he had been camping with his dad, and that he had been fishing with him... I went a few times with them, it was great... they got on so well... Then there is the telly and films where you see this kind of thing happening, dads and lads... that kind of thing.

From what you have been saying is this what you expected your relationship to be like with your sons?

Yes, when Phillip and Ricky was born and everything seemed fine, you start to plan things... you know, things you are going to do... I was looking forward to the day when I could just kick a ball around with him... that was great I can still do that with them, even now, but the other things like going camping, fishing the outdoor type of things...well as you know Chris, neither of them are into it are they, they wouldn't enjoy it and I wouldn't enjoy it... so it has never happened.

How does your role make a difference to your family?

I'm pretty sure if I wasn't here Tania just wouldn't cope, I'm not trying to blow my own trumpet here, but I tend to be the one who deals with Ricky and Phillip's aggression, you know, when either of them has one on them, when they gets physical with us. If I wasn't here Chris they would not be here...

What do you mean, in what context would he not be here?

I'm referring to them not being in this house... If I wasn't able to be here, for whatever reason, or even if I weren't able to manage their aggression they would be living somewhere else, you know, in a residential college or a home in the community, something like that. So my role is very important to Tania, like hers is important to me, she does all the planning, the organising, that kind of thing, like I have said before Chris, we have developed, it's like a partnership, one where we are both important and needed, without one or the other it would not work, for either of us.

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

There have been numerous incidents some comical and some not so funny; one that comes readily to mind involves Ricky. We were at the train station watching the trains; they are a real fascination for him. A train passed by Ricky, as usual started to ask lots of questions "where is the train going?" that kind of thing. A lady was sitting on the bench, minding her own business, Ricky approached her and started to ask her the same questions, she did not answer him. Ricky did not like this and before I could get to him he had kicked her very hard on her legs. As you can imagine she was hurt and very upset, it took quite some persuading on my part for her not to call the police. Ricky as you know looks very normal, that's part of the difficulty, if he had a recognisable syndrome people would probably be more understanding.

What does this tell you?

That you have to be on constant watch and be prepared for any eventuality, it's like living with a ticking time bomb.

If you were to sum up your situation in one or two sentences what would you say?

Life is dominated by Phillip and Ricky with nothing in between, it's all or nothing, full on. Attending meetings, discussing this or that, people coming round to advice on how we should be responding to the boys... but you know what they come they go, ultimately leaving us to carry on...

Is this for you the essence of being a parent?

That is what it is like for me, it is constantly caring and being there for them...

What effect does Ricky and Phillip's disability have on you?

They are both really very different, yet they have a draining effect; I am always tired and have no energy for Tania and myself. My life seems to be devoted to caring for them both, albeit in very different ways...

Such as?

Well Phillip is happy to play computer games with you, he wants me to play with him all the time, I don't get five minutes to go to the loo. He is always shouting for me. Ricky then wants me to sit and watch his videos, the same ones time and time again. You get so frustrated by it all, that is why I feel so tired...

How would you describe your levels of stress – high or low relative to past experiences?

I feel as though I am under constant stress, with pockets of highs and lows. Life in general is and can be very stressful irrespective of having children and I suppose irrespective of having a child with severe learning disabilities... At the moment it is very stressful we are not coping with Ricky and his behaviour. He is wrecking the house and I don't know how much longer we can carry on...

How do you keep on going?

If we don't who will look after them? They will end up in a home; Tania won't cope with that. I think I would, as we would eventually begin to have a life outside of the boys. But for now I just grit my teeth and get on with it. I will sit and play on the computer with Phillip that helps me unwind and when my health allows me I will tinker with my bike.

Have you ever experienced private thoughts about your child/children?

When Ricky is really having a go, like last week when he ripped the electric wires from the wall. I had to disable the electrics but I have got to say it was very tempting to leave it on, maybe a shock would make him stop...

How tempted were you?

Just for a second or two but how would I explain that, I would never have been able to live with myself if he would have really hurt himself. ...it is what you get used to in the end, Ricky has always been difficult, if he doesn't get what he wants we have to deal with a major tantrum, it's been like that for years so we are just used to it.

A case of here we go again?

Very much so, but it is not easy when you are holding him, or when he is hitting out at you. It would be easy to hit him or to hold him that little bit tighter. That's when I

do struggle because I do have those thoughts and I know I shouldn't, but as I have said I have never acted on them...

Tania's story

Can you describe your role as a parent as you see it?

My role as a parent, erm, when they were babies they were all totally and absolutely dependent for everything, all the basic human needs. As they grew I was there to still see to their needs but also to help them develop you know encourage them to walk, talk, play and to become independent so that they can look after themselves. That is part of what being a mother is. For Phillip and Ricky it has been a bit different as they still need help with washing and dressing, I still prepare food for them and look after them generally. As they are now teenagers you wouldn't normally expect to be giving that level of care, but as they have special needs they need that amount of help...

What is it about this role that makes you say that?

This is what mums do, isn't it? When having a child you expect, no, want to provide the best for your new born, to watch them, to keep them safe. There is no difference even when they grow up from the baby stages to the toddler and through their adolescence and into adulthood... things may go pear shaped, like with Ricky and Phillip, they still needs caring for and all that but I still love them both and want to protect them, as I have said that is what mums do...

If your role is made up of certain elements how essential are these elements?

The looking after and caring for the boys is a big part of my day, everyday, I would say it is my day; it's what I do. Peter helps out an awful lot but he gets frustrated with it all. If it is not helping them with getting ready in the morning, cooking food, keeping them entertained and then getting them ready for bed, it is then about attending the numerous meetings, which there are many at the moment [laugh]. These are the things that I do on a day-to-day basis; this is being a parent for Phillip and Ricky.

Would you still be a parent if one or more of these elements were missing?

This depends on how you define parent, for me if the element of being a parent is about nurturing and encouraging your children to grow and develop into responsible adults, that is what being a parent is about... if this particular element is removed or is absent for a variety of reasons then you would not be a parent in that respect... but being a parent involves more than this, so you would as a parent still be a parent, because it involves an awful lot more of being there, doing for, nurturing and encouraging your children, these are just aspects of being a parent...

What is it about your role that makes it matter?

Being here... sometimes I wish I could just disappear, but then what would happen to the boys and to Peter?

To what extent do you think your role has been influenced by ideas from elsewhere?

When I was a girl I always dreamt of having my own children and having lovely times with them. Going for picnics, riding bikes down country lanes all the nice rose coloured spec type things, the things you see in magazines, in films. That is how I imagined it to be, how I wanted my children's childhood to be.

And has it been?

No, nothing like, it might have been different if the boys hadn't their difficulties. We might have been able to do those things then...

How does your role make a difference to your family?

...by being here, that is the really tangible thing that has made a difference to the boys. I don't think it would make any difference to Ricky if it was me or the man from down the street who was looking after him, as long as he can go for a walk, look at the trains, is fed.

The things he enjoys?

Yes, it wouldn't matter if it was me or a total stranger, that's what makes it hard...

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

Going for a bike ride with Ricky, I taught him to ride a bike early on, he can ride but has no road sense. It was a sunny day Phillip was with Peter in the shed so I made some sandwiches got the bikes out and walked with Ricky to the cycle path. Ricky got on his bike and set off at a pace. I couldn't keep up with him, he just went off. I panicked, phoned Peter who managed to persuade Phillip to get into the car. They met me and then headed in the direction Ricky had gone. He wasn't to be seen so I had to phone the police..., ...in the end it was a helicopter search. Thankfully they spotted him and a police car intercepted him and brought him home, much to our relief. That's what it is about, the stark reality of living with two boys who have special needs; things can happen in an instance and at times when you are not prepared for them.

If you were to sum up your situation in one or two sentences what would you say?

If I was to be totally honest I would tell them, erm, that my role is mum to two boys who have special needs. That I provide for them on a daily basis even though they are teenagers and that my life has been altered for the worse as I have to be there constantly... that there is no time to switch off and do your own thing...

Is this for you the essence of being a parent?

For me that is what it is and continues to be about, that whilst I love them and want to see that they get the very best from us and from services, I, we are stuck and we are not able to move on...

What effect does Ricky and Phillip's disability have on you?

Life is dominated by them both, in very different ways though. They both want and need so much attention that at the end of the day there is no time for yourself let alone Peter. Living with the boys has driven a wedge between us, we are still together as a couple but we don't do very much together... it is as though we are here to care for the boys...

How would you describe your levels of stress – high or low relative to past experiences?

... they are relatively high as a constant, this past year, I have to put all my effort, all my energy into the boys. That is what my life is at the moment... it is all about Phillip and Ricky and their needs... I have decided to allow time for me, I have to, I need to, I just feel tired all the time. So I have started going to the gym again... I hope it will give me some time for me and that I might feel a bit more energised. It might help with my stress, as I said before I feel so knackered to the point that I can't or want to do anything.

Have you ever experienced private thoughts about your child/children?

They are my sons and I'll love them for the rest of my life, but there are days when I just think 'f*****g hell' things could be a lot easier, but that's life. I find myself at certain times, like at three in the morning [laugh] thinking for god's sake give me a break, I just want a break from this... not that I would do anything to hurt them, don't get me wrong, just a break from this constant stress of caring, that's all.

How do you deal with these thoughts?

I do shout at them more so at Ricky but I would never strike out at them, I would never do anything like that. I was told last year by my social worker that if I ever felt like hitting out that I was to leave the room and close the door for a short time... that has been the best advice I have been given... and that is what I do if I feeling my self getting wound up. I think the way I think is quite normal, I am in a difficult situation it is not easy bringing up children alone, let alone children with special needs... I have learnt to deal with my feelings and learnt to put them to one side and get on with it in the moment... at the end of the day it is not their fault they can't help being the way they are...

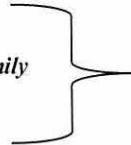
4. Meaning Units of the experience

Meaning units: These were generated from the transcribed interviews (Appendix ten provides a fuller explanation as to how they were developed).

Family and Child

Sub-categories:

Family make up, friends and extended family
Diagnosis
Siblings



These are non-themes family demographic info

1. Being a parent.

- A) Love
- B) Nurturing
- C) Self-sacrifice
- D) Protecting
- E) Being there – not matter what
- F) Setting the moral compass
- G) Conflict

2. Living with Disability

- A) Adaptation
- B) Life restructuring
- C) Role adjustment
- D) Relationships
- E) Isolation
- F) Windows of opportunity

3. A career in caring

- A) Constant-ness
- B) Acceptance
- C) Putting on hold
- D) Suport systems

4. Private individual Thoughts – an over arching theme that permeates all core and sub categories

- A) Impact of disability
- B) Meaning of life
- C) Attributing meaning
- D) Talking about...
- E) Views on disability
- F) Conflict management

PART TWO: The meaning of being a parent and caring for a child with significant learning disabilities: Individual textural and Structural descriptions
Family one

Jane's experiences:

A textural description

As a single parent Jane finds that she fulfils all the spectrum of activities associated with being a parent, she is “alone” and “has to do the lot”. For Jane this means that she is essentially there for her children, to protect them from potential harm, whilst loving and cherishing them. Zoë, as a result of her disability, requires a significant amount of help and support, much more than would be expected from a non-disabled child of a similar age. For Jane this means that she has to put her own needs to one side. This impacts on her social life and has resulted in her becoming more isolated even though she lives in a busy town.

Jane often feels that she is alone; it is her and the girls against the world. She is isolated and has no friends to whom she can turn. Her feelings of tiredness and lack of energy contribute to her feelings of being alone.

A structural description

Living with Zoë's disability has to some extent shaped and maintained Jane's caring role. Her own upbringing has also influenced who she is as a mother: to nurture and care for her children. There has been a battle in establishing a balance between her role as parent and her own individual needs outside of parenthood; Zoë's needs always and will continue to come first.

Jane often thinks and is hopeful that her life, though presently on hold, will resume at a later date. She is also realistic to know that that day will never come.

Family two

Rob's experiences:

A textural description

Life in general is determined by Michael, as a family they are unable to plan ahead without having to think of him and how he fits into the scheme of things, he is and will always be the priority. Rob plays a big part in seeing to Michael's personal care needs now that Christine is unable to manage him physically. He also ensures that Michael is safe and has a high level of supervision. Rob sees himself as being a “brick” when it comes to supporting Christine and the boys.

Rob enjoys taking the boys fishing, camping and motor biking; he is not able to engage in these activities as frequently as he would like. This can result in some resentment from Michael's brothers as they are directly affected by activity restrictions.

A structural description:

As Michael has grown into a young man Rob has become more involved in his personal care. Rob views this as being sensitive to Michael's needs now that he is developed. Rob is also aware that Christine is no longer able to manage Michael due to back strain; a result of providing years of care. If Rob is unable to provide this care then Michael's care would have to be bought in or provided elsewhere, a situation that is not welcomed.

Life can be restricted, particularly community access; the family when 'out with Michael' are unable to engage in normal things. Rob acknowledges that there is an expectation to "give up a whole lot of yourself for your children", but in Michael's case "you give up an awful lot more". There is a sense of hopelessness in that Rob's situation cannot be changed, because it is the way it is; there comes with this a resignation that "we have to make the best of what we have got".

Christine's experiences:

A textural description

Christine on a day to day basis ensures that Michael's needs are met; this is predominantly by orchestrating his care throughout the day, planning and organising with Rob and the other children, attending meetings and making decisions. Essentially fighting every fight that comes his, or the family's way.

Michael still requires an awful lot of care; this involves all aspects of daily living. Christine as a result of 'wear and tear' is unable to have a hands-on approach, as well planning and organising Michael's day she provides a high level of supervision, as she needs to know where he is [in the house] at any point. Her role has developed over many years and has in many respects been determined by Michael.

Life is a major juggling act with varying levels of physical and emotional strains as the caring for Michael takes its toll.

A structural description

Christine is very aware that Michael will always need someone to provide for all of his care for the rest of his life. He still needs her as he did when he and his brothers were babies. It is what she does and it is what is expected of her. Her experiences of social services has been found wanting and as such have resulted in a lack of trust with regard to the quality and level of support and care provided.

If she did not plan or provide high levels of supervision life would be chaotic Michael would end up smearing faeces or be found in the middle of a fit. Christine has reached a point in her life where she is tired and fed up with the amount of effort it takes in caring for Michael. Transitional planning has created more stress for Christine and Rob.

Christine has moments where she questions what it is all about. She acknowledges that when you have children you expect to provide a high percentage of your time

caring and nurturing your children's development. You always expect your children to grow up and become less needy. You can never be prepared or ready for a role that involves constant caring. Nor can you envisage having thoughts of repulsion or feelings of pity when your son has an overflowing mouth of regurgitated food or is in the middle of an epileptic seizure. For Christine these thoughts come and go and they are viewed as normal.

Family Three

Drew's experiences:

A textural description

Drew sees himself as the provider for his family, the one who goes out to work, maintains the home and makes sure that the family can have a holiday. He also sets the moral tone within the home, this includes raising his children to the best of his abilities; he expects this of both his children.

It is important for Drew that he is visible and there for his family. With regard to Brian he sees it as part of his role to fight his corner for him and ensuring that he will always be cared for, wanting the best for him. Drew takes pride when he engages in Brian's care ensuring that he is well groomed, this comes with a physical and emotional price. Brian dislikes being shaved; having his hair, fingernails and toe nails being cut, it usually results in a significant outburst and 'fight' where Drew has to stand and punch back.

Drew often feels tired and weary, his mind is a whirl and he finds it difficult to settle down to do anything; he attributes this to living with Brian and his level of difficulties. As a way of combating these feelings he will sit and have a cigar, a quiet moment of reflection and being able to plan a summer vacation and looks forward to when Brian is in respite care.

A structural description

You have a responsibility, they don't stop, your children will be your children until the day you die. I would kill if anyone harmed them. Drew has had to reconsider his role of father to Brian; one from taking his son out on camping and fishing trips to teaching him how to behave or even tie a shoe lace.

Drew sees himself as a punch bag where he takes the knocks. He has to be physically strong but has an underlying fear of losing his physical prowess and the very real possibility of being hurt when dealing with Brian. Life is also viewed as being tough where massive knocks are frequent, but you have to pick yourself up and keep on going. Coming to terms with Brian's disability is Drew's biggest knock.

Drew has thought about ending it all, killing Brian and himself, but has concluded that he cannot change his situation. He does feel for Brian as he has no life, he will not have a girlfriend, be able to have or drive a car, just to experience normal things. He

sums his life up as there is no greater being who deals out shit, it is all coincidence, pure bad luck, we just have to get on with it.

Marian's experiences:

A textural description

Being a parent for Marian involves comforting, nurturing and supporting your children. It is also about being there for each other.

Having the ability to be able to drive is very important for Marian, without this skill she would be confined to the house when Brian is at home. Living with Brian is seen as being very tough as it is, not being able to go out and do normal things would be unbearable.

Life in many respects is controlled by Brian's disability, you have to be extremely organised, always planning ahead. Being spontaneous is a rarity and when you are able to be so it is when Brian is in respite. Marian has to attend a variety of meetings that are Brian-focused and has to accept professional help; this includes having regular visitors to her home.

A structural description

High stress levels are symptomatic of living with Brian; relief is found in a glass of wine and the thought of and process of planning a holiday.

Marian finds herself questioning life and often asks, "What I have done to deserve this?" She clearly identifies the difference in her relationship with her daughter and her son. She is a friend and companion to her daughter and a carer for her son. Even so she acknowledges that she is his mum as she is the one who brought him into this world and will be the one who will continue to look after him.

Marian does experience private thoughts about the situation she finds herself in. She has a range of negative thoughts regarding Brian and accepts that they are normal for her and pays little attention to them.

Family four

Tony's experiences:

A textural description

Tony is the main carer for his daughter Christine; he sees to most if not all her daily living needs. This includes her personal care, cleaning up after her and preparing for her on her return home from school or other activities. Life is viewed as a massive roller coaster ride of emotions. For Tony it is not easy living with a young person who is highly demanding, this creates physical and mental fatigue. Tony has a clear role that is defined by caring for his daughter; he sees his role as serving a purpose that meets his wife's and his own needs.

A structural description

A reversal of roles he views himself like a paid carer, yet he does not get paid! He is finding it much harder now that Christine is a young woman particularly when having to provide intimate care activities; but he knows nothing else, it is the way it is and will continue to be.

Tony is proud of the fact that they did not listen to professional opinion when Christine was a baby, if they had done so she would not have achieved as much as she has. Tony feels that he has been chosen to look after a very special child, a role he didn't ask for, but one that was given.

Stress is a constant feature of Tony's daily life, Christine plans and controls his day and to some extent his life; he has no say. He finds that he easily loses his temper and says nasty things to her in the heat of the moment, for example hating her for what she has done. Tony rationalises each situation and then carries on. Being able to potter in the garden and in his garage gives Tony the opportunity to chill and have time to himself; these opportunities do not present themselves often enough.

Glenda's experiences:

A textural description

Glenda sees herself as the one who provides a home and equips her children with the skills to live independently. With regard to Christine she is unable to provide the personal care she requires. Her role is more of friend, entertainer and companion.

Christine is the focus of this family's existence; she is always on their minds, the topic of all their conversation. This leaves Glenda with no time for herself and a feeling of being shattered and low energy levels. This is attributed to the level of demand Christine places on them from the moment she wakes to the moment she goes to bed; there is no end to it. There is no chance for peace and quiet.

A structural description

Glenda is repulsed when having to engage in Christine's intimate care; she no longer does so and absolves this responsibility to her husband. Glenda is of the opinion that Christine should, at her age, be seeing to her own needs.

Glenda's own upbringing has strongly influenced how she is 'as a parent'. Her own experiences as a child were punctuated with being severely punished by her father, this has made her resolute that she will never punish by hitting her children. Glenda though experiences conflict as she has strong feelings of wanting to 'swipe' Christine across her face, particularly when she is demanding or squealing at her. Glenda has a tightening in her chest when she hears Christine's voice at this point she wants to vent her anger and tell her to 'shut up'. These thoughts are seen as being normal and a mechanism to help her cope with the daily demands and impact of Christine's disability.

Stress is a constant in her life and she finds coping with stress is getting harder as each day passes by; stress is not always associated directly to Christine. Gwenda finds herself waking early, creeping around the house so not to wake her, just to get some 'self time'.

Family five

Peter's experiences:

A textural description

Peter is the provider for his family; he views this role as very important in maintaining the fabric of the family. He also is the disciplinarian; the one who does the telling off. As Malcolm is now a young man Peter engages more in his care, he will help him to get dressed, toileted and showered. Peter's physical stature is an essential asset that enables him to manage Malcolm during caring activities and when he has to deal with aggressive behaviour.

Peter wants to do his best for Malcolm, he sees himself as a good dad, who cares for his son and his family. He finds caring for Malcolm hard work that has high demands on his own time. This has an impact for all of the family, in particular his relationship with Noella and his older son Daniel who sees very little of his dad. Life for Peter is compartmentalised into separate segments where he goes in one direction and his wife the other, sometimes not having the time to meet or discuss issues. Friendships and social contacts have diminished over the years and are rare these days.

A structural description

If Malcolm did not have his problems Peter would be doing very different things, he would be taking Malcolm to work, and going fishing with both the boys, but as it is he is unable to do so.

Peter believes that Malcolm would, if it weren't for his own ability to manage him, be in a care home setting. His role as a carer has been truly established and defined now that Malcolm is a young man. This role has to some extent been shaped by his upbringing. As a result of his role as carer and provider for the family Peter has been a part time dad to Daniel.

Peter has a special hobby that enables him to be free of his role and to be oblivious to what is happening at home. When he resurfaces from this freedom that stark reality of his life hits him hard. This often results in him thinking about his situation, which causes him to 'freak out' and feel deeply upset and emotional. Peter will end up escaping for his own sanity.

Stress is experienced at varying levels dependant on any given situation, failure to meet work commitments being a major factor. During these times Peter experiences negative thoughts that generally result in family conflict. Frustrations are usually vented verbally and are aimed at Noella and more so at Malcolm; Peter wishing that Malcolm would go away and never return. He feels bad about having these thoughts

but understands that they are only thoughts caused as a by-product of stressful situations.

Noella's experiences:

A textural description

Noella is the planner, the organiser the person who keeps things together. She is the one who makes the decisions regarding household and childcare issues. There is awareness that if she did not adopt this role nothing would get done, as such, this is Noella's most essential role. There is an acknowledgement that the family rely on her too much and in some ways she encouraged them to become dependent on her. Planning and organising is not the only aspect of being a parent, she has a deep love and a desire to nurture.

Malcolm's disability has had an impact on Noella; life is hard with him. Her other child suffers as a consequence but never complains, even though he has a right to do so; he is unable to do normal things with us as a family. Isolation from friends, family and other social contacts is common to such an extent that the family have isolated themselves.

There are real concerns for the future - who will provide the care for Malcolm when they are unable to do so? These thoughts are generally put to one side, even though there is an awareness of time rapidly ticking by. This strategy is seen as a coping mechanism but not a good one.

A structural description

Noella is the decision maker for her family this has had a negative effect, as she is more than aware that her role has contributed to her husband's lack of input. She has created a dependency and accepts that this is in all probability due to her own childhood, one where she has been programmed to be the homemaker.

