# An exploration of the experiences of parents who have a baby described as having a learning difficulty

A thesis submitted to the University of Manchester for the Degree of
Doctor of Philosophy
In the Faculty of Humanities

## 2012

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word count 104040

# ABSTRACT

The University of Manchester

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Doctor of Philosophy Degree
September 2011

**"An exploration of the experiences of parents who have a baby described as having a learning difficulty"**

As parent researcher and in light of perceived failings of studies found in the literature this research explores the experiences of parents who have a baby described as having a learning difficulty by employing an alternative broad methodology underpinned by 'critical hermeneutic phenomenology'. The subsequent ethical trials of adopting such an approach are scrutinised as this bears important relevance to the overall finding that parents' perspectives are rarely taken into account by those who have little or no experience themselves.

Empirical data is generated via recorded and transcribed conversational interviews with four parent participants where the content subsequently informs the critical subject matter discussed throughout the work. The hermeneutic endeavour utilises Interpretative Phenomenological Analysis (IPA) as a guiding channel and although participants' informed consent for the interpreted construction of experience was gained beforehand, significant limitations with this specific process are highlighted. As such, the methods of work in progress are presented in detail with additional reflexive commentary in the extended appendices to facilitate reader understanding of the development of interpretation as well as to promote confidence in the integrity and ability of the researcher and satisfaction regarding the overall quality of the composition.

The findings reveal that parental experience as 'phenomenon' can be contemplated as an emotional passage of a 'self' that is embroiled in 'abnormal' circumstance made most complex via impinging myriad forms of societal organisation. From the data generated, the latter is recognised as being subject to historical legacy at micro as well as macro levels, over time and according to cultural belief. In support of this finding, the socio-historic concept is explored more fully in a dedicated chapter. Further empirical evidence suggests that parents strive to achieve their perceived understandings of normality as brought to consciousness through the associations they make with others and their social environment. Parental activities specifically reveal individual pressures arising as a result of inter-sectional social systems where perceived work and gender roles (for example) also expose anti-social moralistic behaviours. Encouraging further work which promotes a 'perspectives approach' to advance the understanding of parents and their experiences, the thesis concludes with realistic expectations for progression towards an improved societal moral condition.

# **DECLARATION**

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

# COPYRIGHT STATEMENT

# **ACKNOWLEDGEMENTS**

Author's previous research qualifications

Learning Disability Studies Degree (BA) Hons (first class)
Master of Science Educational Research Degree (distinction)

# **<u>DEDICATION</u>**

To my family

# Prologue

> *"The main activity men and women have is living. This means not just eating and drinking and sleeping and lovemaking and procreating and child rearing but also friendships, caring for each other and friends, working productively and if possible, creatively, earning enough to get by and more, learning and teaching, communicating, participating in family and broader social activities, reading, watching TV, playing or watching sports"* (Desai 2000 p.80)

Desai's list may cover many of the activities people engage with in their lives yet it represents only a small part of what it means to be a person and, a tiny fraction for one who is also a parent. I am a parent. I think I am an ordinary parent, although I know that some people may decide that I am not, certainly once I have told them I happen to have a child who has impairment. Do you wonder if this has changed my life? I have attempted to explain something about myself in the first appendix (p.313), although before you refer to this, I would like to prompt another related thought: 'Has your child changed your life?' In the silence of closed interaction that comes with the one way medium of writing a paper, may I say: *I do hope they have*.

Your child (if you have one) may, or may not have impairment, of course I cannot know, yet, I am going to assume the change that you may be considering in response to my prompt holds both positive and warm thoughts: something *good* happened there. My expectation comes from my experience of having children and from an understanding of what it means to be a parent through my encounters with family, friends, associates, people I meet, complete strangers and the world at large. Children appear to bring such joy and happiness, they may fulfil or surpass expectation, when we think about them we smile, we remember something cute or funny they did (perhaps we were not laughing when it actually happened!) and we are glad they came into our world. Of course, we may have experienced difficult periods, things we were not proud of doing or saying, things we may have done differently (if only we had known better) but these are the events that add to our sense of achievement and accomplishment as parents. We strive to reach a sense of fulfilment where overall, our children help us to feel happy, complete and human. As far as I am concerned, that is what *normally* happens in our culture.

However, through my studies at the University of Manchester where my primary interest has been the topic of learning difficulties, I have become aware that some parents do not experience my perceived 'Utopia'. For some parents, maintaining or even reaching a single point of parental happiness or satisfaction appears to be an impossible mission and thus, for some parents, my 'worldly' and personal assumptions appear to be entirely misplaced. This issue led me to wonder what happens within an individual's experience that brings about change from being perceived and/or feeling like, an 'ordinary' parent to becoming a different 'sort' of parent. When I read other studies and investigate research that suggests that having a baby with impairment equates to (and is in fact the *cause* of) negative parental experience, I cannot help feeling that something is adrift, I wonder; 'is it me or *them*?' (and by 'them', I might mean parents or researchers or both). Thus, my fascination with these queries drove me towards the focus of my current doctoral study, the title of which became:

"*An exploration of the experiences of parents who have a baby described as having a learning difficulty*"

# Terminology

Prior to beginning in earnest, I consider it prudent to explain the terminology I have employed in this thesis. This explication is brief although necessary as the regularity in changed language as well as understandings and meanings in this arena has meant words used can be confusing and contradictory, not to mention potentially offensive (Linton 2004, Digby 1996). Oliver and Barnes (1998) put forward strong argument for ensuring correct terminology is in place and I concur with their overall perspective that finding common ground for understanding meanings in order to *"orient our behaviour accordingly"* (p.2) is at the very least useful. However, on balance, I am inclined to agree with Lawson (2001) who suggests the activity of untangling terms can take the focus off other, perhaps more important issues. My personal experience in this supports my underlying assumption: in the UK, a number of people are diagnosed with a condition *written* as 'Down's syndrome', whereas elsewhere globally it appears as 'Down syndrome'. When expressed as a label in conversation, the language hardly sounds dissimilar and furthermore, some of the parents I interviewed referred to children as having or being; 'Downs', 'Down syndromes', 'Downy' and 'the Downs'. As a consequence, I am not sure of the extent to which the terminology here is significant although I shall be adopting the 'official' UK spelling unless it appears as a feature of participant speech.

In addition, I have used the broader English educational term 'learning difficulty' as opposed to learning *disability* (or US 'intellectual disability') as this sits in concordance with preferences from those described as having this condition in the UK (Boxall 2002). When I began the study I discussed this issue with research site partners who, being from a health and medical background, suggested 'global delay' or 'developmental delay' may be more appropriate as this was their shared language with parents. On later speaking with participants I found they had no preference as they were familiar with all these terms given their other associations with pre-school groups and, as this is an academic thesis generated from an English educational environment, I elected to continue to use 'learning difficulty' as a descriptor.

On the even wider issue of impairment and disability, I believe the understanding of meaning behind these expressions *is* very important as these 'locate' the presumed 'difficulty' (Oliver & Barnes 1998). In tandem with current international definitions, I

denote impairment as physical or mental 'incapacity' and as such, this is interchangeable with 'learning difficulty' or more specifically for example, Prader Willi syndrome whereas, 'disability' alludes to:

> *"the disadvantage of restriction of activity caused by a contemporary*
> *social organisation"* (UPIAS 1976 cited by Barnes 2007 p. 205)

As such, a 'disabled person' is one who is restrained, excluded, marginalised or hampered in some way by societal actions and social behaviours. Given the social implication of 'disability' I employ this term when referring to the field of study, related dialogue as well as to it signifying a socially constructed concept through a variety of discourses (Race 2002, Fairclough 2003, Rapley 2004). Following this latter thread, I have chosen to follow Gee's (2005) notion of 'meta-discourse', expressing disability with a capital 'D' to indicate the extent of assigned relevant meaning which has been created through:

> *"combining and integrating language, actions, interactions, ways of*
> *thinking, believing, valuing and using various symbols, tools and*
> *objects to enact a particular sort of socially recognizable identity"*
> (p.21)

'Disability' here is a grand narrative drawing in a multitude of inseparable understandings which ultimately lodge in the mind as a seemingly single, sometimes daunting, imaginary yet tangible cultural concept (Snyder & Mitchell 2006, Rapley 2004). As such, parents in this study are understood to be people who have been literally touched by Disability in that their offspring has impairment. When referring to such individuals, I will simply utilise the term 'parent' or 'parents' as opposed to an over descriptive title of 'parent(s) of a baby described as having a learning difficulty'.

# **INTRODUCTION**

It is well recognised that becoming a parent of a child with impairment is a life changing event (Fisher 2001, Mason & Pavia 2006, Read 2000, Soloman et al 2001, Russell 2003, Kingston 2007). Through this research project I want to explore the many ways in which individuals feel their experience has unfolded as well as attempt to understand the impact that Disability has on their lives. As the title suggests, my intended approach in carrying out this research is to 'go back to basics' supported by an underlying single motive where I endeavour to grasp: 'what happened?' In light of Desai's statement (see prologue), I take the view that participants are people first who are taking part in the multi-layered, multidimensional buzz and confusion of life and to whom a particularly interesting event has occurred.

As such, this study is about the situations people find themselves in, how they negotiate life through seemingly uncontrollable episodes and their ways of reacting in terms of making decisions in relation to 'ways of being'. In this, I am exploring the notion that such a 'choice' survives given the naturally occurring, sometimes turbulent relationship that exists between the individual and the social environment. In turn, I propose that experience per se is not about navigating 'discourses', 'narratives', 'structures', 'psychological behaviours' or 'political minefields'.  Rather, it is the phenomenon of being-in-the-world which encompasses all these in the myriad of complex and constant systems that pertain to an individual's 'lived experience' (Foucault 1984b, Golden 2001, Canary 2008, van Manen 1990). Whilst this is not an attempt at dealing with the irony of what might be termed 'strictly post-structural' research (Grassie 1997, Lather 1992); it *is* an effort to work 'outside of the box' in taking up the daring challenge as proposed by McLaughlin and Goodley (2008):

> *"the difficulty is that whilst post-structuralist writing may be willing to acknowledge varied experiences within people's life worlds, the work itself, for the most part, remains unwilling to do the kind of social research that could explore this"* (p.322)

I am prepared to have a go. My approach toward researching the lived experiences of parents follows a phenomenological and therefore 'open route' that attempts to focus upon the individual whilst taking into account possible impinging and interrelated external factors affecting their 'personal world' (Habermas 1970). Individual

circumstance, historical developments, social contexts and external influences present promising avenues for exploration in addition to hearing parents 'stories' in order to find out 'what happened' (Liu & Hilton 2005, Larkin 2006, Lopez & Willis 2004).

In this, I am viscerally aware of my position as parent myself where I believe my unique researcher perspective offers some advantage to the enterprise (Zahavi & Parnas 1998, Green et al 2005, Larkin 2006, Etherington 2004, Ezzy 2002). My approach to the work is as empathetic 'insider' acknowledging that I potentially have a degree of especially shared feeling and understanding about other parents' experiences (Keen 2006, Eide & Kahn 2008). As such, I am not attempting (if it were at all possible) to *be* the other person rather, I expect our interaction to generate an open dialogue that *"reflects real life"* as it is for 'us', as parents (Green et al 2005, p. 201, McKenzie & Scully 2007).

The study has been funded by the Economic and Social Research Council (ESRC) and includes exploration of the experiences of four parent participants. Given the qualitative nature of the research, the amount of consideration paid to multiple inclusive factors and the extensive subject coverage, this small number was felt to be appropriate to the task (Smith et al 2009). The resultant findings are based upon interpreted accounts of parents' experiences with the understanding that all social interaction is subject to this activity, where I believe the reader will further interpret as they assimilate the text into their own understandings (Gadamer 1965, Betti 1972, Geanellos 1998). Given my aim of facilitating this latter process, I hope the work will be perceived as helpfully detailed, illuminating and comprehensive interpreted accounts of experience.

Although the study is primarily underpinned by philosophy rooted in experiential phenomenology, specific theory in relation to Disability becomes significant. Parents may not have impairment themselves yet having a child who does immediately changes their perceived social identity through relative association (Russell 2003, van Hove et al 2009, Vernon 2002, Canary 2008, Liu & Hilton 2005). By taking social factors such as this into account, the study necessarily draws upon practices associated with critical social theory (Habermas 1970, Held 1980, Morrow & Brown 1994). I appreciate that by adopting this unorthodox combination as a theoretical strategy, I

attract potential criticism. However, the complicated joining of hermeneutic phenomenology and critical social theory was scrutinised and demonstrated as a given possibility in my previous Masters Degree (pilot) study (Wright 2006). As a consequence, I shall not be revisiting this argument here. Instead, I offer a concise description to illuminate readers on the basic methodological principles of joining the two later in this introductory chapter. In addition, my previous thesis includes a literature review which continues to support this current work.

My present 'exploration' thus begins afresh with a bi-fold explication that enables familiarisation with the overall topic of 'being a parent'. To some, it may initially appear that I split the individual from the social context yet my intention here is to take this simplistic binary only for the purposes of presenting data. As the reader will hopefully discover when moving through the work, I describe the relationship of the 'self' living in a social environment as a divide much less distinguishable (Larkin 2006, Reeder 1998, Gergen 1999). In line with the critical phenomenological approach I firstly place a brief 'spotlight' on parents as 'object' and secondly; I introduce the notion of parents' experiences as situate in the context of the wider social arena. My aim is to expose matters arising from these areas and through pertinent compilation of two listed summaries I hope my rationale for conducting this research and taking this alternative approach becomes transparent.

## Being a parent – *'individualised object'*

There has been a myriad of research conducted with parents over the past fifty years, due in part to higher survival rates of pre-term and poorly babies, increased demands on services and concerns regarding mothers coping at home (Lupton & Barclay 1997, Barnes et al 1999, Carpenter 2000, Lohr et al 2000, Hassall & Rose 2005). Contrary to the aforementioned broad perception of 'experience', the bulk of academic literature informs that becoming a parent is likely to invoke several almost standard (and unfortunately this also leaves an impression of simplistic) personal manifestations:

1. A negative reaction at birth and/or diagnosis usually depicted in terms of 'grief' or 'loss' (Gardner & Harmon 2002, Bruce & Schultz 2002, Fisher 2001, Ho & Keiley 2003, Hugger 2009)

2. A difficulty with 'adaptation' (Hall & Marteau 2003, Pelchat et al 2003, Serpa Pimentel & Meneres 2003)

3. A struggle to develop 'coping strategies' (Kerr & Mackintosh 2000, Taanilla et al 2002, Heiman 2002)

These three are usually expected to be accompanied by an overall feeling most often described as 'stress' (Towers 2009, Hassall & Rose 2005). According to Fisher (2001), parents hold pivotal roles in relation to whole family wellbeing and she cites high parental stress levels as likely to create a negative impact. Furthermore, Esdaile and Greenwood (2003) together with Beck et al (2004) disclose the importance of measuring parental stress given evidence which suggests that when present, 'stress' may place a child 'at risk'. To this end, 'stress factors' are commonly investigated with the child being of primary protective concern and the parent as secondary per se (Lohr et al 2000).

It is an oft made assumption that 'stress factors' are represented by not only the arrival, but also the 'on going dilemma' of having a baby with impairment (Baker et al 2003, Eisenhower et al 2005). As such, the child, impairment and impairment related behaviours have been regularly cited as being the root cause of stress and, increasingly investigated during the last decade, instances of depression (Dowling & Dolan 2001, Ray 2003, Olsson & Hwang 2001, Kerr & Mackintosh 2000, Ellis et al 2002, van der Veek et al 2009). Evidence can be found in quantitative styles of research that employ tools such as, 'Abidin's Parenting Stress Index' which in this case is a self-fill questionnaire (for examples see: Esdaile & Greenwood 2003, Hodapp et al 2003, Britner et al 2003). These structured styles offer insight, yet on inspection, they do not account for such diversities as mood controllability, personal tolerance levels or unexpected 'additional' upsetting episodes which may also impact, such as the death of a relative or relationship breakdown (Stiker 1997, Johnson 2000, van der Veek et al 2009, Hugger 2009). As such, it is unclear how these behaviours and feelings could be 'separated' or realised in relation to obtaining specific measures (Parkinson 1995). Furthermore, parents' explications are limited by rigid formats for response yet, more importantly I feel, by their (and the researchers') ability to understand and negotiate (for instance) fluid and temporal psychological systems of the 'self' (Bardill 2000, Freeman 1999, Tappan 1999).

However, there are qualitative studies that also appear to support the measured findings in relation to stress for instance, Kingston (2007) has disclosed stories of mothers who have been 'pushed to the limit' by their impaired offspring. With these collective findings in mind, it is perhaps reasonable to accept that having a baby with learning difficulty per se may induce feelings associated with stress. Certainly, it is possible that the experience might be perceived as an intense responsibility given that many parents feel that no one else can take their place (Ray 2003, Crown 2009).

Over the past decade, the more flexible styles of research have also revealed that whilst stress may be directly linked to impairment, other dynamics have been revealed as significant, for example in:

- Child and parental characteristics (Ricci & Hodapp 2003, Baker et al 2005, Calton 2010, Britner et al 2003)
- Locus of control and perceived support (Hassall, Rose & MacDonald 2005, Johnson 2000, Lohr et al 2000)
- Feeling inadequate and low self-esteem (Robb 2004, Towers 2009, Pelchat et al 2003)
- Balancing work and family life (Henwood & Proctor 2003, Shearn & Todd 2000, Williams 2009, Towers 2009)
- Financial affairs (Esdaile & Greenwood 2003, Pelchat et al 2003)

Canary (2008) and Ray (2003) also found that families experienced 'unique challenges' relating to such varied things as 'invisible' impairment and fluctuating, inconsistent social welfare regimes. This latter issue is important to highlight as families who have a child with a learning difficulty are synonymous with poverty and are vulnerable to suffering from unequal opportunities in comparison to other families who do not have a disabled child (Dowling & Dolan 2001, Ong-Dean 2005, Kingston 2007, Goodley 2009, Shearn & Todd 2000).

Families' sense of equal status can also be affected where Gardner and Harmon (2002) have found that 'outsider' reactions to their child are shrouded by sympathy, usually transmitted in the form of pity or sorrow. Carpenter (2000) implores, parents do not want to be patronised rather, they (naturally) want to be valued, treated with respect and for other people to recognise their uniqueness in positive ways. In this, not only do

parents understand the ways in which their way of life and attitudes may differ from others, they also have a sense of the contradictions occurring between and within their own experiences (Canary 2008, Taanila et al 2002, Grant & Whitell 2000, Russell 2003, Scott-Hill 2004).

With this 'inner' diversity in mind, it is little wonder that professionals who devise policy with intention to inform practice on a 'one size fits all' basis continue to regularly fail parents by 'getting it wrong' (Ray 2003, Woodcock and Tregaskis 2008, Levine 2009, Roll-Pettersson 2001, Abberley 2004). Furthermore, and perhaps more worryingly, some professionals may view parents as a 'barrier' to enabling proposed practical care of their infant (Goodley 2009). As such, parents may feel misconstrued and frustrated where constructive help and a genuine sense of understanding can be difficult for them to obtain (Carpenter 2000, Perryman 2005, Hasnat & Graves 2000). In addition, Kingston (2007) points out that readily available child care manuals rarely even mention Disability, let alone contain valuable relevant information. As a result, resourceful parents who want to know more about their child's condition often find their information sourced through the internet and via networks of other parents (Kerr & Mackintosh 2000, Beatty & King 2008, Ellis et al 2002, Soloman et al 2001).