Life is a mixture of happiness and sadness; when Malcolm achieves something it brings joy, this joy is tarnished with the knowledge that he will never achieve independence, that he will always need someone to help him throughout his life. This causes a range of stressors, ones that cannot be dealt with all at once. Issues are therefore prioritised and sorted into manageable boxes – this helps Noella cope on a day-to-day basis otherwise she would be totally overwhelmed. Reframing in a psychological sense helps her to look at situations differently and more positively. An interest in things psychological has been stimulated as a direct result of her experiences of Malcolm.

When Malcolm was born questions as to one's own abilities in being able to cope were prominent; feelings of guilt and hurt were evident. After a period of reflection a decision to bring Malcolm home was reached, this decision has been far reaching, in present times when things are bad Noella will remind herself of the decision she made all those years ago.

Family six

Jackie's experiences:

A textural description

From day-to-day Jackie does it all, she ensures that the children are well cared for and healthy. Jackie has been a single parent for a few years now and has adapted to her life. As a mother she views parenting in terms of being there to protect, to nurture and to provide. She feels very much alone with little or no support; she tries her very best to keep her family together, this is very important for her – when her children are happy she is happy.

Jackie's ability to manage is seriously compromised when having to deal with and manage frequent temper outbursts and disruption to her sleep, where it is common to be up half the night with Martin. This makes being a single parent even more difficult, the emotional and physical support from a partner is absent you are very much on your own, trying to do your best.

Financial insecurity is a constant pressure and a real stressor, when all these factors are considered together feeling tired and unable to focus and concentrate is commonplace for Jackie.

A structural description

Jackie has always imagined being a parent, having three children, being in a loving family and having a long-lasting relationship; this ideal stems from her own experiences as a growing child. These aspirations have not borne fruit; she lives alone with her three children. Martin causes a range of concerns; worry being a predominant one, particularly when he runs off. Jackie has to call the Police and is at her wits end with worry until his safe return.

There is a range of conflict between family members, Martin being central to this. Stress levels fluctuate from highs to lows dependant upon situational factors. This causes Jackie to clock watch and get herself more and more anxious as the time for his arrival home nears. She experiences a tightening in her chest, a heightened awareness of outside noises, 'was that a car door closing is he home?', 'what mood will he be in?'

A cigarette and copious amounts of coffee help to reduce the stress levels so does thinking thoughts about her situation, in particular Martin, these are seen as her safety valve that allow her to think about rather than act.

Family seven
Doug's experiences:*A textural description*

Doug is the foundation stone of this family, the one who provides for their every need. He is the one who goes out to work, who works hard so that he and his family can have a lifestyle without financial worry. This includes being able to buy in the care that Dean requires.

Doug is very aware that Dean will never be able to do the things that he hoped they would be able to do together; going trekking and sailing; things that are of importance to him. Because Dean requires an awful lot of care he has ensured that he will be well catered for when he is an adult.

If Dean did not have his problems things would be totally different for Doug and Mildred they would be off just the two of them to sunnier climes.

A structural description

Doug's work ethic has been instilled from a very young age. As a child he watched his father and his grandfather going to work, working long hard hours so that they could provide for their respective families. This has also driven Doug to work and to ensure that his family are well provided for.

When Dean was born Doug secretly wished that he would die; Dean was very ill and had a profound handicap. As Dean pulled through and gained strength Doug pursued his business interests; it was and remains his way of coping. When Doug is away from home on a business trip he feels guilty knowing that Mildred is home caring for Dean. These thoughts are countered with his belief mechanisms, that he is the provider and Mildred is the carer.

Mildred's experiences:*A textural description*

Mildred's role is important to her; she ensures that all aspects of Dean's care needs are met, be it directly or indirectly. As his mother it is her job to provide a loving home and to offer support and guidance to my children. It is important that her children are close by, to have regular contact; this is being a mum.

Dean requires an awful lot of caring, much more than is expected for a young man of his age. It is Mildred's responsibility to fight his corner, trying to secure the best available services for him. This has been a feature of Dean's care and will continue to be, the current battle is trying to secure a adult placement that will meet his care needs not to provide further education. There is a real fear of who will care for Dean if a placement cannot be found. Mildred has accepted that Dean even as an adult will always be like a big baby, who will need constant care and attention.

A structural description

Life would be very different for Mildred now that her children are adults, Dean without his difficulties would not need the level of care he does. More time would be spent with Doug.

Mildred's ideas about parenting and being a mother have been influenced and shaped by her own personal experiences as a child; coming from a loving parental relationship. She has had a longing to be normal as a family but is accepting that this is not going to be achievable; she does though question life's cruelty and harshness, but knows that she has to get on with it. Being unable to have a real break from caring causes fluctuation in stress levels as does thoughts about Dean's future; will she be able to continue caring for him and possibly her mother who is becoming more feeble? This causes feelings of resentment towards Dean particularly when Doug is on a trip in a sunny country; if Dean did not have his problems she would be by his side.

Mildred realises that she is caught up in a situation one that she cannot change or escape. It is a situation that no one would like to find him or herself in but she is, she will have her rants and raves and then just gets on with it.

Family eight

Terry's experiences:

A textural description

Being able to provide the financial security for my family and giving them, us, the means to live a decent life is an important element of being a parent. Terry is clear about his role and acknowledges that he helps out with the care of his children but not to the same extent as his wife Kate. Life according to him is for living and should be fun.

Engaging in housework and some childcare is not uncommon for Terry. He accepts that this can be provided by an outside agency but it is not the essential features of being a parent, this for Terry is more about the deeper emotional bonding that takes place over time, wanting to be there, to protect and to cherish your children.

Living with Gwenda causes feelings of embarrassment particularly when outside of the house, there comes with it a feeling of trepidation: what is she going to do? Past incidents have resulted in Gwenda and family being restricted as to where they can go. Caring for Gwenda on a day-to-day basis is hard work; there is little time for normal family things. For Terry that is the reality of having a child like Gwenda.

A structural description

Terry's experiences of growing up on a farm have left him with residual memories and a desire to create that same loving and happy childhood and home life. Being

together as a couple is intrinsic to this, it makes the difference between coping and not coping.

Stress is experienced as a fluid thing; levels are up one minute and down the next. High stress levels directly relate to how Kate is coping with Gwenda and how they are getting on as a couple. Things can get very heated. Conflict is not easily managed and results in Terry taking himself from the situation, he will do some office work, mess about or stare into space. This time helps the situation to cool down. Having a pint of beer at home also helps to relive stressful events.

Thoughts about life without Gwenda or Gwenda without her difficulties are frequent for Terry; Gwenda would be a normal girl with her own friends. Roy would have a proper sister and as a family, normal experiences could be had. There is a preoccupation with these thoughts but a realisation that things cannot be changed.

Kate's experiences:

A textural description

Life for Kate revolves around seeing to Gwenda and Roy's needs. In spite of Gwenda being older than Roy, Kate spends a lot her time meeting Gwenda's personal care needs and organising her day. Her role is viewed as carer, overseer and provider for Gwenda's emotional and physical needs and to a lesser extent doing the same for Roy. Within this role Kate finds that she has to fight service providers to get the support that the family feel they need.

This high level of care would not be required if Gwenda did not have her disabilities. Kate would still be there for her children offering the love, the support and encouragement. She would also be able to do the 'girly' things with Gwenda. It is important for Kate that as a parent she should be there for her children and provide the best for them; that they should come first. She is there for them but is at her wits end having to still be caring for her daughter. Pubertal issues and the amount of care and support Gwenda will require are a concern, Kate feels this will have more an impact on her as Terry will not be able to engage in intimate care activities.

There is no 'me' time, simple activities like going for a walk. When Gwenda is in school there is time but being exhausted and having no energy gets in the way, you end up sitting and vegetating in front of the television, before it all starts again. There is a recognition of being burnt out and needing a total break from caring.

A structural description

Parenting for Kate as a concept is a hand-me down from her own experiences as a young girl growing up in a small community. Being together as a couple makes a difference even though there are rows.

There is a feeling of being trapped in the caring role and a resignation that this is the way it is and will continue to be. Feelings such as these actuate higher stress levels; weekends are a significant factor. Having Gwenda home all weekend for full days are

physically and emotionally tiring. There is a dawning, when watching other children of similar age to Gwenda playing; she is in a world of her own. She will never manage to live and lead her own life and that there is a real possibility that they, but the mother in particular, will end up caring for her until they die. They get to the point that they would accept any sort of help because they get so weary with it all.

There are times when feelings of pity are experienced, usually when looking at her naked and twisted body. Thoughts such as this are not as frequent as time has enabled adjustment and adaptation to Gwenda's disability and their situation.

Family nine

Mike's experiences:

A textural description

Mike views himself as being the provider for the family, being able to go out to work enables him to provide the income for the family to live in their home and have an annual holiday.

Mike's role in relation to caring for Deborah is now secondary now that she is a teenager he used to be more involved in all aspects of her care. He does however assist in sharing the care burden with his wife Jenni, who provides most her physical care needs.

There is a strong feeling of parental responsibility on Mike's part in that he is there to guide and teach his children how to behave in a manner that is socially acceptable. He often has to deal with and manage Deborah's difficult behaviour that causes distress and family conflict.

A structural description

Mike's style of parenting has been shaped by his own childhood experiences of living in a happy home with supportive parents.

Mike finds it very difficult in managing Deborah's challenging behaviour, more so when his other daughter is the target. Situations like this provide an opportunity for Mike to talk with Jasmine about how they feel; sometimes it results in them having a cry together.

Higher stress levels are a constant feature of Mike's day, worrying about Deborah's long term future, the effect of her behaviour and care needs on family functioning are the three main elements of stressors. Going to work enables Mike to keep ongoing and helps him to remain sane.

Jenni's experiences

A textural description

Jenni views her role as one of providing for her children; this includes the practical chores of housework as well as protecting and providing a loving, caring home for the family. Jenni engages in most of the childcare activities but acknowledges that her husband Mike helps out when it comes to looking after Deborah.

Living with Deborah has become increasingly more difficult as she has got older; there are elements of feeling worn down with it all as Deborah's care needs have not really changed since she was a toddler. Jenni experiences a range of emotions which are directly linked to being with Deborah, she can experience great pleasure and at other times she could get hold of her and 'strangle her'. Mike provides a real boost for Jenni and helps her cope with high demand situations, without his strength and support she is of the opinion that Deborah would now be in full time care.

A structural description

Jenni feels that as individuals and as a family unit they have remained stuck, unable to move on; this is attributed solely to Deborah's disability. There are clear thought patterns that questions about what has happened to them and what they must have done to deserve having a child like Deborah. Deborah's disability is blamed for their situation and she experiences private thoughts about how different their situation would be without her. She also experiences feelings of anger and hate towards Deborah and feels unable to make any real plans for their future.

Jenni's views and feelings towards having a family have been influenced by her own upbringing. Her parents divorced when she was a teenager and as a consequence wanted to get married, have children and 'live happily ever after'. Jenni believes that she is more resolute to succeed where her parents failed.

Family ten

Shaun's experiences

A textural description

Shaun sees himself as the provider, the man of the house who goes out work thereby providing the finances required. He states that he is a part time father due to working away from home and only being home at the weekends. In view of his work commitments he is very proud of his children and that he feels privileged to have been given the role of being Robin's dad, and that it comes with a huge responsibility.

Stress is experienced at a low level during the working week, this is however an acknowledgement that Joan has the greater share of responsibilities caring for all of the children. As such he takes on the responsibility of caring for Robin each weekend, this takes the form of driving around for hours at a time; this provides Joan with a welcome break and allows the other children to have some of their mum's time.

There is a comparison between Shaun's own childhood to his own role as father and husband and that there are clear similarities: being the provider, the leader; having the final word.

A structural description

Being a part-time father results in Shaun not having to deal with the daily hustle and bustle of family life; this clearly contributes to his low stress levels. Nonetheless he holds very strong views on being a parent, in that he is there for his children irrespective of whatever has happened.

Life in general, due to work routines and Robin's disability is restricted. They as a family are unable to do normal things, simple things like hunting for the key before going to the toilet is a chore [most of the internal doors have to be locked as a way of denying access for Robin], this causes real hardship and frequent conflict. Families should not have to live like this.

Shaun, like his wife, experiences regular physical assaults and feels that he can no longer take any more of it, he has a fear that one day he might snap and possibly do some damage. When Robin does hit out and connects properly feelings of hatred are directed at him and it takes a big effort in controlling himself. Further thoughts of resentment are as a consequence of them not being able to do usual family things like having a holiday or even for them as a couple to spend a weekend away.

Joan's experiences:

A textural description

Being a parent is a job for Joan, it is what she does. It is her role to be there for her children, making sure that they are free from harm and safe. She views all her children equally but accepts that due to Robin's disability he requires constant supervision and a great deal of caring; to such an extent that the needs of her other children take second place. Joan is the principal carer for her five children and due to Shaun having to work away from home has developed good routines and organises and plans ahead. If Shaun were home during the week life would be easier as the responsibilities of the care load would be shared.

Living with Robin is not easy; it can be very stressful when he is constantly posting his own and their belongings in the bin or when he is being aggressive towards them.

A structural description

Joan comes from a large family; she experienced a happy childhood living with her brothers and many animals. She has, for as long as she can remember wanted to be married with five children. This was and is her ambition in life and is on the whole very happy being a parent.

Joan has thoughts about life in general and questions whether what we get in life is fated or plain bad luck. These thoughts are specific to Robin's disabling condition. Robin's difficulties present Joan with a range stressors, he cannot be cared for by the

average 'child minder' this means that the family are restricted in what they can do as a family unit. This has a significant impact on Joan, as she is unable to have time for herself during the week. The only solution would be for Robin to receive longer breaks away from home – this though opposes Joan's beliefs.

Planning for Robin's future is a major stressor for Joan as there are no local colleges that are able to meet his needs. This created feelings of fear and panic as she will have to consider a residential college placement many miles from home, with these thoughts Joan is attempting to address Robin's needs and balancing the needs of her other children, Shaun and indeed herself.

Family eleven

Peter's experiences

A textural description

Peter does help out with household chores and childcare activities his main role however is to keep the boys entertained when they are at home. Peter's role has changed as the boys have become older and more challenging; he is the one who deals with the physical aggression and property damage.

Peter had always hoped that he would be able to do the 'dad' things, going camping, fishing, playing football, this never happened which for him has been a big disappointment as he never had this relationship with his own father.

A structural description

There is a sense of weariness and tiredness when Peter describes how difficult it is when having to deal with and manage the boy's physicality; more so now that they have become older and much bigger. This is Peter's main responsibility, as he cannot expect his wife Tania to deal with this level of behaviour. If it weren't for his ability to cope both the boys would not be living at home and would no doubt be in a care setting somewhere.

His life is totally dominated by the boys and that it is particularly stressful as Ricky's behaviour is very challenging, destructive and potentially dangerous. Peter concerns himself with thoughts about how long he will be able to cope with the frequency of the outburst and the high levels of stress he experiences.

Tania's experiences

A textural description

Tania's role as a parent has been to care for her children, to ensure that they are happy and free from harm. As they have grown up some aspects of her caring role have changed. She continues to see to their dietary needs and sees to their general care. Tania continues to view her role as 'being there' for the boys whilst they remain at home.

Dealing with high levels of aggression and destructive behaviour is feature of Tania's day-to-day living; this creates a range of stressors, which at the moment are very high, what with having to attend planning meetings in respect of Ricky.

A structural description

Tania is very clear about her role as parent to the boys; she feels that she carries out most of the caring and emotional responsibility and that it is not really shared. Each day is completely taken over by the boys and their needs, whether this is engaging in practical activities or offering emotional support to Peter. Whilst this is accepted as her role there is to some extent resentment, in that, she has no time for herself or for Peter. Life has been altered for the worse.

Tania often thinks about having a break from the constant stress of caring, but would then also stress herself about the quality of care being given to her boys. She has learnt to deal with these feelings and put them aside whilst she gets on with the task of everyday life.

PART THREE: The meaning of being a parent and caring for a child with significant learning disabilities: Composite textural and structural descriptions.

This section provides a clear and vivid account of the composite textural and structural descriptions of being a parent of a child that has a learning disability.

Composite textural

The experience of being a parent of a child that has a significant learning disability is an intense and emotive journey. This is particularly so for those who do not have the emotional and physical support of a partner. For some parents there is an overwhelming sense of feeling isolated and alienated from society that creates a sense of confinement, with their lives being put ‘on hold’. Whilst they are living each day there is limited or no opportunity to discuss long term plans and their thoughts about their own and their children’s futures. These parents often end up suppressing all of these emotions.

Some individuals experience being criticised by their spouse, peers and society in general for their apparent inability to cope with the care demands. It seems that these individuals place additional burden on themselves in their failure to cope, as they see it as their duty to be able to cope. This is partly due to the general expectation that as parents they should get on with it, as “this is your lot”. Some parents set high self-standards for themselves, which in turn may cause increased levels of stress and conflict that is either internalised or externalised. Internalised conflict relates to their failure in meeting these exacting standards and externalised conflict relates to support systems be they informal or formal. These individuals become pre occupied with their high volume demand lifestyle that becomes isolated and insular with no escape from

the caring, planning and organising role. Several parents in this study described their lives as being 'couples non-existent' with no apparent solution to change hence the expectation that this is how life is meant to be. Other parents over time gradually realise that they will be unable to experience being 'normal' as a family. This is described as being able to go fishing, playing football, and going out for a meal and general socialising. This realisation becomes more grounded as the child with learning disabilities matures and moves through the life cycle; and can leave parents with an uncontrollable sense of loss. Where there are other siblings, these feelings and thoughts can be extended towards them. This can manifest in feelings of sadness as their other children have "missed out" on a normal childhood as a direct result of having a brother or sister with a significant learning disability.

Parents mentioned that there is a darker side to their thoughts and expressed accounts of feelings of anger, hate, resentment, hopelessness and despair that are directed specifically at their learning disabled child. Some thoughts were directly linked to high stressful events such as the child's challenging behaviour or as a general resentment for the parent's life being "put on hold" indefinitely. Private thoughts were always experienced individually and for some resulted in feelings of self-loathing and guilt for having such thoughts, while for others there was an acceptance that these are normal thoughts that act as filters for highly emotional situations.

There is a strong link between all of these parents to a general feeling of being isolated and alienated from society. This extends to family and friends. This leaves the parents feeling trapped due to the high demands placed on them each and every day. Alongside this comes a feeling of no escape from this burden of constantly caring: a

career in caring. This describes a situation of not being able to be flexible and to “change one’s mind at the last moment”. This can create a significant restriction in an individual’s social life with no prospect of any change with a sense of a diminishing opportunity as time goes by.

Composite structural description.

Being a parent of a child that has a significant disability can be experienced by feelings of being alone and separated from the outside world, as though you are being firmly held in a microcosm where your cause is hopeless with no possibility of change. As a result of this sensation there is an associated disruption to the normality of life as it was expected to be. The care demands and lack of movement along the life cycle are a precursor for and the maintenance of this sense of hopelessness. There is also a sense of being ‘left out’, forgotten even by friends and family, which hastens their sense of no hope. Parents out ‘of duty’ or a resignation to their ‘lot’ forfeit or put on hold ‘who’ and ‘what’ they are as individuals that leaves them with diminishing opportunities as time passes by.

A common feature for some parents is the search for support, be it from a partner, other family members or from formal support systems. This search is to facilitate assistance or help, be it on a practical or financial basis. Parents may experience heightened sensitivity to other parties’ comments or opinions that can and often does impact on their self-esteem and well-being. As such they may be confronted with an alarming negativity when they consider their lives and life’s meaning.

The parental role is clearly defined and set out before them, one that is governed by their own childhood experiences of being parented, but as parents their parenting

expectations are altered to reflect the needs of their children's disabling condition and how it manifests itself.

Parents become attuned to the isolation, the weariness and fatigue of being in a long-term caring relationship, not as a distinct possibility but as a stark reality to their existence. Further to this fathers and mothers discover early on, in this caring role, that their own individuality and needs become invisible to services, that is, unless there is a desire and fire to 'battle' it out.

Parents experienced feelings of being of 'stuck' and became accustomed to the ongoing care demands. Further to this, parents of children who challenge behaviourally experienced greater social isolation. Parents in this study talked of the range of emotions that they experienced some that were projected internally and others that were projected at their learning disabled children. Feelings ranged from a deep love and warmth to extreme and intense feelings of hate, anger and resentment. The negative feelings were accompanied by a personal sense of self-loathing and a position of being a 'bad' parent. Some parents accepted these feelings as being normalised, a facet of being human, ones that act to help them 'vent' and 'filter' in situations of stress.

PART FOUR: The meaning of being a parent and caring for a child with significant learning disabilities: A textural and structural synthesis.

The experience of being a parent is characterised by three core themes and sub themes that act to illuminate the parental lived experience. Further to this there is a theme that permeates and interlinks each core and sub theme together. Each is explicated in the presented model and synthesis of meaning as follows:

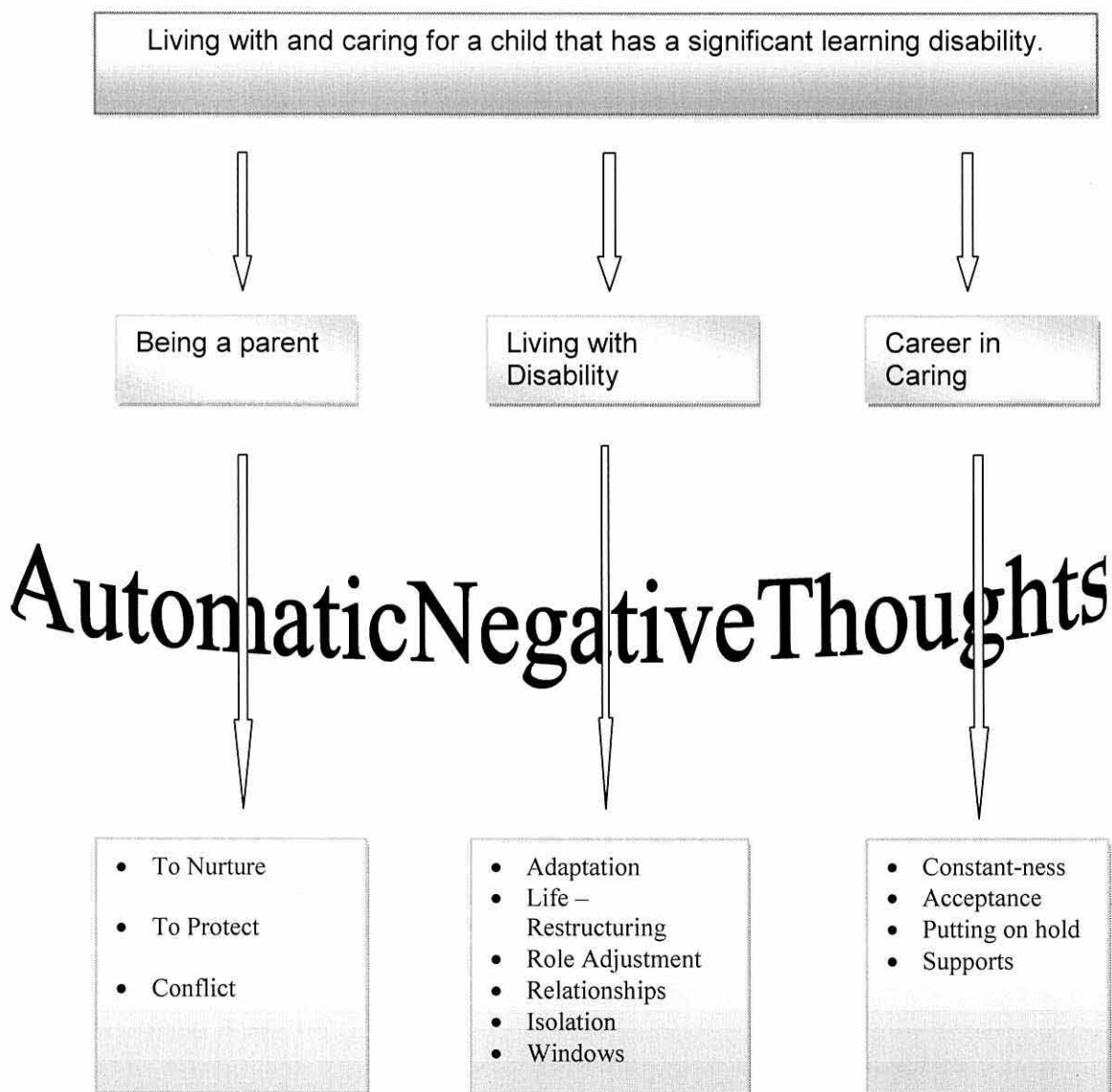


Table four: Parenting Model

Being a parent is a paradoxical experience that leaves each parent in a care-giving dilemma. The parenting experience is defined by one's own individual experience of being a parent of a child with additional needs. There is an experience of change that reflects the struggle in coming to terms with a child's disabling condition. The letting go of what you expected from the relationship to a new position of what is practicable and achievable. This position though is markedly determined by the characteristic, personality, gender and level of the child's learning disability. Parents from this study expressed their desire and expectations of being a parent, these expectations being drawn from their own childhood experiences of having been parented. For these parents their hopes, wishes and desires have been altered inextricably, as such, normalised expectations have been altered to reflect the needs of their learning disabled child/children.