In the face of this apparent strain and hardship, it may seem that parents have nothing positive to say as a consequence of their experience, yet on closer inspection of the literature, glimmers of hope can be found, for instance: Read (2000), Heiman (2002) and Kingston (2007) report mothers who love and enjoy being with their (impaired) children; Hastings, Beck and Hill (2005) inform that parents feel the benefit of a raised sensitivity towards others whilst they also take pleasure in feeling less materialistic; Trute et al (2010) cite that parents recognise the potential for self-development and personal achievement and; through their focus group study, Pelchat et al (2003) found parents who believe their lives have been enriched by their experience. On finding such instances as well as having understandings originating from my own experience, I wondered why research has not revealed more of these 'alternative' perspectives. I believe the answer partially rests in the framing of studies which are often (non-parent) researcher led and where perspectives may be lacking parity whereby the following statement illustrates my point:

> *"there was growing recognition that some parents **actually** make a positive adaptation to having a child with a disability and that a more comprehensive model of family adjustment was required"*
> (Gardner & Harmon 2002 p.61 my emphasis)

As a parent, I was quite alarmed by this comment however, as a researcher I was almost relieved to find this 'tangible evidence'. Despite the ways in which feelings and opinions may impact upon the research process, researchers can be very careful to not disclose their bias' or personal attitudes believing in their neutrality towards the issues and people under investigation. It appeared to me that Gardner and Harmon (2002) were amazed that parents *could* feel positive about their situation, not least as they seemed to forget that parents are ordinary people for whom their children as described above, provide the *"emotional core"* to family experience (Phillipson et al 2002 p.115, Pelchat et al 2003, Race 2007). Furthermore, I was astonished that Gardner and Harmon's (2002) instinctive response was to 'modify' their model. It is fairly clear they were aiming to capture understandings of 'family adjustment' yet, only on their own terms, generously making allowances for this single 'deviation'. I am surprised this did not alert them to the possibility of many other 'unexpected' (from a non-parent perspective) issues arising. As such, the only 'model' that could potentially capture these, in my view, would be one that was entirely altered to be open ended and thus, not really a model at all.

Nevertheless, Gardner and Harmon (2002) join a growing body of researchers who seek to examine with specific focus, the effects that having a positive mental attitude, a resilient disposition and an optimistic outlook has upon experience where again, the findings are expected to aid understandings in relation to 'adaptation', 'coping' and it follows; the progress and wellbeing of the child (Trute 2010, Hastings et al 2002, Heiman 2002, Kingston 2007, Shearn & Todd 2000). To this end, many researchers appear to scrutinise families with a view to devising methods for advisory purposes in relation to efficient and effective professional policy and practice rather than attempting to understand experience and share perspectives (Carpenter 2000, Canary 2008, Swain & Walker 2003, Perryman 2005, Abberley 2004). Goodley and Tregaskis (2006) make valiant efforts in this latter direction yet their following ironic comment illustrates my point that professional practice is ever prioritised:

> "*neglecting parental perspectives results in a failure to understand and promote their involvement in the enabling care of disabled babies and infants*" (p.632)

I understand statements such as these are subtle where the reader may be thinking, 'what is wrong with that?!' and, 'surely, this is a positive remark, moving in the right direction!' It is, and I applaud Goodley and Tregaskis for drawing attention to the need for a 'perspectives' approach, whereby Tregaskis declares she too has impairment and thus a relative degree of empathy with parents. Never the less, in her observations in relation to professional behaviours, Gunaratnam (2002) points out:

> "*they have, however, neglected to address the complex ways in which power relations can produce, and be produced by, the **tiny detail** of everyday practices, identifications and interactions*" (p.158 my emphasis)

My 'detailed' issue is revealed in Goodley and Tregaskis' (2006) comment when placing specific focus upon the words: "*their involvement*". It is as if parents are third parties and *"enabling care"* is somehow removed or disconnected from being the parent. An alternative remark that comes from a *parental* perspective might be:

> 'Parents may wonder how they can involve professionals to support them in ways which will enable them, as parents, to care for their baby in the best way possible'.

I think this anomaly also demonstrates that whilst Tregaskis may have a shared understanding of what it might be like to have impairment in the family, she cannot really know (MacKenzie & Scully 2007). The fact that she herself is impaired and is a daughter, (not parent) means she has another, alternative perspective and thus agenda (Keen 2006). Whilst detailed and subtle remarks may be overlooked as petty, as Gunaratnam (2002) implores, it is acquisition of these 'real' understandings which make the difference; 'correct' policy and practice would automatically follow if the perspectives were properly shared.

In spite of this, I appreciate the aim may be to improve conditions for parents and thus I can see that attention is often lavished on the deficit situation in order to make attempts to 'put it right' (Fisher 2007, Maxwell & Barr 2003, Scott-Hill 2004). I am

not suggesting this approach is incorrect, far from it as much valuable information has been gleaned so far however, in light of studies which suggest poor interaction from professionals it would seem clear the 'how to' message through the medium of research conducted in this way, apparently ignoring a range of parents' feelings, is not working as well as it might! (Deeley 2002, Vehkakoski 2007, Manthorpe et al 2003, Neufeld et al 2008).

Where parents are reporting experience as unique to their family, for some, this may be linked to the ways in which contemporary families are comprised (Perryman 2005, Phillipson et al 2002). Carpenter (2000) informs that family structures have become so complex, they cannot be typically described where Lewis (2002) adds to this comment with her warning that there is no such thing as the 'normal' family. Winton explicates why this might be so in the following illuminating passage:

> *"Families are big, small, extended, nuclear, multi-generational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage or from a desire for mutual support. A family is a culture unto itself with different values and unique ways of realising its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighbourhoods, communities, states and nations"* (1990 p.4 cited by Carpenter 2000 p.136)

As such, families may also act as a 'window' on society, reflecting and personifying societal values in their behaviours and revealing the ways in which members perceive and respond to such things as old age and impairment (Green et al 2005, Canary 2008, Gunaratnam 2002). In addition, over ten years ago Lupton and Barclay (1997) reported that functions within families also appeared to significantly differ from previous decades: more women were partaking in fulltime work and more fathers were staying at home. This finding has been more recently supported by Doucet and Merla (2007) and again, can be seen as a continual growing trend from a recent national survey carried out with specifically fathers who have a child with impairment (Towers 2009). Mason and Pavia (2006) suggest that family structures and functions change in line with the market place and despite these understandings some disability research

appears to have continued to perceive and investigate families as entrenched in traditionally designed formats; two parents (of opposite sex) with one or two children.

Furthermore, although the term 'parent' is not gender specific, studies have generally focussed upon mothers as being representative of the (two) parent role (Fisher 2007, Canary 2008, Neufeld et al 2008, Goodley & Tregaskis 2006, Lohr et al 2000, Grant & Whittell 2000). This particular detail may be substantiated by Stueve and Pleck (2001) who suggest that in any parenting relationship, mothers *are* more likely to wield significant control and influence over fathers in relation to caring for their offspring. Yet, there has been a consequential anomaly which appears to be that research with families which includes fathers' 'voice' or is father specific is lacking in volume (Carpenter 2000, Towers 2009, Robb 2004).

When research does focus upon being a father (of any children) the concern generally targets specific behaviours and the subsequent impact of these upon the overall condition of the family. Ultimately, the aim of such findings is to reveal implications relating to the national welfare state with intentions to forecast the potential 'financial burden' if families are seen to be 'dysfunctional' (Torr 2003). Research often takes an almost intrusive and accusative perspective with regard to what constitutes appropriate male behaviour determined by such things as the father's relationship with his wife and children, his work and leisure activities and, his levels of absence and financial contribution (Lewis 2002, Gavanas 2002). Studies rarely take the form of in-depth interview where instead, statistical formats are employed in attempts to primarily address the healthy and 'normal' development of the children. As a consequence, fathers who have a child with impairment are highly likely to be captured for this *specific* area of scrutiny (for examples: Ricci & Hodapp 2003, Simmerman et al 2001).

It is little wonder that fathers may be reluctant to participate in investigative research which may be seen to treat (and subsequently has the potential to portray) them as *"walking wallets"* (Gavanas 2002 p.227), as 'feckless absentees' (Lewis 2002) or, '(in) appropriate fathers' (Henwood & Procter 2003). Whilst, adding insult to injury, when their 'opinions' are noted they may be melded to become the voice of an anodyne group of faceless (no)bodies (e.g. see Towers 2009). However, this rationale is less likely to occur to researchers than stereotypical attitudes of how men would

likely respond to an invitation to participate in 'sensitive' research (Williams 2009, Robb 2004, Csank & Conway 2004). Unfortunately, I am all too aware of the unintentional ease in assuming men would not take part on precisely this basis given that I (and others involved in designing the protocol to this research) initially fell prey to this thinking. Clearly, it is important this negative stereotypical view is countered by 'real life' exposure as it also carries further (and serious) implications for the growing number of male primary carers whose experiences are unlikely to be heard in context (Doucet & Merla 2007, Larkin 2006).

Similarly, despite the fact that children with impairment are more likely than their able bodied peers to live in a one parent family where the single parent is most likely to be the mother, there is little research to support this eventuality either (Fisher 2007, Levine 2009). To this end, it would seem appropriate to consider a range of family circumstances when embarking upon research given that 'nuclear' family and gender stereotypes appear no longer adequate (van Hove et al 2009, Mason & Pavia 2006, Perryman 2005).

The issues I have highlighted thus far in relation to being a parent represent a number of pressing research drawbacks which I believe need to be urgently addressed. By way of a summary, I list them as follows:

1. Becoming a parent constitutes a multidimensional, individual and socially interdependent as well as emotional activity and the literature does little to reflect this complexity.
2. Parents are often portrayed as victims of an unfortunate and negative personal experience given that much quantitative research (supported by some qualitative findings) appears to take a 'child at risk' and 'deficit' approach.
3. Through more flexible styles of research, parents' are able to inform researchers of their unique experiences, as well as report their positive feelings in relation to their understandings of being a parent: this area remains under-represented.
4. Much research continues to be carried out with small regard for personal circumstances and associated family relationships where married

mothers who take the primary care role continue to be targeted for parent related research. It is important to address this imbalance to encourage a wider understanding that moves away from inappropriate beliefs based upon stereotype.

5. Researchers and professionals (and others) continue to misunderstand family experience and I believe the difficulty is situated in policy and practice driven research where instead, a 'perspectives' approach may be more useful.

Clearly, (and unfortunately) there may be many more specifically individual parenting issues arising from the current literature that ought to be tackled however, in relation to my research I feel the ones I have exposed here are most pressing. I now introduce some of the contextual issues surrounding parents that are absent from the literature which I feel are also relevant to this particular study.

## Being a parent – *in the social context*

As previously indicated, becoming a parent is an event both personal and significant to the individual however it is also something which occurs in the context of the wider social environment (Ray 2003, Woodcock & Tregaskis 2008, Larkin 2006). As such, parents:

> ".. *'cannot be studied in isolation, without acknowledging historical, social and cultural contexts'*.." (Connor 2008 p.42 cited by Bjornsdottir and Traustadottir (2010 p.50)

And in agreement, Canary (2008) further explains that:

> *"developing a more complete understanding of intellectual disability involves moving beyond abstract concepts and generalizations to examining experiences and relationships within contexts"* (p.438 my underline)

To this end, Canary (2008) suggests that individual experience (in this instance, of learning difficulties) can be vulnerable to the impact of the contemporary social climate where implications abound. In relation to this research, for example: cultural and racial understandings of what it means to be a parent, as well as local, political and

economic circumstances may exert influence upon the way a baby with impairment is received and accepted and thus how parents feel and perceive their situation (Synder & Mitchell 2006). Taking this argument a step further Bjornsdottir and Traustadottir (2010) propose that 'intersectional systems' such as class, race and gender are fundamental to experience given their relational propensity to devalue individuals where they advocate:

> *"We need to abandon present practices that focus on individual limitation and recognise these different interconnected social systems of oppression that simultaneously influence all aspects of lived experience"* (Bjornsdottir & Traustadottir 2010 p.60)

In congruence with Oliver (1990) with a strong accent on 'oppression', Bjornsdottir and Traustadottir (2010) appear to make a valid point as Ong-Dean (2005) and Calton (2010) illustrate with particular explanation regarding social class. They argue that belonging to a more affluent group may determine the nature of a parent's experience given the likely encouragement to develop the skills to communicate effectively and take control. As such, these authors suggest that opportunities to be involved and proactive as well as being confident, for example to care for extraordinary needs or criticise experts, are underpinned by (in essence) an educated, experienced and financially resourced background. However, Stiker (1997) implores that despite individual contextual background, a most likely denominator to governance of parental experience is inherent personality. Characteristic traits such as levels of resilience and tolerance (Kingston 2007, Pelchat et al 2003), sense of moral obligation (Beatty & King 2008), depressive tendencies (Olsson &Hwang 2001), optimism (Baker et al 2005, Trute et al 2010) and aptitude for negotiation (Mason & Pavia 2006) are all more recent examples from the literature which lend evidence to this theory.

By returning briefly to the individual I hope to have brought to light the conflict apparent in the suggested ideas which in fact rather resembles the old 'nature/nurture' debate, that is:

*Does social class (as example of societal impact) determine individual capability and thus shape (or devalue) an 'able' personality?*
Or,

*Does an individual begin with certain personality traits which he or she must attempt to employ in order to 'deal with' societal conditions which surround specific experience?*

Do not fear, I am not going to attempt to unpick an argument that cannot be settled (Gergen 1999) however, in drawing attention to these issues I wish to demonstrate the complexity of experience which many researchers appear to regard as *either* an issue pertinent to the individual *or*, society at large. In addition, within this latter approach, despite attempts to address social implications in relation to experience, focus often fails to reach beyond an individualistic or 'micro' level (Dowling & Dolan 2001, Woodcock and Tregaskis 2008, Case 2001).

I shall attempt to elucidate my point further by utilising Lynne Ray's (2003) comprehensive study for the purpose of example: Ray conducted a useful qualitative enquiry guided by Gidden's Structuration Theory in order to identify 'societal barriers' in relation to parents' experiences where she initially detected "*Conditions acknowledged by parents*" (2003 p.286). These incorporated for instance: 'poor service coordination', 'access' and 'allocation of resources'. Ray (2003) also classified a second set of 'barriers' entitled "*Conditions less acknowledged*" (p.293) and these included such things as: 'societal perception of disability', 'feminisation of care-giving' and 'state reliance on parental commitment'. In the first instance, Ray (2003) highlighted 'barriers' which, although 'socially derived', were localised and particular to the individual. My point is that researchers often confine analysis to this level when societal factors are taken into account (for examples see Woodcock and Tregaskis 2008 and Dowling & Dolan 2001). In the second 'less noticeable' collection, Ray (2003) expanded the perspective beyond the individual level to that of the broader 'macro' contextual field. Here she entered the realm of vast taken-for-granted assumptions that are associated with being-in-the-world and I believe this is why they appeared to be less recognisable to her participants as 'social barriers'.

Within this macro social arena subconscious understandings are often derived from concepts such as 'Disability' and 'Parenthood' whose meanings are created through contemporary collective perceptions and as such, are laden with value judgements (Canary 2008, Fairclough 2003, Gee 2005). They are formidable socially constructed genres that carry different meanings for different people across time, place and culture;

evolving with developing customs and creeds that are often endorsed by advances made with global technology (Synder & Mitchell 2006, Reynolds Whyte & Ingstad 1995). Significant to the ways in which socially produced meanings progress therefore, is the historical route through which they have generationally traversed and subsequently emerged (Gadamer 1965, Oliver 1990, Stiker 1997, Held 1980, Synder & Mitchell 2006, Digby 1996, Matchinske 1998). The flux of conceptual change might be revealed where, for example: on a 'micro' social level, discourses may be recognised as being outdated through grandparent behaviours whilst; at the 'macro' level, 'fresh' understandings might transpire via (for instance) heightened awareness of social intolerance for the birth of babies with certain genetic conditions that, given the technological ability, could have been 'avoided' (Barnes 2007, Hughes 2009, Hubbard 2006).

Through socially constructed discourses individuals may be subject to a great deal of external pressure as they can be seen to dictate and 'drive' appropriate 'ways of being' (Fairclough 2003, Hugger 2009). Furthermore, there may be conflict within experience where it becomes an impossibility to ascribe to opposing models (Lupton & Butler 1997, van Hove et al 2009, Hearn 2002, Fairclough 2003, Gadamer 1971). In this, Bjornsdottir & Traustadottir (2010) acknowledge the element of 'individual will' through which parents' resistance to and the challenges of (oppressive) social systems and concepts can be identified (Fisher 2007) and, I would add here, premeditated 'submission', as well as, unintentional compliance may also be detected.

To this end, there exists subconscious delicate interplay, as well as difficult conscious struggles and challenges with any number of prescribed societal principles through which an individual gains a developed sense of what is 'normal' or not (Knafl & Deatrick 2003, Morse et al 2000, Fisher 2001, Lewis 2002, Golden 2001, Walsh 1993). The extent to which societal and familial norms become obviously present or absent may occur in direct relation to an individual's personality type (Pelchat et al 2003). However, for most people, the generalised understanding of normality has a significant bearing upon lived experience overall given that it represents the social conditions particular to being-in-the-world (Morris 1994b, French 1994d, Walsh 1993). Normality not only relates to being, but also to 'what usually happens' where it sometimes refers to those things typically available to everyone (Walsh 1993).

Furthermore, it may be perceived by the beholder to be ideal (Kingston 2007, Mason & Pavia 2006, Canary 2008, Fisher 2007). As such, normality becomes the desired condition (to *feel* normal) simultaneously spurred by the notion that abnormality is associated with social stigma and marginalisation (Case 2001, Goffman 2006, Oliver 1990, Stiker 1997, Biernat & Dovidio 2000).

In the upset of 'normal' life, experience may become an emotional journey where the quest to regain such things as a sense of equilibrium, stability and certainty is a process likely to bring about a degree of self-awareness and doubt (Fisher 2001, Roll-Pettersson 2001, McLaughlin & Goodley 2008, Parkinson 1995, Bardill 2000). In searching for meaning in relation to a changed identity, contrary impressions such as belonging and isolation may stir and may feel exaggerated through events involving social interaction (Russell 2003, Soloman et al 2001, Swim & Thomas 2006, Jenkins 2004). A spouse shares the adoption of a new identity and their behaviours as well as the attitudes and reactions of others, particularly those who are significant, is likely to influence, if not further confuse an extraordinary individual experience (Stueve & Pleck 2001, Golden 2001, Bergman & Hobson 2002, Hugger 2009).

The aspect of socially derived influences that may contribute to individual emotional turmoil in finding a sense of 'normality' completes a 'revolution' where now, I necessarily return to the earlier stages of this introduction. Formally, I explained other researchers' tendency to examine parental adaption and coping strategies in relation to their precedent described feelings of grief and loss on the advent of the birth of their baby with impairment. I have no doubts that the experience of having a baby described as having a learning difficulty carries many significant and life changing implications for parents. Yet, my concern is that some investigations that attempt to reveal what these might be have tended to narrowly focus on the parent in terms of a predicament they appear to have created entirely by themselves where the outcome is personal stress.

As such, I believe research with parents is currently failing to address a number of issues in relation to context and I summarise these as follows:

1. Intersectional systems such as gender, race and social class are often researched as separate topics whilst all are intrinsically linked to Disability and being a parent.

2. The relationship between society and the individual is inter-relational and thus complex. It is difficult to assume one exists in isolation from the other and yet researchers tend to approach investigations accepting this as a possibility.

3. Societal systems operate simultaneously on many levels where some have 'naturalistic' propensities that may go unnoticed.

4. Societies create and develop ideological concepts which press socially accepted meaning onto given situations such as becoming a parent. In turn, this may facilitate understandings of what it means to be and feel 'normal'.

5. Social systems may be perceived by some as oppressive yet, driven by their emotional desire to achieve a sense of normality, individuals may also wish to conform.

And overall;

6. Individual experience is bound to be influenced by the eventuality of having a baby described as having a learning difficulty although as a consequence, the feature of impairment per se is often prioritised over other possible triggers to emotional parental behaviours.

Points 5. and 6. (from above and 1. from the previous section) lead to a contentious research issue: *emotion*. This rarely appears in educational and more specifically, disability literature as a researched phenomenon yet, it is overtly present as a dominant feature of human experience making it a strong indicator of what it means to be human (Parkinson 1995). As Chrisman (2011) implores:

> "*experiential knowledge is necessarily emotional knowledge*"
> (p. 179)

As such, I accept that dealing with this subject may appear as an 'obvious' factor to others where some may feel it unworthy of detailed exploration (Toye 2010). It is also possible that emotions could be considered irrelevant when conducting research that

aims to build policy and inform practice, however, most likely: discussion of this type may often be ignored or glossed over because it is such a difficult and emotionally engaging issue to examine. One has to think about feelings, taboo subjects *and* be compassionate, a traditionally frowned upon activity in academic research circles (Lupton & Barclay 1997, Toye 2010, Chrisman 2011). With specific reference to disability studies, Donaldson and Prendergast (2011) suggest the difficulty lies in part, in associations with the 'sentimentalist literature' produced in the US during the nineteenth century. They cite possible dangers in undermining the disability rights movement by returning to notions of pity and sympathy and, as an additional effect, Chrisman (2011) warns of a potential trap in unnecessarily sensationalising experience.

As a consequence, it appears that emotions, more often than not, are treated empirically as 'definitive object' or as 'mechanical process' where there are few studies that have explicated or interpreted 'emotion' from the 'real life' perspective of those who have felt it (Williams 2009, Parkinson 1995). Much research surrounding parents tends to present feelings found within experience as a tedious list, without much (if any) attention paid to how, for example, 'anger', 'shock', 'upset' or 'frustration' actually manifest. Often these adjective types are grouped or simply renamed to adhere with academically mature terminology which in turn allows for studies on such things as 'grief', 'stress' and 'adjustment', (for examples see: Britner et al 2003, Pelchat et al. 1999, Eisenhower et al 2005, Baker et al 2003, Ellis et al 2002).

Whilst informative, I believe difficulties abound with these approaches where emotions are often presented and appear as neither accurate (from a parent perspective) nor relative in the context of overall parental experience (Larkin 2006). As such, emotions may be inappropriately described as well as disproportionately reported, serving to perpetuate assumptions that they appear to perhaps manifest as automatic processes, permanent recurring nightmares and/or as a one dimensional, (therefore 'understandable'), negative eventuality (Read 2000, Parkinson 1995). To this end, anodyne representations of emotions may undermine or even completely remove the meanings associated with the powerful feelings that ultimately underpin *any* personal experience as they are:

*"fundamental to our political, social and intellectual lives, even (...) to thought itself"* (Donaldson & Prendergast 2011 p.131)

Where parents' experiences are being explored 'emotional knowledge' is likely to include feelings pertaining to *love.* This might necessarily include notions of 'care', 'nurturing' and 'bonding' as *signifiers* of love, as other researchers have amply discussed and examined, yet the core issue of love per se has yet to be brought into focus. In concord with Toye (2010) who advocates the exploration of 'love' in the academic context as a genuine and worthwhile endeavour, I feel that the emotional turbulence that parents undergo when they have a child with impairment would benefit from review. In this, ways of writing about and describing emotions need to be explored and devised to enable 'acceptable' incorporation of this phenomenon within educational and social research findings where Prendergast (2008) suggests:

> *"the field would be most advanced by participating in the circulation and recirculation of emotion, rather than trying to arrest it"* (p. 242)

In order to conduct research that attempts to encompass the myriad of matters arising from this introduction I propose the most suitable study vehicle to be 'critical hermeneutic phenomenology' (Lopez & Willis 2004). Rather than focus too heavily on the theory per se (as this has been done previously, see Wright 2006), my intention is to outline the main theoretical principles here, as these ultimately support this body of work.

### Critical Hermeneutic Phenomenology

It is generally accepted that the basic premise of any scholar's undertaking is to work towards 'understanding' the 'object' under scrutiny. Renowned philosopher Emilio Betti (1972) endeavoured to explain the 'object' of interest in phenomenological terms whereby, no matter what form it takes, it is not considered to be a straightforward, static, one dimensional article. The object may consist of a 'simple' vase or a complex event, all 'things' are deemed to have a history, specificity and meaning derived from it's 'being-in-the-world' (Heidegger 1953, Gadamer 1971, Sokolowski 2000). To this end, all 'objects' can be considered to be a part of 'the whole' (world) whilst being a 'whole of itself' and simultaneously consisting of constituent smaller 'parts' (van

Manen 1990, Moran 2000). A concept originally explored by Friedrich Schleiermacher (1819), this oscillating relationship between the 'whole(s)' and the 'parts' is that which is of primary interest to the phenomenologist as it leads to the hermeneutic endeavour (Smith et al 2009, Gadamer 1965, Reeder 1998).

As such, the 'whole/part' relationship is further complicated by the presence and thus inclusivity, of the investigating 'subject' (Larkin 2006, Reeder 1998). Betti (1972) thus describes the ways in which the examiner is intrinsically linked to the 'object' given their prior understandings and prejudices developed through what is 'already known'. These understandings have been described by Gadamer as '*tradition*' and in phenomenological circles his term '*horizon*' is often used to denote current and developing understanding (Gadamer 1965, Moran 2000, Fleming et al 2003, Habermas 1970). Having attempted to recognise and ascertain one's 'horizon', the subject is also challenged to scrutinise the object with an 'open mind' in order to be inspired into understanding what (else) can be known (Crotty 2003, Betti 1972, Ezzy 2002). As the overall activity is interpretative, Merleau-Ponty suggests a 'new' onlooker is likely to meet the 'object' and make further and different interpretations (Moran 2000, Geanellos 1998). As such, the aim of analysis made with two or more individuals is to arrive at shared meanings and understandings thus reaching a 'fusion of horizons' (Ricoeur 1973). The process is facilitated by encouraging an 'open' attitude as well as adopting reflexive behaviours, where according to Gadamer, 'subjects' must:

> "*endeavour to acquire as much historical transparency as possible*"
> (1965 p.201)

Having Gadamer's (1965) 'approval', the usefulness of Betti's approach is that it synthesizes the concept of phenomenology which has taken various forms over the past century (at least) and he creates a workable methodology previously avoided by other philosophers. As such, development of theory has progressed via a number of diverse characters and other directions have sprouted from this line of thinking, in particular; symbolic interaction and pragmatism (Crotty 2003). In spite of 'investigation' taking place in the social context, these shared theoretical perspectives all refute the notion of social causality. From the foundation work of Edmund Husserl, phenomenology is specifically renowned for being an activity which involves 'going back to the things themselves' and interpretative actions are considered 'universally

hermeneutic' (Heidegger 1953, Gadamer 1976). The idea that society could be responsible for individual experience would be to create antithesis which would in turn go against this encompassing and interactive principle (Gergen 1999). As a consequence (disappointingly) interest lies with the '*what?*' but not the '*why?*' that might underlie a given experience (Morrow & Brown 1994).

However, in tracing a methodological route through five prominent phenomenological thinkers: Edmund Husserl (1859-1938), Martin Heidegger (1889-1976), Hans-Georg Gadamer (1900-2002), Maurice Merleau-Ponty (1908-1961) and Paul Ricouer (1913-2005); I was able to draw together an appropriate phenomenological theoretical perspective that created an opportunity to consider understandings in relation to a particular form of 'explanation'. In associating meaning with the earlier works of sociologist Max Weber (1864-1920) where asking '*what*?' of a situation becomes synonymous with attempts to understand the '*why*?' and the '*how*?', the sharp edge of reason is removed (Crotty 2003, Wright 2006). In this, '*why?*' is not to be understood as a logical and attributive factor as was supposed by Dilthey (1964) who originally contributed to the dichotomy of (positivist) 'explanation' *or* 'understanding', rather; it takes the form of 'rational justification' which (re)combines the two: one cannot have one without the other (Ricoeur 1973, Wright 2006).

As such, a closer examination of social factors within experience becomes possible and under the influence of critical social theorist Jurgen Habermas (1929-) this activity involves 'bringing to consciousness' underlying oppressive social norms that may otherwise go unnoticed (as in Ray's (2003) '*conditions less acknowledged*' above) (Guess 1981). To some, this may appear to be 'emancipatory disability research', introduced by Oliver in the1990's and later espoused by Barnes (2004b) and I wish to make a distinction here. In promoting the 'emancipatory' framework, Barnes (2004b) suggests:

> "*social researchers have yet to devise adequate ways of collectivising experience, and experiential research has yet to yield any meaningful political or social policy outcomes*" (p.50)

With the focus on 'collective experience' and political ideology, Barnes adequately demonstrates what critical phenomenology is *not*. Oliver's emancipatory research is

embedded in notions of structural oppression making assumptions about what is 'wrong' with society that can be remedied through changing such things as government policy to suit the individual. In other words, there is a noticeable attempt to separate 'social' and 'individual' activity (Synder & Mitchell 2006). The process in which the comparatively swift process of 'rubber stamping' a document takes place does not allow for attitude or cultural accommodations. In contrast, according to Held (1980), the ultimate aim of critical hermeneutic activity is to:

> "*further self-understanding of social groups capable of transforming society*" (p.250 my emphasis)

In this endeavour, prevailing cultural discourses, social concepts and ideologies are necessarily placed under the spotlight with a view to understanding the entwined relationship of the individual within, between and across society and other people. In so far as:

> "*The linguistic infrastructure of a society is part of a complex that, however symbolically mediated, is also constituted by the constraint of reality*" (Habermas 1970 p.240)

Habermas argues this enables identification of *"conditions outside tradition"* (p.241) including *"world-comprehension"* (p 241) where perspectives and actions may begin 'manoeuvring' towards an alternative course through *"communicative action"* (Conle, 2001 p. 23) (that is, *not* structural).

However, despite fostering shared understandings, the idea of 'forward movement' creates further conflict with phenomenological thinking in so far as 'being-in-the-world' is a *current* eventuality. In this, historical factors underpin the essence of ontological experience, thus, eschatological possibilities are considered irrelevant whereby meaningful consent is required and this is impossible as Gadamer argues:

> "*one must always reckon with the possibility that the opposite conviction, whether of the individual or of the social realm, could be correct*" (1971 p.294)

French philosopher Ricoeur (1973) provided the phenomenological connection between Gadamer's 'past' and Habermas' 'future' which appeared to close their

apparent impasse. Ricoeur (1973) suggested (although a little less simplistically) that nothing of the present, or the future, could happen without carrying the values and understandings of the past. In other words, the very idea of 'being' or *potential* being is rooted in ideas and understandings of what has gone before; in that sense, the 'future' is to some degree comprised of what is already known and is thus inseparable from current or past experience.

Having established that 'everything' in relation to 'being-in-the-world' (as 'object' of experience), including the 'future', is available to the researcher interested in embarking upon phenomenological enquiry, the task ahead begins to look a little over facing (Rapley 2004). However, certain topical boundaries must be set in order to maintain a sense of focus. Primarily, critical social theory is a vehicle through which normative theories may be 'applied' to the research endeavour and in this case, the ideologies in relation to the 'narrower' focus of Disability are appropriate and relevant to this project (Guess 1981). My previous work was a pilot study aimed at trialling ideas and in that, I elected to somewhat simplify the contemporary debates surrounding Disability and chose to employ the (then) prominent and relatively crude 'social model' through which to purposefully identify potential 'external influences'. This worked well however the social model alone fails to address some of the issues currently facing many parents given that it appears to be a unidirectional, one dimensional paradigm (Rapley 2004, Synder & Mitchell 2006). As such, this introduction digresses slightly with a brief overview of disability theory which in turn, explains the bearing for the focus of the whole of this study.

## Disability Focus

In accordance with phenomenological thinking, it can be said that much of the contemporary concepts surrounding disability theory have been developed from legacies of the past. For the past fifty years at least in the UK, the focus has been centred on the struggle of disabled activists wishing to shake off oppressive behaviours of perceived dominant social regimes. For many, this wrangle 'began' with the formation of the Disabled People International group evolving into the Union of Physically Impaired Against Segregation (UPIAS) who campaigned tirelessly during the 1970's in order to gain widespread recognition of the ways in which society

disables people with physical impairment (Barnes 2007, French1994e, Kimberlin 2009, Race 2002a). For instance, in '*The Fundamental Principles of Disability*' (1976, cited by Barnes 2007), Vic Finkelstein and Paul Hunt set out to distinguish definitions of 'impairment', 'disability' and 'handicap' in opposition to the traditional perspective. The latter stemmed from the World Health Organisation's classification terminology which at the time implied all three descriptors were derivative from the individual's condition.

The progression of thinking led to seminal work by Michael Oliver in 1981 (cited by Barnes 2007) which he latterly outlined in great detail through his book 'The Politics of Disablement' (1990). Oliver is often accredited with the development of the 'social model of disability', simplistically declaring that societal systems and structures were the product of able bodied thinking and doing, where no positive input had been allowed or included from the disabled population. As such, Oliver espoused that this level of oppression had led to the current state of affairs whereby people with impairment were vulnerable to exclusion and marginalisation. Oliver's succinct line of argument, adopting a human rights approach borrowed from the US, hit a chord with UK government. The social model has since been implemented throughout educational and social practice and policy, perhaps most notably in the government white paper, '*Valuing People. A new strategy for learning disability for the 21$^{st}$ century*' (DH 2001).

This landmark document is underpinned by four core principles in relation to the treatment and 'value' of people who have impairment, honouring them with notions of: 'rights', 'choice', 'independence' and 'control'. In keeping with the 'New Labour' political drive of 'effectiveness and efficiency' inherited from a Conservative regime, the underlying message of 'Valuing People' was one that promoted individuality and autonomy (Deeley 2002). Continued through '*Improving the life chances of disabled people*' (2005) report, the most current development in this area has been the introduction of 'individual budgets' where people with impairment may draw funds from their local authority in order to buy in support services (Barnes 2007).

As such, it can be said the social model approach has been extremely successful: it was an unambiguous message that government and organisations could clearly

comprehend; it brought about social change where people with impairment are now less likely to be automatically excluded and; it facilitated the notion that individuals should be given choice (Barnes 2007, Goodley 2001, Shakespeare 2006). Oliver's (1990) ability to propel the social model forward no doubt came as a consequence of establishing a foothold in the creation of an 'arch enemy'. The 'individual model' was entrenched in a 'scientific' and medical approach to disability thus is most commonly coined the 'medical model' (Boxall 2002, Barnes 1999, Thomas 2007).

At the time of the social model conception, greater awareness of institutional practices and medical interventions were being publicly realised as horrific intrusions where denials of human rights were witnessed (Atkinson et al 1997). For Oliver (and others) this epitomised the level of oppression. Professionals were seen to carry out investigations on individuals, about individuals with, more often than not, no consent from individuals (Foucault 1984b). Moreover, this devaluing aspect also held further implications: people with impairment could be viewed as a burden to society, their family and themselves, and as 'charity cases' pitied and tragic in their 'undesirable and *abnormal* condition' (Race 2002a, Boxall 2002, French 1994e, Davis 2006a/b, Drake 1999).

The strength in the social model argument was thus formed in the context of reinforcing messages of a medicalised and oppressive history of disability which in fact, is ironic: it does the subject matter few favours in perpetuating current positive ideas behind what it means to have impairment (Synder & Mitchell 2006, Reynolds Whyte & Ingstad 1995, Rapley 2004, Drake 1999, Shakespeare 2006). Furthermore, the 'history' as popularised by the fervent route of expected 'emancipation' was relevant for some, but not all, of the disabled population (Liu & Hilton 2005, Hughes 2009). In adopting an exaggerated style in order to no doubt attract attention, the history of the concept itself turns out not to be a 'eureka' or defining moment as many are led to believe (Borsay 2005). For instance, Masala and Petretto (2008) argue that notions pertaining to social model principles were underway at least twenty five years prior to its pronouncement through the work of Egyptian/American Saad Nagi who suggested that 'disability' was:

> "*an expression of a physical or a mental limitation in a social context*" (Nagi, cited by Masala & Petretto 2008 p. 1234)

In returning to the phenomenological way of thinking about 'alternative' routes to the past, it becomes clear that the 'social model' is only one small part of the whole concept of Disability (Finkelstein 2004). In sticking with narrow principles which have made it so popular (and governmentally sanctioned), the forceful position of the social model has 'blocked out' many other important issues as well as facilitated the generation of some other difficult 'side effects' (Hughes 2009, Shakespeare 2006). Taking the apparent focus away from the individual appears to have endorsed the detrimental neglect of important (public) discussion surrounding for instance:

1. Impairment, the meaning of it and how it might manifest and thus, *feel* (Thomas 2007, Watermeyer & Swartz 2008, Donaldson & Prendergast 2011). Sklar (2011) suggests that emotions, including pity and sympathy should be encouraged believing that these are elementary signs of humanity and expressing them opens opportunities to face ethical issues and diversity in human being. As Watermeyer and Swartz (2008) aptly suggest:

> "*all humans require validation and acknowledgements particularly of our more painful and difficult experiences, in order to foster self-compassion and acceptance*" (p.602)

2. Gender, class, race and religion as intrinsically linked to having impairment (Masala & Petretto 2008, Riddell & Watson 2003, Borsay 2005). For example, Vernon (2002) points to a hypothetical situation whereby an individual may be black and have impairment: appropriate access on a bus may get the individual to a job interview, but race discrimination or rigid gender work role determinants may prevent her or him from getting the post.

3. The nature of impairment, where:
   a. The social model failed to be inclusive of all impairment types, notably learning difficulties (Walmsley 1994, Goodley 2001, Rothman 2010). Walmsley (1994) argues that having a learning difficulty is a label associated with socially constructed concepts driven through the development of IQ tests and measurements of competency against predicted 'able' norms. In agreement, Goodley (2001) suggests the significance here is that the social model has fallen into the trap of presuming (with traditional undercurrents) that as an 'intrinsic' (and

sometimes invisible) impairment, learning difficulties cannot be 'negated' with altered societal structures, when in fact, it might. As a consequence, people described as having a learning difficulty can be perceived as remaining 'marginalised', even by a concept that might otherwise have been supportive.

b.  The social model assumed all people with physical impairment 'agreed' with and wanted to engage in social model principles (Ong-Dean 2005, Landsman 2005, Thomas 2007). Hughes (2009) proposes that a growing number of people with impairment do not appreciate the notion that their (or their child's) difficulty could be negated by societal adaptation. Rather, Hughes (2009) draws attention to those who, as a consequence of their 'bio-diversity' necessarily engage with and see themselves as defined by their particular impairment. In turn, their 'sense of belonging' and social identity is preferably fixed with 'bio-social' groups who are more interested in eschatological means to find cures and better 'ways of being' on a personal basis than they are about 'structural societal oppression' per se.

and, in spite of being a '*social* model', minimal attention has been forthcoming in respect to:

4.  Cultural attitudes and conflicting concepts. For example, exploring ethical positions such as society and individual responsibilities which have been confused not least by 'advances' in genetic engineering, pre-natal testing and selective abortion (Synder & Mitchell 2006, Reynolds Whyte & Ingstad 1995, Rothman 2010, Kimberlin 2009, Race 2007, Rapley 2004, McCoyd 2008, Hubbard 2006, Saxton 2006, Davis 2006b). This particular issue is perhaps the most contentious given that it addresses the 'bare bones' of the topic. Debate surrounds human values and moral codes and during the course of this work, this underlying feature, (as with those above) will naturally keep 'bobbing to the surface'. However, this thesis does not have the space or the scope to address such issues in depth yet, as an exploration of the phenomenon of experience per se I attempt to do more than simply acknowledge their presence.

The decisive issue in being able to address disability as theory appears to be centred on the binary divide that has been escalated between the 'medical model' and the 'social model' whereby it is taken for granted the two are polar opposites. In this, Rapley (2004) highlights the difficulty in utilising these 'separate' models:

> *"both the medical model and the social model seek to explain disability universally, and end up creating totalising, meta-historical narratives that exclude important dimensions of disabled people's lives and of their knowledge. The global experience of disabled people is too complex to be rendered within one unitary model"* (p.66)

However, what Rapley (2004) fails to acknowledge is that, whilst the theories may appear contradictory, they do in fact form (part of) 'one unitary model': 'the whole', and as such are inextricably linked (Gadamer 1971). The following explication offers some insight into the ways in which the two models work 'as one' in practice.

One of the generated 'side effects' of the social model is highlighted by the *un*surprising ease with which the UK government took on the guiding principles. Social model notions of 'rights' and 'independence' dovetailed with spending cuts and thirty years later has resulted in the current 'complementary' policy of 'individual budgets' (Barnes 2007). The notion of encouraging independence and autonomy is not new; since at least the 1960's work towards the 'normalisation' of individuals has taken place in the development of prosthetics, adaptation of equipment and programmes of specialised learning (Masala & Petretto 2008, Drake 1999, Deeley 2002, McIntosh 2002). In attempts to raise the profile of 'devalued' individuals, influenced by Scandinavian developments and the work of American Talcott Parsons, in 1972, Wolfensberger (1998) introduced the theory of 'Social Role Valorisation' (SRV). Evolved from 'normalisation' theory, the goal of which was to help individuals with impairment attain levels of achievement set by usually medically defined criteria relating to human ability, SRV outlined ways in which individuals with impairment might become more highly valued by society if they could be seen to fulfil socially acceptable (normal) roles. The 'Valuing People' document took a similar perspective in focussing upon the individual in promoting 'inclusive' practice through advocating participation in society to achieve a 'fulfilling quality of life' (DH2001).