Wanting to nurture, cherish, to be with, to care and provide the physical and emotional support is a fulfilment and expectation of the parenting role; that is until your child reaches a stage of development when they can effectively be independent from you. All parents in this study have not yet experienced this milestone with an overwhelming sense that it will never be realised, leaving them in a position of being 'permanent carers', that is, for as long as their children remain in their care. All parents talked of having to let go of the once held expectations hopes and dreams they had for their son or daughter. These normal life style expectations are never achieved thus causing further parental distress. All parents experiencing sorrow and sadness as a trajectory during the child's life, with accompanied emotions of love, hate, joy and anger that are experienced contingent on situational and transient events.

To Nurture

Some parents set themselves high standards when it comes to parenting and caring for their disabled child. Their inability in maintaining these standards created additional stress that was more often internalised. Most parents felt that their learning disabled children were being blocked from experiencing 'normalised' experiences; examples of this refer to choice of education establishment offered. These 'blocks' were attributed primarily to the type, nature and characteristics of the disabling condition. In addition to this parent's talked about how the odds are stacked against them and their learning disabled child and wider family in the quest for normality. There was a clear inevitability that their learning disabled child/children would experience limited opportunities throughout their life course thus adding to and compounding feelings of emotional pain.

Parents from this study clearly expect the same for their disabled child as they would for their typically developing children in terms of life course events. As such some families formulated a clear 'life' plan that would eventually involve the child leaving home to experience college be it as a boarder or as a day student. There was a stronger commitment to the planning process from the mothers' who hoped that their child would realise these opportunities; father's more often than not being secondary to this process. Irrespective of who takes the lead, this form of planning indicated that parents saw it as their own chance to reclaim their identities either as individual's, as a couple or as a family unit. Single parents aspired to these life course events, but had to endure the planning process as a solo activity.

To protect

Mothers' in particular talked of the need to fight for and advocate for their child's rights, normally above and beyond normalised expectations. Some fathers expressed feelings of "hurting inside" with an overwhelming feeling of helplessness, particularly in situations when their child arrived home from school with cuts, bite marks and bruises sustained by another disabled child/children. The feelings of helplessness stemmed from their inability to being there. Mothers and fathers expressed concerns as to their child's safety when away from home; one mother detailed by stating "He cannot speak, so how can he tell us if he has been bullied or hurt by someone else". Further to this as parents often had to rely on special school transportation, as such they missed out on the 'school run' as experienced with their other children. This furthered their sense of "not being there".

Mothers at time of transitional planning placed importance on the geographic location of the college or community living placement. A closer to home location would enable them to remain involved, albeit at a distance. It would however enable them to monitor the care. Fathers echoed this view, yet preferred not to talk about the planning process seeing it the domain of their partners.

Conflict

There is tangible evidence of arguments and tension between partners, other children 'in family', extended family, friends, neighbours and professionals. As such, most families, in this study, experienced varying and intermittent levels of conflict. Individual parents (mothers and fathers) experienced feelings of being criticised – either from their partners, the general public or from formal support agencies. This

created conflicts in terms of their perceived ability/inability in their coping. Statements of 'I should' and/or 'I ought' to be able to were formed and contrasted with polar opposites 'I can't' and 'I won't' be able to. Fathers, in particular, talked of being complained about by their partners for doing too much for their son or daughter – “giving him more help than he needs” or conversely “doing too little” when it comes to child care activities. Further to this, both parents expressed dissatisfaction with their partner's performance, mainly relating to how they managed difficult child behaviour situations. Parents in this study shared these views with each other, which on occasions created further conflict situations and bad feelings towards one another.

Most partners reported heated discussions and states of impasse when discussing their child's management. Some conflict resulted as parents held differing opinions as to service inputs – one parent wanting additional support such as respite care, whereas the other partner rejecting this suggestion out of hand, with mothers mainly seeking formal supports.

All parents with other children reported sibling conflict that tended to focus on differing house rules that were perceived as being unfair and inequitable. Comments such as “why can he do and I can't” were commonly reported. Another common feature was the ‘open’ resentment about the amount of parental time spent with their learning disabled brother or sister with the typically developing siblings asking “when can we/I do this with you?”, and “it's not fair” statements that were generally proffered as a form of protest.

Service conflict was reported mainly by mothers who detailed the gulf between what was wanted in terms of service provision against what was on offer. Often resulting in a battle and fight with service providers/commissioners for what is considered a fair and appropriate level of support.

Some mothers introjected blame for the causation and maintenance of their child's challenging behaviour. This cycle of blame is seen to be reinforced externally by other people that includes partner, other family members, friends and professional support staff and has a tendency to engender a position of giving in: "anything for a quiet life".

Parent's *living with their child's disability* can experience a range of adjustments to their role; they often restructure life patterns in order to meet their children's physical and emotional needs. Two and lone parent families develop strong routines in an attempt to normalise family life. Some of these routines have developed out of necessity thus preventing escalation of challenging behaviours. Some families talked of living separate lives even though they lived under one roof. Activities were often split with one parent doing activities with the other children and the other parent seeing to the needs of their learning disabled child. A consequence of the life change impacts and the new demands placed upon parents evokes emotions of anger, hate, resentment, hopelessness and despair. They are often focused in the direction of the root cause – the child with disability. There are tangible links to chronic and high levels of stress often perpetuated further by lack of sleep. Parents develop an individual perspective about their situation, often with feelings of self-loathing and guilt, particularly when experiencing negative emotions towards their child and their

situation. Coping strategies used tend to be emotion focussed that provide immediate amelioration of stressors by either engaging in regular drinking and smoking.

All of these factors add considerably more stress and deplete already low energy levels. Parents in this study had experienced the frustrations of securing appropriate levels of support and care. Such examples focus on poor standards of care and inappropriately matched supports. One mother explained that her son was being cared for by a newly appointed support worker, who unfortunately did not provide the desired level of supervision. This mother returned to find her son, his bedroom and two other rooms covered in faeces. Other parents talked of their children being offered over night breaks, which at that time was very welcome, only to find that their children had been sharing with other disabled children, who were either of different ages and ability levels.

Adaptation

Couples talked of a connection with each other and a reorganisation of life commitments; this is evidenced by the fact that most of the families were still in it together. Some parents do make positive adaptive changes and make adjustments to their lives. They utilise a range of coping strategies that make the difference between coping and not coping. There is within this a potential to come to terms with their situation, to accept, to adapt and find ways in reaching a state of happiness thus reclaiming personal identity and self-worth: "being an individual"

All parents engaged in 'comparison behaviours' that is contrasting 'one's own lot' against other families who were viewed as being better or worse of. This helped them

adapt and adjust to their child's difficulties and presenting problems. It also enabled them to come to terms and accept the reality of their situation. Some parents survived from one day to the next. This is a commonly adopted coping strategy particularly by those parents who were experiencing severe child behaviour problems. These parents talked of the lack of opportunity to be flexible and spontaneous from one day to the next where routines are generally fixed and rigid.

Life restructuring

Parents created a 'mindset' where they reorganised and restructured their lives so to meet the new demands of caring for their learning disabled child. This redefining of their situation often involved challenging their belief systems, a consequence being that they put on hold or forfeited who and what they are as individuals or as a couple. As time passes by there is a further diminishing of opportunities, which further compounds the sense of life being placed on hold.

Fathers in this study had clearly reflected on and attributed their situation to: "it being God's will" or "it has happened for a reason". Life disruption is an expected consequence of having a child with additional needs with the lack of movement along the life cycle maintaining a sense of hopelessness with further feelings of being lost and left out. Some mothers felt that they had been forgotten.

Role adjustment

Working as a team has ultimately brought two parent families closer together and is a common feature of the lives of these parents, further to this families talked of how the care sharing role was evenly distributed. There are of course differences from one

family unit to another, but on the whole there appears to be an agreed and accepted spilt when it comes to who does what. Fathers in this study engaged in household chores, this often involved house cleaning, cooking and shopping. If they were up first in the morning they would engage in direct care activities such as washing, dressing, and changing soiled clothing. They would prepare and administer medication and occupy their children. However, roles within these families are largely based on traditional gendered role trends. Mothers having an expectation of taking the primary role in child care and general home based duties while fathers provided the financial and emotional support. In some two-parent families there are evidenced shifts in these normalised patterns, more so when the child matures. These patterns are either agreed or evolve over time. It is clear that roles were defined over time and changed over time with fathers taking on more care based activities with their learning disabled son. Some fathers expressed that they were uncomfortable with the thought of having to assist with their daughter's personal care, particularly when they reached puberty, preferring not to. This would suggest gender sensitivity. Mothers however continue to see to their son's physical care needs, for some out of necessity and for others out of habit. These findings would concur with Grant's (1986) theory that care giving roles are established and fixed early on. There needs to be an acceptance that care giving patterns can and do change as a result of the changing family dynamics.

Validation of one's own role is clearly linked to child's level of dependency. Mothers viewed one aspect of their role to be that of teacher and advocate. This need becoming more evident once the child had entered the education system. Families in this study had established work and support patterns, with fathers being the ones who went to

work. In spite of this there is clear collaborated evidence that fathers engaged in a range of child care activities and household duties.

Relationships

The child's condition and presentation can have a detrimental effect on family relationships. Some mothers and fathers referred to 'supporting' each other; providing support helped them cope with the daily demands. This 'in family' support suggests that they are 'in it' together. Two parent families in this study illustrate a commitment to each other and their children, this suggests that they have and continue to adapt and cope, more often than not in 'dire' circumstances. As a couple "you are in it together" but there is an element of being a "couple non-existent" with never enough time to do things together. Life is consumed with the caring and planning role with a deepening sense of there being no way out of this situation; this brings about the position: "no hope".

The effects of caring can be numerous and time consuming with an all exclusive focus on the needs of the learning disabled child; often at the expense of other family members. Family therefore can and never will be normal, with other children having to 'fit' in, which precipitates the feelings of chronic sorrow.

Isolation

Most mothers and some fathers talked of being isolated and insular with cognitions of "why us". For some there is an overwhelming sense of feeling and actually being alienated from society that leads to a position of being "confined", where "life has been placed on hold. For some mothers and fathers this is an unchanging position.

Most mothers and fathers experienced isolation where feelings of “you are very much on your own”, “fighting for survival”, “for supports” are experienced. These parents are essentially fighting for recognition, with life being perceived as a form of imprisonment with “no way out” and “no conceivable escape” from the situation they find themselves in. Some mothers who constructed a ‘way out’ often found that the construct is all too easily demolished furthering the sense of entrapment. Life therefore can be bound with confinement, mundanity and predictability, with unwanted but necessary routines being a key feature of day-to-day existence. Thus creating an enhanced feeling of “being stuck” – the greater the care burden the more isolation is experienced. This is typical of parents who have to manage complex behavioural challenges, with isolation being experienced as families or as individuals.

Families also talked of how life was “inflexible” where normal daily activities required a fair amount of physical effort in terms of planning and managing. Often resulting in parents being unable to be flexible and responsive to opportunities as and when they arise.

Some mothers felt that they were also emotionally isolated as if they were “the only one in this situation”. Several of the mothers expressed a need to maintain a semblance of social contact as a family and as an individual: “maintaining an identity”. The care burden often acted to further this sense of social isolation. The reduced contact with family and friends compounded further the feelings of being trapped. Parents reflected on their position often resulting in them retreating further into the career of caring: “that is all I know”.

Window of opportunity

Life style opportunities are viewed by all parents as being limited, with their learning disabled child dominating family life. This impacts significantly on family based activities. The burden of caring has a detrimental effect on family spontaneity; families being unable to engage in family based activities without significant planning and sub planning effort. Simple activities like going to the shop involve major effort when the child with disability is home. As such families experience being spontaneous only as a 'window' of opportunity, this usually occurring when their learning disabled child is away from home i.e. at school or when at respite care. Further to this, parents experience a welcomed decrease in supervision duties when their disabled child is away from home: "not having to lock doors and windows" and "being able to wander around the house without having to think about X and what he is doing". It gives them opportunity to engage in normalised parenting with their other children: "being able to go to the park, or cinema without that much thought and planning".

Opportunities are often restricted with planning being a major component of family life. The learning disabled child's behaviour further limiting activities and opportunities. Some parents strived for 'normality' never being able to experience this fully when their learning disabled child was at home. Other children in the family experienced decreased 'at home' contact with friends; often preferring to spend more and more time at their friend's house or up in their bedroom. Parents reported that their other children are either embarrassed by their sibling's behaviour or disabling condition, and/or that their friends reported to be scared, particularly when an older brother or sister challenges behaviourally.

Parents are more than likely to be subsumed into a *career in caring* with an alarming certainty that there is no “get out clause”; with a huge sense of being stuck. This was described as a perpetual turning wheel that revolves around the provision of high levels of personal and supervisory care for their learning disabled children. A career in caring as a dynamic therefore perpetrates a general feeling of fatigue, weariness and a sense of isolation. One’s own identity and individuality can be rendered invisible to service providers: “you are merely a conduit for the caring role”. For some mothers and fathers there is an acceptance that there is going to be an on-going commitment in providing physical and personal intimate care to someone. For some parents in this study, there was an internal struggle in coming to terms and accepting that this is the way life will be. Paradoxically there is a limited sense of self in the context of caring. Putting on hold and sacrificing their own needs to that of their learning disabled child.

Most of the parents experienced a range of personal private thoughts. These thought patterns were on a continuum from loving to hating, from protecting to wanting to harm and from attributing meaning to a higher being to it being pure bad luck. The more extreme thoughts of hate, resentment and anger seize and embraced parents at times of distress. These feelings, for some, are carried as an additional burden with introjected thoughts of guilt and shame. Other parents viewed these thoughts as protective mechanisms; ones that helped them deal with high emotive events and without such filtering systems felt that they would otherwise be at risk of acting out.

Constant-ness

Living for each day within a routine that has been firmly established and embedded over several years cements the parental view that there is no or limited opportunity to discuss long term plans: “there is a sense of futility” and “how can you plan for something when you don’t know what it is you are planning for”. This circular dynamic affects parents as individuals, as couples and as families. Parents in this study have subsequently reached a position of: “there is no end to this” coupled with a sense of resignation to the ‘actuality of what is’. Some parents struggled with the concepts of having to provide long term physical care outside of the expected ‘norms’. Some fathers talked of their frustration in not being able to make change with a sense of inevitability that nothing will change. This is a significant feature of day to day living for these parents.

Acceptance

The development of a construct where parents are constantly reminded of their situation. As such parents come to accept their situation, even though they may be unhappy with it. Several parents talked of a feeling of being ‘on call’ where they felt that they could not leave the house, just in case they were called upon to deal with any child related emergencies. The advent of mobile phones, has for some, lessened this feeling. Parents nonetheless still feel ‘trapped’ in a state of having to be readily available. Parents acknowledged that as the care demands can be both physically and emotionally exhausting they required support from external sources.

Putting on hold

The majority of parents in this study talked in a manner that can be best described as a position of ‘acceptance’ that their lives were now in a state of suspension, for some this was a permanency. Mothers in particular held a firm view that they would resume and fulfil their own aspirations once their son or daughter had left home. Fathers who engaged in ‘normalised’ work patterns experienced a life focus; nonetheless their role as supportive partner was restricted as they often came home from work to commence their “second shift”: ‘relieving their partner from the caring role’.

Parents out of a sense of duty and commitment to their learning disabled child did not seek or ask for help – this sense of being was borne from a notion of not wanting to burden anyone else.

Support systems

Family support impacted on the emotional, physical and financial needs of the families in this study. All families in this study valued support whatever form it took, be it from immediate family, friends or formal supports. Mothers expressed the importance of having someone who they could talk to. Having this form of informal support was highly appreciated and welcomed where they were able to talk without fear of recrimination or being judged. The ‘talking’ support came from their own mother or close friends. It is common for families to receive support from maternal and paternal grandparents or their own siblings, in terms of helping out with child care, household duties, sitting in or offering overnight stays albeit predominantly for typically developing children. This support had a tendency to reduce over the passing years, either because of family relocation, their increased inability in managing the

child with learning disability, ageing grandparents, significant illness or death. Other family members/friends experiencing decreased capacity due to their own family commitments and inability to cope with the demands of the learning disabled child. Some parents talked of having the additional burden of having to support and care for their ageing parents, thus placing them in a further stressful situation.

Some families received financial support from family members and formal support services that acted to augment daily living costs such as purchasing any specialist equipment and the repair or replacement of broken household items i.e. beds, mattresses, T.V's.

Inevitably parents talked of their search for support out of family. Parents experienced a range of knock backs that heightened sensitivity to other people's comments and opinions. This places additional costs to parental self-esteem and well-being. Mothers and fathers talked of the "cost" to securing support from formal support systems with the on-going assessment, the funding constraints, and the time taken to complete assessment and secure specialist equipment. Some mothers explained that they often found that their child had outgrown the equipment before having opportunity to use it. An example of this was the ordering of a 'safe suit'. The young person having grown significantly before it arrived, rendering it useless.

The conclusions drawn from this research are identified in the following, and last chapter of this thesis where the essences of parental experiences are discussed in the context of the literature together with a reflective account for practice and policy.

CHAPTER TEN: A reflective account: implications for theory and practice

1. Introduction

The aim of this chapter is to draw conclusions from the findings of this study that answered the question of what it means to be a parent who lives with and cares for their child/children that has a significant learning disability. It will also discuss whether the findings make a contribution to the body of current knowledge, and what impact this has for theory and practice. The limitations of this study and the implications for further research are also considered. A further discussion as to the truthfulness and credibility of this study coupled with a pragmatic look at whether these aims have been achieved will be engaged in. To conclude there will be a final reflection on the phenomenological approach and whether this project captured Husserlian methodology as it intended.

2. The context of discussion, this and previous research.

Social policy and Literature pertinent to this study was examined and presented in chapters one and two. Whilst there is a plethora of relevant family-based research there is a lack of available literature that focuses on both parents in an equitable and meaningful manner. This study therefore adds to and builds on our understanding of families who live with and care for a child that has a significant learning disability. During this discussion links will be made to existing literature with a view to confirming or contrasting opinion.

3. The meaning of being a parent (the terms parent/couple, father and mother will be used interchangeably throughout the following text).

All parents in this present study talked of their commitment to the task of being a parent, where they have created and attempted to maintain a loving and safe environment for their children as they grow from baby to toddler, right through to the teenage years. This is in accord with Wheeler *et al.* (2008) who reported mothers to view their role as being extremely important, satisfying and rewarding despite the effect their child's disability may have had on their quality of life. Wheeler *et al.* (2008) reported mothers to have made reference to their own personal identity and their desire to maintain such. Instrumental to this is their need for an improved balance between their role as carer and that of being a parent (Beresford *et al.*, 2007). In this current study the role of caring has come to dominate the lives of parents and this has affected the way in which they viewed themselves. Key areas, such as, work, hobbies, interests, friendships are sacrificed or put on hold as they engage in long term caring; some seeing it as their duty to do so.

Fathers and mothers in this study acknowledged and explained that being a parent required a lot of effort, adjustment and commitment. By nature parenting involves an element of care giving, at other times as a teacher, a guide, friend or companion; often these roles merging into one. It is likely that parents, in and outside of this study, will experience their children's dreams, their anxieties, joys and sorrows and to be the primary provider of love, approval and support. This can be considered a normal expectation of parenthood, yet many parents in this present study spoke of how some of these expectations would never be realised.

Father/mother early experiences of caring for a young child are normative in that it is an expectation. However, caring for a child that has a life-long disability may create a dependency that can impact on the emotional well-being of parents; one that significantly alters the experience of being a parent. This is documented by Kirk *et al.* (2005) who found parents of technology-dependent children to construct a role of specialised care provider as well as that of a parent. Parents in this present study have likewise constructed a role that encompasses one of being a parent that is bound by their need to love, cherish, nurture and protect their child/children and the role of being a carer that involves providing high levels of physical care to a child that will be enduringly reliant on them for life.

It is clear that parents in this study see it as their responsibility and duty, irrespective of their child's needs, to provide for their child/children with no strings attached. There appears to be a stronger commitment in two-parent families to each other and their children with lone parents often feeling more isolated and left to fulfil all elements of the parenting role. Mothers more so than fathers expect the same outcomes for their learning disabled child as they would for their typically developing children. In this study mother's were the planners and organisers; with father's typically taking on the secondary or peripheral role. This dynamic can be explained as a 'gendered' issue where support services predominantly engage with the mother. I would argue that service configuration in some ways colludes with the notion that the primary 'actors' in child care are the mothers. As such appointments and meetings with professional supports tend to occur during 'normal' working hours. This way of delivering services will naturally exclude fathers from contacts and engagement with the planning process. A recent report from the Equality and Human Rights

Commission found fathers wanting to spend more time with their children, thus sharing child care and work life responsibilities (Ellison *et al.*, 2009).

It is evident from this study that 'conflict' is a feature of parent's lives. Conflict can be experienced 'in-house' between partners and children, extended family, friends and professional supports. Fathers talked of being criticised by their partners for either being 'over' or 'under' involved with their child/children. Being 'under' involved suggests that fathers are reverting to traditional trends where mothers are viewed as the primary caregiver. Conversely, fathers who are 'over' involved would suggest that they are sharing the child care arrangements. Further to this both parents expressed dissatisfaction at each other's performance when managing their children's behavioural challenges. Parents talked of the need for consistency in management approaches and readily voiced their opinions, thus causing additional conflict. Glen (2007) makes reference to a conflict model where mothers openly criticise their partners for lack of perceived supports. Fathers subsequently withdrew from family, leaving mothers in an enhanced unsupported position. It is suggested by Glen (2007) that marital dissatisfaction and ultimate relationship breakdown is generally experienced; with the greater proportion of learning disabled children being cared for in lone parent families. This study struggled in securing two 'birth' parent families; however, those families that were secured illustrate a commitment to each other. Therefore it would be indicated that research should also consider whether pre-existent marital problems that were manifest have been exacerbated by the birth and subsequent 'altered' parenting? Another consequence of internalised parental conflict is the formulation of intrusive negative thoughts. Most parents in this study

experienced negative emotions about their situation that were attributed to a central foci: their learning disabled child.