Notions pertaining to 'normalising' principles have been criticised by members of the disabled population for being both oppressive and discriminatory (Walmsley 1994, Morris 1994b, Race 2002b) where French has declared:

> "*the pressure to be normal is often at the expense of the disabled persons needs and rights*" (1994d p.51)

Despite aiming to distance itself from originally medical 'normalising' principles the social model appears to be embroiled with it (Hughes 2009). Conflict in relation to the ethical ideals associated with the social model has appeared whereby the activity of being included is a matter of debate regarding the question: '*on whose terms?*' Furthermore, the encouragement to organise structures to such an inclusive level creates alternative issues for those who have impairment. Access may be forthcoming and the 'barriers' may be removed (in so far as this may be possible (Shakespeare 2006)) yet, the *impairment* does not go away. The danger is that services may be reduced or dissolved whilst they are likely to continue to be required (Rothman 2010).

As such, issues surrounding impairment cannot be ignored (Shakespeare 2006). For many people, including parents, 'the impairment' is proof of entitlement to funding and services, the claiming of which is exercising one's 'rights' (Kimberlin 2009, Ong-Dean 2005, Landsman 2005, McIntosh 2002). In turn, the latest 'individual budget' system can be likened to the stigma of applying for and collecting alms as seen throughout centuries of pre-modern history (explored in the subsequent chapter). It already has a derogatory 'tag line' in being dubbed 'cash for care' (Barnes 2007) and, it removes as much responsibility from the state as is perhaps possible. The onus of organising, co-ordinating and negotiating support is placed in the hands of the individual or their parents. As such, the 'person centred' approach that stemmed from social model principles can be seen to be not that far removed from the '*individual* approach', where the 'burden' of responsibility rests entirely with the individual.

To this end, Hedlund (2000) aptly asserts that:

> "*by deconstructing the domains of ruling principles describing disability according to a biological or social framing, one can see what information is brought to the surface*" (p.770)

In recognition of the pitfalls of creating specific disability theory from a position trapped within its own predetermined boundaries, current popular debate has (finally) ventured into the wider field. This progression can be seen to have worked in tandem with the medical arena, who for so long, has been shunned by principle disability theorists (Thomas 2007). Conceptions of much more complex definitions of 'disability' for the WHO's International Classification of Functioning (ICF) have been formed through revised versions of Saad Nagi's original 1950's four tier definition (nb not three), where work in this arena became fervent at the turn of the millennium with Patrick Fougeyrollas' multi-faceted 'Handicap Creation Process' (Masala & Petretto 2008).

Welcomed back, medics (who never really went away) are being appreciated for their continued contribution to 'condition improvement' where a:

> "*disembodied view of disability is no longer tenable*" (Hughes 2009 p.686)

As such, Hughes (2009) considers the notion that 'biological citizens' are moving away from ties to an 'oppressive past' and are looking to the future thus creating the rise of a *"post-medical age"* (p.636). With this and ICF definitions in mind, other researchers have looked to ways of combining biological, psychological and sociological paradigms in developing 'working models'. Synder and Mitchell (2006), Riddell and Watson (2003) and Rapley (2004) promote the notion of 'cultural awareness' whilst Thomas (2007) and Watermeyer and Swartz (2008) favour a psycho-emotional approach. As such, a contemporary 'working model' may resemble something like Rothman's (2010) 'bio-pyscho-socio-cultural-spiritual model', an 'all in one' set of principles.

However, the directions that I find most stimulating are those that have an even broader and thus phenomenological appeal and they are also highly relevant to critical theory in that they constitute 'attacks' on the individual/social conscience. I have drawn upon three such approaches from the literature and afford each a paragraph in order to enlighten the reader as well as reveal the supporting disability theory 'critical undercurrent' to this research:

1. *Constructive Functional Diversity*, introduced by New Zealander, Philip Patston (2007). As the title suggests, this theory focuses upon the diversity of human being. Patston is clear this is *not* about deviation from a predetermined norm, it is pure human creation in all the many forms it may take. As such:

   > *"It aims to provoke and inspire dialogue about our current paradigm of human function in relation to value and capacity"*
   > (Patston, 2007 p.1625)

   Patston suggests this may come about in addressing the nature of human function and the possible consequential fear of dysfunction. Patston employs the term '*dysfunctionphobia*' to propose that people develop fear through believing in their inability to cope, rather than having direct fear of impairment per se. This may be substantiated by McCoyd's (2008) study of mothers participating in prenatal testing. The findings revealed mothers' main criteria when making decisions about termination surrounded their perceived (in)ability to cope with a child with impairment; how they would 'fit' into (or conversely disrupt) the family's current ways of being were chief worries. In addition, Manthorpe et al (2003) revealed that learning disability nurses have found other professionals to be frightened of impairment and thus find talking to parents awkward. As a consequence, I feel this theory would work well if integrated with those associated with emotion given the accent upon facing fears and fostering compassionate understanding of 'other' (Sklar 2011, Watermeyer & Swartz 2008, Eide & Kahn 2008, Keen 2008).

2. *Political science and Disability*: this is an interesting development encouraged by American Sara Kimberlin (2009) who has noticed that disability theory has maintained a narrow study base throughout its conception. In the US, 'disability' is situated in literary departments, being likened to and thus following feminist movements (Prendergast 2008). In the UK, it has been placed amongst the corridors of education, nursing and sociology. Despite political connections made through the social model movement Kimberlin espouses, it has never been fully engaged with political science in the region of *moral* justice. As such, Kimberlin explores 'justice theory' and the ways in which this may relate to disability politics and moreover, the notion of disability in relation to being situate in an encouraged 'moral society'.

Clearly, this is treading upon delicate ground given that in the past, disability has been linked to notions of (moral) 'sin' (Rothman 2010, Barnes et al 1999). However, Kimberlin suggests a 'just' society would be steered towards fairness, consideration and recognition. Race (2007) has noted a similar turn already underway in Sweden, a country which has attempted to follow through with the original principles of SRV, ensuring emphasis is made on societal values, rather than value 'falsely' directed at the individual per se.

3. *Welfare model*: despite the anodyne overtones, English researchers Savelescu and Kahane (2011) propose a daring and venturesome argument with their 'welfarist approach' which attempts to address the most difficult of issues in disability: ethical and moral decision making regarding life and wellbeing. They explain that wellbeing is an inherent normativity that is relevant to self and society and is thus dependent upon values, justice and cost. Using their deficit definition of disability, they consider it to be a *bad* or to at least allude to an uncomfortable way of being where the aim is to work towards and achieve a sense of wellbeing. Their controversial argument allows for channels of discussion surrounding the 'allowance' of genetic engineering, prenatal testing as well as making positive decisions to keep an impaired foetus (Hubbard 2006, Saxton 2006). In taking a 'welfarist approach', dialogue would take place on what might be termed 'neutral' territory. In this, Savelescu and Kahane (2011) are *not* suggesting eradication of impairment (as if that were possible, they acknowledge impairment can mean different things to different people) instead, they propose a justifiable debate based upon a *relative* 'good life'.

These three paradigms appear to have a common thread which I find very appealing*: human values*. It seems that by working towards creating a society in which people value themselves, as well as each other, tolerance of diversity and fair systems to accommodate that diversity would follow. As Saxton advocates:

> "*people who are different from us (whether in color, ability, age or ethnic origin) have much to share about what it means to be human*" (2006 p.108)

In this proposed social environment, the tricky moral debate on what constitutes 'wellbeing' (and for whom) might have less significance yet, simultaneously would be made more accessible. A values system, not based on individual 'worth' per se, but on truly *valuing people* incorporates everybody and as a consequence, for it to be successfully embedded in society, I believe a relatively slow and steady changing of perspectives must ensue where I do not suspect this to be an impossible 'Utopia' as it is already happening in Scandinavian countries (Race 2007, Levine 2009, Bergan & Hobson 2002, Erikson 2003). As a consequence, my study hopefully constitutes a contribution to the on-going process which I understand, (for the sake of future generations), *will* happen in the UK.

**The Research**

Having explained the motivations, foundations, rationale and theoretical directions that underpin my research, I now move to familiarise the reader with the contents of the chapters to follow which contain the body of my work. In chapter one I explore some of the historical developments that have contributed to our understandings of modern day parenting with the premise that:

> *"History provides us with narratives that tell us who we are, where*
> *we came from and where we should be going"* (Liu & Hilton 2005
> p. 537)

Rather than remain focused on a single period that yields frequently recurring explications of events surrounding notions of oppressive, medicalised, institutional and educational activity, I have chosen to take a broader multi-disciplinary approach (Digby 1996). Working with themes that were generated by the empirical data from this study, I briefly examine five eras dating back to ancient Greece and move through the Dark Ages, the high and late Middle Ages and the 'pre-modern' period in order to identify social and individual interactive behaviour culminating in the creation of social norms and thus pressures that occur in the process of finding ways of being (Walsh 1993, Fairclough 2003, Habermas 1970). As such, I attempt to explain the ways in which each period is germane and comment upon the connections and links that can be found with modern day experiences of being a parent.

In chapter two I explore theoretical perspectives in relation to being a parent and these specific subject areas were also identified via the practical fieldwork. As such, I examine notions of (self) regulation whereby experience is considered to be an emotional enterprise through which individuals may undergo a sense of 'losing' and 'finding' their understandings which in turn, relates to their heightened awareness of 'normality'. This is further investigated with a view to what it means to be 'normal' as well as feel 'normal' and thus the interactive element of being-in-the-world is brought under the spotlight. In this, I examine social 'features' that appear to contribute to experience covering such concepts as 'appropriate' and 'good' ways of being a parent which in turn may be identified by parents through living under perceived societal 'observation'. In contemplating socially expected ideals surrounding gender roles and through placing focus on social systems of employment and welfare, I draw attention to the differences parents may experience between sexes, partners, other parents and others in general. I conclude that the myriad of 'worldly intrusions' make a significant contribution to parents' emotional condition as well as their experience overall.

I have utilised the space in chapter three to explain more of the empirical issues relating to my study. As such, it covers issues relating to methodology and the ethics and the methods I employed. In this, I argue that methodology per se can be a constraining and unhelpful concept if it is approached with a view to it being an inert and obdurate strategy (Billig 1988). Having previously described critical hermeneutic phenomenological research theory *as* methodology (Wright 2006), I take the opportunity here to explore this notion through my experience with setting predetermined official protocol for this study. I expose the obstacles I came up against as this data offers important insight into the undercurrent (and thus normally invisible) struggles found within modern day experience of being a parent with specific relevance to being (mis)understood by those who have little or no experience themselves.

This endeavour leads to an exploration of the ethics of 'methodology' via development of research regulation and current governance which can be seen at the highest levels to accommodate interpretative styles of research yet, on being interpreted via a number of (sometimes conflicting) channels, the guidance becomes inappropriate and thus,

*un*ethical. By investigating ways in which other styles of qualitative research have encouraged assimilation of inapt scientific approaches into interpretative paradigms, I demonstrate the ways in which participant parents in this study have been affected and again, I believe this adds considerable relevant substance to the findings of my study.

Having explored the methodological and ethical issues that relate to this research, I conclude that appropriate guiding principles in terms of integrity and honesty which underpin the researcher's activities and behaviours are more appropriate to phenomenological enquiry than those espoused by 'scientific' enquiry. As such, in the final section of chapter three, I endeavour to expose as much of my way of working as is reasonably possible. I begin this element with detailed explanation of the ways in which I selected the four participants, interviewed them and subsequently transcribed the data. I follow this with specific illumination of the ways in which I analysed the texts by presenting examples from transcripts, tables I created during the process as well as photographic 'evidence' of the practical tasks I undertook. This includes further organisation of the resultant data in order to devise a chart of themes which informed the direction of additional reading required. Ultimately, this served to support discussion of the findings (chapter five) as well as the topical literature in this introduction and the underlying themes pertaining to historical and theoretical perspectives (chapters one and two). This ensured continuity whilst also maintaining a relevant (direct) focus on the interpreted understandings that came from the participants.

I provide further opportunities to understand my way of working in the appendices (6a-d p.329-337). Amongst this additional data I include reflexive notation which is an activity in keeping with this research genre as it fosters openness and thus more clarity of 'reasoning' behind my interpreted findings (Etherington 2004, Smith et al 2009). The comments also indicate the ways in which I have judged my own performance and thus offer insight into self-evaluation of the study project. Whilst I believe these comments might be helpful, I placed them in the (optional) appendix as I did not intend to treat the thesis as a place for inappropriate subjective indulgence. Although I am a parent myself, I consider this study to be an interpretative approach to understanding the meaning of 'being a parent' and in this, I have attempted to position (other) parents as central to this endeavour.

As such, I have devoted chapter four to the participants' interpreted accounts of experience where I have interspersed the text with their 'voice' to enhance my prose and add a 'real' flavour of the individual. Although I could not stretch this thesis (as much as I would have liked), to include disabled parents and those coming from diverse cultural backgrounds, I have attempted to work with participants coming from a range of contextual settings which offer a variety of meanings to the experience of being a parent (Ong-Dean 2005, Barnes et al 1999, Bell 2006, Malacrida 2009, Kingston 2007). Overall, I have attempted to respond to calls for disability research to engage in meaningful narratives, paying attention to existential feelings and moving away from stereotype in the genre (van Hove et al 2009, Levine 2009, Golden 2001, Barnes et al 1999, Bell 2006). The four parents who took part have lived through distinctive circumstances and have met with unique challenges whereby, generously sharing their understandings of these they revealed their multiple and complex perspectives. It was these aspects I hoped to capture through interactive interviews, my subsequent analysis and interpretations of their accounts as 'findings' (Calton 2008, Ray 2003, Carpenter 2000, Stadlen 2004, Green et al 2005).

In the final chapter (five), I present my discussion of the issues that arose from the findings where I hope to foster a sense of directional correspondence by following the structural format of the topics undertaken in the exploration of theoretical perspectives (chapter two). In so doing, I contemplate the participants' individual experiences against the thematic subjects that arose from the combined interpretations post-analysis in order to draw conclusions through working with an imaginary 'whole'. From this way of working, I am able to identify the peculiarities as well as the similarities found amongst the participants' experiences, contrasted with each other as well as the 'outside world'.

Having explored a variety of concepts that are particular to individual *and* social understandings pertaining to the experience of being a parent, I close the thesis by taking a reflective stance. I consider the specific contributions I believe this research has made in the relevant field as well as the limitations against which I outline recommendations for further exploration. In this, I make suggestions for further research to adopt particular areas of focus in order to expand upon what can be known,

specifically pointing to the building of parenting history(s). I finally consider the meaning of the current findings in relation to the 'real world' proposing that ultimately, these can be seen to inform possible and realistic discourses for the development of alternative social understandings and ways of being relevant to 'what happens' now and in the future. This conclusion results from the underlying research thread regarding (social) behaviours that recognise and uphold social moral obligations, responsibilities and values. The ideal of a society that accepts difference and diversity works in tandem with the notion of understanding 'other' through attempts to (at least) consider their perspective. As such, through the chapters in this thesis I hope to have made an overall contribution to the particular process of understanding parents' perspectives and this begins with the following chapter (one) which explores matters of perceived historical significance.

# CHAPTER ONE

# **HISTORICAL PERSPECTIVES**

**Introduction**

By taking a critical stance in so far as looking for understandings in relation to individuals living an experience situated in a social world, I feel the social 'pattern' and 'progress of life' (and *lives*) of parents and the related subject of disability are highly relevant to the enterprise of this study (Gadamer 1965, Oliver 1990, Stiker 1997, Held 1980, Lopez & Willis 2004). The ideas of what it means to be a parent are *"embedded in our (...) cultural belief systems",* developed over time and throughout history (Walsh 1993 p. 24, Silva 1996, Liu & Hilton 2005). As such, the intention of exposing historical 'routes' here is to provide a contextual setting in preparation for reading the subsequent findings as presented in chapter four.  This apparently unusual step is particularly relevant in a field in which the past often begins in the early years of the last century and is portrayed as a straightforward eventuality.

Prior to embarking on the task of finding data that might support this understanding, bearing in mind the specific socio-geographical locale of the empirical element of this study, I reviewed the ways in which 'this history' has already been defined in the western (mainly European) context. At once, I realised the 'social normality' of parenting (and thus, abnormality of the same) has taken fashionable as well as strongly selective directions in this sphere (Thomas 2004, Carmi Parsons & Wheeler 1999). It is barely recognised or acknowledged that, on (hardly) closer inspection, the historical endeavour of parenting is much more complicated than that espoused (O'Day 1994, Stiker 1997, Borsay 2005, Foucault 1984b).

In previous works, in order to formulate contextually persuasive chronicled 'evidence' which supports their *"evolutionary perspectives"* (Oliver 1990, p.26), authors have looked, in the case of disability scholars, to such things as government educational and institutional policy with reference to individual lived experience, often sprouting from (or at least in relation to) medical grounds (Atkinson et al 1997, Borsay 2005, Walmsley & Rolph 2001). In parenting, the second wave feminist literature covers the development of ideas surrounding motherhood, family and patriarchal systems (Oakley

1979, Ehrenreich & English 1979). A shared foundation can be found where both arenas draw heavily upon the works of writers such as Karl Marx (1818-1883) and Michael Foucault (1926-1984) who explain capitalist societies as being built upon relations of power and dominance which in turn accounts for the collective treatment of oppressed peoples such as those with impairment and women (Ehrenreich & English 1979, Everingham 1994, Bonner 1998, Oliver 1990, Barnes et al 1999, Hearn 2002, McIntosh 2002).

In attempts to untangle the roots of large scale phenomena (that which happens overall) and locating responsibility for setting its lived doctrine and boundaries, obvious 'blame' factors have been cited. These are usually historically powerful figures, organisations and movements that are synonymous with white, mostly English speaking, always of at least middle and upwards social class, able bodied and male (Oliver 1990, Race 2002, Oakley 1979, Kitzinger 1978, Ehrenreich & English 1979). Associated notions of human relations which take a functional or 'role' systems stance as espoused by the likes of Emile Durkheim (1858-1917) and Talcott Parsons (1902-1979) are also often raised (Everingham 1994, Thomas 2007, Barnes 2004a, Lupton & Barclay 1997, Walsh 1993). In addition, many scholars describe the (chosen) history through applying their prevailing concept of power relations undoubtedly influenced by their contemporary perspective which is likely to include modern emotional reactions (Scheper-Hughes (1992) cited by Carmi Parsons & Wheeler 1999, Gadamer 1976).

In these 'histories' the reader is (only) offered group struggles and as a result, the locus of investment for the characters involved becomes problematic (Read 2000, O'Day 1994). Too often, generalisations are made based upon available statistical data and from individual accounts that are not 'counteracted' or contrasted with others but lack variation and meld as 'one voice'; these closely connected narratives are often cited as representative of all involved (O'Day 1994, Huneycutt 1999, Borsay 2005, Thomas 2004, Lupton & Barclay 1997, Atkinson et al 1997). Little attention is therefore paid to such things as individual autonomy and/or proximity to socially produced moral codes which facilitate *"aesthetic response"* (Bauman 1991 cited by Abbinnett 2003 p.20).

It is also worth noting that understandings of disability and parenting history appear to have emerged from the mid-eighteenth century onwards (Drake 1999). Seemingly triggered by the industrial revolution and the myriad of information made available through printing press development and without apparently searching much further afield, writing in this arena has been prolific. To this end, authors have suggested definitive 'beginnings' to the process of understanding historical social concepts and I can think of no better example than that provided by Aminatta Forna (1998) whose chapter on the history of motherhood proudly begins with this sentence:

*"Motherhood was invented in 1762".* (p.25)

Whilst finding a place to begin is understandable, I do not consider this approach to be entirely appropriate or useful. When investigating history that only refers back to a comfortably recognisable era (one that introduced familiar mechanical industry and medical advancement) much of the hubbub that preceded and created the context underpinning later events is sadly forgotten (Digby 1996 e.g. Cheung Chung & Nolan 1998). Furthermore, I believe the conceptual 'start date' of how events occurred is much less distinguishable whereby, in concord with Foucault (1984b), I understand that:

> *"It's not a matter of locating everything on one level, that of the event, but of realising there is actually a whole order of levels of different types of events, differing in amplitude, chronological breadth, and capacity to produce effects".* (p. 56)

I do not suppose that I am able to achieve this complicated realistic representation even to a satisfactory degree, yet I attempt to elucidate by offering a range of perspectives, set amongst (brief) 'physical' context that covers a broad span reaching back beyond the modern era. Viewed from a wider angle, taking many competing factors into account, I believe it is possible to better understand the ways the surge of change, influx of thinking and furore of activity tumbled together and shaped the destiny of a time ripe for technological advancement in the latter eighteenth century (Matchinske 1998). From working in this way, the overall picture is hopefully made richer where my intention here is to provide 'food for thought', rather than an inert descriptive passage (O'Day 1994, Gadamer 1965).

Extending my exploration into areas of (inter)national history, science, art and religion over a longer period of time (scratching the surface of unfamiliar territory), these combined areas conjure alternative perspectives where temptation to adopt the unfortunate habit of stereotyping groups of people is reduced (Neugebauer 1996). For instance, it is often taken for granted that prior to the modern era, children in Britain were treated with cruelty or indifference and impairment was synonymous with institutionalisation (Forna 1998, Huneycutt 1999, O'Day 1994, Borsay 2005, Rushton 1996). As such, I hope to dispel some of the myths whilst addressing issues in relation to individuality whereby:

> *"lived experience, whether of few or many, can be easily obscured or even erased by an ideological program into which such experiences do not comfortably fit"* (Scheck 2008 p.3)

Investigation of such things as stories, art and 'real lives' opens the avenue of thinking at the time where using data linked to wealthier families becomes far from irrelevant to 'ordinary' family life (as has often been assumed) given that the former offers an exaggerated and magnified version of arrangements for 'ways of being' (Huneycutt 1999, Shadis 1999). As Partner (1999) suggests for example:

> *"the unyielding gender constructions of medieval Europe stand out in high relief around aristocratic women"* (p. 371)

Data of this type can also facilitate reminders that 'official' history is that which was *supposed* to have happened whereas, upon examination of diaries, letters and other personal effects belonging to the wealthier class, contradictions occur (Stiker 1997, Partner 1999, Leyser 1995). Anomalies can also be found when contrasting such things as legal documents and parish papers with the ways in which they were actually interpreted on the ground (Rushton 1996).

In taking this considered approach my goal is to depart from the well-trodden paths (accessed via authors such as these: Atkinson et al 1997, Race 2002, Borsay 2005, Forna 1999, Barnes et al 1999, Everingham 1994, Wright 2006) and instead, staying attuned to phenomenological ways of working, I aim to 'stand back' in the vein of Henri Stiker (1997), Wright and Digby (1996) and Rosemary O'Day (1994). I believe the advantage of adopting this stance comes in overseeing a large portion of 'what

happened' whilst also giving opportunity to identify detail. My approach is thus inspired by the hermeneutic tradition of examining the 'parts' in relation to the 'whole' (Schleiermacher 1819) and from this perspective it becomes clear that the past 250 years appear as a mere fragment in the passing of time.

To this end, I explore five periods from pre-modern history to expose interactive activity in the social world as is possible to readily reveal through the application of hindsight and (further) interpretation (Matchinske 1998, Liu & Hilton 2005, Gadamer 1965). Clearly, the potential subject matter found within this broad multi-disciplined spectrum is immense and as such, I felt it made sense to explore historical content guided by the empirical data from this study (not least for thesis continuity). As a consequence, the historical themes I have chosen were generated from issues that emerged via the participants' data whereby, subject matter from the past in relation to the parents' themes also showed potential for expansion far beyond the scope of this work. I therefore narrowed the field by relenting to work with themes that appeared most relevant to all the participants as well as being clearly pertinent to the moralistic theory underlying this research.

Beginning with Classical Greece, I investigate the notion that modern civilisation and thus current 'ways of being' have been founded on ancient ideas given their obvious persistence throughout two millennia. In an atmosphere that dictated health and wellbeing as primary to the (socially) accepted functioning of men and women, I look at parental roles and contemplate the process of establishing understanding of these, as well as information retrieval, through relationships with 'experts'. Following this, I turn to the pagan era in order to highlight notions of stereotyping, the possibility of there being 'alternative explanation' and the importance of context. In explaining these elements, I hope to contribute to the understandings behind perceived social actions (potentially allaying some of the myth) whilst also reinforcing the rationale for paying attention to individual accounts of experience. In the process, I scrutinise oft cited pagan 'brutalities' with a view to conjuring reflection of modern day whereby I argue there appears to be little difference between activities of then and now.

Subsequently, I delve into the central and late Middle Ages to investigate ways in which a dominant regime can be seen to direct individual behaviours whilst

simultaneously emulating social movement as already happening 'on the ground'. I attempt to illustrate this by emphasizing (specifically) the Catholic church's interplay with individuals where, in the earlier period, I examine the 'introduction' of ideas pertaining to diversity and benevolence recognising that the 'family' was targeted as a resource for the filtration of perceived societal control. From the later period, I draw attention to the processes of 'societal thinking' through identifying differing strands of culture gathering momentum and culminating to form renewed attitudes and ways of being in relation to parenting. In this, I investigate the ways in which the seemingly authoritarian church can also be perceived to have been at the mercy of a 'progressive' body of people. Taken together, the two periods illuminate social interaction through development of confused understandings in relation to the ways impairment was accepted socially as well as individually where it seems, similar ways of conceptualising disability appear to preoccupy modern times.

Finally, I consider the early modern period in order to demonstrate apparent societal 'progress' as striving to create and perpetuate socially accepted norms relating to particular ways of being. In this, I explore how individuals seemingly work towards a collective goal, steadfastly guided by socially derived and agreed principles which in turn foster pressures to conform. I show this activity as supported by the widespread adoption of Protestant ideals and as pertaining to the ability to earn money and be autonomous explained in terms of a given 'work ethic' and the development of 'social care'.

The overall purpose of this endeavour is to grasp some understanding of the cultural foundations which underpin modern understandings of experience of '*being a parent*'. My historical exploration therefore encompasses events relative to both mother and father as ordinary people situated in the broad social context where, ultimately I have searched for 'clues' that correspond to parents' experiences today. Despite distancing ourselves from the pre-modern eras (in time, space, being *and* purpose) whereby we imagine ourselves to be more 'civilised', 'advanced' and 'progressive', familiarities in attitudes and parental behaviours with the past appear rife. As such, the longevity of 'ways of being' may illustrate the contributions that have been made to the 'shaping' of who we are as well as what we do today (Digby 1996, Liu & Hilton 2005); I feel this also demonstrates how little has changed for social actors over time, overall.

As a consequence, with ideas akin to those of Frédèric le Play (1806-1882), the 'historical' activity might be viewed as a vehicle for comparison in order to critique our contemporary experiences and thus, it may become a learning exercise through which modern day 'solutions' may be found (O'Day 1994, Borsay 2005, Liu & Hilton 2005, Walmsley & Rolph 2001, Habermas 1970). I thus aspire to find the essence of 'what happened' by seeking out history with the understanding that whilst events and human behaviours are relevant to their own time, space (place) and being (Dally 1982, Carmi Parsons & Wheeler 1999), they are not necessarily *specific* to all three.

## Historical Eras

### Hellenistic Greece

This era appears to stand out as that which future generations particularly revisited and aspired to 'recreate'. As a consequence, much of the assumed wisdom and 'clarity of thinking' is traceable from this period to modern day. In what follows, I draw upon three pertinent issues that are particularly visible now: the affirmation of 'biological' male and female leading to relative gender 'functionality' and the perceived consequential requirement of 'expert intervention'.

*Context*

The development of 'scientific' knowledge was situated in a period of prosperity where notions of 'beauty', 'education' and 'art' were encouraged for the 'free' and wealthy who maintained a stratified society. Underpinning this were the religious beliefs of the era, where deities were personified and idolised and to whom atonement for perceived human error was observed. Being summonsed through the 'will of the Gods', Disability was dealt with as being 'tragic' (bad luck) *and* 'logical' where deformity appeared in the realm of the (dis)order of the life world and was thus classed as 'unnatural' (Stiker 1997). The issues pertaining to being 'a man' or 'a woman', producing healthy and attractive children, stemmed from and was intrinsically linked to these socially formatted criterion (and thus individually experienced pressures) of the day. An understanding of human reproduction which included the functional role of mothers and the way(s) this differed to fathers was therefore considered vital.

*Biological differences*:

Theories consistently made reference to the teachings of Hippocrates (c.460-377BC) and his ensuing biological and medical descriptions relating to both men and women (Moss 2010, Temkin 1973). He wrote 'Aphorisms' in c.400BC depicting symptoms which could aid the diagnosis of ailments and he coupled this with advice for possible action towards prevention or cure. His basic understandings came from his belief that illness resulted from an imbalance in the production of human fluids: healthy men were naturally 'warm' and this balanced their fluid production keeping them 'dry'. Conversely, women were perceived as always 'cold' and as a result, they were unable to 'digest' all their bodily fluid as evidenced by their 'superfluity' purged on a monthly basis (MacLehose 2009). The presence of 'residual fluid' indicated that women were susceptible to illness and this served to explain in part why women were the 'weaker' of the sexes.

In turn, these observations gave rise to notions of definitive 'masculinity' and 'femininity' where 'manliness' could be developed and maintained as something different from, as well as superior to, being female (Moss 2010). This thought process was encouraged by Aristotle (c.384-322BC) in his focus on healthy child development. He suggested that male infants should be kept cool to prevent them from becoming weak and thus 'feminine'. This thinking was later expounded by Galen (c.200-130 BC) who suggested that effeminate men were (amongst a variety of other 'causes') likely to have been previously exposed to humid environments given that moisture was synonymous with being female (Moss 2010). From these accumulated deliberations, exaggerated distinctive parental roles ensued: being 'naturally' strong and able, men's fathering role was perceived as the 'supportive provider' and, given women's perceived 'natural frailty' as well as their additional weakness whilst pregnant, mothers were to be supported.

*Gendered 'Functionality'*:

Aristotle produced a body of work entitled 'Nicomachean Ethics' (c.350 BC) in which he explored relationships including an examination of friendships, parents' and parents' love (see books 8 and 9)(Aristotle 2004). In framing gender differences between the parents, Aristotle concluded that each brought different virtues into the relationship (which differed from simply being friends) and these constituted what it

meant to be a *'good'* parent (Bonner 1998). In this, much of what he observed and wrote appeared as doctrines on appropriate parental behaviours, for instance, he described a parental ideal of achieving happiness through both parents (particularly mothers) making 'sacrifices' for their children and expecting less love from their child than they gave (e.g. 8:viii Aristotle 2004). He advised that mother's love would be greater than that of father's given her 'natural connectivity' facilitated by her ability to carry and give birth to the baby (8:vii, Aristotle 2004). This special relationship was thought to further enable mothers to take responsibility for the child's intellectual, moral and spiritual growth. Aristotle thus ascribed the notion of parental roles through his ideas of sex related 'functionality' which he closely associated with observations of specific family relationships.

*Intervention*

Due to the absence of menstrual flow during pregnancy Aristotle assumed the foetus was formed from the retained blood. As the fluid was thought to be potentially toxic if not purged, Galen later suggested that formation of the foetus was initiated by the introduction of sperm. Both scholars upheld Hippocrates' theory that the fluid remained absent as the mother continued to produce additional 'heat' in forming the foetus and after the birth, the fluid was converted into mother's milk. This biological reasoning provided explanation for bodily (mal)functions which in turn opened avenues for pregnancy and infant related guidance, instruction and recommendation (MacLehose 2009). For instance, Soranus (Galen's contemporary) utilised this biological information to produce practical parenting information suggesting suitable food stuffs for the mother during pregnancy whilst advocating the ideal attributes of a 'wet-nurse'. Interventions such as these were considered vital as pregnant women were judged to be weaker than usual and especially so once they had given birth where their own milk was felt likely to lack nutritional quality having undergone extreme exertion (MacLehose 2009).

*Comment*

Repeated reinterpretations and reinforcements of these ancient ideas resonate throughout history and as such, have dominated our 'ways of being' over the last 2000 years. In this, our desire to produce 'healthy' babies has been a continued human obsession that has driven science and medicine along a determined course of perceived

'risk reduction'. Clearly, this (pre)occupation of westernised nations is not exclusive, nor did it 'start' with the scholars of Hellenistic Greece. Their work was gleaned from understandings devolved from the Egyptian dynasties and similar knowledge development was the focus of other ancient peoples such as Arabians and Asians who ultimately recognised reproductive value as a force for continuity (Temkin 1973).

However, the drive towards this goal has previously been singularly attributed to the rise of medical 'power' through dominant male thinking and although prominent figures were men, it is unlikely that the scholars writing at the time were oppressing women in their separation of the sexes as we understand these terms today. Their approach appeared to be more simplistic and practical in trying to understand relationships and reproduction in respect of being a man *or* a woman. As such, it seems they developed theory by describing their observations and interpreting given 'facts' where, for example; 'free' women (those under scrutiny) did appear smaller and slighter than men. A developed sense that there existed suitable and practical parental roles therefore appears to be an obvious direction and although aimed toward a contemporary audience, these ideas have remained steadfast over time.

Despite witnessing change through for instance, the particular escalation of scientific knowledge during the 'enlightenment', medics, educators, religious leaders, social commentators and social actors continued to aspire to gender differences and behaviours that were observed prior to the first millennium. Although feminist activists have more recently drawn specific attention to gender issues over the course of the last century, it would seem these and other 'ancient' matters (looks, health, wellbeing etc) have endured and remain pertinent within parental experiences today. To this end, the 'power' and persistence arising from accumulated knowledge cannot be seen to have developed through its collection alone; the mode of dissemination and usefulness to recipients possibly shaped a climate of supremacy. For example, in ancient Greece, women were reliant upon female midwives whose traditional practices could not 'guarantee' a successful pregnancy and labour. As recipients (and requesters) of information, (wealthier) parents would both welcome and respect knowledge beyond their means of attainment that appeared to offer explanations, if not solutions, to their 'life or death' problems. In light of the latter concern, it would seem predictable that advice offered by esteemed scholars would be treated with total social reverence and

trust. In effect, the 'answers' appeared to be clearly worth the consequential weight of the 'invented' social pressures to conform, for instance in finding a 'wet-nurse'.

In late twentieth century literature and beyond, we are often led to believe the rise of the 'expert' has been a modern era phenomenon and as that which created a 'power' imbalance between the 'knower' and the ignorant. Yet, as this Grecian period hopefully demonstrates, humans generally have always had a propensity for knowledge that we feel will improve our existence and thus our experiences in life. Exchanges of information are thus not only based upon power but also through a mutual willingness to find and give it on the one hand and receive and follow it on the other (Borsay 2005).

## Pagans (c.400-900AD)

I have included what follows as this stretch of history is notorious for 'barbaric' behaviours yet, upon closer inspection, this proposed 'normality' of life appears quite different from that which has since been revealed as actually experienced (Leyser 1995). As such, it aptly illustrates how, if viewed through the lens of an opposing sect, differing cultures can be misunderstood (Liu & Hilton 2005). Taken together these factors highlight the importance of investigating individuals' behaviours where the particular focus on parental behaviours allows for direct comparison to those of modern times thus revealing an opportunity to question our own societal progress (Walmsley & Rolph 2001).

*Context*

Roman inhabitation prior to the first millennium ensured classical Greek philosophy and medicine reached Britain. Over the subsequent 400 years, the Roman culture infiltrated the South and East and superseded the once dominant Celtic customs. However, the collapse of the Roman Empire signalled the disintegration of the precedent civilisation and the Celts returned in force. Invasions from areas of what is now modern Scandinavia, Iceland, Ireland, Germany and France were regular where through notorious brute force over a span of five centuries, groups such as the Saxons, Jutes and Angles, followed by the Danes and Vikings made settlements (Chadwick

1924). The traditions of Celtic culture, Norse and Bracton law and pagan religion were (re)instated and prevailed in the majority of the various kingdoms across the land (Wright 1939, Coss 2006).

Throughout Europe, this era became known as the Dark Ages due to the paucity of literature and art (Chadwick 1924, Leyser 1995). Understandings of the people have therefore since been gleaned from writing developed in later centuries under the negative influence of medieval Christianity (Jochens 1999). The tribes inhabiting Britain were depicted as heathen whereby their customs relating to infanticide, fostering and illegitimacy were cited as evidence of their collective indifference towards children and family life and this intense imagery has endured with time (Jochens 1999, Liu & Hilton 2005).

*Pagan parenting customs:*

If acceptance from the father of a newborn was not forthcoming the infant was 'exposed' meaning it would be left outside to perish (Jochens 1999). This was a custom underpinned by Old Norse law which asserted that each child had a father and thus a named person responsible for funding their development (Leyser 1995). Exposure was therefore founded on a policy of sponsorship and was an accepted and approved part of common law. It also appeared to be part of the long established system of favouring 'legitimate heirs' who (ideally) were produced through monogamous relationships. As such, the treatment of unmarried mothers, particularly by their financially burdened fathers and brothers was at best, unpleasant.

Fostering infants until they were young adults also appears to have come as a result of the law regarding legitimacy. This practice entailed handing babies over to families and older couples who were paid to look after the (usually male) child. The payment implies the relationship was one of concord where it is known the 'new father' was bestowed with the responsibility of the child's care and education. As a binding agreement, foster children could become heirs to their new parents' property and the wealthier biological parents regarded this as a fair option for a second son who could not inherit directly from them (Jochens 1999).

*Parents' lived experience*

The Icelandic family 'Sagas' are a collection of prose, short texts and stories constituting rare contemporary sources of information regarding the social history of pagan people in Europe during this period (Wright 1939). Amongst that data, Jochens (1999) found stories of family love, relationships and bonding including motherly loyalty. She found examples where 'ordinary' parents were devoted to their children as well as their foster children and concluded that these countered other narratives depicting the more commonly cited hatred, callousness and disloyalty of mothers and their propensity to incite their sons into battle and to kill for revenge.

Grundy (1999) adds a further dimension to Jochens' explication of relationships found in the texts by suggesting the Sagas reveal much about the socially *expected* roles of parents of the time. Mothers were beholden to the fathers of their children in terms of financial support and in turn, fathers were held legally responsible for their offspring, yet in the Sagas: men were portrayed as legendary heroes who as 'grown children' continued to turn to their mothers (biological or adoptive) for parental guidance. As such, the mother figure was often depicted as a clever and controlling witch as it was from her awesome 'supernatural' powers as well as through her ability to "*act(s) as counsellor, strategist and mediator*" (Grundy 1999, p. 223) that sons (men) could gain their strength. As a result, Grundy (1999) suggests the Sagas acknowledged and further encouraged the protective and devoted, 'special' and social role of mother whilst reinforcing notions of the father as being able to offer 'grounded' stability and financial security for both mother and offspring.

*Comment*

In review, what becomes clear amid the chaos of (re)settlement in this period is the social action towards the 'order of things' where men, despite being creators of the law were 'socially supervised' by women (Grundy 1999) and in turn, women were the beneficiaries of male provided security. Despite the cultural gap from Greco/Roman understandings, the notion of 'functional' behaviour relating to biological difference is strong. However, the mixed race Britons appeared to appreciate traits they saw as particular to being female in ways the ancient Greeks (and thus Romans) appeared to ignore (and later revile). Pagan women were expected to work and be strong willed.

Held in high regard, they were perceived as the protectors of their children and known as feisty, keen and very capable (Scheck 2008, Leyser 1995).

This era was harsh and difficult for the occupants of a battling Northern Europe, with unrest covering much of the land it is perhaps understandable that 'family history' was depicted through narratives of their struggles and strengths: Boudicca is an example from specifically English history at the time of the early Roman battles and Beowulf from the later period (Wright 1939, Leyser 1995). Although legendary, these stories and the Sagas reflected 'real life' and thus became contemporary, de-sensitising narratives for ordinary families who were experiencing bouts of death and destruction (Liu & Hilton 2005). As such, the characters' behaviours were used as exemplars of good or bad conduct against which other 'ordinary' folk could gauge their circumstances and actions (Grundy 1999).

However, transposing 'modern' emotions onto the behaviours of people from the past incites alarm regarding their apparent violence and brutality whilst it is also reassuring to consider the ways in which we feel we have progressed. However, the 'cruel', 'unfeeling' and 'hard faced' activity of the pagan people can be applied to *any* era, including present day. Fostering is currently commonplace and it is tempting to apply modern connotations of 'unwanted children' on this ancient activity although, pre-modern parents fostered out their children in the firm belief that it offered a better outcome for their child (Jochens 1999). 'Sacrificial' behaviour (in Aristotlean terms) can also be recognised in modern times as an underlying parental goal and in this respect, it seems little has changed. In addition, the issue of illegitimacy regarding father's rights, responsibilities and financial support for children is also an on-going 'saga' as well as being a part of constitutional law, for example in the Child Maintenance and Other Payments Act (2008).