Other children 'in-family' routinely experience 'altered' parenting and family life which is directly associated to their learning disabled brother or sisters presentation. Whilst it has never been the intention of this study to focus on siblings their needs in terms of being a typically developing child in a 'disabled' family does require further consideration. Service providers do need to capture family holistically with the view of offering families the opportunity to experience being an inclusive family; thus reducing the disabling affect.

4. The meaning of living with a child that has a significant learning disability

Being a parent to a child with significant learning disability brings with it a variety of challenges. For some parents there is a feeling of being 'stuck', being unable to move on and recapture their lives as individuals, as a couple, or as a family. They attribute their child's level of physical care and supervisory needs as a causal factor. Some mothers explained that they would like to be able to resume 'normal' activities such as being able to go out for a walk in the evening. Parents also commented on how restricted life is and that managing on a daily basis is a major juggling act, having no time for themselves or for others. This includes their other children in family, partner, family and friends. Another manifestation of this can be understood in terms of the 'burden of caring' which is often viewed by parents as being terminally isolated. Parents spoke extensively of how their lives have been determined and shaped by the needs of their learning disabled child/children. This limits family experiences and subsequently family expectations with a lack of opportunity to be spontaneous as

individuals and as a family. A direct correlate to this 'caring burden' is the resignation to their situation and a position of 'doing one's best'. Many parents articulated a concept of 'window of opportunities'; where families were able to experience being 'normal'. Being 'normal' was important for parents yet only occurred when their learning disabled child was being cared for elsewhere. Some families described that they were only able to do things either as individuals, as couples or as a family when their learning disabled child/children were away from home. Others stated that they were too fatigued and spent their time recuperating from the 'care burden'. Some mothers explained how they spent time with their other children during these breaks in caring, engaging in activities such as watching television, playing games and talking. For a few families it meant that they could use the house as 'intended', without having to navigate locked internal/external doors and windows without the fear of their learning disabled child absconding.

All parents talked about a significant feature of their lives; making reference to the difficulties in living with and managing child behavioural difficulties that were of high intensity. Behavioural difficulties ranged from: physical aggression aimed at others, property damage, child self-harming, excessive ritualised behaviours and routines, faecal smearing, regurgitation and eating inedible items. Fathers explained that they tended to deal with the physical side of managing their child. This often resulted in physical interventions. When fathers were absent mothers had to deal with these situations. Behavioural problems are a regular feature of daily life for this group of parents and have in many respects adjusted to and adapted family routines, placing importance on them in how they cope from day to day. Lewis *et al.*, (2006) indicated high parental stress levels to be directly linked to their child/children's level of

behavioural challenges. In this study parental response to child behavioural difficulties perpetuated feelings of anger and resentment. Some Mothers and fathers were extremely open when discussing their thought processing, in this regard negative thought constructs, such as anger, hate and loathing were experienced intermittently and were dependent on situational events. Parents also experienced behavioural difficulties as a night-time issue, mothers and fathers talked of the need for a full night's sleep; often having frequent disturbances where they had to settle their learning disabled child or get up with them at an early hour. For some mothers this meant sleeping with their child. A resultant factor of sleep deprivation being higher levels of experienced stress, symptoms of fatigue and an overall affect on personal well-being. Fathers who were in full time employment talked of how they commenced a second shift on returning home from work as a way of offering support to their partner and also as a way of spending time with their children. They found it particularly difficult in terms of tiredness when experiencing sleep disruption. The 'fatigue factor' was significantly magnified over time particularly when having to get up early the next day to go to work. The findings from this study mirror that of Towers (2009) where fathers in full time employment engaged in childcare activities after work and at weekends. Short breaks enabled all family members an opportunity to experience a 'window' when they did not have to think about or engage in care and supervisory duties and offering the chance to catch up on lost sleep.

Another effect of living with your learning disabled teenager is to manage pubertal issues. Many parents experienced their son's sexualised behaviours, which is a real concern for parents particularly when accessing their local community. There are several examples where parents' described a situation when their son had masturbated

openly in public. Further to this, fathers talked of their difficulties in managing and seeing to their daughter's intimate care, as they are now young women. A key finding from this study relates to the changes experienced in the caring role, this is evidenced primarily when children reach puberty or when the child becomes physically harder to manage. Some fathers talked of how inappropriate it is for them to care for their daughters, particularly for their intimate care. They found themselves in a difficult situation, as they wanted to continue offering support to their partner and reconciled this dilemma by offering support from a distance, by way of supervising their daughters albeit from a distance. Some fathers, particularly those who were the primary carer, did not recognise 'gender sensitivity' finding it acceptable to engage in formal caring, rationalising it by stating that their daughter doesn't know any different, which is certainly a reflection on how they view their child's disability. It is common for mothers, in this study, to continue providing personal care for their sons. This would suggest that they do not consider gender issues, but rather, out of necessity: 'it needs to be done' or 'purely out of habit' – "It's what I do". A number of mothers from this study discharged this duty to their partner, not through gender issue consideration, but more to do with the wear and tear of caring and the physical difficulties in lifting and moving their sons. Contrary to the commonly held view that fathers seldom participate in direct childcare and household activities, this study has evidenced that they do indeed play a significant part in their child's physical care and general household duties. This is described by Towers (2009) national survey where fathers had a strong sense of involvement in providing care and support to their children and partner.

Many mothers from this study talked about how they dread school home time. There is a sense of heightened anxiety and expectation. The 'not' knowing what mood their child/children will come home in. Some mothers experiencing physical events such as increased heart rate, for others it merely meant that they had to get back in to carer mode.

It is evident that two parent families from this study were 'in it' together where some, but not all, perceived themselves to have reasonably good social supports. Irrespective of perceived supports mothers and fathers experienced and viewed stress as a constant feature of their lives. The stress experience fluctuating dependent on life events. Factors such as episodic behavioural challenges and associated family conflict were the main constituents. The evidenced levels of mutual and reciprocated support in these families should according to Wheeler *et al.* (2008) and Sgarbosa & Ford-Gilboe (2004) ameliorate high stress and depressive symptoms, thus increasing positive perceptions of one's quality of life. The findings from the present study suggest otherwise, in spite of 'perceived' supports most families experienced stress level as a 'constant'. It is also worth considering here that is it always going to be difficult to predict how parents are going to cope in the future. The nature of stress and adaptation is always going to be fluid and transient dependent on how they as individuals and as a family adapt. Likewise, adaptation will also depend on how their learning disabled child develops and matures over the life cycle.

It is also noteworthy to mention the nature of the children's diagnosis, level of cognitive impairment and for some the co-morbid diagnosis such as autism. It is more likely that these parents will experience different degrees and patterns of stress. These

findings are consistent with those of Lewis *et al.* (2006) where mothers of children with Fragile X syndrome are presented with more challenges to their mental psychological well-being than mothers who have a child with Down syndrome. It is clear from this study that parents expressed higher levels of pessimism about their learning disabled child and experienced more child related conflict within family. Parents of children with a co-morbid diagnosis of autism reported lower levels of reciprocated closeness than the other groups of parents. Some of the parents talked of the lack of social connection with their learning disabled child, in comparison to their non-disabled children. Behavioural traits that are common with the children in this study can lead to family members into dispute situations. Such disputes are reported to be about how to control and manage the child's behaviour. Being 'in it' together and knowing how each other works in terms of care and management styles can bring about a situation where parents instinctively know the best way of offering support to each other. This knowing of 'we are in it together' is a great source of support on an emotional level. The making of shared decisions about childcare and service provision, leisure and other family activities is also a source of mutual support. Whilst it is acknowledged that mothers in this study tend to lead on planning and organising, there is evidence contained within the transcripts where both parents in two parent families mutually support each other in general decision making and discuss with each other worries or concerns. This is reflected by Beresford (1994b) who suggests that partners were privy to worries that the other partner is unable to share with others. Those parents that were able to share worries/fears found it reassuring knowing that other parents had similar worries and faced similar difficulties as them.

Higher levels of child behavioural problems are a precursor to lowered parental well-being. The child's adaptive functioning marginally moderated the relationship of role and well-being. According to Eisenhower and Blacher (2006) multiple role occupancy enhanced mother's well-being when their child was functioning adaptively at the level of a 28 month old. These mothers were said to be either better able to find childcare or to benefit from the presence of a spouse or in employment where they could diffuse the parenting stress. This is evidenced in this study by married mothers who found employment. These mothers reported better well-being than mothers who were both unemployed and unmarried. Similarly, raising a child with significant deficits in their adaptive functioning may be more stressful and detrimental to their well-being irrespective of marital or employment status. All parents from this present study were subject to frequent episodes of significant and often complex child behaviour problems. The nature and impact of the child's disabling condition was discussed by parents in this study. The findings suggest that there is a tangible link to higher levels of experienced stress and family dysfunction to their learning disabled child. It is important to reiterate that the children's profiles indicate significant intellectual disability with concurrent deficits in adaptive functioning. These experiences are similar to the research conducted by Herring *et al.* (2006) where mothers reported higher correlates of stress and mental health issues as a consequence of their learning disabled child's emotional and behavioural problems rather than the child's diagnosis (in this instance Pervasive Development Disorder) developmental delay or gender.

For some parents in this study 'hope' is a feature in their lives. Hope as a concept has received some attention within the literature. According to Wheeler *et al.* (2008) it is found to provide resiliency in the face of stress. In parents where hope is lacking there

is a reported decrease in self-confidence and less subsequent success in achieving goals. These factors are synonymous to an increase in depressive symptoms (Kwon, 2000, 2002). Hope is also instrumental in parents abilities to problem solve, for their positive psychological health and in their coping response to ongoing stressors. It is also associated with adaptive coping strategies and provides parents with a sense of control in how they achieve goals, as such it is more than likely to play a significant role in the ability of parents who are at risk of emotional distress to mobilise social and personal resources. Parents in this present study who expressed a sense of hope presented as being more likely to adopt a warmer and nurturing parenting style, with a more cohesive and active family environment than those parents who had no sense of hope. Kashdan *et al.* (2002) suggest that parents 'given' hope are often better at utilising coping strategies when raising children who exhibit significant behavioural challenges; this is reflected in some of the parents' statements (see chapter nine). According to Wheeler *et al.* (2008) and Huprich and Frisch (2004) there is a clear correlation to low quality of life, stress and depression, with mental health issues being an important part of parents lives. Parents in this present study discussed their levels of perceived stress and the factors that contributed to higher experienced stress. Although stress experiences and coping styles differed between fathers and mothers there was an overall consistency in their perceived level of stress, as such, stress is a regular feature of caring for their children. This is reflected in a variety of studies where parents of children, especially those with significant intellectual disabilities with associated externalised behavioural problems, have been found to experience increased levels of depression, anxiety and stress in comparison to parents (in the majority of these studies mothers were the only measure) of children without disabilities (Baker *et al.* 2002, 2003, Wang *et al.* 2004). Similarly, Wheeler *et al.*

(2008) found higher levels of parental stress and child problem behaviour to be significantly correlated. This suggests that child problem behaviour plays a role in parent's experience of decreased quality of life and an increase in overall stress.

Gray (2006) suggests that parental coping strategies change over time. Parents in this study have over time developed a range of coping mechanisms; with fewer parents coping through their reliance on service providers and other family support systems. There is evidence of them withdrawing socially and relying on their own individualism. Parental coping in this instance can be viewed either as a distinctive behavioural style or an accommodation to an event that requires both behavioural and emotional responses and regulation (see Glidden *et al.*, 2006). All parents in this study tended to use less Positive Reappraisal strategies, which is in keeping with the findings from Glidden *et al's* (2006) study. Positive Reappraisal strategy is an emotion-focused strategy where an individual positively interprets events so to achieve personal resolution and growth. This approach can act to delay a solution to the problem as the individual will engage in a period of redefining the situation as less problematic; this strategy though is an effective one when faced with a situation that is not easily changeable, particularly when having to manage high level and frequent negative child behaviour. In this study the age and characteristics of the child shaped parents use of an Escape-Avoidance strategy as a way of coping with the daily demands of living with their child. This approach unfortunately has a tendency to reinforce the negative effect that is associated with the stressor.

Some parents articulated that they have used their religious faith and beliefs as a coping mechanism; this too is consistent with that of Gray (2006). According to Gray

(2006) 'aging' is linked to parents' use of emotion-focused strategies such as reappraising their situation. This can involve an appreciation of their child's positive qualities. Coping strategies can shift over time from problem-focused towards emotion-focused coping. Potential reasons for this shift are attributed to improvements in the child's condition, and being less disruptive. Family life becomes more routine and consequently parents experience lower levels of stress. Whilst this may be true for some parents it is not the case for parents in this present study. They all indicate experiencing high levels of stress as a consequence of their child's continued challenges and greater child care demand activities. This is in spite of firmly embedded family routine and an acceptance that 'this is how it is'. Todd and Jones (2005) capture this phenomenon entirely where families have been exposed to a new source of stress: the realisation that their child's condition is not going to improve and will in all probability result in them being unable to be independent when reaching adulthood.

5. The meaning of having a career in caring

In some ways caring for a child with learning disabilities becomes a given. For some mothers and fathers it is what they do, because if they did not do it, who would? Daily living has been discussed earlier in this chapter. However, in respect of this, many parents, particularly mothers, spoke of the necessity to develop strong family routines as a direct response to managing daily life with their learning disabled child. It is a common feature of family life to develop and maintain routines as a way of ameliorating behavioural challenges, therefore without these routines parents reported significantly higher incidences of behavioural disturbance. Routines are symbolic for most families in this study; a feature that is commonplace to a larger or lesser extent.

All parents in this study made reference to how they organised and divided family time. It is one strategy that enabled them to manage family routine that is meaningful to the family as a whole, particularly when there are other children in family. Some parents took the step of dividing up their roles, where one parent took the lead in activities that revolved around the care of the disabled child. These activities included: attending meetings, seeing to therapy and dealing with professionals who visit the home i.e. social worker, community nurse; whilst the other parent took care of the other children. Fathers reported taking the other children out, for example, for fishing trips and/or football practice. As I have discussed some parents adopted a team approach where they were “in it together”, this method enabled both parents the opportunity to participate with all family members in different activities as they occurred; this included activities that they would otherwise be unable to engage in with their learning disabled child/children. This way of being allowed family members to engage in family activities, albeit not together, but at least they were able to share some interaction. These findings are in harmony with the results from Schneider *et al.* 's (2006) study. Whilst it was not a focus of this research it would be of use to examine what comes first: routine or difficult behaviour? Or do they evolve over time through the shaping of parental responses by negative reinforcement.

Many parents from two-parent families explained that they would not be able to cope without the support of their partners. For lone parents this form of informal support is not available, often magnifying the care burden and marginalises them from social contacts. An expectation for most parents is the progression from ‘actual’ hands-on caring to caring in other forms such as offering advice and support. This progression usually occurs as children develop and consequently need their parents less. An

inescapable finding of this study is parents' continuation, beyond the expected 'norm', to care for their child's personal needs. This can manifest in an increase in parental stress, with exacerbated physical and mental fatigue. With this there is an acceptance that nothing 'will' change and an actuality that nothing 'does' change: a state of constant-ness.

Many parents talked about how they have had to learn and acquire new skills over the years. These skills include giving rescue medication, learning and rehearsing behaviour change strategies and working in partnership with their partner and support services. Another key feature associated to the caring role was described by mothers: the role of overseeing and planning. This involves all aspects of planning for their child/children irrespective of need. For their learning disabled child this would be often over and above what they would expect, which provides tangible links to how they actually feel about their continued role of carer. Mothers from this study clarify the effect of caring over time; there are clear examples of physical wear and tear as a direct result of providing day-to-day care. There is also an emotional element attached to the caring task: the ongoing demand of providing the high levels of supervision. Parents also expressed a need to maintain and enhance family life that ensures positive adjustment of all family members. This sentiment is reflected in Beresford *et al's*. (2007) findings.

Schneider *et al.* (2006) identified 'internal' and 'external' factors as two types of family level challenges that impacted on family life. These factors can be applied to the parents in this present study as they have all been challenged by the enforced changes to individual and family role (an 'internal' factor). As a response to these

changes both mothers and fathers stated that they have had to divide up family time, protecting some members from too much involvement and engaging others in family activities. Families are also confronted with challenges from service disharmony (an 'external' factor). Families as a means of coping employed strategies that included advocating for their child and forfeiting a desired alternative provision.

For a minority of families activities were organised that encouraged 'time' together; this met the parental desire for shared family experiences and the fostering of positive regard for each other. For the majority of families planned activities were disparate and unrelated to the needs of each other, and as a family unit. The common factor being the child's disabling condition and social behaviour that was presented as the reason for non-family based activities. Whilst it was not a core element of this study, it is important to recognise that a failure to address the social-economic position of families can lead to an overly pathological trend that assumes the child with intellectual disabilities are a burden and a reputed cause of parental distress. Kersch *et al.* (2006) suggests that the vast majority of mothers are said to be fairly or very happy with their lives and that any differences to this may be attributed to socio-economic disadvantage and maternal health than to caring for a child with intellectual disabilities. This aspect did not appear to be a feature of this present study and should warrant further exploratory research. Financial constraints are reported to affect the productivity, emotional well-being and health of all family members. This may indicate that income level is not a predictor of life, but rather is related to specific well-being variables, such as hope or stress, that may have a more direct impact on life quality (Park *et al.*, 2002). Most families in this study were home owners; they varied on their reliance on formal supports, with most securing aid from the benefits

department. This conflicts with Emerson *et al.* (2008) who suggested that three out of four families with a learning disabled child 'in-family' had experienced disadvantage that included living in social housing.

Marital satisfaction and the relationship to levels of stress have been well documented. Kersch *et al.* (2006) explored the contribution of the marital relationship to the well-being of both parents of children with developmental disabilities. In this instance parental well-being is termed as: mental health, parenting stress and parenting efficacy. Kersch *et al.* (2006) suggests that higher marital satisfaction predicts lower parenting stress and fewer depressive symptoms above and beyond socio-economic status, child characteristics and social supports. Kersch *et al.* (2006) support the notion that marital quality predicts all aspects of parental well-being with the exception of parenting efficacy for fathers. Further to this, child behaviour, not their adaptive and cognitive functioning, was indicative of parental well-being. Child behavioural difficulties were found to be predictive with parental stress and efficacy for both parents. Child behaviour problems also predicted depressive symptoms in fathers but not in mothers. It is well reported in the literature that evidences children with disabilities and their propensity to engage and exhibit higher levels and frequencies of challenging behaviours than typically developing children (Baker *et al.*, 2005). These findings conflict and are at odds with this present study. Some parents from two parent families clearly articulated that they are 'in it together', that the care burden is shared and that their relationships are mutually supportive. This would suggest higher levels of marital satisfaction; yet these parents experienced stress as a constant feature of their daily living. Stress being attributed to the characteristics of their learning disabled child and qualities such as: the level of daily

care that is required, the amount of supervision needed and the severity of presenting child behavioural difficulties.

It is suggested that parents of children (with or without disabilities) experience similar levels of stress that relates directly to the challenges and duties of parenting (Kersch *et al.*, 2006). Whilst I accept these claims, there are possibilities that parents who are unable to move normally through the life cycle with their children experience differential levels of stress and mental health problems. Further to this the feeling of and experiencing being stuck with 'life on hold' propelled both mothers and fathers into a realm where automatic negative thoughts about 'life situation' were experienced.

In this study partners (referring to both mother and father) were classed as being the greatest source of support in terms of supporting each other; this included watching over, playing with the children and getting up in the night. It appears that for some families, when both partners were home, responsibility for the children became equally shared. In other instances one parent would take over the caring role. Fathers in particular assumed the role of lifting a heavy, older child and being the one to discipline or keep control. In most instances it was the father, when present, who engaged in any physical interventions purely because they are physically stronger than their partner. This sharing does bring about consequences for fathers who were in full time employment and mothers who generally worked part time. Particularly in terms of employment choice and hours worked in any given week. Several fathers gave accounts of having to be called from work at times of emergencies; that usually related to their learning disabled child/children. As such they felt that their career

options were limited as they would find it hard to find another employer who was a sensitive and sympathetic to their situation.

Tiredness is a dominant feature of providing high levels of care for this group of parents. Fathers particularly in the evenings and at weekends giving their partners a break; this was reported by fathers in Towers (2009) survey. Grandparents when available would help out by offering non-disabled siblings over to stay; often causing mothers some upset as their learning disabled child was often excluded from this activity. These aspects reflect and mirror Beresford's (1994b) study where support was gained directly from partners, if present and by other parents who also have a child with disability. Some parents in Beresford's (1994b) study sought support by attending specific support groups that were considered a crucial source of information.

Household duties tend to fall to the main carer (in Beresford's, 1994b study: the mother). This was not reflected in the present study, there appears to be a shift in who does what with regard to household duties, here most fathers engaged in these activities meaning that this aspect of family life was shared in two parent families. Parents who do not have the support from their partners have a tendency to use less productive coping strategies when faced with stressful events, often resorting to excessive 'lone' drinking and alienating themselves from friends/local community.

All parents in this present study made some reference as to how they as individuals and as a family have had to make adjustments in how they function as a family. Those parents who continue caring for a young adult stated how overwhelmed they were by

the amount of care they have to provide despite their children now being young adults. For the parents of younger children this issue is not yet paramount but may be an issue for them in years to come. These aspects neatly fit into Summers *et al's*. (2005: 172) model that illustrates disability as impacting on families in three broad ways: “by potentially increasing caregiver burden, influencing family functioning, and requiring the family to reorganise and make accommodations for the individual with disabilities”. Beresford (1994b) in her study captures some essences of being a parent that is reflected in this study. She posits that stressors directly associated with caring for a disabled child include meeting the child’s physical care and medical needs, supervising and watching out for them, dealing with and managing sleep and behavioural difficulties. Emotional stressors such as witnessing your child’s pain and suffering especially when diagnosed with a life limiting condition.

A dynamic to parenting: the construction of automatic thoughts is evident to this group of parents. This dynamic permeates and interlinks the core and sub-themes as presented in Chapter 9: part 4 and earlier in this chapter. Within the reviewed literature there is scant evidence that focuses specifically on extreme parental private thoughts in the learning disability arena. Hornby (1992) in his review of the literature highlights two fathers’ extreme negative reactions to having a disabled child. He notes quite rightly that this finding is seldom, if at all, reported in the literature. In spite of this apparent oversight there has, since 2005, been several reported extreme incidents in the United Kingdom where a parent has taken the life of their learning disabled child. Wendolyn Markcrow killed her 36-year-old Down syndrome son by smothering (Appendix eleven A). This mother and her general practitioner had repeatedly pleaded with local authorities for assistance with his care; these pleas were not acted upon.

Andrew Wragg in an act of ‘mercy’ smothered his son who suffered from a degenerative condition ‘Hunter’s Syndrome’ (Appendix eleven B). Alison Davies, with her son who had a diagnosis of Fragile X, jumped to their death (by drowning) from the Humber bridge (Appendix eleven C). Alison was reported to have felt like a prisoner in her home due to the care her son required, she was highly anxious and fearful that her son would be taken into care – hence her actions. These examples are on the extreme end of the continuum of ‘acting’ out private thoughts. In this study two fathers talked of ‘ending it all’, they provided a clear rationale for taking their learning disabled child’s life, not as an act of desperation, but as an act of mercy and as a way of ending the families caring burden. These fathers did not and have not acted on these thoughts; but it begs questions as to what circumstances can a thought of taking your child’s life become an ‘actual’ act? It is clear that the two mothers, as reported, were deemed as being depressed and at their ‘wits’ end, being unable to see a way out of their dilemma.

Research unrelated to the learning disability arena discusses the dynamic of parental negative automatic thoughts (including causal/maintaining factors and treatment. Negative automatic thoughts have been described by Becks as far back as 1967 are embedded in his schema theory. Further to this Abramowitz *et al.* (2003) suggest that negative automatic thoughts or distressing intrusive thoughts are related to situational stressors and are common within the general population. This position is echoed also by Larson *et al.* (2006). It is posited, in Larsen *et al.*’s. (2006) study, that maladaptive strategies for managing negative automatic thoughts play a significant role in shaping and maintaining obsessive compulsive disorder type problems. Veale and Willson

(2005) likewise suggest that mothers develop obsessive compulsive disorders as a way of managing and neutralising negative automatic thoughts.

In Godress *et al.* (2005) study parents were reported to experience higher levels of grief in relation to their child's mental illness. This manifested as intrusive thoughts and feelings of avoidance as well as distress associated with the reminder of their child's illness. Similar findings were found in Fairbrother and Woody's (2008) study where "almost 50%" of their respondents reported unwanted thoughts of intentionally wanting to harm their infant. High levels of parental stress and low social support predicted the occurrence of thoughts of intentional harm. In this study there was scant evidence of association between aggressive parenting and negative automatic thoughts.

It can be concluded from these studies that there is a general acceptance that negative automatic thoughts of wanting to harm your infant are a relatively normative experience during the early postpartum period. It is of some note that I have been unable to trace any existing literature in the learning disability field that focuses specifically on parental negative automatic thoughts be it postpartum or later in the child's life. This subject matter would benefit from additional research across the caring domain.

In the present study all parents were given the opportunity to reflect on their thought processing and talked of their private thoughts (positive/negative – mundane/extreme) about their learning disabled child. Some parents described how they became frustrated with the sameness of everyday and the restrictive nature of living with

disability. This directly related to their feelings of resentment as they blamed their child for their situation. Most parents experienced feelings of hatred and anger as a result of having to manage, at times, very challenging child behaviour. Feelings such as these were transient and reflected high stressful events, parents conversely experienced feelings of guilt and shame for having such thoughts. Some thinking that they were really bad parents, whilst for other parents they were seen as a way of coping during time of duress. A number of parents were of the opinion that these thoughts are normal, a phenotype of being human.

There is a clear dynamic to these thoughts. They are on a continuum, one that is affected by high stress situations of a transient nature. Thoughts range from feelings of love and warmth to hate and resentment, from pride and protection to pity and harming, and a search for a reason from there is a greater being to it is nothing but bad luck. On the whole thoughts remain private that are rarely, if at all, shared with close family members and indeed with professional workers. They are rarely acted upon and when they are parents from this study explained that they manifest in higher levels of frustration, shouting at and removing the child with disabilities to another room. According to Wheeler *et al.* (2008) parents found meaning and purpose through their own faith and spirituality; they found it beneficial in their quest when seeking understanding and attributing a meaning to life. This study reported that about one fifth of the women interviewed indicated that their religious faith to be an important factor in how they perceived their quality of life (Wheeler *et al.*, 2008: 171).

The next section in this chapter focuses attention on the findings of this study and the implications they have for practice and/or policy development.

6. Implications for practice

One of the striking features of being a parent of a child that has a significant learning disability is the way the parenting role alters. A shift from the normally expected patterns of bringing a child into the world that is characterised by a period of physical caring and sustained emotional and practical support to a new position of providing a high level of personal and supervisory care through the term of childhood and into adulthood. Parents in this study have adapted to this new position, the adaptation taking place over several years, and some will continually adapt to the changes and challenges brought about by their own and child's maturation. It is essential for effective policy and practice that support services recognise this dynamic. The National Service Framework (2006) (see Chapter 1) recognises as a core aim that parents should be given the practical support that will assist them in caring for their child. With this regard supports such as short and longer breaks would enable parents to participate in some of the lifestyle events that parents of non-learning disabled children experience. In my own experiences of supporting families I have evidenced a lack of formal support systems that reflect and meet the needs of this group of children and their parents. Parents often experience a demarcation in service provision as a result of their child's challenging behaviour. This is a severe failure on service infrastructure as they are not resourced financially nor are they equipped with appropriately trained and skilled support staff to meet this level of need. An unsavoury result of this lack of provision is the impact on families as they either receive no formal support outside of regular educational provision or they are forced to seek alternative methods such as formally complaining or securing residential care facilities, often outside of our immediate locality. If we are to assist families to achieve a balance where they can effectively deal with the internal and external

challenges and make preferred and meaningful adjustments, it is crucial that service providers and commissioners gain a deeper understanding of the dynamic of family functioning and an appreciation of the demands that these families are faced with.

One of the recommendations from Glidden *et al.* (2006) is for clinicians to involve parents in a programme that would reduce the use of negative coping strategies, for example, Escape-Avoidance with a view to increasing the usage of positive coping strategies such as Positive Reappraisal. The use of Cognitive Behaviour Therapy is deemed an appropriate approach in altering parental coping styles. Professional support staff should as a service standard be adequately trained to offer this level of intervention.

Being a Parent

Service providers and clinicians from all service elements need to fully understand, rather than pay lip-service to, the processes of adaptation that individual parents encounter as they grapple with their changing needs of being a parent to a child with additional needs. Being fully conversant with these processes can only assist formal supports in successfully assisting positive parental adaptation to their situation. The provision of a bespoke parent training package coupled with a robust and fully supportive early intervention programmes can only enhance parental adaptation and coping.

Living with Disability

Workers are required to consider how families organise their daily routines, which includes their values, goals and beliefs. This will assist them to understand parent

behaviour and work in an effective manner that enables them to maintain family-based care. The need for an early intervention programme to address the behavioural and emotional needs of very young children should be well recognised. This is based on research that has shown behavioural and emotional problems to persist into adolescence and adulthood. The findings from this can be linked to other studies (see Hastings 2003, Baker *et al.*, 2005) in that a child's emotional and behavioural difficulties can significantly impact on the parental stress and mental health problems. Most research and intervention models have focused on mothers. Assessment and intervention **must** consider the family as a whole. This was highlighted in Dunst and Bruder's (2002) study. An assessment tool such as the Family Quality of Life (FQOL) can assist in the measurement and identification of priority areas for support and the development of a tailored intervention plan.

Parents want to receive practical and financial support that enables them to meet the needs of their learning disabled child and the rest of the family. Parents would also like to feel confident with the services they are engaging with, particularly working in partnership. These findings are consistent with Beresford *et al's* (2007) study. Likewise, according to Wang *et al.*, (2004a) parents perceived quality of life were influenced by the quality of the child's education programme and the relationships that they have with the professionals they work with – this is comparable to parents in this study.

Career in Caring

Parents would benefit from formal assistance with practical help around the house and care-related activities. For example, the amount of appointments if better organised

across services could free up parents valuable time. The development of more robust services that are capable of meeting the physical and behavioural needs of children are required, services such as: sitting-in services, day care, short and long term breaks and after school care would be a good starting point. Some parents have directly attributed their child's disabling condition as the primary cause of marital dissatisfaction and breakdown. Services need to better understand the family support needs both on an emotional and financial level thus reducing the potential for family distress.

From this present study fathers would seem to have fewer opportunities than mothers e.g. accessing early intervention services and as such are unable to practice parenting skills. Greater service effort is required to improve the quality and access to instrumental supports. This has been identified in the current literature (see Hornby 1995).

There are many other similar issues one could pursue in drawing together implications for practice and theory: Does the experience of being married and in employment alter the experience and well-being of parents who care for a child with significant learning disability? Further to this question are there differences in well-being (perceived and actual) amongst mothers and fathers who care for their child/children across the life span?

8. Ethical considerations

This study has exposed one issue that was not considered in the ethical arena. This has created a personal conflict and focuses on my role as a researcher and that as a clinician and how I should act in given situations. All of the co-researchers in this

study have been open and truthful in describing their situation, their experiences and their thoughts. I anticipated this as being a major stumbling block to the research process – would parents who were known to me be totally candid during interview? On the contrary this concern proved to be ill founded; parents who were known to me in my ‘then’ capacity of community nurse were very open and shared experiences and thoughts that had never been aired previously. On reflection it is likely that my relationship, which for some extends over many years, had enabled them to be forthright during the interview. This level of frankness presented me with a very different dilemma: how do you deal with and manage disclosure that could be considered contentious and potentially a child protection issue? One father made it very clear that he, as a way of controlling his son’s aggressiveness, engaged in a physical fistfight. Further to this, all of the co-researchers made reference to private thoughts about their child/children, these thoughts were on a continuum that ranged from not liking their child/children to hating them and from wanting to smack them to thinking about ‘ending’ it all.

It is clear that parental disclosures form two distinct groups: ‘thinking about’ and ‘actualising’. As a clinician when being presented with a tangible actual act of harm, irrespective of the causal factors, one as a responsible practitioner has a duty to report and evoke the All Wales Child Protection Procedures. In this context, the father who reported engaging in a fistfight with his learning disabled son was referred and investigated via the child protection procedures. In my role as a clinical practitioner my actions would be justifiable, one attempting to protect a vulnerable young person and two, in attempting to support a family who are clearly experiencing difficulties and struggling to cope with a challenging young person. However, in this instance my

actions created a real issue for me. Firstly, I had invited, in this case, the father to participate in a research study; this involved in-depth interviewing that resulted in the disclosure. Secondly, the disclosure in all probability would not have been made in normal working situations; I can be confident in this matter as the majority of contacts are with mothers, fathers either being absent at their place of employment or out due to other commitments or because they have left the marital home.

As a way of managing these tensions I have had a variety of discussions with colleagues from a range of backgrounds that include: Lead Nurse for Child Protection (Health), Child Protection Co-ordinator (Social Services) and the Research Governance support staff. These discussions have in some ways allayed some of my fears, particularly the tension between being a researcher and being a practitioner. Although not easily resolved I have accepted that some disclosures irrespective of what 'hat' I am wearing requires further action. I have also sought reassurance from the statement made by a senior colleague: 'how do you as a researcher or as a practitioner police someone's thoughts?' Nevertheless, I still feel there is a moral obligation to notify services because of the 'what if' situation where a parent reaches a point of not having any more to give other than a final engagement in a final act. I have however concluded that 'thinking about' is an act that applies to the private sphere of a person's mind. In this context does 'thinking about' inform the nature and intent of a person's actions? It should not be implied or seen as a given that a parent will act upon thought constructs. Negative automatic thoughts albeit alarming to the person experiencing them and indeed to a professional worker who encounters them during their working day should never view them as being illegal or criminal. On the

contrary they clearly indicate a state of mind that should, if disclosed, act as a trigger for additional social care supports.

I have also recorded my own thoughts, feelings in a reflexive journal, an example of this can be found in Appendix six. This activity has enabled me to put into words my thoughts and concerns and in doing so has proved invaluable in assisting me to continue with my studies.

9. Truthfulness and credibility: a pragmatic look at whether this study has achieved its aims?

Chapter five provided a brief discussion as to quality standards pertinent to the qualitative research method. Here I will deliberate further whether this study appropriately met my pursuit of establishing the credibility of the findings. I have considered a variety of criteria that best fit this purpose. In chapter five I outlined Polkinghorne's (1989) six-point framework as a potential contender for this role. Having carefully re-considered the questions I do not feel this framework serves my purpose. I am of the opinion that some of the questions are subjective in nature, ones that I can easily respond to. My responses would not be easily verifiable and therefore could be considered void, hence my rejection of this method. Cutcliffe and McKenna (1999) advance a three point evaluative process of: 1) to make explicit what qualitative approach is used. They deem a blurred method as being central to interfering with the establishment of the credibility of any research. 2) To make explicit what method has been employed. This will establish the credibility of the interpretation of the data and 3) Taking the findings back to the co-researchers in an attempt to gain verification. In response to these questions, throughout this study I

have made explicit the research methodology thus explicating the meaning of being a parent. Likewise the manner in which I have set out and presented this thesis allows a greater amount of transparency as to how I have managed the research processes. Further to this I have routinely taken back to parents and discussed the findings as they were emerging. Granted this activity has not been formalised by arranging feedback meetings or focus sessions. There is however a strength in the manner in how I have discussed the findings. During the initial stages of the research I was in a position to discuss regularly with all but three of the co-researchers, this activity took place during routine home visiting. The discussions occurred naturally as the parents were interested to hear how my studies were progressing therefore asking, thus giving me an ideal opportunity to check that the findings reflected their experiences. Parents who were not party to this had the opportunity to discuss the emerging themes and meanings prior to commencement and following the semi-structured interview. Further to this I have had the opportunity to discuss this research with other parents not directly associated with this study. It is important to state here that when discussing disability issues in the context of this research with these parents there is a acknowledgement, a clear resonance, and in some instances a 'wide openness' as though a professional should not have this level of insight. This questions, and in some way targets, the integrity of the researcher. In response to this question I can only assure the reader that I have acted in a professional and proper manner throughout the course of my studies and that the content of the co-researchers descriptions has only been altered in parts so to protect their identity. Any alterations do not in my opinion detract from the phenomenon that has been explored.

This study is presented in such a way that the processes engaged in are totally transparent to the reader. It is therefore easy to navigate through the processes I undertook in my arrival at the composite textural/structural descriptions and indeed the synthesis of these elements that constitute the meaning of being a parent who lives with and cares for their child that has a significant learning disability. Such transparency is one measure of reliability in qualitative data analysis of any kind. It has always been the intention of this study, as it is in keeping with Phenomenological research, not to imply general applicability of findings to a larger population. However, the essence of being a parent and engaging in long term caring is more than likely to be relevant in other situations such as those caring for a person who require high levels of daily care irrespective of their age or ability level.

10. Limitations of this study

One of the main limitations of this study can be levelled at the lack of generalisation of the findings to a wider population. Whilst this issue has been discussed elsewhere (see chapter five) it is reasonable to suggest that the findings from this study are applicable to parents who find themselves in a similar ‘caring’ position: that is caring for their child/children that has a significant learning disability, *and* having to engage in regular personal care activities *and* managing complex externalised challenging behaviours *and* those who care for others, be it an older person or someone who has a significant mental health issue. It would also be reasonable to argue that the generalisability of the findings cannot and should not be assumed, however, using the results and testing them out with a larger population, would assist in demonstrating the significance and applicability to this population of carers and indeed to other carers who provide high levels of care long term.

Future research with a cohort of parents who care for children who are technologically dependent, or those who have a formal mental health diagnosis and of course parents who care for children who have a learning disability across the age range would be indicated. It also would be worthwhile to use the findings of this present study to test whether the essence of living with and providing high levels of daily care to a person over a long period of time has the same impact for this group of carers. This research could be targeted against those who care for a person irrespective of age, gender, religion or disability to explore further the relationship between their coping strategies and well-being i.e. what causes stress, how it is managed and what impact this has on individual, family and social functioning. It should also focus on the relationship and the effect on quality of life.

As previously discussed parents in this present study have illuminated their experiences of negative automatic thoughts, usually during times of duress relating directly to transient situational events. This actual phenomenon does require further research with a larger cohort of parents, thus determining causal factors and strategies to ameliorate them. It is clear from other areas of research that this phenomenon is considered common, particularly mothers postpartum. There is evidence in this study to suggest that such thoughts are equally common for both parents irrespective of the child's age when faced with high stress situations.

11. Final reflections on phenomenology

As a starting point I do need to ask the question: have I achieved what I intended to when I commenced this journey? It is also necessary, even at this late stage of my studies, to ask myself if I feel fully conversant with phenomenology and all of the

philosophical stances. In this regard I can clearly say that I am not – I have a good comprehension of Husserlian philosophy, its interpretation within nursing parlance and how it can be applied in the research arena. It would be foolhardy to claim that I am fully cognisant of Husserlian philosophy or indeed other philosophical stances. I hold the view that it would take years to achieve and reach this state. All I can do here is discuss my own journey, one where I have had to immerse myself in literature and make attempts in understanding complex language and concepts that at first sight might as well have had been spoken in a foreign tongue. I am constantly drawn back to the issue of bracketing, which I feel requires further deliberation. I have at several points in this thesis discussed the core concepts of bracketing that can be considered a process, but not one that can be conducted in a linear manner. I am of the opinion, that bracketing is a state of mind where you have to prepare and train yourself to be able to set aside and suspend all judgements. Thus enabling you to compare and contrast what is ‘real’ against what is ‘presented’ to you. One thing that is certain is that this process is central to transcendental phenomenology and conducted as intended measures the success or failure in one’s search for meaning.

Here I will provide further evidence and critique by reflecting on bracketing ‘in action’. The setting aside and suspension of all knowledge to a given subject matter is not a simple and straight forward activity. I have over the years grappled with these concepts and questioned whether they are in fact achievable. I have during the course of this thesis made many references to my own personal experiences as a father and also as a ‘seasoned’ practitioner in the arena of learning disability practice. In real terms this means upward of 28 years of being a father and 30 years of working with and supporting parents whose children significantly challenge.

The first activity I engaged in was to repeatedly list my own views, beliefs and value systems (see chapter 8) relating to ‘my’ meaning of being a father and how I perceived what it may be like to be a parent of a child that has a significant intellectual impairment. I found it much easier to sit in quiet contemplation thinking about my role as a father, as opposed to sitting and writing about it. The use of visual remembering assisted this process – here I held on to memories, however recent or long past and fully immersed myself in them; which I can only describe as being similar to being in a meditative state. This position allowed me an opportunity to crystallise the memories in the full knowledge that they were my own thoughts, feelings and views that emanated from my own reality. It was at this point that I audio recorded them and later transferred them to written form. This reflective/meditative state was performed repeatedly throughout this study and to some extent I continue to engage in this style of transcendentalism.

Replicating this process with my thoughts and views as to what it **must** be like for parents in this study did not come as natural to me. I found the process much harder to engage in – I have uncovered that my difficulty was in separating what is real for the parents and what my own set of views were. This I now understand is the inherent difficulty in stripping away completely many years of experiences. That said I continued to endeavour with this reflective state – it always occurred in private and in total quietness. These conditions were deemed pre-requisite to achieving the desired state where I could clear my head and focus on the issue at hand.

I experienced other difficulties particularly when in the ‘field’ during interviews. Even though I had engaged in the process of emptying my head I still felt compelled

to share my thoughts and views. An example of this was when a father disclosed his thoughts of having wanted to harm his son. This statement hit me hard; it opened personal memories of experiencing similar thoughts when in extreme stressful situations. My immediate 'thought' reaction was to share my own experiences. The considered 'thought' reaction was to put aside these thoughts and concentrate on listening to his story. I am very aware that my counselling training has assisted and provided me with the necessary skills to redirect my thoughts and to focus on the task at hand: listening to a parent's story. However following this particular interview my thoughts were catapulted into another realm of reflection where I engaged, again in quiet contemplation, attempting to understand the content and structure of what had been disclosed.

Being able to bracket takes an awful lot of mental control and determination. There is an element of having to be congruent to the process, there are times when your own thoughts/feelings and ideas surface and cloud your thinking. It is very easy to get caught up with your own thoughts, which can run ahead of you. The skill is to be aware of this when it occurs and hold those ideas/thoughts in abeyance until you are able to explore them more fully. The use of field notes post interview was an essential tool in detailing such incidents.

I have been practicing these techniques now for over 8 years, so I have had plenty of opportunity to train myself to be able to block my own thoughts when listening to another person's story. Having said this, thoughts do 'pop' up occasionally, but these are managed consistently, as described.

12. Efficacy of this method

The phenomenological method uses actual words and direct quotes to determine the essence of the co-researchers lived experiences. As such, this study has produced clear statements that, in my view, have established the truths of things: the ‘what’ and the ‘how’. That is, the meaning of being a parent who lives with and cares for a child that has a significant intellectual disability. Further to this, phenomenology as a method has enabled me to look ‘inward’ at my own experiences about being a parent: a father, before turning outward towards the parents under study. It is the very nature of looking inward and outward in a continuous cycle that enables the search for all possible meanings and divergent perspectives. This said the task has been time consuming and extremely demanding often leaving me perplexed and in a quandary. In spite of my increased knowledge I still feel as though I am an infant in terms of development as a phenomenologist – even at this late stage my journey is far from being complete.

13. Concluding statement

I would posit that this study has furnished the sphere of learning disability practices with additional knowledge on the subject of what it means to be a parent: to be a father or mother of a child that has a significant learning disability. It also offers an important contribution to furthering our understanding as to how parents provide daily care to their child/children and what impact this has for them and their family. This study has illuminated the life world of parents who engage in day-to-day care. It illustrates the degree and the complexities of their roles; this is paramount and is detailed in chapters eight and nine. The experience of being a parent has underlying structures that can be considered common to all parents. The reader should arguably,

after reading this manuscript, come away with a better understanding of what it is to be a parent of child that has significant intellectual impairment and complex behavioural problems.

This study does appear to be unique in terms of the current literature and chosen methodology. As such it should be expected that some aspects of this work would provide practitioners and service planners a much greater understanding as to the nature of care giving and the potential impact this may have on the carers. It would also be useful in the preparation of students who aim to work and support families in this field.

As has been previously stated there has been a large amount of data generated from this study: in excess of 500,000 words of interview text. Whilst the tape recordings have been destroyed; a recommendation from the local research ethics committee; the interview transcripts though are currently stored on removable disk format. This would enable further analysis/and or interpretation by other researchers providing fully informed consent was to be obtained.

In conclusion, I would suggest that this study has acted to illuminate further the experiences of parents who live with and provide daily care for their significantly learning disabled child/children. As such it could be considered a useful reference in the ongoing learning opportunities for both pre- and post-basic training for Paediatric services. There is also scope for the findings of this study to be used in the context of social work and voluntary sector training. This will have the potential to better prepare practitioners who support families thus improving the understanding of

family, the care burden and associated stress – an aim worth reaching for and grasping.

Finally, on a personal level this study has allowed me to explore my own thoughts in relation to being a parent to my son, who as described in chapter one has a chronic mental health issue. There are striking similarities to my world and those of the parents in this study. I have indeed experienced negative automatic thoughts, particularly when he has entered into a dark place. I clearly remember experiencing internal dialogue repeating and regurgitating these thoughts, experiencing a huge sense of guilt thinking that I was incapable of being a good loving parent: “I must be for having such thoughts”. I have during the course of this research been able to console myself in the knowledge that these thoughts are considered to be ‘normal’: a trait of being human.

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APPENDIX ONE

Interview Schedule One – focused open-ended discussion.

Can you say a little about your family?

(Additional prompts – composition of family, ages, employment)

Can you describe your child's needs? (Referring to child with learning disability)

(Additional prompts – formal diagnosis (if any), level of need i.e. what help does he/she require during the day/night, behavioural difficulties and how they manifest))

What does a typical week in the life of your family look like?

(Additional prompts – who does what? Whose responsibility is it to provide the care)

What are your hopes and fears?

(Additional prompts – For now and for the future?)

APPENDIX TWO

Interview Schedule Two – semi-structures questionnaire.