Yet, perhaps most 'shocking' to the modern parent is the matter of infanticide and this activity becomes more intriguing when given contextual placement on an aged and international stage. The ancient Greeks and Romans are known to have 'returned' their impaired to the Gods (Veyne 1987) and exposure has been an enduring and accepted taken for granted reality as a method of disposing of unwanted babies all over Europe (at least) and has visibly reoccurred throughout centuries since (Forna 1998, Kitzinger

1978, Leyser 1995). According to Dally (1982), the activity of disposing of a newborn did not warrant the death penalty in England until after the sixteenth century and dead babies remained a common sight in inner city London as late as the 1890's (Smart 1996). Although in our current society we may not physically 'expose' children, we continue to openly encourage the disposal of unwanted and 'unhealthy' babies. Eugenic practices were promoted throughout the first half of the twentieth century culminating in scientific developments which made allowances for 'official' procedures (Shakespeare 2006). Our current 'advantage' therefore is the hidden nature of the practice where we have the technology and know-how to allow for removal prior to full term birth.

Given that historical centuries are glossed over in a mere sentence or paragraph, it is difficult to comprehend enforcement and development of laws and customs as occurring through generations over time aiding the process of 'naturalisation' where individual behaviour can be understood as 'intrinsic' and thus 'normal' (Forna 1998, Walsh 1993). The Sagas and other presumed works of the time since vanished (Wright 1939), characterised notions of 'ideal' right and wrong relevant to time and circumstance. Clearly, an individual would have been deemed unusual and possibly rejected if they did not adhere to the overriding 'rules' which were established to make sense for a whole community (Swim & Thomas 2006). Furthermore, whilst there is evidence to suggest individuals 'complied', there is little that responds to a question of 'how many did not?'

It is too simplistic to view these matters with modern emotions that emerge within the context of the modern era; we are socialised in such a way that we do not question the notion of 'exposure'. We assume it to be as shocking as it is wrong. In this, we review 'other' past lives from a particular perspective where we have no *real* understanding of what it was like and thus, 'what (actually) happened'. Understandings require proportion and when other cultural information comes to light such as primitive precursors to charitable behaviours (widowed mothers were given a cow in the summer and an ox in the winter (Leyser 1995)), a broader understanding of the people and their motivations may be obtained (Liu & Hilton 2005). As such, parents of the first Millennium appear to have been much maligned by their successors as they

probably underwent considerable anguish through living with their socially prescribed constraints and dictums just as many parents may do today.

## The High and Late Middle Ages (c.1000 – 1450AD)

Through investigating events of the Middle Ages it is possible to identify societal attitudes as being clearly channelled through a dominant source (Stiker 1997). The Christian church during this period is an important gateway to revealing the customs and cultures of the time that continue to haunt modern thinking. As a consequence, it is interesting to explore (if only briefly) the relationships between the church, the 'state' and the people. During this process, I am avoiding making reference to:

> "*the tired historical accounts of a medieval world rife with superstitious treatment of mental disorders and an early modern Europe swimming in the red tide of witchcrazes*" (Neugebauer 1996, p.39)

These narratives are not entirely representative of the period and as Neugebauer (1996) implies, through sensationalistic interest they have 'hi-jacked' this area of history. Instead, I wish to draw attention to the ways in which officially prescribed doctrines and ways of thinking can cause confusion and divisions in the proposed understanding of ways of being. To cover all aspects of this would be an impossible task, thus, my focus here in relation to parents highlights the issues surrounding: 'Charity' and 'Marital relationships' during the central (high) Middle Ages and from the later period; 'Medicine', 'Disability' and 'Family'.

### High Middle Ages (c.1000 – 1200)

*Context*

By the eleventh century Christianity had become the prevailing religion of England where advocates referred to St. Augustine's (c. 354-430AD) epic '*City of God*' in order to support their Biblical interpretations which in turn, underpinned the doctrines of the day (Flint 2006, Barnes et al 1999). This was made possible as the church appeared to control the rich through papal supremacy and direct the poor through its highly visible presence (Stiker 1997). The growing numbers of Christians were notoriously intolerant of the so called:

> *"pagan abominations and the obscenity, as well as, absurdity, both of the substance and ceremonies of their pretended religion"* (St Gregory of Nazianzus (c.329-390 trans.1662) no page number)

Attempts were thus made to replace the customs of spiritualism and 'witchcraft' with notions of divine healing through prayer and pilgrimage. Concurrently, universities were being established (Oxford 1167 and Cambridge 1209) where scholars shared the language of the church (Latin) and a growing sense of national identity was developing through common use of the Anglo-Saxon language. Whilst strength in unity was the aim of the contemporary Norman regime, the majority of people were kept poor whereby the notion of 'human commodity' and worth was cemented by the instigation of the Domes Day Book (1086-1090) (Rigby 2006, Leyser 1995). However, according to Stiker (1997) this was a time during which Disability momentarily 'disappeared' where:

> *"the Gospels dismantle(d)the rule of a strictly religious conception in favour of an ethical one"* (p.87)

As such, the Christian disapproval of the 'barbaric' habit of exposure meant that infidelity, illegitimacy and infant abandonment had become a growing social problem (Dally 1982, Jochens 1999). A climate of moralistic change ensued, apparently led by the church, materialising in new forms of 'charity' and 'marital relationships'.

*Charity*:

Although initially unpopular with aristocracy through his suggestions of equality in human being, St Francis of Assisi's (c.1181-1226AD) interpretations from the 'City of God' regarding human diversity became widely accepted. His preaching added credence to the ban on 'exposure' as well as support towards the 'solution' of its social consequences. The court 'fool' and the 'village idiot' are often cited in this period (Andrews 1996, McDonagh 2008) and they possibly represented contemporary acceptable and 'useful' examples of the 'diversity' St Francis espoused:

> *"But whoever is anywhere born a man, that is, a rational, mortal animal, no matter what unusual appearance he presents in colour, movement, sound, nor how peculiar he is in some power, part or quality of his nature, no Christian can doubt that he springs from that one protoplast. We can*

*distinguish the common human nature from that which is peculiar and therefore wonderful"* (St Augustine, City of God 16:8)

To this end, impairment reminded people of their own 'normality' whilst facilitating the notion of there being 'other worldliness' (McDonagh 2008). In this, Stiker (1997) believes disabled people may have been viewed in a similar way to monsters where the latter were fantastical art forms and the former were the real-life equivalent creations from God. As impairment was part of God's broad scheme, an impaired baby was to be accepted as a gift representing 'His goodness'. This thinking conveniently countered previous habits of 'returning' deformed infants and, as they were integral to the 'variety in life', the church advocated their worth in terms of requiring financial support.

This persuasive 'moral objective' resulted in acts of charity being enforced via the church where the aristocracy were encouraged by the promise of 'salvation' to establish and support neighbouring alms houses (Duffy 2006). The approach appeared to be one of benevolence, where the growing number of poor, infirm and needy who could not support themselves were pitied and taken under ecclesiastically funded and organised care (Duffy 2006). As such, many groups came together, including those with impairment and as they merged, they were generally perceived and thus 'dealt with' by society under a whole category: 'the poor' (Stiker 1997).

*Marital relationships:*

Concurrent  to the mounting number of 'charitable cases', the church promoted the notion of taking 'moral responsibility' for blood relations and forming stable relationships (O'Day 1994). In advancing this precept, perpetuation of the Christian population was assured as 'souls' could be nurtured from an early age within an intimate religious environment (Fleming 2001). Although marriage was an already established concept in England, the church realised it upheld state law and property rights rather than spiritual and trusted relationships (Leyser 1995). 'Blood ties' amongst large groups had previously been feared and discouraged as these signalled possible uprising and attack (O'Day 1994). Instead, 'loyal households' had emerged consisting of a figurehead and of many members who may, or may not, have been related (Fleming 2001). The peasants working the land were subordinate to the estate

owner and although free, had few opportunities to voice opinion or improve their lot (Dyer 1989). In recognition of this, the church endeavoured to make 'loving' relationships seem appealing by endorsing autonomy within marriage thus, Pope Alexander III (1159-1189) decreed matrimony to be a matter of privacy between husband and wife (O'Day 1994).

Within such relationships, despite being classed as inferior by the church (having been formed by man's rib), women were evidently valued for the specialised roles they fulfilled (Scheck 2008, Leyser 1995). Partner (1999) explains that the expected activities of a young woman from the aristocracy of the period appear to reflect the tasks of other, 'common' women yet, for the former she implores life was much more difficult. A 'rich' girl had less freedom than a villein and their ability to achieve gendered assignments associated with their typical 'training' was firmly placed in the domain of a usually strange and large household and thus, 'public' spotlight (Partner 1999).

However, many aristocratic women's status changed once married whereby they needed to be exceptionally robust (Scheck 2008). The 'lady of the house' was expected to be in charge of affairs given that an absent husband or being widowed was highly likely (LoPrete 1999, Shadis 1999). These women often carried a great deal of power, not only in their immediate community but in the wider social sphere (Shadis 1999, Partner 1999, Hunecutt 1999). Mothers were responsible for networking and facilitating 'business related' arranged marriages between their children and as such, many played out an important controlling matriarchal government of their family's lives (Shadis 1999, Partner 1999, Hunecutt 1999, Leyser 1995). The accompanying expectation was that fathers would spend time away from the household, uninvolved with their immediate family and thus, adopt the position of an overseeing, remote provider. Furthermore, these gendered identities were apparently followed in the common households: men would work outside whilst 'women's jobs' kept them closer to home (Leyser 1995, Fleming 2001).

*Comment*

What becomes apparent during this period is the propensity for change levelled at the church's ability to organise and mobilise the public mindset (Duffy 2006). Yet, whilst

dominant, the church was dependent upon the upper classes for support and although these and the peasants were obliged to adhere to the principles through allegiance, in practice, they may not have *agreed* with them (Scheck 2008, Leyser 1995, Coss 2006). As such, the swollen alms houses suggest that 'acceptance of diversity' was not complete whereby charity did not necessarily always 'begin at home'. The alms houses appeared to create opportunities for a continuation of the 'disposal' principle where it became acceptable to deposit for example, an illegitimate or impaired baby effectively putting the child out of sight. In turn, this flouted messages of acceptance and moreover, appeared to be the (enforced) making of benevolence at a distance whereby this particular social behaviour ostensibly began the custom of segregating 'social deviants'.

Despite being restricted in their movements however, it is clear the peasants had some autonomy (Leyser 1995) for instance, paganism was revealed as a continued practise during the plagues of later centuries and amongst some groups it enjoys popularity even today (Crisciani & Pereira 1998). It is therefore safe to assume that some parents would have continued the undercover practice of 'exposure' as this was also witnessed in later periods (Smart 1996, Dally 1982). Combined, these factors lead to an overriding issue which sets the tone of the whole Middle Age period: the church may have been a dominant force yet, there was an inherent unwillingness of people to fully commit to the dictated laws of Christianity per se where:

> *"even in the midst of reform, (…) resistance sometimes asserted itself in the form of outright refusal to comply"* (Scheck 2008 p.23)

This may have been due to some of the papal directives being contradictory to the interests of the English state as a whole (O'Day 1994). In holding personal worth and employment value significant, the state encouraged the notion of ability, as opposed to diversity and commodity in contrast to the preached morality (Kowaleski 2006); (factors which could easily apply to modern policy). Furthermore, the church advocated family bonding and close proximity in relationships and this appeared to, conflict with both the state regarding powerful kinship *and* the landed gentry whose marriages appeared to be founded on business related convenience (O'Day 1994, Leyser 1995). If men spent more time at home, the potential for generated income

from elsewhere would be reduced. In addition, many marriages were between older men and younger women in part due to women being vulnerable to loss of life during child birth and this led to men being married several times over (Sheingorn 1999, Fleming 2001). To this end, the church's encouragement of sustained physical closeness did not appear to relate to the practical relationships that actually happened.

That said, it is difficult to know how marital relationships really felt between partners (Leyser 1995). Through leading almost separate (and private) lives, sometimes short lived, it would be easy to assume there was no love at all in these relationships. However, snippets from personal letters and poetry such as one examined by Quattrin (1999) that reveals a Lady's feelings for her husband Knight (she faints upon hearing he died) can provide clues. As such, an alternative perspective is possible: it can be argued that the church was merely preaching what could be already observed where much of the religious idealisation of relationships mirrored that which was in place. Iconography of the day was deeply symbolic (a legacy from the pagans) and depicted Joseph as an older, subservient man to Mary's controlling and 'mother superior' youth (Ouspensky & Lossky 1982, Duffy 2006). Their relationship reflected the 'power' and ability of women (including the speciality of mother's love) complemented by the 'wisdom' and 'providing' capacity of men (Ouspensky & Lossky 1982). As such, the church appeared to be encouraging a continuation of this predetermined style of 'coupling' and thus emphasized and promoted the contemporary behavioural aspects of 'loving family life' (Coss 2006, Leyser 1995).

By highlighting these issues, I hope to have drawn attention to the ways in which interplay existed between apparently dominant social forces and the individual actors whose lives were affected and played out within the regime. The relationship of influence and counter-influence is furthered during the following period where events can be seen to lead to an ultimately confused mix in ways of thinking and thus being.

## Late Middle Age period (c.1200-1450)

Significant to this period is the apparent reversal in attitudes pertaining to previous 'moralistic behaviours' in relation to Disability. In a time of social crisis, the church can be perceived as a structuring force in their attempts to regain a sense of societal

order (Duffy 2006) yet, in the process, the message also appears to preach a continued reflection of circumstances already in place. With this particular focus in mind, I highlight three relevant elements belonging to this period: 'Medicine', 'Disability' and 'Family'.

*Context*

During the twelfth century there had been a steady rise in cottage industries and from this platform the late Middle Age period became renowned for growth based upon a booming wool industry which in turn, heralded the rise of independent farmers, wholesalers and tradesmen (Rigby 2006, Kowaleski 2006). However, interruptions from the Black Death (c.1348-50) and wars abroad brought about a severe reduction in the population and the feudal system was sent into disarray never to be fully restored (Neugebauer 1996, Dyer 1989, Rigby 2006). During the epidemic the church, depleted of members, also lost some credibility: 'divine prayer' was seen to fail and people reverted to paganism in their desperation to find cures (Barnes et al 1999, Crisciani & Pereira 1998). Alms houses had already become oversubscribed prior to the plague and the church began to blame parents (particularly mothers) if they produced a further 'burden' to society (Stiker 1997). The church's renewed attitude towards Disability remarkably coincided with the medical assumptions of the day.

*Medicine*:

Official medical practices came via Arabic (through French influence) and southern European sources where in both streams, theories continued to be developed through (the paralysing) understandings of Hippocratic, Aristotlean and Galenic philosophy (Stiker 1997, Leyser 1995, Temkin 1973). MacLehose (1999) explains that during the early twelfth century William de Conches had attempted to make contributions to the field of reproduction when he claimed menstrual blood impaired the newborn given that unlike other animals, man could not walk from birth. Conches further suggested that contact with the 'potent fluid' in utero could lead to additional deformity and this was more likely to occur if the mother's cravings for peculiar foods were not met. Medics of the late Middle Ages revived and scrutinised these claims, concluding that the menses were in fact dangerous (Leyser 1995). Mothers subsequently became dichotomously understood as being the provider of life and nourishment as well as the potential killer or cause of disfigurement of their unborn child (MacLehose 1999). In a

repeat of times past, a flurry of interventional measures were denoted replicating previous advice in terms of nutritional intake and 'essential' use of a wet-nurse (Leyser 1995, Fleming 2001).

*Disability*:

Although approached from a differing perspective, the medics' conclusions appear to correspond with the changed view from the church regarding impairment. Ecclesiastical *re*interpretations of St Augustine's 'City of God' replaced notions of impairment being a 'gift' or angelic sign of God with alternative preaching that it essentially materialised as God's judgement in response to sinful behaviour. Dramatically echoing the horrifying reality of the Black Death, priests came to regard remarks in the text such as: "*He fashions the human nature*" and "*monstrous births*" (St Augustine16:8) to mean diverse human form could be actually monstrous.

Concurrent to this development in thinking, the economy reached crisis point, the collapse of large households reduced communal stability, alms houses became financially unsupported and many plague survivors became vagrant (Dyer 1989). Wanderers included beggars, pilgrims, thieves, impaired, frail and elderly people (Duffy 2006) and they were generally classed as the same type: needy and useless (Stiker 1997). People with impairment who were already viewed as a product of sinful and 'bodily' malpractice and as a 'monstrous burden', also gained the label of representing 'evil' given their associations with criminals and rogues, further informed by additional interpretations from St Augustine's tome referring to 'demons' (Stiker 1997, Barnes et al 1999). As a consequence, disabled people no longer 'blended' into society and instead, many were treated as visible 'disgusting outcasts' (Andrews 1996).

Due to the rising number of alms beggars auxiliary specialisation relating to 'deserved' provision became seemingly imperative (Stiker 1997). Despite the distinction between terms such as 'lunatic' and 'idiot' not being made official until 1845, the language (and current meanings) were in use for example, The Bethlam Lunatic Asylum (est.1247). Places such as these catered for people who were thought to have a mental illness ('lunacy') as opposed to impairment which was deemed physical and permanent ('idiot') (Borsay 2005, Digby 2006). This early practice

appears to have underpinned the eventual habit of categorising and 'labelling' more extensively where also, understanding of 'hierarchy' and the 'politics' of being impaired significantly advanced (Neugebauer 1996, Cheung Chung & Nolan 1998).

*Family*:

In a bid to restore 'the faith' and social stability, the church continued its focus upon familial relationships. For a century from c.1350 'Cradle Plays' and associated rituals were encouraged throughout Europe which portrayed the 'ideal family' (Sheingorn 1997, O'Day 1994, Drage-Hale 1999). These were performed as theatrical animations of the iconography displayed in churches where the 'family' was formed as "*holy but human*" in a bid to create 'spiritual reality' (Drage-Hale 1999, p. 106, Ouspensky & Lossky 1982). Initially therefore, Joseph was played by an aged man who symbolised the wisdom of God and took a caring, loyal and supportive role in tending to Mary's needs. In tandem with this image, he was also publicised as being a bumbling fool who was ridiculed by the audience for his antics when trying to (unsuccessfully) bathe or feed the baby. The intention was to highlight Mary's female superiority, not just in her Holiness, but also in her child care and rearing skills whilst simultaneously exhibiting perceived male inadequacies of the same (Drage-Hale 1999).

As with the iconography, these first plays reflected relationships as they already appeared between partners. However, in the fifteenth century and coinciding with the emergence of the burgher class, the Vatican was petitioned for grant of permission to reflect the changed times in the plays where Joseph was eventually allowed to be:

> *".. transformed into a mirror image of mature productive laymen advancing from peasant to bourgeoisie and rising from servitude to authority and dignity*" (Drage-Hale 1999 p.102)

In later iconography as well as in the plays, Joseph no longer appeared as elderly, kneeling and subservient (Ouspensky & Lossky 1982). According to Drage-Hale (1999), he took an 'upright' position to reflect the 'new father' status he held as he came to be perceived on equal terms with Mary. Their relationship had changed to reflect 'real life' and Sheingorn (1999) also suggests that the changed Joseph character highlighted a further dimension to this representational role play: emotional romanticism. Women would aspire to marry someone like Joseph as his character

instigated *"feelings of hope and a sense of well being"* (Sheingorn 1999 p.95). The plays therefore offered escapism ideals by creating an atmosphere of 'hero' and 'heroine' that had direct appeal in relation to both male and female perspectives.

*Comment*

This period demonstrates that over time, prevailing attitudes and behaviours can seemingly develop into extreme opposites to those of previous generations. The altered state may have been triggered by unforeseeable and uncontrollable circumstances yet, what is *less* clear are the ways in which change infiltrated in order to mobilise human praxis (Held 1980). In this case, medical 'evidence' made available to support the potential for change was not used for this specific purpose when it first emerged (c. 1135) (MacLehose 1999) and the church chose a specific place in time to reinterpret St Augustine's passages. It may be that given the shared language of the disciplines, the moment was ripe for sharing this information at the 'elitist' level as scholars were busy establishing themselves as a professional body alongside the church (Neugebauer 1996, Leyser 1995, Temkin 1973). Regardless of this speculation, impairment did come to be viewed as something negative and to which 'blame' could be attributed whereby, the severity of the message was underlined by not one, but two distinct influential fields.