Living with...

How would you describe X's disability and the effect this has on you?

(Additional prompts – your partner, other children, family and friends)

Individual roles... being a parent

How would you describe your role as a parent in relation to your child/children as you experience it?

What is it about this role that makes you say that?

If your role is made up of certain elements how essential are these elements?

Would you still be a parent if one or more of these elements were missing?

What is it about your role of mother/father that makes it matter?

To what extent do you think your role is influenced by ideas from elsewhere?

How does your role make a difference to your family?

Have there been any specific incidents, events or situations that stand out for you. Ones that have made it clear to you about what it is all about?

If you were to sum up your situation in one or two sentences what would you say?

Is this the essence of being a parent?

Managing stress...

How would you describe your level of stress – high or low in relation to past experience?

(Additional prompts – What techniques do you employ to alleviate high levels of stress? Do these approaches work, if so how? Do you have opportunities to discuss your feelings, if so with whom?).

Private thoughts...

Have you ever experienced private thoughts about your child/children?

(Additional prompts – How often do these thoughts occur? What do they consist of?
How frequent are they? How do you deal with them?).

APPENDIX THREE

Research Ethics Committee

16 May, 2000

Mr. C. Cathemll,
Community Nurse
Learning Disability
Services, Henllan
Centre, Henllan,
Denbighshire.

Dear Mr. Catherall,

Re: "Fathers' and Mothers' experiences of caring for a adolescent son/daughter with learning disabilities, their perceived role and responsibilities"

Thank you for submitting the revised documents for the above mentioned study. These were received and noted by members present at a recent meeting of the Research Ethics Committee held on 4th May 2000. The version relating to "your child, where appropriate, will be verbally informed" was approved and noted by members present. Members also noted your assurances that " parents taking part in this study will not incur any charges whatsoever ".

Following their discussions, members were able to give approval for your study to proceed.

Approval is granted on the understanding that the Committee is informed of protocol amendments, serious adverse events and recruitment problems as soon as possible during the course of the study.

We will be contacting you in twelve months time to see how the study is progressing and whether any problems have been encountered.

Yours sincerely,

Mr. C. Catherall,
Senior Nurse - Childhood
Disabilities, Royal Alexandra
Hospital,
Marine Drive, Rhyl,
LL18 3AS.

Dear Mr. Catherall,

Study Title:	"Fathers' and Mothers' experiences of caring for a son/daughter with learning disabilities, their perceived role and		
REC reference:	30/03/2000		
Protocol no:	N/A	EudraCT no:	N/A
Amendment no:	[2]	Amendment date.	19/04/2006

Thank you for submitting the above amendment, which was received on 19th April 2006. It is noted that this is a modification of an amendment previously rejected by the Committee as per our letter of 10 April 2006.

The modified amendment has been considered on behalf of the Committee by

the Chair. **Ethical opinion**

I am pleased to confirm that the Chair on behalf of the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation. **I would point out however that the Version Numbers and dates on the documents submitted as part of the "modified amendment" were changed on receipt - please ensure that the numbers on your copies correspond to those detailed below as a condition of approval.**

Approved documents

The documents reviewed and approved are:

Document Received:	Amendment No:	Document/ Amendment
Covering Letter		11/04/2006
Modified Substantial Amendment Form	2	19/04/2006
Information Sheet	5	19/04/2006
Consent Form	4	28/03/2006

Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number]: 30/03/2000 Please quote this number on all correspondence

Yours sincerely

Ethics Coordinator

APPENDIX FOUR

PATIENT INFORMATION SHEET

1. Study: A comparison between Fathers' and Mothers' experiences of caring for and living with their sons and daughters: their perceived roles and responsibilities.
2. You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your G.P. if you wish. If there is anything unclear or you would like more information please ask me. Take time to decide whether or not you wish to take part.
3. Study purpose: To compare your individual views as to everyday experiences of living with your children. This study aims to extend current knowledge of family life, with a particular focus on fathers'.
4. You have been chosen because you are the parent of your child/children and engage in caring for and living with your child. Your personal experiences are invaluable to extend our knowledge of family life as experienced by you the parent.
5. It is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not in any way affect the standards of care you receive.
6. If you do decide to take part you will be asked to participate in an audiotaped interview that will be arranged to take place at a mutually convenient time. The interview will last no longer than one hour. The questions will explore your personal views as to living with your children.
7. You may find that some of the questions asked will provoke strong feelings and emotions. There are no other possible disadvantages or risks attached to taking part in this study.
8. There will be no possible benefits for you, if you do decide to take part in this study.
9. All information, which is collected during the course of this research, will be kept strictly confidential. Any identifying features will be altered so that you cannot be identified.

10. The results of this research will be used primarily within the body of a PhD dissertation. Some aspects of the findings will be offered to relevant journals for consideration to publish.
11. This study is being part funded by the principal researcher and Conwy & Denbighshire NHS Trust.
12. The Research Ethics Committee has reviewed this study.

Contact for further information:

Mr Chris Catherall,

Centre Number:

Study Number:

Patient I.D. number:

CONSENT FORM

Title of Project: A comparison between Fathers' and Mothers' experiences of caring for and living with their sons and daughters across the child age range.

Name of Researcher: Mr Chris Catherall

Please initial box

1. I can confirm that I have read and understood the information sheet dated (version ??) for the above study and have had opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study. ☐

Name of parent/Date/Signature

Name of person taking consent/Date/Signature (If different from researcher)

Researcher name/Date/Signature

Copy: 1x parent, 1x researcher

Version Number:

Date:

APPENDIX FIVE

EXTRACTS OF RESEARCH JOURNAL – INTERVIEWS

Interview one - Mike

General comment: I have known Mike for some time as the families specialist community nurse.

Unstructured interview: The interview went very well, Mike was responsive to the questions and was very open to the interview. He appeared at ease and relaxed even when he talked of his private thoughts about Deborah.

Semi- Structured: This interview continued in a similar vein. Mike was very receptive to the questioning. Another good interview that revealed insights to Mike's life and how he attributed meaning.

Interview two – Jenni

Like Mike I have known Jenni for many years.

Unstructured: Jenni was very relaxed during the interview. She talked freely and easily about life with Deborah. The interview went well, which I put down to my professional relationship with Jenni.

Semi- Structured: The second interview with Jenni was unremarkable in that it went very smoothly, covering the interview format. The interview provided ample data as to Jenni and her role as mother.

Interview three – Rob

I have known Rob for a few years in a professional capacity. He has often participated in discussions when I have visited the family home.

Unstructured: A quick interview, even though Rob and I know each other he was a little tentative and gave quick short responses to the questions.

Semi- Structured: Rob was more relaxed to day and participated more fully during the interview. He made reference to the first interview and stated that he felt uncomfortable with the audio tape recorder. I reassured him that the tape recordings would be destroyed once transcribed and that identifying features would be altered so as to protect anonymity. The interview there after flowed well and provided an insight to family life according to Rob.

Interview four – Christine

Christine and I have known each other professionally for over ten years. We have presented at student nurse lectures together.

Unstructured: A fairly quick interview Christine responding to the questions with her usual enthusiasm.

Semi- Structured: A much more in-depth discussion with Christine that illuminated her frustrations with services, particularly the lack of provision and her battles in trying to secure services that she appropriate in meeting her families needs.

Interview five – Drew

I have known Drew really in passing, only having brief conversations when he returned home from work early.

Unstructured: Interestingly I was feeling somewhat apprehensive about conducting this interview. I have reflected on this and have concluded that in all probability my unease was due to interviewing someone who I did not know. My apprehension was unfounded, Drew quickly settled me with his humour and directness. In all a very good interview that enabled Drew to explore some very private thoughts about Brian.

Semi- Structured: Drew again was very receptive to the interview. I am of the opinion that the timing of the interviews were perfect for him as it gave him a forum to chat about his life, his feelings and experiences; something that he had never had the opportunity to do previously.

Interview six – Marian

I have known Marian since Brian was five years old, when he was referred to community nursing services.

Unstructured: A very easy and relaxed interview. Marian was open and forthright in her responses.

Semi- Structured: This interview followed on from the unstructured interview in that Marian was responsive and open to the question format. She illuminated further her world, one that I have been privy to for a number of years.

Interview seven – Tony

I have never met Tony before these interviews.

Unstructured: Tony warmed to the interview process quickly and responded well. He was able to focus on his experiences of caring and being a father to his daughter with ease.

Semi-Structured: This interview mirrored that of the unstructured interview. Tony was focused and eloquent, discussing and describing his situation. Tony at the end of

the interview thanked me for allowing him time to reflect on his life; he found the whole experience highly rewarding.

Interview eight – Glenda

I have never been acquainted with Glenda, yet I know her daughter from the schools that I visit.

Unstructured: This was a very difficult interview; Glenda was extremely nervous and fidgety throughout the course of this interview. I offered to terminate the interview but she insisted on carrying on as though she had a duty to herself to do so.

Semi-Structured: Glenda presented as she did in the first interview, again she was offered the opportunity to terminate the interview, which she declined. In spite of this the interview went fairly well where Glenda discussed her role in family and illustrated the changes ‘in who does what’ I family – referring to Tony’s role as main carer.

Interview nine – Peter

Peter and I have never met before, nor I have I met his son.

Unstructured: A very difficult interview Peter became distressed when discussing Malcolm’s difficulties and the conflict it caused him on a personal level. I terminated the interview as I was of the opinion that Peter was not in a position emotionally to continue. I stayed with Peter for several hours flowing this discussing his feelings; only leaving when he was more composed and relaxed.

Semi-Structured: Peter presented more positively today and was eager to participate. He stated “I am not going to blab today”. Peter was frank and open during the course of the interview, which allowed him to focus on his ‘lot’. The interview progressed well through the themes that highlighted for me how alone some fathers are, struggling to cope with the demands whilst having an exterior façade of ‘I’m coping because I am expected to’.

Interview ten – Noella

Like Peter I have never met Noella before today’s interview.

Unstructured: An unusual interview in that I found it extremely difficult to get a word in. It was as though Noella had something to say and no one was going to interrupt her flow. Nonetheless the interview covered what I expected it to and provided information as to family life.

Semi-Structured: A much more focused and evenly balanced interview. Noella not as vociferous thus resulting in a free flowing interview that captured family life and Noella’s reflection as to her role and mother and wife.

Interview Eleven – Terry

Like Drew I have known Terry for a few years now, but rather informally, as he would occasionally pop in from his 'office' to say a quick hello.

Unstructured: Given Terry's employment as a manager I began rather nervously with the interview. I wasn't aware of Terry detecting my initial nerves. In fact Terry was the more nervous and responded by providing short quick answers to the questions. Not an easy interview as I found it hard to engage Tony in deeper conversation.

Semi-Structured: This interview progressed more easily; Terry was more relaxed probably because he knew what was expected of him this time round. Terry remained frank with his responses but there was more depth and thought to them. A much better interview.

Interview Twelve – Katie

I have known Katie for three years as her daughter's community nurse.

Unstructured: A great interview that was free flowing, as though Katie had thought about the issues beforehand. Katie expressed herself well that allowed us to discuss her experiences of being a parent to a disabled child.

Semi-Structured: Another flowing interview that brought to life Katie's experiences of being a parent.

Interview Thirteen – Doug

I had never met Doug before this interview

Unfocused: Doug wasn't an easy man to engage. He answered his phone on several occasions – this reflected his world of business. When I managed to engage him his answers were short and to the point – as though he was going through the motions.

Semi-structured: A much better flowing interview. I did discuss with Doug before starting the importance of no disturbances; he promptly turned his phone off. Despite the initial difficulties Doug discussed openly his experiences of living with Dean and how he viewed his role – a distant father who provided for his family.

Interview Fourteen – Mildred

I knew Mildred from her role within the special school but have never had professional contact in relation to her son Dean.

Unfocused: Mildred was very eloquent and talkative throughout this interview. She reflected on and captured her 'world' as a mother and left certain areas open for further discussion at the next interview i.e. private thoughts

Semi-structured: Mildred remained as enthusiastic as she was in the first interview. She offered further insights as to her thoughts about Dean and how she managed such thoughts.

The following parents were interviewed only once as part two of this project.

Interview Fifteen – Jane

I did not know Jane and family at the time of interview.

Semi-Structured: This was not an easy interview. Jane spoke very quietly at first as though she was very aware of the microphone and audiotape recorder. She then increased her volume but proceeded to speak directly to the microphone. Asking Jane questions about her friendships and hobbies appeared to improve her responses.

Interview Sixteen – Shaun

I have known Shaun for a number of years professionally even in spite of him working away from home.

Semi-Structured: Shaun was very easy to interview. He was open and talked freely about his life and his role in caring for Robin. He fixed on to his own limitations as a father as if seeking reassurance from me. We did spend time post interview discussing these issues, which I felt were beneficial for Shaun and may have been beneficial had they been included in the research – but I agreed that I would not use any aspect that related directly to these discussions.

Interview Seventeen– Joan

I have known Joan since Robin was five years old. My knowledge and experience of this family is immense, as I have had weekly and fortnightly contacts over a fourteen-year period.

Semi-Structured: Joan was a very easy and relaxed person to interview, probably due to our long-term professional relationship. She was open and reflected on her role as mother and parent to her children, in particular Robin. This was a very good interview that was focused.

Interview Eighteen – Peter

I have had regular contact with Peter for the past four years visiting on a two-weekly basis.

Semi-Structured: Peter was somewhat hesitant initially but soon warmed and focused on the interview questions. Quite happy to spend time reflecting and refocusing on questions. A very useful interview that firmly described his life with two sons who have significant disabilities.

Interview Nineteen – Tania

Like Peter, Tania known to me and service for a number of years.

Semi-Structured: Tania very talkative did not skirt the issues and was open when reflecting on her role as mother to her children. Another good interview that provides a wealth of pertinent information as to how this family cope and manage daily.

Interview Twenty – Jackie

Jackie has received service inputs via clinic appointments for the past four years. This approach to delivering services meets her needs.

Semi-Structured: Not an easy start to the interview as the tape recorder decided to play up; this is in spite of pre recording checks being made. After several minutes of ‘fiddling’ I managed to get the machine working again. Jackie during interview was focused and talked extensively about her role as a single parent, the difficulties she faced on a daily basis and the lack of family support that often left her feeling isolated. I was struck by this mum’s resilience and how she managed to keep it together sometimes in the face of her sons very difficult behaviour.

APPENDIX SIX

EXTRACTS FROM REFLECTIVE DIARY – PERSONAL REFLECTIONS

Due to the nature of the diary, personal information such as names, places and other identifying features are evident. To protect anonymity I will present the extracts in type format – this will allow such personal details to be altered
A clinical/research issue:

Date: 14/09/2000

I'm a bit concerned! I have been toiling with a disclosure Mike made during his interview; he made reference to thinking about taking his daughters life. Whilst I do not think this is strictly a child protection referral I have found myself grappling with the issue of research confidentiality and a clinical professional duty to act. Do I report my concerns and whom do I report them to? And in doing so what effect will this have on the research relationship?

Thinking about Mike's statements I can fully understand what he had thought and openly stated and I can take some reassurance that he has not acted on these thoughts. During his disclosure Mike was able to describe the conditions that led to these feelings and thought processes: high stress levels associated to the demands of caring for Deborah, who I know from personal experience can be very challenging and difficult to live with.

Several questions were charging around my head. On a clinical level would it be appropriate to make a child protection level? Or a child in need referral?

Date: 15/09/2000

I have made a decision; I am going to discuss my concerns with the child protection co-ordinator (Social services) who I know professionally and personally. I will also raise this issue with my research supervisor and my line manager with a view to gauging their opinion.

Date: 18/09/2000

Discussions with my line manager and research co-ordinator were very helpful in assisting me to focus on the main question: Does the disclosure place Deborah at significant risk of harm? And Mike at risk of acting out his thoughts when in a high stress situation? The outcome of these discussions clearly points me in the direction of my original thought: to have a discussion with the child protection co-ordinator.

Date: 21/09/2000

Contacted ***** child protection co-ordinator and outlined the issues and my concerns. The discussions were very helpful and supportive that essentially reached a conclusion: How do we as clinicians act on, police and monitor parental thoughts; in this instance Mike's disclosure does not warrant a child protection referral.

Contacted family social worker to inform them of my discussions and made a request for a carer assessment in light of the families' potential to experience high stressful events.

Date 22/09/2000

I found myself still churning this issue around and around. Have I acted properly? In answer to this, as a clinician I feel that I have, but as a researcher I'm not so sure. I need to discuss this with Mike; if I was to make a child protection referral as a clinician I would, if the situation was safe, inform Mike and family of my intended actions. I have not done this. I feel it is only right and proper to have this discussion with Mike and give him the opportunity to have his say. I do find myself in a double bind type situation, as I do not want this issues to affect the research relationship – on a personal level I cannot afford to lose another co-researcher!

Date: 23/09/2000

I contacted Mike and arranged to see him at home. We discussed my concerns and my actions. Mike was very understanding and to my surprise he apologised to me for putting me in a difficult situation. Mike works in a residential setting and is fully conversant with child protection procedures, so he fully understood my dilemma.

We agreed that we should continue with the research.

A research conundrum

Date: 14/11/2000

I'm struggling here with no one to discuss this with. Colleagues just look and stare at me as if I've lost the plot when I attempt to engage them in the discussion of 'bracketing'. How can I bracket? Does it actually happen? Is it possible to hold at bay one's own bias and presuppositions?

I feel totally lost here – I have read umpteen nursing related journals and books, but I get more confused. Husserl's writings, now I have access to them, act to confuse me further – it is a foreign language to me. HELP!!

Nursing research seems to be far removed from what Husserl intended, but I do understand that he and his associates are coming from a pure philosophical standpoint – but should there be a similarity between nursing phenomenology?

I cannot find this when I read the journal articles and books, it is as though they have interpreted the spirit of the devices and developed a 'new' phenomenology that 'fits' nursing research. This leads to question what I am doing here – should I follow suit and use this 'new' method? Or should I seek to undertake my studies as true to Husserl as I can?

Date: 14/02/2001

More reading, more confusion but I have resolved one question at least: I will attempt to follow the path trodden by Husserl. Paley has helped me here his articles have shed some light on nursing phenomenology and the differences between Husserl and others. I now understand that whilst nursing phenomenology is valid in its own right it should never be justified against the work of Husserl.

I think I have resolved some methodological tensions, for now at least. As I travel further along this road I will no doubt come across new and familiar tensions again. Like bracketing – is it possible? At this moment in time I think it is, but time will tell.

Research Governance

Date: 03/2006

Ethics!!! More time wasting!

I have been informed today that my application, the lengthy 50 odd page REC document needn't have been completed at all. All I needed to do was to complete a two-page amendment form; I was given wrong information! This has set me back another few months – but try to be positive here I can at least get on with some chapter writing!

Date: 04/2006

New information. I now have to apply to the Trust's newly formed Governance committee in order for me to proceed. I am feeling totally frustrated and thwarted by red tape. I fully understand the need for tight controls on research activities that ensure patient safety. There must surely be a better way of co-ordinating between one committee to the next, they must communicate mustn't they?

Date: 04/2006

Five months and hey I finally have approval from both I can now get a move on.

APPENDIX SEVEN

TABLE OF STEPS

Van Kaam (1969)	Moustakas (1994)	Colaizzi (1978)
	Horizontalisation: listing every relevant expression and perform preliminary grouping	
Classification of data into categories		Extraction of phrases or sentences pertaining to the experience
Reduction and linguistic transformation of the selections into more precisely descriptive terms	Reduction: testing each expression – does it contain a necessary and sufficient moment of the experience? Can it be abstracted and labelled?	Transforming phrases into own words, resulting in a list of ‘meaning’ or ‘significant’ statements
Elimination of reduced statements not inherent in the experience	Elimination: remove expressions not meeting the above requirements	
	Clustering remaining invariant constituents	
	Applying thematic labels to the invariant constituents	Clustering of individual themes to produce a further reduction
First hypothetical identification and description of the experience		Production of hypothetical ‘exhaustive’ lists
Application of description to randomly selected protocols to test necessary and sufficient constituents	Checking invariant constituents and their theme against the complete record of research participant for explicit expression and compatibility	Moving back and forth between meaning statements and successive hypothetical lists until themes are accurately reflected in clusters
Valid identification and description of the experience	Construction of individual textural description; individual structural description based on ITD and imaginative, variation and textural-structural description incorporating invariant constituents and themes	Essential structural description
	Repeat the above step for each co-researcher	
		Return of description to subjects. Revision of description, if necessary
	Develop composite description of meanings and essences of experience for group as a whole	

Hycner (1985)	Priest (2001)
Bracketing and phenomenological reduction – openness to meanings and suspension of own meanings and interpretations	Reflection an intuition, sensitising researcher to the phenomenon and to preliminary ideas, presuppositions, assumptions and bias
Delineating units of general Meaning	
Delineating units of meaning relevant to the research question	
Training independent judges to verify units of relevant meaning	
Eliminating redundancies	
Clustering units of relevant meaning	
Determining meaning from clusters of themes	
	Production of initial description of the phenomenon against which data may be compared
	Examination of data from first participant; highlighting all statements relevant to the phenomenon. Adhering to horizontalisation
	Comparison of each selected statement from the first participant with the initial textural description and integration of these into initial description
	Creation of second textural description out of the initial description plus integrated statements and additional elements
	Repetition of steps with data for each participant
Return summary and themes to participants/second interview	
Modification of themes and summary	
Identifying general and unique themes	
Contextualisation of themes	
Composite summary of all interviews capturing essence of phenomenon. Note significant individual differences	Production of final textural account of the phenomenon

APPENDIX EIGHT

CODING STRIPES, NODE LISTING AND DOCUMENT CODING REPORTS

NODE LISTING

Nodes in Set: All Free Nodes

Created: 25/05/2008 - 16:55:12

Modified: 25/05/2008 - 16:55:12

Number of Nodes: 51

- 1 A break from caring
- 2 Adapting to the news
- 3 Ages - family members
- 4 Am I bad~
- 5 Being confident and positive
- 6 Being stuck
- 7 Conflict and coping
- 8 Diagnosis
- 9 Employment
- 10 Family relationships
- 11 Family support - relations
- 12 Frequency and duration of thoughts
- 13 Frequency of thoughts
- 14 Friends - nature
- 15 Friendships
- 16 Future - hopes
- 17 Getting help
- 18 Hating your child
- 19 Hopes - Employment
- 20 Impact of disability
- 21 Impact of disability - parent
- 22 Jackie Right I've got 3 children

Description:

InVivo node created from Interview 1

- 23 Living with disability
- 24 Living with Disability - caring aspect
- 25 Managing behaviours
- 26 Managing thoughts
- 27 My time
- 28 No support - partner
- 29 Not letting it get to me
- 30 On being a parent
- 31 On coping
- 32 Parenting - conflict
- 33 Partner coping
- 34 Private thoughts
- 35 Role - agreeing a role
- 36 Role - being a mother
- 37 Role - being a parent
- 38 Role - elements
- 39 Role - influences
- 40 Role - influences on
- 41 Role - making a difference

42	Role - on my own
43	Role- differences
44	Role- what matters
45	Sibling coping
46	Someone to talk to
47	Stress and stress management
48	Stress levels and management strategy
49	Thoughts as filters
50	Thoughts on thoughts
51	Transient - when things are bad

DOCUMENT CODING REPORT

Document: JA INT 2

Created: 25/05/2008 - 16:56:46

Modified: 20/08/2008 - 11:44:15

Description:

Source File: D:\JA INT 2.doc

Nodes in Set: All Nodes

Node 1 of 51 Adapting to the news

Passage 1 of 1 Section 0, Paras 69 to 71, 414 chars.

69: At first no, we were both devastated, we couldn't believe it... our cute little Deborah, something wrong with her, was it something we had done...

70: Chris= yes, yes.

71: Jenni= we were in shock when you look back... in a state of numbness. But when she fell and hurt herself, she was still our little Deborah, she still needed us to protect her, to love her... so those feelings never have changed... just new ones have emerged...

Node 2 of 51 Ages - family members

Passage 1 of 1 Section 0, Para 4, 135 chars.

4: Jenni= Um, Deborah has a severe learning disability, autism, tuberous sclerosis and Challenging behaviours er.. what did you ask next?

Node 3 of 51 Am I bad~

Passage 1 of 1 Section 0, Paras 167 to 217, 6553 chars.

167: Chris= This is an odd question but have you ever experienced private thoughts about your child/children?

168: Jenni= Oh... [long pause] I don't know how to answer this er, there are times, mostly when she is being badly behaved. I have felt, said to myself, god I wish you had died when you were younger, I can't stand you I hate you for what you have done to us. There are times when I think to myself, and I mean to myself, 'what the hell have we done to deserve this?' You know we are not bad people, we have never harmed anyone, caused anyone any pain or trouble. But we find ourselves in this state of perpetual stagnation...

169: Chris= What do you mean by this?

170: Jenni= As a family we have remained stuck, have not moved on and I can't see us ever moving on, not unless Deborah leaves home... but that is a point of contention, I'm fearful of this, I have a sister who has a learning disability and to be honest she did not fair well in an institution, so I am reluctant for Deborah to go anywhere other than staying at home; this causes arguments between Mike and me...

171: Chris= What effect will this have on you?

172: Jenni= As I have said we remain stuck, not able to do normal things, you know, just put our coats on and go out for a meal. Not asking for major life things here, just things that other normal families do. For us it is a real effort that involves a lot of planning, er, arranging someone to sit in for us, which is not easy as Deborah can be very difficult. So I do keep asking that question why us? Why me? If it wasn't for Deborah and her disability things would be so different... it is her disability that I don't want or like it has had such an effect on us all. It is not Deborah's fault, she can't help that but I project that blame onto her, as though it is her fault, so at times I really hate her for what she brought to my family.

173: Chris= How do you deal with these feelings as you said that you 'think these things to yourself'?

174: Jenni= I do keep these thoughts to myself, I'm sure Mike would think me a horrible person if he could hear my thoughts... I don't think I am a horrid nasty person I am responding to the situation. My feelings towards Deborah are of hate and detest but not always, they come and go, you know, they are brought to the fore when either, er, like for example, recently we were invited to a family wedding, we couldn't arrange for anyone to look after Deborah, I said that I would stay home as the wedding was on Mike's side of the family. He would have none of that, if we both couldn't go then we wouldn't go... so that was it... because of the way Deborah is we often lose out on being able to do normal things.

175: Chris= So these feelings towards Deborah are transient?

176: Jenni= Yes they come and go depending on what is happening, be it her difficult behaviour or if we are not able to do something.

177: Chris= How long do these thoughts last?

178: Jenni= They are only moments, seconds even, but they do come and go frequently.

179: Chris= Do you mean them then?

180: Jenni= At the time I guess I do, otherwise I wouldn't say them.

181: Chris= Do you speak to Mike about these thoughts?

182: Jenni= Oh god, not at all, he would think me evil and unfit to be a mother.

183: Chris= Do you ever experience similar thoughts with Jade?

184: Jenni= No, not in the same vein, I will sometimes think that I don't like her for what she has done, but never wishing that she had died or would be dead.

185: Chris= That's a slight difference to what you had said

186: Jenni= What?

187: Chris= You stated earlier that you wish Deborah had died when she was younger, you have just said that you wished her dead. What do you mean by this?

188: Jenni= Well, at times when she's at her worse I do wish that she would die, and leave us be, in peace so that we can get on with our lives. Am I awful thinking these thoughts?

189: Chris= I think you are experiencing thoughts that most people do in similar situations as yours, it's just that people keep these thoughts to themselves.

190: Jenni= Like me?

191: Chris= Yes. So you deal with these thoughts by dismissing them? Do they ever play on your mind?

192: Jenni= To be honest yes, they do, I think there must be something wrong with me to think these thoughts. I want to tell Mike but I can't as he may think me mad or bad or worse.

193: Chris= All I can say is that such thoughts have been reported in the research journals before so you are not alone. That is one of the reasons I have asked this question. So that I can find out how common this is for parents under extreme stress.

194: Jenni= Oh I see.

195: Chris= To summarise you experiences intrusive negative thoughts about Deborah only, when she is being extremely difficult. These thoughts are of the nature of wishing her dead, wishing that she had died, as a young child, hating her for what she is and what she has done to you and your family, is this right?

196: Jenni= Yes.

197: Chris= Are there any other times when you think negatively about her?

198: Jenni= Erm, yes there are. Sometimes when I look at her I find myself thinking to myself what a mess she looks. She is odd looking, all top with no legs. I wish I could change that, but I can't. I suppose I am thinking that she is ugly.

199: Chris= Is that more about how you think other people view her, when you are out and that is a reflection on you?

200: Jenni= In some ways I agree with what you are saying. I try not to think about others staring and tut tutting, when we are out with Deborah, but you can't help it, it's like sharp irons piercing your body, you are so aware of it. But, if she wasn't odd looking or didn't have a disability nobody would look or even care.

201: Chris= Okay and finally, are there any particular stories that come to mind that best describe living with Deborah?

202: Jenni= You would think that I could pull out loads, but I can't think of one just yet, let me think for a minute... erm, er... every day events, you know, Deborah do you want to go to the toilet, ff she trots, up the stairs, two minutes later she comes downstairs, knickers around her akles. We go upstairs to help her usually she does it herself. She has had a wee, but emptied the contents of the toilet on the floor, using the bin. The floor is wet and full of wet tissues. This is an example of how a simple task of going to the toilet can turn into a major event. There are loads of stories to tell. All I can say is that Deborah is Deborah we love her to bits usually, she can bring fun and joy to us all, but usually it is more pain and grief because of her lack of understanding of our world and rules.

203: Chris= Many thanks.

204: Jenni= That's okay.

205:

206: Interview concluded.

Node 4 of 51 Being stuck

Passage 1 of 1 Section 0, Para 172, 740 chars.

172: Jenni= As I have said we remain stuck, not able to do normal things, you know, just put our coats on and go out for a meal. Not asking for major life things here, just things that other normal families do. For us it is a real effort that involves a lot of planning, er, arranging someone to sit in for us, which is not easy as Deborah can be very difficult. So I do keep asking that question why us? Why me? If it wasn't for Deborah and her disability things would be so different... it is her disability that I don't want or like it has had such an effect on us all. It is not Deborah's fault, she can't help that but I project that blame onto her, as though it is her fault, so at times I really hate her for what she brought to my family.

Node 5 of 51 Conflict and coping

Passage 1 of 1 Section 0, Paras 120 to 131, 1454 chars.

- 120: Okay. If we move on then how do you deal with issues of conflict and do you have opportunity to talk about your feelings and if so with whom?
- 121: Jenni= Three questions [laugh], well I talk then argue with Mike. Afterwards we do talk about what has happened and try to reach a compromise, until the next time [laugh]. In a way I will go to the shop and arrange flowers, that help me relax and think things through, to calm me down.
- 122: Chris= Do you need calming down?
- 123: Jenni= Oh, sometimes, as I said I hold on to things for long times, so I need time to calm and think through things. Doing my flowers helps with that. Going for a walk also helps, we are close to the prom so I can just get out and walk for ten minutes or so to help me calm.
- 124: Chris= So you are saying relaxation by flower arranging [previously, known to interviewer] and going out for a brisk walk?
- 125: Jenni= Well I wouldn't say brisk [laugh] just a walk so that I can think about what has gone on, but yes that's right.
- 126: Chris= And in relation to talking about?
- 127: Jenni= I have opportunity to talk with some of my friends, you know, I've had a shitty day with Deborah, which has caused a major blow up with Mike, that kind of thing. As I said I also talk with Mike when we are both calm. That always helps.
- 128: Chris= It doesn't cause further rifts?
- 129: Jenni= Sometimes, but we are usually calmer when we do talk and if it does re-blow I will just walk out.
- 130: Chris= Out of the house?
- 131: Jenni= Usually, yes.
-

Node 6 of 51 Family relationships

Passage 1 of 2 Section 0, Paras 20 to 26, 989 chars.

- 20: Oh, at the moment she hates Deborah, can not be in the same room, this is because Deborah is horrid to her, wanting to pull her hair and pinch her. Jade wants to be out all of the time only is home when Deborah is in school [hostel] or respite. The family is better when she isn't here.
- 21: Chris= Has this been the case always?
- 22: Jenni= Oh no, I used to play with Deborah when they were younger, she knew no difference, Deborah was Deborah they just got on with it...
- 23: Chris= When did things change?
- 24: Jenni= When Deborah changed into a young woman, she became more difficult with her tempers. I also think Jade got more embarrassed as Deborah would walk around the house semi naked and was not bothered. Jade never, and still doesn't bring friends around if Deborah is home.
- 25: Chris= Does Jade talk to you about Deborah and how she feels about her?
- 26: Jenni= No not to me, I don't think she does with Mike either. She does argue with Deborah and will say openly that she hates her for what she is...
-

- 28: Well Mike's parents live away from us, so we do not see them that often...
- 29: Chris= Is this as a result of Deborah?
- 30: Jenni= Oh no, we, moved to Wales before Deborah was born, so no, they were upset and didn't know what to do or say. I guess they had lost their hoped for granddaughter. When they visit they have nothing to do with her now. They cannot cope with her and her ways, so I'm glad they live far away...
- 31: Chris= Your parents?
- 32: Jenni= Well they live close by, they are divorced, but we see them quite a lot, not so much with Deborah. Like Mike's parents they find it hard to cope now. It was different when she was younger, but now, well lets say they would find it easier if she lived else where, you know, out of sight out of mind.
- 33: Chirs= Have they said this to you?
- 34: Jennni= Oh, they wouldn't want to upset me, but you have a good idea what they are thinking they just don't talk about her, it is all Jade and no Deborah.
- 35: Chris= Does that upset you?
- 36: Jenni= It used to quite a lot, but I have got used to it now, it is the way things are, just get on with it.
- 37: Chris= What about any brothers or sisters?
- 38: Jenni= Well, we do have them but we rarely see them. We don't go to them at all, er, it is hard as Deborah doesn't sleep well in strange places, so it is something we do not do.
- 39: Chris= So you are saying that as a direct result of Deborah's difficulties you have limited or no contact with your or Mike's brother's or sisters?
- 40: Jenni= Yes that's right.
-

- 167: Chris= This is an odd question but have you ever experienced private thoughts about your child/children?
- 168: Jenni= Oh... [long pause] I don't know how to answer this er, there are times, mostly when she is being badly behaved. I have felt, said to myself, god I wish you had died when you were younger, I can't stand you I hate you for what you have done to us. There are times when I think to myself, and I mean to myself, 'what the hell have we done to deserve this?' You know we are not bad people, we have never harmed anyone, caused anyone any pain or trouble. But we find ourselves in this state of perpetual stagnation...
- 169: Chris= What do you mean by this?
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203: Chris= Many thanks.

204: Jenni= That's okay.

205:

206: Interview concluded.

Node 8 of 51 Friends - nature

Passage 1 of 1 Section 0, Paras 43 to 61, 2172 chars.

43: Not exactly, er, we moved to Wales several years ago. We therefore had to make new friends.

44: Chris= Was Deborah born in Wales?

45: Jenni= Yes.

46: Chris= So do you still maintain that circle of friendships?

47: Jenni= Well, no. I still talk with some of them, whenever I see them. But they are not friends like they used to be.

48: Chris= Can you explain?

49: Jenni= Er, we, I don't go out with them anymore. That changed when Deborah was bom. I suppose they did not know what to say or do, and as time went by we lost contact. You see we could just go out, it was hard to get a sitter for Deborah. That got worse as she got older, no one would or could cope with her so we stopped going out like that, and as I said my friends, and Mike's stopped calling round. We then moved again and had to start again.

50: Chris= Would you say your new friends or acquaintances have a child like Deborah?

51: Jenni= Some of my new friends, which I made at the other house as well, do have a child with disabilities, I suppose I wouldn't have met them but for Deborah. This is only the same as meeting other parents at the school gate and building a new friendship.

52: Chris= Yes, but the difference surely is that you would not meet other parents at the school gates because children like Deborah are transported to and from school by taxi or mini-bus. So in some respects parents are denied that opportunity as well.

53: Jenni= Yes, I would agree with that.

54: Chris= So how did you meet these friends?

55: Jenni= At school events, like coffee evenings and by being on working groups.

56: Chris= Do you have contact with your new friends out side of school events?

57: Jenni= I sometimes meet with them during the school day, for coffee say, but very rarely meet with them in the evening.

58: Chris= Is that due to Deborah or other aspects?

59: Jenni= In the main it is due to Deborah, as I said before we find it hard to get a sitter these days, well we never have been able to find one who is reliable. So yes, D stops me and M from going out as a couple.

60: Chris= Are there any times that you can go out, for example when D is at Respite?

61: Jenni= Well, the chance is there for us to go out but we are generally to knackered so we tend not to.

Node 9 of 51 Getting help

Passage 1 of 1 Section 0, Paras 147 to 149, 561 chars.

147: After many meetings yes. It really helped us to cope, just having a couple of extra nights in the hostel helped. It was our life line to coping and to be able to carry on looking after Deborah.

148: Chris= So in some respects you are on a constant roller coaster ride of stress. It is always there but on a continuum.

149: Jenni= Yes that about sums it up. I would say similar to us. She is up and down. You sometimes wonder whether it is because of her own growing up that is causing her moodiness, I suppose some of it is, but Deborah has a part to play in it as well.

Node 10 of 51 Impact of disability - parent

Passage 1 of 1 Section 0, Paras 101 to 119, 2304 chars.

101: Oh, Living with Deborah is really hard, there are good times don't get me wrong, but there are an awful lot of bad times when you feel really low and have no energy to carry on; that's how I am affected...

102: Chris= Thank you, does living with Deborah cause you and family any conflict?

103: Jenni= Erm, conflict... sometimes there are conflicts of thought, I mean... oh what do I mean. You see sometimes I wish Deborah would go away, out of this house, but she is my daughter I want her safe, the only safe place really is at home.

104: Chris= Safe in the sense of?

105: Jenni= Well, we know that she gets the care and attention that she needs, if she was away elsewhere, well, you read the papers don't you, anything could happen to her, and she wouldn't be able to tell anyone.

106: Chris= Are there any other aspects, for example that relate to Mike and your self?

107: Jenni= Oh yes we do argue about Deborah, more about who is doing it right.

108: Chris= In what way?

109: Jenni= Er, dealing with her bad behaviour, I tend to shout and hold grudges for ages, whereas Mike will explode, deal with it and its all forgotten. He's much more able to deal with the bad days. I suppose that is due to his work.

110: Chris= So the arguments?

111: Jenni= Well, we will have words, sometimes strong words where we really fall out , sometimes for days, just because we can't agree on how things should be done for Deborah.

112: Chris= In respect of managing her behaviour?

113: Jenni= Yes, as I said Mike is better at than me. So we do talk about it, but more often than not we argue to the point of having words.

114: Chris= Do you find your self in a similar position when discussing Jade?

115: Jenni= No, we seem to be able to agree much easier when it comes to Jade. It is easier though isn't it? Jade is normal, who is growing up and what all that brings. We tend to be united in making decisions.

116: Chris= For example?

117: Jenni= Well, if she wants to go out at night with her friends, that's usually okay, it is when she wants to stay out later. That is when we both say no together.

118: Chris= To summarise then, Deborah tends to cause more conflict for you individually and as a couple than Jade does. Would you say this is because of Deborah's disability and the differences between raising a handicapped child and a non handicapped child?

119: Jenni= Erm, yes I guess that is true.

Node 11 of 51 Living with disability

Passage 1 of 2 Section 0, Paras 5 to 15, 1987 chars.

5: The effect of D disability on you.

6: Jenni= er... at times I find it really hard, you know, to cope, particularly when she is being bad, I just sometimes think, why me, why us. Most of the times though I just get on with it, I don't think about it. Just carry on as normal. Mind you things aren't normal are they? We would not have to plan things all the time...

7: Chris= What do you mean by planning things?

8: Jenni= Well, simple things like going out in the evening we cannot do those kind of things without huge effort... asking for respite from social services, that can be a real drain, cos' it is not always there when you want it or need it most.

9: Chris= Is there any other aspect to Deborah's disability, which has an effect on you?

10: Jenni= I suppose when you think about it, her disability has wide ranging effects on me, it's something I have not really thought about deeply, as I said before I just get on with it without thinking, yet when she is being bad, screaming and shouting around the place well that is when I think I cannot cope with this any more, I want out from it, so in response to your question, yes Deborah disability has quite an effect on me,

more than I would admit to. If you ask me this again next week I would be able to give you a fuller answer...

11: Chris= How would you describe the effect of Deborah on Mike?

12: Jeni= Oh, now that's even more difficult, although we do talk, we don't to that level. I would think through living with him that he is deeply affected by Deborah.

13: Chris= Can you explain?

14: Jenni= Well he really wanted a daughter, well as you know she wasn't perfect in that sense, her disability. I suppose like me he has just got on with it. He isn't the type of man to run of and work all hours, but he does go out more, playing golf like. I suppose he needs that though to cope. When Deborah is being bad she can be awful in the house there is a lot of screaming and shouting from all of us. He sometimes gets upset with her.

15: Chris= In what way?

Passage 2 of 2 Section 0, Paras 95 to 97, 702 chars.

95: Sometimes it is a great pleasure... most of the time it is a pleasure... there are other times when we want to get hold of her and strangle her. I often tell her to sit there [pointing to a chair] and tell her not to move, to stop pinching me... just to stop. ...You are given these things in life and you just get on with it. So it's no use belly aching about it. Just have to get on with it... it is all that I, we have known for the past sixteen years.

96: Chris= If you were to sum up your situation in one or two sentences what would you say?

97: Jenni= A constant longing of wanting... wanting to be able to do things in a spontaneous way, without thinking about it, without having to plan... just being able to do it...

Node 12 of 51 Managing behaviours

Passage 1 of 1 Section 0, Para 18, 339 chars.

18: For me yesterday, Deborah was really bad, in her tantrums, throwing things around the place suppose Mike felt that way too as he went off into the other room to be left alone. It's something we do not talk about. So yes, Mike is affected by Deborah um, the loss of his little girl, the loss of being able to do normal things as a family...

Node 13 of 51 Managing thoughts

Passage 1 of 1 Section 0, Paras 167 to 217, 6553 chars.

167: Chris= This is an odd question but have you ever experienced private thoughts about your child/children?

168: Jenni= Oh... [long pause] I don't know how to answer this er, there are times, mostly when she is being badly behaved. I have felt, said to myself, god I wish you had died when you were younger, I can't stand you I hate you for what you have done to us. There are times when I think to myself, and I mean to myself, 'what the hell have we done to deserve this?' You know we are not bad people, we have never harmed anyone, caused anyone any pain or trouble. But we find ourselves in this state of perpetual stagnation...

169: Chris= What do you mean by this?

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172: Jenni= As I have said we remain stuck, not able to do normal things, you know, just put our coats on and go out for a meal. Not asking for major life things here, just things that other normal families do. For us it is a real effort that involves a lot of planning, er, arranging someone to sit in for us, which is not easy as Deborah can be very difficult. So I do keep asking that question why us? Why me? If it wasn't for Deborah and her disability things would be so different... it is her disability that I don't want or like it has had such an effect on us all. It is not Deborah's fault, she can't help that but I project that blame onto her, as though it is her fault, so at times I really hate her for what she brought to my family.

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203: Chris= Many thanks.

204: Jenni= That's okay.

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206: Interview concluded.

Node 14 of 51 On being a parent

Passage 1 of 1 Section 0, Para 99, 203 chars.

99: It gives an idea as to what it is like to live with Deborah, that we are in many ways prisoners to her. I love her to bits and I'm sure Mike does, nor would I just abandon her no matter how hard it gets...

167: This is an odd question but have you ever experienced private thoughts about your child/children?

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Node 16 of 51 Role - being a mother

Passage 1 of 1 Section 0, Paras 64 to 65, 479 chars.

64: Is your role as parent to Deborah different then?

65: Jenni= No not really, er, it is with regard to the looking after because that bit of being a parent hasn't stopped. Even though Deborah is fifteen years old we are still looking after her, making sure that she is safe from harm, that she is fed and that she is kept clean and tidy. But in relation to providing the love and nurturing home that is no different really... except she can be a real handful and she can make life hard...

Node 17 of 51 Role - being a parent

Passage 1 of 3 Section 0, Paras 62 to 63, 1077 chars.

62: Thank you, If we move then, can you describe your role as a parent as you see it?

63: Jenni= It's not my job nor is it Mike's job, it is whoever is around at the time [referring to care needs]. Whoever is up first in the morning sees to her, you know, takes her to the toilet, sometimes it is me and at other times it is Mike. We tend to share the care load when it comes to looking after Deborah. I tend to be the person who does the housework, that kind of thing, whilst Mike goes out to work. So as a parent my role is to be there for Deborah and to see that her needs as well as the needs of the rest of the family are met. ...to protect my children from whatever may act to harm them, to provide a loving caring home that nurtures them. To provide the care that they need, you know, as babies and toddlers they need an awful lot of looking after, making sure that they are fed, kept warm, I suppose it is about seeing that their basic needs are met consistently until they can do it themselves, that is look after themselves, so my role as parent is then as a teacher as well.

Passage 2 of 3 Section 0, Para 73, 436 chars.

73: Whilst I still love Deborah and would protect her from harm. I have become harder I suppose, more worn down over the years. that hasn't helped at all having to keep on doing the things for her that you did when she was a toddler... as if time hasn't moved on for her... but for me it has, I have grown older and more weary with it all... so feelings of wishing that she would reach an age where she can leave this home to go to a residential

Passage 3 of 3 Section 0, Para 79, 521 chars.

79: Getting back to your question, yes I would still be a parent, a mother even if I wasn't able to see to Deborah's immediate needs, you know feed and wash her... I would still be there in the background hovering around making sure that these things are done for her... I don't think that those feelings of love for your children ever go away, no matter what they do or bring to your door, you can hate or not like them for what they have done, but you will always be there to protect and help them... that is my duty as a parent.

Node 18 of 51 Role - elements

Passage 1 of 2 Section 0, Para 67, 1290 chars.

67: Deborah needs constant care and supervision throughout the day. She wouldn't care if she didn't get dressed, washed, have her teeth brushed, her hair combed, er, her bum wiped or even her sanitary towels changed... these things are not important to her, they are meaningless. The only thing of importance is food and drink... she will search and scrounge for food and has even taken the water from the toilet pan to have a drink. So without me being home throughout the day Deborah would not be safe nor would her needs be met... As I have said I see it as my duty to be there to protect, to hurt when they hurt, to be happy when they are happy... that is what being a parent is about, for me at least. I remember when I was carrying Deborah we were both so excited about having a child together, that was still the same when she was born... nothing was wrong then, that didn't happen until she was two and a half years old. We were there for her, we doted on her, when she fell, we were there to console her, to wipe a way the tears. When she took her first steps we were there to watch to encourage, to laugh and show how proud we were when she did something new. When she uttered her first words. That is what being a parent is about it is to be there, to share in the joy, to love, to protect.