However, as with the church's policy on diversity seen in the earlier period, behaviours on the ground may not have been altogether responsive (Coss 2006, Leyser 1995) and conversely, the social actors on this occasion may have devised and encouraged the 'authoritarian' change themselves. For example, it is well known that ordinary people resented making tithe payments where much of the funding went directly to the remote Vatican. It is perhaps reasonable to assume therefore, that a large number may have also resented paying for charitable 'off site' causes. This conjecture is supported firstly by the 'dividing practices' adopted to refuse relief to those deemed as 'undeserving' (Borsay 2005, Stiker 1997, Foucault 1984a) and secondly; by the church being perceived as retrieving excessive funds using Disability as a premise (O'Day 1994). Therefore, in the absence of early records regarding these matters, it might be supposed that the (combined) scholars were merely reinforcing societal attitude. This turnabout does not seem unusual given the sensational level of adaptation found within the cradle plays.

Clearly, not everyone was swept away with the apparent tide of 'monstrous' change and this was witnessed in the official processes of finding 'deservedness' where a uniform system had not been established (Borsay 2005). People were judged with regard to their level of competency rather than on the grounds of them being for example, 'demonic' or sinful. This approach related to property ownership laws and thus cases were made on an individual and 'specialised' basis (Neugebauer1996). Furthermore, continued acceptance of 'diversity' (as opposed to repulsion) appeared via the 'family' home as it remained the most likely place of immediate refuge for those with impairment (Stiker 1997, Neugebauer 1996). Although, this may not have always happened out of 'benevolence' given that some parents felt guilty through inferred 'blame' (from whatever source) and may have hidden their infant in the house (Stiker 1997).

To this end, harmonious family relationships depicted in the cradle plays were likely to have encouraged people (more than ever before) to sentimentally reflect upon their own individualistic behaviours (Sheingorn 1999). The characters appealed to individuals' senses of who they were as well as the relationships they desired and the lifestyle they aspired to achieve (Maddern 2006). As such, the plays serve to highlight 'emotion' as a consuming force which directs, drives and dominates behaviour (Parkinson 1995). In turn, the late Middle Age period as a whole demonstrates the extent to which cultural representations appear to market, facilitate and reinforce ideals where iconography in particular brought forward the ultimate in visual messaging (Duffy 2006) given that:

> *"the doctrine relating to the image is not something separate,*
> *not an appendix"* (Ouspensky & Lossky 1982 p.28)

This era also illustrates the ways in which doctrines from differing disciplines may work in tandem to contribute towards the 'bigger social picture'. Taken together, no single medieval 'force' could be pinpointed as that which altered circumstances, feelings or attitudes where throughout there appeared to be mixed reaction to powerful ideals.

As Stiker (1997) points out: in its attempt to enforce a dominant standard and subsequently reverse principles over a relatively short space of time (whether imitating or leading the flow of current thought) using simplistic re-interpretation (e.g. of *'monster'*), the church lost momentum and this appeared to contribute to the loss of any controlling power it may have once had. The confusion in the message seems to have amounted to greater freedom for responding and behaving in a multitude of ways where individuals were left to decide for themselves such things as whether God had sent impairment as a punishment, a gift, an opportunity for salvation, a chance to display goodness of character, a sign of the devil or, as a symbol of His omnipresence (Stiker 1997). Unsurprisingly, many conflicting messages and misguided confusion (although perhaps not in direct relation to the church per se) remain apparent amongst parents in modern society (Rothman 2010, Patston 2007). The added dimensions of 'freedom of thought' through education and democratic politics together with access to a vast array of information, rather than solving issues, has perhaps compounded the 'problem' (Liu & Hilton 2005, Hugger 2009, Fairclough 2003, Held 1980). Employing our reflections of the past, we might wonder: 'could it be that no one quite knows how, or what to think about impairment when 'it happens' to them on a personal level?'

### The early-modern era: Reformation and Renaissance (c.1450-1750)

In this final section I investigate the ways in which society appears to organise 'itself' as if guided by a collective understanding that creates an underlying driving force. As such, in developing what appears to be a 'societal norm' as borne out of shared capacities and apparent willingness to aspire to similar goals, it remains difficult to assume that any particular or 'real' force is at play in shaping ideals. Given the multiplicity of impacting factors, this could be messy and complicated to explore yet I shall endeavour to stay focussed by addressing the areas of 'work ethic' and 'social care'.

*Context*

Throughout this era, poverty fluctuated in tandem with the national business economy although a steady increase in the total numbers of indigent people happened overall. This was reflected in the first Poor Law being passed in 1563 which aimed to replace

funds lost to alms through the dissolution of the Catholic Church. The new Protestant religion had left many parishes without a local religious leader and the concentration levelled on regimes of state power in effect, momentarily allowed for those 'on the ground' to continue as an almost independent social movement. This activity attracted social commentators noted for their contribution to modern humanities: Robert Filmer (1588-1653), Thomas Hobbes (1588-1679) and John Locke (1632-1704) are regularly cited as the founders of 'social theory' where notions surrounding 'patriarchy', 'human rights' and 'social contract' are attributed to these writers (Bonner 1998, Matchinske 1998). At the time, their ideas were made public and popularised through widely distributed pamphlets and texts, where for instance, the work of John Locke extended into 'human understanding' covering the matter of 'idiocy' (Goodey 1996, Race 2002a) and, his *Some thoughts concerning education'* (Locke 1693) was eagerly absorbed by middle and upper class parents in their bid to 'correctly care' for their child (Bonner 1998).

Under this guidance, both parents were responsible for the raising of their children whereby the male 'role model' for expected behaviours had significantly altered from a demure and attentive 'Joseph' (Hanawalt 1999). In an age of exploration and discovery, the early-modern era admired 'gentlemanly' behaviour permeated through characters such as, the 'courteous' Sir Walter Raleigh and 'composed' Sir Francis Drake. These contributors to societal behaviours were not engaging in passive actions and observations. Their behaviours coupled with popular writing served to reinforce ideals which coincided with the reorganisation of government (later emerging from the collapse of a republican model) and bore heavy reference to Protestant religious moral codes of the day.

*The Protestant 'work ethic'*

The ruling principle that civil and church matters should be separate and that punishment and sin should not hold monetary value effectively loosened the financial grip of Catholic worship whilst the new religious canon that idleness was a sign of the devil encouraged money making activities. Leading Protestant clerics Martin Luther (1483-1546) and John Calvin (1509-1564) held the basic premise that the Bible was the ultimate and therefore, *only* source of knowledge where delivery of God's message did not require a hierarchy of persons. They believed that, if taught basic reading skills,

people could learn for themselves from the direct source. As such, church led schooling became widespread although minimal where everyone, if able bodied, was expected to work (Borsay 2005).

Through the struggle of adaptation to large scale economic supply and demand, local parishes witnessed the formation of numerous small businesses and the emergence of practicing 'experts' requiring a complement of assistants and labourers (O'Day 1994). In turn, this gave rise to varying degrees of lower class wealth and sustainability fostering realistic aspirations for upward social mobility (Leyser 1995, Coss 2006, Maddern 2006). Employment statutes were introduced that prevented women from undertaking a variety of creative work roles thus, generally speaking, men tended to manufacture goods whilst women sold them. However, Hanawalt (1999) suggests that women were "*not mere puppets in the paternal game*" (p.239) as it was they who appeared to control circumstances. This is further demonstrated in relation to property obtained through marriage transfer where O'Day (1994) argues that female ownership provided governance over:

> "*family feeling, responsibility and relationships in a way that historians have not recognised*" (p.127)

O'Day (1994) draws attention to the (continued) matriarchal role of women in being devisors of the social 'rules' witnessed through their historically perpetual activities surrounding 'social climbing' and networking at all levels (Hanawalt 1999, Maddern 2006). This latter conduct was particularly prevalent amongst working mothers who were proficient at organising child care. Emulating the aristocracy of previous periods, infants were sent to 'wet nurses' and young children were grouped in local 'nurseries', 'boarded' or fostered out (Forna 1998). These behaviours ensured the variation within households was so great that a stereotypical family of the period (still) did not exist (O'Day 1994). Most consisted of relations as well as mixed numbers of other families and unrelated people, where the advantage as such, was that it created a number of opportunities for 'home care' (O'Day 1994, Andrews 1996, Dally 1982). However, despite this eventuality the number of people who required socially provided assistance during the period steadily rose.

*'Social care'*

As the cost of living continued to rise, lower class wages which related to the majority of the workforce, often failed to be sufficient to meet basic needs (O'Day 1994, Borsay 2005). In turn, this led to a crisis of destitution on a scale of some magnitude, as Foucault (1984a) describes:

> *"Even England, of all the countries of western Europe the least dependent on the system, had to solve the same problems. Despite all the measures taken to avoid unemployment and the reduction of wages, poverty continued to spread the nation"* (p. 131)

This economic state of affairs appears to have left little room for the spirit of charitable giving where the Protestant ethic of '*God helps those who help themselves*' echoed sentiments of the labouring population. Yet, Renaissance painter Pieter Breughel (1525- 1569) regularly included people with impairment picturing them amongst the hubbub of his 'framed' society (for example, see *'Battle of Carnival and Lent'* 1559). As such, it seems this group were an accepted, visible part of life, although it is also known that Disability remained in association with notions of monsters and demons (Stiker 1997, Barnes et al 1999, Rushton 1996). These ideas appear to have been reinforced by legacy mingled with an altered contemporary biblical interpretation. Calvinistic followers preached 'individual predestination' through being an innate 'saint' or 'sinner' where those with impairment were bound to be 'sinners'. Moreover, Lutherian preachers deemed this group to be 'filled with Satan' whereby some children could be understood as 'changelings' (Andrews 1996, McDonagh 2008). Perhaps unsurprisingly, cases of reported 'accidental' infant mortality rose during this period (Stiker 1997).

In spite of this, Breughel's paintings illustrated the ways in which Disability within the community appeared to be regarded in the ordinary run of life and this generally seems to be as 'charitable cases', not as 'evil sinners' to be avoided (see '*The seven acts of charity*' 1559, '*The Cripples*' (or '*The beggars*') 1568, *'The parable of the blind'* 1568). Clearly, the paintings also lend evidence to an underlying fact that people with impairment could be beleaguered and part of the rising number of indigent requesting alms. This large impoverished group had become increasingly difficult to manage not least as it appeared some were flouting the 'work ethic' being perceived as shiftless whilst simultaneously seen to be enjoying a 'free meal ticket' (Stiker 1997).

The turn of the seventeenth century thus heralded the beginning of a period of intensive activity across Europe which Foucault describes as *"the great confinement"* (1984a p.124). Beggars were to be removed from the streets and the burden on workers created by 'idlers' was to be reduced. This took place in England under the supporting legislation of the renewed Poor Law (1601) (Borsay 2005, Rushton 1996). 'Parish overseers' collected property linked tax to fund 'outdoor relief' for such things as fuel and clothes and to finance 'indoor relief' which was an institutional alternative (Borsay 2005). Progress with this policy ensured that by the mid eighteenth century, specialist buildings (becoming 'work houses') were commonplace in each parish for the purpose of being filled with those marginalised by the overall 'movement' of society (Foucault 1984a).

*Comment*

The portrayal of people belonging to this era often assumes stereotype of either being extremely rich or terribly poor where societal goals were ostensibly selfish and materialistic. Furthermore, the modern perception of the poor classes conjures supposition that *all* indigent people were miserable, destitute and living as beggars. However, learning from past eras (e.g. the pagans) and armed with a greater volume of articles revealing 'real lives', it becomes clear that these generalised descriptions are not reasonable representations of 'the people' (Rushton 1996, Lui & Hilton 2005). At the local level individuals can be seen to be at the mercy of officially directed socially derived systems and 'norms' as well as creating their own.

In this, the leading scholars of the day appeared to generate a sense of fervour towards accumulative (self) wealth and wellbeing. For example, in his *'Two Treatises of Government'* (1689) Locke espoused 'social contract' theory suggesting 'compliance' by the masses came from a shared willingness to work towards a common societal goal. In cases where this activity was ostensibly impossible (e.g. through impairment), the solution appeared to him (and others) to be found in creating the 'means' by making 'false work' available (Goodey 1996). Viewed as a 'rightful' response to an escalating social problem, the bonus side effect was high production via cheap labour. What was not foreseen was that this system undermined the 'real' economy or that the inhabitants of the institutions may suffer 'unnecessarily' (Foucault 1984a).

Although this design colluded with informed Protestant philosophy, similar societal behaviours and policies were sweeping the continent where Catholicism prevailed. The development therefore, towards intolerance of the needy and idle cannot have been underpinned by particular religious beliefs alone. The new found level of autonomy through education and work appeared to permit individuality on the one hand, whilst creating an overall climate of discernible and burdening pressure to conform on the other (again, a familiar modern picture). Through this movement, denigration was encouraged towards those who were not seen to be following the 'rules' and despite periods when for some, paid work was inaccessible or unavailable, the psychological work ethic campaign appeared to continue relentlessly.

In light of this and, given accounts of the huge buildings developed for mass 'confinement' for instance, the French Hôpital General (Foucault 1984a); it is simple to assume that everyone who could be described as poor and/or impaired was 'rounded up' and locked away. Whilst this applied to a great many people, it did not apply to significantly more, especially as the majority of the population were classed as poor which makes the notion that they could all be institutionalised nonsensical (Borsay 2005, O'Day 1994, Stiker 1997). Moreover, the assumption that most families living on the margins of society were interned ignores self-government and emotional pride; receipt of charity was perceived as a shameful exercise and requested entry into an institution was considered an absolute last resort (Borsay 2005, Rushton 1996). As such, 'ordinary folk' appeared to have their own 'solutions' to the social 'fall out' that was consistently apparent. In addition to the local networks of family and friends who physically looked after each other, extremely successful independent 'Friendly Societies'[1] evolved a system of providing financial aid and thus, looking out for each other (Borsay 2005).

The creation of such social means bears more relevance to the imagery found in Breughel's art than to religious doctrines surrounding notions of 'evil'. Impairment and family crisis does seem to have been met locally with sympathetic and charitable response, however; this 'kindly' reaction was just as likely to have generated adverse

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[1] **Footnote:** *The Friendly Societies were founded to insure for 'proper' funerals yet grew to cover other eventualities amongst the community. Although official records do not appear until the early 18th century, societies have been traced back to the mid 17th century and forward to present day where The Oddfellows Society continues in the Manchester area.*

feelings from parents as those derived from accusations of blame from the church and/or medics. I make this final conjecture as it comes not least from knowledge and understandings relating to modern experience and on this basis, elaborations can be made with confidence: the actions from others probably served as emotional reminders of parental status (regardless of wealth) and as such, promoted likely feelings of guilt in relation to being understood as not only a burden, but also a *failure*.

**Conclusion**

With regard to previous styles of culturally relevant history researched in this academic arena I concluded that it tends to be 'short lived', uncomplicated and it predominantly highlights oppressive activity (Thomas 2007). In the specific case of learning disability, despite attempts to create distance from the medical field, history here has seemingly emerged from clinical practices as if this parameter defines where the subject belonged at least up until the introduction of the Social Model in the 1980s (Oliver 1990, Digby 1996, Drake 1999). In response to this and in order to facilitate understanding of current experiences, I have attempted to explore in context a variety of historical themes in relation to being a parent of a child with impairment.

In not wishing to remain blinkered by educational, medical and feminist theoretical developments, this undertaking involved broadening perspectives through accessing data from alternative fields. It also involved regressing beyond the usual focal 'starting point' within the 'known' areas in a bid to look at 'what happened' prior to the regularly cited period of 'industrial revolution' (Drake 1999). In not taking a specifically oppressive route and not tracing 'disability' or 'parenting' as isolated parameters, per se, I have attempted to locate social characters in the broader field, aiming to examine complicated yet more realistic events that may have shaped experience. In so doing, I have attempted to account for individuality in my endeavour to avoid stereotyping and in making clear that at an individual level, despite having things in common, people are not necessarily the same as each other as is often espoused when referring to groups (Liu & Hilton 2005). This is furthered by the notion that, despite being equipped with a battery of information, it is never possible to fully understand the experiences of the people living in the past as we are confined to the knowledge and sensational emotions that are relevant to our own time.

Through my alternative approach, I have attempted to highlight the ways in which parents seemingly lived with social pressures derived from the legacies of past eras, as well as, from those relative to their own time (Matchinske 1998). As such, 'cultivated' social perceptions appeared to contribute to their experience as much as the actual events and subsequent (re)actions that occurred. In this, individuals' experiences were apparently part of a continuum of cultural social experience felt through perceived levels of acceptance or rejection made at distinct and localised levels (Liu & Hilton 2005). In turn, this phenomenon shed light upon 'the whole'. In working across five ages where social behaviours in isolation appeared to contrast and contradict what went before, common threads appeared in retrospect that seemed to suggest the contrary: similarities between periods abound. This correlation seemed to apply to the generalisation surrounding societal behaviours which appeared to respond and react to events and developments as a matter of repetitive course (Walmsley & Rolph 2001). For example, Stiker (1997) reminds us that with regard to the late medieval proclamation of Disability as being directly related to:

> *"ideas of sin and demonology, these themes do recur in pronounced form in times of collective calamity"* (p.86)

As such, regardless of 'what happened' I hope to have demonstrated that the 'behaviour' by (re)action appeared to remain 'the same' in so far as; on one level, it represented a consistently 'simple' return to past ideology as well as 'ways of being' and on another, it symbolised a complicated interplay between the social 'collective' and the individual 'self' in the contemporary moment.

I believe this appeared very evident via the consistent use of imagery, stories and art which has been exploited over time with the aim of shaping ideals (Duffy 2006, Ouspensky & Lossky 1982, Hugger 2009), Yet, it was also observed to mirror that of the 'on-going' experience and in turn, eventful experience could be seen to counter-influence the imagery employed. Reciprocal interaction such as this has been apparent through all eras and never more so than in our own where the multi-media field is a constant source of feed and reflection of experience per se (Morgan 2002, Liu & Hilton 2005, Fairclough 2003). Through making this historical journey I hope to have shed light upon the ways in which physical social interaction and subsequent desire, including fulfilment (found only just beyond that which satisfies 'real need'), may play

a part in moulding experience (Parkinson 1995, Donaldson & Prendergast 2011). Given a sense of autonomy, individuals can be seen to continue to refer to the 'collective' where through this, they may feel pressures to conform 'to be like' (or liked) or, they may just as easily not (Swim & Thomas 2006). As such, I explored the matter of being individual and autonomous as highlighted by behaviours in some eras which have apparently flouted the expected (and more often reported) 'norm', for instance in the Icelandic Sagas.

Despite the scale or mode of 'what happens', it appears that individuals create social means to overcome difficulties and possible personal trauma and in effect, the format of such a society encourages individuals to become role models and 'experts'. Repeated historical behaviours of: networking; publishing advice (repeated in content as well as by activity per se); devising gendered ideals and; responding to systems that differentiate members of society, are examples that I have explored which substantiate this point. It is also notable that these same 'timeless' behaviours are those which appear to create the (recurrent) pressures relating to 'ways of being' and this not only refers to experience at the socially accepted level, but also returns to the (questioning) individual.

To this end, what I hope to have shown by picking my way through particular histories in relation to parents (and Disability) is that individuals appear to be faced with the prospect of untangling the 'mess' of multidimensional (time, place, content, power and so on) social norms on a daily basis in their determination of finding 'appropriate' (interactive) ways of being-in-the-world. As a consequence, lived experience becomes one of specificity and peculiarity to the individual as they are confined to their given circumstances on the one hand whilst able to make decisions to conform or resist on the other. Within this process, inescapable contradictions abound and in making (moral) judgements in relation to ways of being, (mis)understandings are likely to be at the root of confusion and subsequent upset. In recognising this eventuality, I shall explore this concept in further detail through the following chapter (two), entitled 'theoretical perspectives'.