Passage 2 of 2 Section 0, Paras 75 to 77, 1069 chars.

75: Having to look after Deborah is really important to me, she has to be well dressed and clean, nothing else will do, Mike knows that too, I am very particular, so it is very important, or essential as you say for Deborah to be presentable...

76: Chris= Would you still be a parent if one or more of these elements were missing?

77: Jenni= Being a parent is made up of many different facets, when you have a child like Deborah she is always going to need someone to look after her,, that is my job at the moment, that is what I do every single day when she is home. When she goes to school that care is transferred to them, they do it, it might not be to the same standard, as I would do, but it is done, Deborah is looked after and kept safe. So the difference here is the emotional angle, school or any other form of help, being paid or otherwise will not have the emotional attachment that I and Mike have for Deborah. She is our daughter at the end of the day, she is made from us, she is our flesh and blood...So for me it is important that her care is of the highest standard...

Node 19 of 51 Role - making a difference

Passage 1 of 1 Section 0, Paras 91 to 93, 508 chars.

91: I think it makes a huge difference to Mike and Jade, Deborah probably doesn't care, it could be the milkman as long as she is fed and watered. It wouldn't bother her if she never had a wash, cleaned her teeth... by being part of a team, Mike and me that's what matters and by us being and doing together, well most of the time, it has an effect on Jade...

92: Chris= In what way?

93: Jenni= She is quite together as a person, very understanding of our situation and I really do believe it is down to how Mike and I are.

Node 20 of 51 Role- what matters

Passage 1 of 1 Section 0, Paras 81 to 89, 1739 chars.

81: Being part of a unit, being together as a husband and wife team, being friends and sharing together the care load, the meetings. Without each other I don't think we would be able to manage it alone, so my role as wife and mother is very important to this family, I am part of the machine that helps to make it work for us... Mike is a real support, as I have said we have grown together and learnt how to cope together. So me being there for him and for the children really matters. If I wasn't here or even if Mike wasn't here for whatever reason this family would not be able to cope, it would break down.

82: Chris= What do you mean by this?

83: Jenni= If I or Mike were single parents living and coping with Deborah on a day to day basis, I don't think either one of us would cope... Deborah would end up in care somewhere. As a couple we have gotten used to supporting each other, you know, where one breaks off and the other comes in... it is a partnership and without this partnership things would go bad...

84: Chris= To what extent do you think your role has been influenced by ideas from elsewhere?

85: Jenni= This might sound a bit crass and stupid but I have, well, as a teenager always wanted to get married to the most handsome bloke and have his children and live forever happily [laugh]... This is probably because my mum and dad divorced when I was a teenager and I wanted to prove to myself that it can be done...

86: Chris= And can it?

87: Jenni= I think so, life isn't a bed of roses I know that now, life is hard and it comes with many knocks, but I have Mike and Jade has come out of all this...

88: Chris= So from what you are saying your experiences of your parents divorce has made you more resolute to succeed where they failed?

89: Jenni= Definitely.

Node 21 of 51 Stress levels and management strateg

Passage 1 of 2 Section 0, Paras 134 to 146, 2680 chars.

134: Do you feel as though you are under stress, how would you describe your levels of stress - high or low relative to past experiences?

135: Jenni= At the moment I would say my stress levels are fairly low, the highs tend to come around any school holiday when Deborah is home for more than three days. Deborah needs assistance throughout the day and night, when she is having a bad spell with her sleeping we all get very stressed. One of us has to get up through the night putting her back into her bed, making her stay in her room, switching the lights off at two, three, four, five and six o'clock in the morning. You can't have a lie in to recover from a what is like a night shift, you have to be up no later than 9 o'clock because Mike has been up since 7 o'clock dealing with her, you know, making sure that she is safe from the point of her getting out of bed for the day. So any school holiday puts more stress on us as a family.

136: Chris= How would you describe Mike's levels of stress?

137: Jenni= I would say he is quite stressed out. But he just copes and gets on with it, we just have to don't we? He will... you can see the stress in him sometimes, in the way he is with everybody. You know... he wants to be left alone. When he talks with Deborah, in particular, he will have this kind of grimace on his face, his words are loud and to the point. as though he is angry.

138: Chris= So at the moment your stress levels are relatively low and Mike's stress levels, according to you, are relatively high. Have they been any higher? And at what point have they been high?

139: Jenni= Oh... they were really high about a year ago, we were at the end of our tether, we wanted Deborah out of the home. She was awful to live with. She wasn't sleeping at all, up all night. We had to watch her in shifts, it was really hard when Mike was on nights. I was up so much in the night, I was knackered. On top of that she was bad in school as well, so that brought more problems home. She was pulling her hair out in lumps and smearing oo at any opportunity. We couldn't take her out because she would just sit down on the floor and scream her head off. All this meant meetings with lots of people.

140: Chris= Like me?

141: Jenni= Yes, that causes additional stress, you feel as though you are being blamed for Deborah's behaviour as though you have done wrong.

142: Chris= Do both of you feel that way?

143: Jenni= Yes, we do. I suppose most parents in our situation would.

144: Chris= So Deborah's behaviour had got far worse to the point where both you and Mike had had enough and wanted Deborah to leave home, for good?

145: Jenni= Oh no, we just wanted respite from her and I suppose her from us.

146: Chris= Did you get the help you wanted?

Passage 2 of 2 Section 0, Paras 150 to 164, 2090 chars.

150: Okay, we have talked about family stress. If we look at what you do to reduce the high levels of stress, what techniques do you use?

151: Jenni= As I said before, going out for a walk, flower arranging.

152: Chris= Any other ways?

153: Jenni= Yes, going out [when I, we, can] you know having a few drinks helps me to relax.

154: Chris= Do you drink often?

155: Jenni= Oh, now that's asking... er, yes, I will have a drink most nights a glass of wine usually does the trick for me. I sometimes think about my situation and of my friends, some of whom are much worse off. That helps a lot, knowing that I am not alone.

156: Chris= So, you use physical exercise, relaxing by flower arranging, drinking, talking and

157: comparing others' woes against your own as vehicles to managing your stress. Do these approaches work for you?

158: Jenni= Not always, but on the whole they do. As I said going for a walk, having a drink or two help me to think about and to relax, they make me feel better. It's like my punch bag. I can get it out of my system quicker than without doing it. Flower arranging is my hobby, something that I have always enjoyed doing. It is my time to be creative, it helps me unwind totally and forget about things.

159: Chris= You said forget about things, flower arranging helps you escape from your life?

160: Jenni= Yes, I think it does, without it I don't think I would be able to cope.

161: Chris= Do you engage in this activity a lot?

162: Jenni= Not as much as I would like to, it's no use having the stuff here. 'Cos I would not be able to escape I need to be able to get out of the house be alone somewhere to do it.

163: Chris= And being part of a group with parents who are in the same boat, does that really help you manage your stress?

164: Jenni= Yes, it does as I said it helps me put things into perspective, you know, somebody is always worse of then me. In a funny way it really helps me come to terms with Deborah's difficulties. You know I'm , we are not alone there are others out there going through similar difficulties. It really helps me cope when at the worst times. I can also talk to these parents, which also helps.

Node 22 of 51 Thoughts on thoughts

Passage 1 of 1 Section 0, Paras 167 to 217, 6546 chars.

167: This is an odd question but have you ever experienced private thoughts about your child/children?

168: Jenni= Oh... [long pause] I don't know how to answer this er, there are times, mostly when she is being badly behaved. I have felt, said to myself, god I wish you had died when you were younger, I can't stand you I hate you for what you have done to us. There are times when I think to myself, and I mean to myself, 'what the hell have we done to deserve this?' You know we are not bad people, we have never harmed anyone, caused anyone any pain or trouble. But we find ourselves in this state of perpetual stagnation...

169: Chris= What do you mean by this?

170: Jenni= As a family we have remained stuck, have not moved on and I can't see us ever moving on, not unless Deborah leaves home... but that is a point of contention, I'm fearful of this, I have a sister who has a learning disability and to be honest she did not fair well in an institution, so I am reluctant for Deborah to go anywhere other than staying at home; this causes arguments between Mike and me...

171: Chris= What effect will this have on you?

172: Jenni= As I have said we remain stuck, not able to do normal things, you know, just put our coats on and go out for a meal. Not asking for major life things here, just things that other normal families do. For us it is a real effort that involves a lot of planning, er, arranging someone to sit in for us, which is not easy as Deborah can be very difficult. So I do keep asking that question why us? Why me? If it wasn't for Deborah and her disability things would be so different... it is her disability that I don't want or like it has had such an effect on us all. It is not Deborah's fault, she can't help that but I project that blame onto her, as though it is her fault, so at times I really hate her for what she brought to my family.

173: Chris= How do you deal with these feelings as you said that you 'think these things to yourself'?

174: Jenni= I do keep these thoughts to myself, I'm sure Mike would think me a horrible person if he could hear my thoughts... I don't think I am a horrid nasty person I am responding to the situation. My feelings towards Deborah are of hate and detest but not always, they come and go, you know, they are brought to the fore when either, er, like for example, recently we were invited to a family wedding, we couldn't arrange for anyone to look after Deborah, I said that I would stay home as the wedding was on Mike's side of the family. He would have none of that, if we both

couldn't go then we wouldn't go... so that was it... because of the way Deborah is we often lose out on being able to do normal things.

175: Chris= So these feelings towards Deborah are transient?

176: Jenni= Yes they come and go depending on what is happening, be it her difficult behaviour or if we are not able to do something.

177: Chris= How long do these thoughts last?

178: Jenni= They are only moments, seconds even, but they do come and go frequently.

179: Chris= Do you mean them then?

180: Jenni= At the time I guess I do, otherwise I wouldn't say them.

181: Chris= Do you speak to Mike about these thoughts?

182: Jenni= Oh god, not at all, he would think me evil and unfit to be a mother.

183: Chris= Do you ever experience similar thoughts with Jade?

184: Jenni= No, not in the same vein, I will sometimes think that I don't like her for what she has done, but never wishing that she had died or would be dead.

185: Chris= That's a slight difference to what you had said

186: Jenni= What?

187: Chris= You stated earlier that you wish Deborah had died when she was younger, you have just said that you wished her dead. What do you mean by this?

188: Jenni= Well, at times when she's at her worse I do wish that she would die, and leave us be, in peace so that we can get on with our lives. Am I awful thinking these thoughts?

189: Chris= I think you are experiencing thoughts that most people do in similar situations as yours, its just that people keep these thoughts to themselves.

190: Jenni= Like me?

191: Chris= Yes. So you deal with these thoughts by dismissing them? Do they ever play on your mind?

192: Jenni= To be honest yes, they do, I think there must be something wrong with me to think these thoughts. I want to tell Mike but I can't as he may think me mad or bad or worse.

193: Chris= All I can say is that such thoughts have been reported in the research journals before so you are not alone. That is one of the reasons I have asked this question. So that I can find out how common this is for parents under extreme stress.

194: Jenni= Oh I see.

195: Chris= To summarise you experiences intrusive negative thoughts about Deborah only, when she is being extremely difficult. These thoughts are of the nature of wishing her dead, wishing that she had died, as a young child, hating her for what she is and what she has done to you and your family, is this right?

196: Jenni= Yes.

197: Chris= Are there any other times when you think negatively about her?

198: Jenni= Erm, yes there are. Sometimes when I look at her I find myself thinking to myself what a mess she looks. She is odd looking, all top with no legs. I wish I could change that, but I can't. I suppose I am thinking that she is ugly.

199: Chris= Is that more about how you think other people view her, when you are out and that is a reflection on you?

200: Jenni= In some ways I agree with what you are saying. I try not to think about others staring and tut tutting, when we are out with Deborah, but you can't help it, it's like sharp irons piercing your body, you are so aware of it. But, if she wasn't odd looking or didn't have a disability nobody would look or even care.

201: Chris= Okay and finally, are there any particular stories that come to mind that best describe living with Deborah?

202: Jenni= You would think that I could pull out loads, but I can't think of one just yet, let me think for a minute... erm, er... every day events, you know, Deborah do you want to go to the toilet, ff she trots, up the stairs, two minutes later she comes downstairs, knickers around her akles. We go upstairs to help her usually she does it herself. She has had a wee, but emptied the contents of the toilet on the floor, using the bin. The floor is wet and full of wet tissues. This is an example of how a simple task of going to the toilet can turn into a major event. There are loads of stories to tell. All I can say is that Deborah is Deborah we love her to bits usually, she can bring fun and joy to us all, but usually it is more pain and grief because of her lack of understanding of our world and rules.

203: Chris= Many thanks.

204: Jenni= That's okay.

205:

206: Interview concluded.

Node 23 of 51 Transient - when things are bad

Passage 1 of 1 Section 0, Paras 167 to 217, 6553 chars.

167: Chris= This is an odd question but have you ever experienced private thoughts about your child/children?

168: Jenni= Oh... [long pause] I don't know how to answer this er, there are times, mostly when she is being badly behaved. I have felt, said to myself, god I wish you had died when you were younger, I can't stand you I hate you for what you have done to us. There are times when I think to myself, and I mean to myself, 'what the hell have we done to deserve this?' You know we are not bad people, we have never harmed anyone, caused anyone any pain or trouble. But we find ourselves in this state of perpetual stagnation...

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203: Chris= Many thanks.

204: Jenni= That's okay.

205:

206: Interview concluded.

APPENDIX NINE

FORMAL SEARCH STRATGEY

A formal search strategy was utilised to locate and obtain relevant literature that aided the development, discussion and argument presented in this thesis.

A list of terminology and key words were generated that includes the following: Learning Disability, Mental Retardation, Intellectual Impairment, Parents, Carers, Child, Children, Stress, Well-being. I adopted a Boolean search strategy when browsing computer databases such as Parents **or** Carers **and** their children with a Intellectual Impairment. Combinations of these key words were used throughout my search strategy.

The scope of the search included a date range between 1960 to current; once searches had been exhausted the date range was refined to annual searches i.e. from 2007 to current. The geographical region was also considered, as was the language and literature type. All journal and book references that were written in English and of an academic literature style were considered during the initial trawls. Those that had been subject to peer review were deemed more authoritative and were consulted. Key articles that were obtained provided another source of information as they had bibliographies that led to other relevant articles/items.

Computer databases (Indexes, abstracts and bibliographies) and other electronic sources such as www. were routinely used. This included regular interface with the

following health, psychology and social sciences databases: Medline, Cinahl, PsycINFO, Cochrane and British Nursing Index.

Inter library loans were used to obtain and collate appropriate literature be it from relevant journals or books.

Manual searches were also conducted when I frequented NHS and University libraries where I sourced relevant books pertinent to the thesis topic.

APPENDIX TEN

MEANING UNIT GENERATION

Thematic clusters from this study were initially generated by use of NVivo computer assisted software. Each statement was considered with equal importance and read and reread several times. As a process I listed by highlighting each repetitive statement and attaching a descriptive code (see appendix eight). These codes were further refined once all of the transcripts had been allocated their initial codes. Nvivo enabled each document to be coded and uncoded, it also allowed me to search all codings used throughout this project with a view to reallocating and redefining.

The refined codes were then grouped into 'invariant meaning units' (Moustakas, 1994) that formed the themes as presented within the body of chapter nine. It is important to reiterate here that the theme acts to describe an aspect of the structure of lived experience (Van Manen, 1990).

APPENDIX ELEVEN A, B and C

NEWSPAPER EXTRACTS

guardian.co.uk

Woman, 67, admits manslaughter of son with Down's syndrome

- Victim found drugged and suffocated
- Father died of natural causes two weeks later

Patrick Barkham

The Guardian, Saturday 24 September 2005

A mother yesterday admitted killing her son, who had Down's syndrome, after caring for him in her family home for more than 30 years.

Wendolyn Markcrow, 67, of Long Crendon, Buckinghamshire, pleaded guilty to manslaughter by reason of diminished responsibility after the death in March of her third son, Patrick, 36, who was autistic and also had behavioural difficulties.

Watched by her two other adult sons, Martin and Jonathan, in a packed public gallery that included a number of friends and supporters, Markcrow denied a charge of murder at Reading crown court. The prosecution accepted her plea and Judge Jonathan Playford agreed, adding: "I am entirely satisfied that this is the correct course for the prosecution to take."

He granted Markcrow conditional bail, providing that she resides either at home under the supervision of a family friend or in hospital.

Nicholas Browne QC, for the prosecution, said the case had been considered at some length by the Crown Prosecution Service.

"We have considered the overall picture with senior police officers and lawyers and, bearing in mind the overwhelming psychiatric evidence, we have decided that the proper course to take is to accept the plea that has been tendered," he said.

Police were called to the house where Markcrow lived with her husband, Paul, 70, in the village of Long Crendon on March 29, where they found Patrick's body. Police later confirmed that he had died of plastic bag suffocation while intoxicated on the drug zopiclone.

Two weeks later Markcrow's husband, a retired architect and former district councillor, died of natural causes, believed to be a heart attack.

According to villagers, Markcrow used to work as a school dinner lady but gave up the job more than 10 years ago to give her son full-time care. She received respite care from the local council and carers described Patrick as "a loving, private man", who enjoyed swimming and a coffee in the local community.

Betty Payne, 75, who lived near the family, described Markcrow as a "devoted mother" and a "lovely, bubbly, friendly woman" who would wait in the lane outside her home each day for Patrick to return by bus from a day centre.

"You could not make contact with him at all. I used to say hello and ask how he was but it was like he hadn't noticed you," she said. "I believe he would wake up in the middle of the night shouting. He stopped going to the day centre 18 months before. She never once complained but I know she would have liked for Patrick to go to someone a few afternoons a week so she could rest."

Another neighbour, who did not wish to be named, said Markcrow had been dedicated to her son: "I don't know what happened but whatever did, it was not her fault. We are all behind her and would welcome her back."

Jeff Steadman, pastor of the local Baptist church, said that the mood in the village was one of "profound sadness and sympathy" for Markcrow. When she was arrested, villagers gathered and wrote messages of support which were then sent to her.

"She is well respected with people who know her but a private person and that may have been compounded by the fact that she wasn't able to mix with people [because of her caring responsibilities]. There is more sympathy than criticism. Patrick had special needs and that was an enormous pressure for her. She was very conscientious in her care for him."

The judge ordered that a further psychiatric report be completed by October 21 in time for an expected sentencing before a high court judge sitting at Oxford crown court.

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Killing your son is not proof of love

By Mary Wakefield

Published: 12:01AM GMT 18 Dec 2005

[Comment on this](#)

On Monday morning Andrew Wragg walked free from Lewes Crown Court with a two-year suspended sentence, though he admitted freely that he had smothered his 10-year-old son to death. How did Wragg get off so lightly? Well, his son, Jacob, was severely disabled, with a rare genetic disorder that left him unable to walk, talk or hear properly. And though the official verdict was that Wragg suffered from "diminished responsibility", what seemed to really sway the court was that he was motivated to kill Jacob by love.

"Mitigating factors are your belief that what you did was an act of mercy," said Mrs Justice Rafferty. "I accept that your genuinely held belief was that what you did would bring to an early end a life afflicted and drawing inexorably to a close."

"My son wanted me to do it, because he had a terminal illness," said Wragg, and members of the jury wept as he spoke. Perhaps I should feel sad, too, but I don't; I feel out of kilter with the sentiment in court. Why weep for Andrew, not Jacob? Why be moved by Wragg's testimony, to anything but alarm? It's true, Jacob only had a few more years left to live, but that just makes each lost year more of a tragedy.

What gives me the particular creeps is the thought that this verdict might encourage others to think that the law is lenient to mercy killing and that it's ok to judge the quality of lives very different to their own. Elderly, incontinent parent? Whack 'em. Sick child? Only kind to kill. For a healthy adult to imagine they can know what it feels like to be a disabled ten-year-old, is less compassionate than lethally stupid.

One of the most important ways in which Jacob and Andrew's lives were incomparably different, was that Jacob couldn't compare. "Jacob never judged his own life, he was a happy, loving child," said Mrs Wragg. So what made Andrew Wragg do it, and, more important, what made the judge and jury so sympathetic to his point of view?

Then, leafing through the reports, I noticed a detail that I'd missed before. A few days prior to suffocating his first-born, Wragg watched a movie called *Lorenzo's Oil*, about a couple who struggle to look after a disabled boy, and cried like a baby throughout. Once I knew about the flick,

everything clicked into place. I haven't seen *Lorenzo's Oil*, but the sentiment surrounding Andrew Wragg is Hollywood through and through.

In the movies, it's not an easy way out, but almost a moral obligation to end a pain-filled or disabled life. Think of *Billion Dollar Baby*, and *The Sea Within*: both make the case for euthanasia as heroism.

"I looked into Jacob's eyes and sensed that he wanted to die," said Andrew Wragg - straight from a second-rate script. But the Wragg case is, unfortunately, real, and the reality is that Andrew Wragg was far from a hero. It seems that he didn't love Jacob enough to stay faithful to his wife - he had a weakness for one-night stands and left when Jacob was six to have a series of long affairs. It also seems that Andrew Wragg didn't love Jacob enough to want to continue the day-to-day grind of caring for him until the natural end of his life; he only loved him enough to kill him.

AUTISM: ALISON DAVIES BODY FOUND

Published by webmaster for Autism Awareness Campaign UK in Communities

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It is believed that the body of forty year old Alison Davies has been found by a member of public in the River Humber, near Brough. Humberside Police confirmed they have informed the family of Alison Davies of the discovery.

Alison Davies together with her 12 year old autistic son Ryan fell from the Humber Bridge.

The Autism Awareness Campaign UK have called for a review of autism and public services in the wake of the Humberside tragedy. They have also appealed to the Chancellor Gordon Brown to initiate an autism allowance and find ways and means of easing the financial burden for families with autism.

Many families are at breaking point as a result of the cost implications of autism in the light of councils refusing to help with public services. Many parents and carers have had to re-mortgage their houses and take loans to fund therapies and public services. Others are unable to even do this and have had to suffer without any public services.

Ivan Corea of the Autism Awareness Campaign UK has appealed to the Secretary of State for Education, Ruth Kelly, to provide more support at secondary school level and access to further and higher education for young people with autism in the wake of the Humberside Tragedy. The Autism Awareness Campaign UK are calling for structured support for young people with autism and Asperger's Syndrome, training for teachers and room assistants at secondary school level and for local authorities to build and fund autism units in mainstream schools. There is also a crying need for respite care.

'Let Ryan Davies' death not be in vain. We are calling upon the Prime Minister and the Government to listen to the voices of parents, carers and people with autism who desperately need help, we need public services in education, health, specialist speech therapy and respite care. Marriages are breaking down as a result of the pressure - we urge Gordon Brown to provide funding and launch initiatives to help families with autism before they reach crisis point. People are struggling without adequate support - the authorities at national and local level need to realise that young people with autism have so much potential. Now is the time for action on autism right across our nation,' said Ivan Corea.

Four weeks ago Ivan Corea presented autism awareness ribbons to the Prime Minister and Cherie Blair in London and urged for more support for families with autism. The Autism Awareness Campaign UK has called for a fundamental review on autism and public services in the wake of the Humberside Tragedy.

Ends

Press release issued: April 30 2006