## CHAPTER TWO

## <u>THEORETICAL PERSPECTIVES</u>

**Introduction**

Becoming a parent constitutes significant life change for an individual and this has been evidenced in the work of Beach-Copeland and Harbaugh (2010), Stadlen (2004) and Doucet and Merla (2007). These particular researchers advocate the case for parents who do not have a baby with impairment although the common assumption is that having such a child will also alter one's life course: the difference may be that the latter scenario conjures a range of negative and possibly unpleasant connotations (Fisher 2001, Ho & Keiley 2003, Vehkakoski 2007, McGill-Smith 1993, Lohr et al 2000). Given that parents describe themselves as being "*just like everybody else*" (Canary 2008 p.453) and, in light of the issues raised by the literature examined in the main introduction, strong evidence exists to suggest that the 'problem' lies with the appearance of impairment in the family and associated notions of what this might mean.

My investigations regarding this issue have so far led me to make additional explorations beyond the parenting literature which entailed consideration of a variety of historical periods with related discussion in the previous chapter (one). From this, I offered an intermediate conclusion to propose that individual behaviours (and understandings) can be significantly linked to their immediate as well as remote social environment. As a consequence, in this chapter I have attempted to critically explore this notion in theoretical terms making a direct correlation between individual experience and societal expectations. As with the earlier historical perspectives and in an attempt to foster continuity in support of my thesis argument, I have followed themes that originated from the empirically generated data. For the purposes of further organising the specific content of the chapter I considered the participants' information as a 'whole'. Through my interpretation this emerged as an experiential 'story' of the 'self' journeying through social forms of interaction that raise internalised questions

and deliberations on making decisions about and understanding ways of being-in-the-world.

Against implications made by a number of psychologists, Gergen (1999) argues that introverted activity cannot occur without external influence yet, where others have suggested that individual cognitive processes are entirely underpinned by interaction with other, he also points to sensations of autonomous need. He suggests the nature of the connectedness between individual and social being is indistinguishable although in making this point, Gergen (1999) is not simply playing 'devil's advocate'. He suggests that the 'self', as situate in a social environment, always presents a binary conundrum given that:

> *"when attempting to create the sense of a unity, we are inevitably forced to speak of that which enters into the unity - thus essentializing the very elements we wish to transcend"* (p177)

I therefore recognise that despite being intrinsically linked, in order to discuss this relationship or write about the connection in theory, separation of the 'self' from 'society' cannot be avoided. For practical purposes therefore, I begin the parent 'story' with specific focus upon the individual.

As such, my initial aim is to unpick some of the theoretical detail in matters relating directly to the psychological 'self' with considerable focus placed upon emotion and the meanings of these in relation to personal experience. In this, I do not include mechanisms of potential 'external' support such as significant other, service provision and professional intervention as these are not relevant to this immediate inquiry. I want to investigate 'systems' of self-management and cognition to better understand personal internalised modes of transition through change and potential upset. I follow this with an exploration into emotional behaviours, including meaning conveyance and being understood where feelings can be experienced as unusual, dualistic, oscillatory and of variable intensity. Subsequently, I explore two specific examples extracted from the abundance of mixed emotions that parents may experience. Firstly I highlight 'grief' to illustrate the ways in which the literature appears to inappropriately categorise and standardise emotional experience and from this I am able to reveal perceived detrimental effect for parents (as well as disability discourse) of 'applying'

psychological 'grief' theory to their situation. In contrast I draw out a second example of 'love' which constitutes an exploration into virtually 'unchartered' territory in this field (Donaldson & Prendergast 2011). I suggest this more positively grounded concept holds potential for being an alternative discourse that parents and practitioners might adopt as a channel for explaining personal feelings in more appropriate ways.

I propose that undergoing introverted emotional turmoil happens as a consequence of both a desire to feel and be 'normal' as well as from the resounding impact that the personal activity involved in working towards this condition may have upon an individual (Reynolds Whyte & Ingstad 1995, Snyder & Mitchell 2006). In briefly considering some of the multiple meanings that might relate to a sense of 'normality' I demonstrate that parents may become unstuck through realising their confused and altered identity. In turn, this may lead to awareness of such things as: not belonging, segregation and exclusion, contrasted with feelings that may be understood as new forms of reassurance, comfort and inclusion. I therefore assume parents to be operating at the 'interface' of a multidimensional social environment whereby they (the inner and personal self) must negotiate unfamiliar paths and different ways of being amongst others. Through the 'journey' I scrutinise potential 'influencing factors' to this process which includes disability and parenting social discourse and (following previously highlighted historical activities), these perspectives incorporate discussion on modern gendered theoretical ideals as well as socially expected functional parenting behaviours.

In the final section of this chapter, I draw attention to the vast realm of 'grand society', a domain that appears intangible and unchangeable as social life is presented via unsubstantiated and faceless, seemingly 'given' ways of being. Here the individual may be perceived to be at the mercy of 'what happens' within the rumblings of 'society at large'. In order to identify current collective societal (moral) attitude from this arena, I explore perspectives through the filter of socially developed systems surrounding 'work' and 'welfare benefits'. In reviewing social organisation in this way, procedures and structures can be identified as 'barriers' to inclusion, yet moreover; they provide evidence to shed light upon the ways impairment related issues are dealt with in terms of socially generated moral responsibility, obligation and values. Given the perceived societal neglect of 'accepting' and compassionate behaviours, coupled with a lack of

encouragement to foster alternative (social) ways of being, undergoing their particular experience in such a world switches focus back to the individual parent and their reactive behaviours. Their apparent altered state and emotional disturbance can be seen to result from their complicated negotiation, mediation and difficult personal endeavour that all appear to be necessary requirements for 'simply' being-in-the-world. As such, this consequential upset signals the close of the 'parents' story' given that my adopted concept has travelled 'full circle' in returning to the psychological understandings of the socially responsive and inner-regulating 'self'.

**The 'Self'**

When attempting to understand individual experiential processes, Bardill (2000) advocates a *"relational systems model"* (p.65) where in brief, the 'self' can be perceived as operational in four distinct areas:

1. Self-awareness of 'being in existence'
2. Awareness of and exchange with 'other' (people and objects)
3. Awareness of and the creation of reality in a social context
4. Spatial understanding of the whole through spiritual and sensory being

Bardill (2000) suggests that the key to continued harmony of the four and thus a sense of inner stability may be achieved through a process of self-differentiation as worked through three psychological 'systems'. The first he identifies is 'self-regulation' and this includes behaviours that incorporate such things as internal thinking, control of emotions and command of personal responses to 'what happens'. Secondly, he supposes individuals, through yearning to be autonomous and/or with others, develop their sense of 'self-definition'. This differs from notions of identity per se in that it centres on notions of internally felt connections that enable 'self' to experience a sense of comfortable being through controlled proximity. Bardill (2000) describes a third system as 'self-distinction' through which individuals organise their sense of creativity, beliefs, values, roles and their priorities in order to feel internally satisfied. As such, the overall activity of managing the 'self' is governed by innate behaviours that favour self-protection and the aspiration to gain a sense of achievement through personal growth and development.

In managing such systems and making decisions, Tappan (1999) explains behaviours in terms of the 'self' being a moral agent: individuals control their personal actions, and reactions through the influences of socially assimilated dialogue that has occurred from an early age. Individuals eventually become independent decision makers able to exercise such things as value judgements through command of their *"internally persuasive"* voice (Tappan 1999, p. 121). In accordance with this theory there are reports amongst the literature of parents who tell themselves to 'keep going' and 'stay positive' (Crown 2009, Mason & Pavia 2006). These psychological behaviours thus appear to be self-governing however, Freeman (1999) makes an attempt to 'transcend' Gergens 'component parts' (of self and society) by explaining the phenomenon of being in the world via his (psychological) theory of *"poetic construction"* (p.102).

Freeman (1999) explains that individuals who undergo changed circumstances can be understood to mould reality with visionary purpose and passion to form a more intense version of what is known. Freeman (1999) perceives this as self undergoing an intrinsic process of *"imaginative labor"* (p. 104) and despite claiming romantic foundations, he also posits it as a practical activity that requires an interpretative context where, (borrowing from Heidegger) interaction with others and understandings of the original and subsequent new condition can be gained.

Interactive development has been the focus of Arlie Hochschild who has produced seminal work in relation to 'self-management', bringing emotion related behaviours to the forefront of social (cultural) experience (Parkinson 1995). In taking a symbolic interaction approach, Hochschild has attempted to displace traditional scientific notions of 'emotion' being either instinctive (a Darwinist position) or libidinous (a Freudian perspective). As a consequence, she argues that 'self-management' occurs in relation to socially expected behaviours where feelings are moderated by the individual to fit with circumstance and situation (Parkinson 1995). Within the realm of social expectation, Hochschild assumes gender to be relevant where for instance, men are expected to maintain a sense of reasoned judgement and stifle potential tears and, in contrast, women are vilified for over indulgence in 'masculine' behaviour such as 'anger'. However, the degree to which this process is successful (emotion is controlled) Hochschild suggests is also dependent upon individual personality and

character and as a consequence, when considering multi-dimensional 'emotions management', Bardill's model might work particularly well with her theories.

Theories such as these may be recognised as being useful in light of evidence that shows for some parents, having a baby who has impairment can herald the end of life as it was previously lived where they feel their 'normal' (family) life has stopped (Kingston 2007, Fisher 2001). Emotional turmoil is almost inevitable as parents attempt to 'right' their situation and control their inner 'self'. As such, this element of experience will be particular and personal to the individual and as a result I explore this eventuality in the following section.

**Emotions**

As a consequence of change, parents may experience a strong sense of being 'different', their 'world views' may alter or their routines may be 'simply' disrupted and according to Mason and Pavia (2006) the unsettling consequences of these eventualities should not be underestimated. Many parents suffer from an on-going fear of the 'unknown' whilst others have experienced frustration in feeling they have (or should) sacrifice their career and seemingly, their 'whole life' (Kingston 2007, Calton 2010). This latter aspect is perhaps unsurprising where parents have gained a previously unimaginable set of circumstances through having an unexpected baby (Russell 2003, Pollack & Stewart 1997, Hugger 2009). As such, they may find it difficult to recognise anything that has 'carried through' from their old (comfortable) ways of being McLaughlin & Goodley 2008). The 'road ahead' may thus seem a daunting prospect, especially in relation to being a single parent who may feel very alone and unsupported (Levine 2009).

However, as indicated in the thesis introduction, this transformation is not always detrimental nor is it always difficult. In concord with Hugger (2009), Crown (2009) believes that, as parent, she is stronger and wiser as a direct consequence of her experience and other parents that have reflected upon the process of similar self-development report a sense of pride, achievement and above all, love (Williams 2009, Read 2000, Gardner & Harmon 2002, Calton 2010). Carpenter (2000) suggests that despite working with new (and experienced) parents, professionals remain clueless with respect to the emotional issues that stir and he cites behaviours such as

insensitivity, ill-timed information giving and poor proximity to have caused upset. In addition, professional's expectations may be that parents might not be able to accept, let alone love, their newborn child. This lack of understanding may also come as a result of some practitioners approaching parents in what is expected to be a 'professional' manner which, far from being compassionate may take an inconsiderate, 'aloof' stance (Pollack & Stewart 1997, Gunaratnam 2002, Deeley 2002, Brinchmann et al 2002, Hasnat & Graves 2000). This disparate perspective and indifferent attitude also remains prevalent in the research domain where this may reflect the legacy of a positivist tradition (Toye 2010, Prendergast 2008).

*The difficulty of conveying meaning in relation to 'self':*
In some research carried out with sensitive topics, other authors have turned to research paradigms such as 'emotionalism' which encompasses (and can be said to even encourage) emotional behaviours from participants in order to elicit 'real life' experience (Gubrium & Holstein 1997, Prendergast 2008). This is clearly fervent territory in terms of the 'ethics' debate that might ensue yet, a gathering body of researchers, some from feminist backgrounds, implore that research with emotional focus does provide a legitimate perspective to lived experience that has been formerly ignored in the (male dominated) literature (Harding 1987, Maynard 1994, Toye 2010, Donaldson & Prendergast 2011, Chrisman 2011, Sklar 2011). As previously stated, I do not profess to be taking an emotionalist, nor an overtly 'feminist' approach to my work. I decided that to have done so might have been at the expense of 'other issues'. The exploratory route has the aim of exposing many facets of experience which may appear to be at the mercy of 'emotion' but never the less, may also be explained in more practical and recognisable ways (Vehkakoski 2007).

Although, it seems that under the influence of being able to utilise 'convenient' levels of criteria, other researchers have also attempted to treat emotion as a practical category (Donaldson & Prendergast 2011, Parkinson 1995). Indexes, measures and scales have been developed to report on parental emotional behaviours in relation to 'stress levels', 'coping strategies' and 'adaptation' (Eisenhower et al 2005, Hastings et al 2002, Hassall et al 2005). In this process, researchers may not be aware that the descriptors they employ, such as 'shock', 'anger' and 'guilt' may imply differing meanings across and between separate fields of study, amongst the participants *and* for

the recipients (professionals) of the findings (Roll-Pettersson 2001, Ricoeur 1973, Ho & Keiley 2007, Geanellos 1998). Yet, in spite of this anomaly, I must concur that the mobilisation of a reductionist classification of sensation is in fact necessary. The immediately apparent difficulty with 'emotion' is the intangible conveyance that arises: emotions cannot be reproduced via written report, no matter how 'thick' the description (Eatough & Smith 2005).

As a consequence, 'emotionalist' research is often re-enacted, conveyed through poetry, verse, dance or reproduced using imagery (Gubrium and Holstein 1997, Donaldson & Prendergast 2011, Keen 2006). This latter alternative approach has been particularly useful for example, when communicating feelings of hopelessness and devastation experienced by recent Tsunami victims in Japan. By showing film and photographs of destroyed and decimated villages, a shared depth of understanding is encouraged where the event becomes a more localised 'reality'. However, this level of graphic imagery is not possible for parents who also experience 'utter devastation' where the sensations they feel are on-going and cannot be captured on film or made 'real' for anyone else. Furthermore, in agreement with Rosaldo (1989), unless the 'onlooker' has felt the depth and variability of emotion that experience creates, it is almost impossible to *really* understand what it might actually feel like no matter who or what describes it. As such, the innate condition is one of extreme personal experience expressed with differing levels of intensity (Pelchat et al 2003, Parkinson 1995).

This leads to an additional issue in relation to the difficulties of making meaning of emotions and conveying that meaning to others and this is found in the dualism of experience (Crown 2009). Parents may sense concurrent and opposite feelings such as happiness and sadness, love and hate, despair and hope where these contradictions add possible trauma with confusion, guilt and self-doubt (Balsa 1998, Johnson 2002, Trute 2010). These mixtures can be experienced as so intense that attempts to measure them do appear nonsensical (Parkinson 1995) yet, where parents have been able to locate their own meanings, some researchers have confined them to predetermined criteria. This is problematic where parents find their own ways to communicate, for instance they may use metaphor to explain their experience or, given the propensity to feel many different things at once (not just an opposing binary), they may 'separate'

emotions in ways that researchers may not recognise (Goodley 2009, van Hove et al 2009). For the purpose of citing a 'simplistic' example of the latter scenario, Roll-Pettersson (2001) found that parents differentiated between their feelings of 'acceptance' towards (in no particular order): 'disability', their 'child' and their 'situation'. They also reported that they had considered the notion of there being a possibility of achieving '*total* acceptance' and whilst for some this may have meant the sum of all three, others referred to realising each over time, intermittently or never.

As such, the perplexity also appears to come about through the instability and uncertainty that occurs (Fisher 2001, McLaughlin & Goodley 2008). As with most parents, no two days may feel the same (Stadlen 2004) yet for a parent who has a child with impairment there may be an added 'unexpectedness' that manifests via (for instance) medical or behavioural difficulties (Ong-Dean 2005, Landsman 2005). Parents' relationships may undergo difficult periods, single parents may feel the emptiness of being on their own and individuals may feel the strain of working or experience anxiety due to lack of finance (Levine 2009, Walsh 1993). It thus follows that parents may struggle to describe the complex ways they feel as an exclusive and/or constant part of their experience (McGill-Smith 1993). Furthermore, as a consequence of finding difficulty in articulating their feelings, some parents may develop and harbour emotions associated with inadequacy, isolation and abnormality and in turn, these may be interpreted falsely as being directly connected to 'impairment' (Bruce & Schultz 2002, Hugger 2009, Towers 2009).

Harbouring feelings is an issue that may bear more relevance to men than women given the volume of research which suggests men do not tend to express their emotion as readily as women (Blaska 1998, Lohr et al 2000, Beatty & King 2008, Pelchat et al 2003, Brown et al 1993). In some 'stress' related research fathers were invited to participate yet only limited numbers took part (see for example, Barakat and Linney 1995 and Hastings et al 2002). Whilst this factor may be connected to specifically 'male issues' such as perceived welfare state 'intrusion', other possibilities exist that may be related to gendered ideals (Hochschild 1997, Simon & Lively 2010). Research suggests that some fathers may feel uncomfortable talking about their intimate feelings to strangers, similarly, they may not wish to complete questionnaires that resemble an 'admittance' or 'confession' (William 2009). Likewise, this may also be the case for

men speaking face to face with an interviewer who purports no apparent connection or potential to understand, that is; responses in all instances could be perceived as unbalanced and out of context (Blaska 1998, Lohr et al 2000, Perryman 2005, Pelchat et al 2003). As such, this latter point highlights a further difficulty with conducting sensitive research with any participant via 'narrow' focus or single dimension: the emotional 'issue' can become disproportionate and distort the whole experience (Read 2000). In the latter scenario studies can fail to achieve the presumed aim of enabling understanding whereby researchers may compound and perpetuate the 'problem'. To further explain, I use the commonly explored avenue of 'grief', reviewed in short as follows:

*A minor exploration:* 'Grief'

It is well documented that on discovering their infant has impairment, parents undergo a range of expressed emotions and these are often collectively described as 'grief' (Barnes et al 1999, Serpa Pimentel & Meneres 2003, Pollack & Stewart 1997). Yet, grief is commonly associated with the emotion(s) experienced by people who have suffered loss in life and in particular, the death of a family member (Maxwell & Barr 2003, Perryman 2005, Ho & Keiley 2003). To understand more about this phenomenon it is necessary to momentarily re-enter the field of psychology where research here exposes 'grief' as a self-developing process consisting of five possible psychological states. These are thought to be initiated by 'denial' and go on to include such things as panic and anxiety, which can be revisited before eventually emerging with a sense of full acceptance of the changed situation (Kubler-Ross 1969, cited by Blaska 1998).

Describing 'grief' as an unfolding, almost mechanical and predictable process that inevitably reaches a satisfactory conclusion was deemed inappropriate by Olshansky (1962, cited by Bennett & Algozzine 1983) who understood that not all those who suffer bereavement experience a sense of 'closure'. In light of this, Olshansky described those candidates who continued to feel upset as suffering from "*critical sorrow*", defining a state of permanent but not pathological, upset (Bennett & Algozzine 1983 p. 6). More recently, this concept has been modified by Bruce & Schultz (2002) who introduce the notion of "*non-finite loss*", their term to describe parents (or anyone) who feels "*a sense of disconnection from the mainstream*" (p. 9).

They and others, theorise that parents' feelings akin to 'grief' happen as a result of experiencing the loss of an 'idealised child', whilst they also gain an unwanted or unexpected baby in his place (Hugger, 2009, Russell 2003, Pollack & Stewart 1997, Ho & Keiley 2003). The on-going development of such a child becomes a "*living reminder*" to their parents of 'what might have been' (Kornblum & Anderson (1982) p.172).

As with Olshansky, Brown et al (1993) argue that feelings of 'grief' remain unresolved. However, they do not agree that 'grief' equates to parents continually experiencing 'it' as a permanent state of mind. In support of this latter point, Blaska (1998) suggests a condition to which she offers the term "*cyclical grieving*" (p.3), a descriptor for the way parents experience:

> "*the intermittent reoccurrence of one or more emotions which are part of the grieving process*" (p.3)

As such, events and encounters may 'trigger' revisiting emotions and thus many researchers are clear that emotions related to grief do *not* occur in any particular or fixed sequence (Brown et al 1993, Blaska 1998, Johnson 2000, Roll-Petterson 2001). It follows that 'grief' may be represented in (both) parents in different ways, at differing times, over different periods and concurrently with other 'non-related' feelings (McGill Smith 1993, Perryman 2005, Van der Veek et al 2009, Hugger 2009).

Despite these latter understandings, some research continues to discuss parental feelings associated with 'grief' from a singular, 'meaningless' perspective which perpetuates an incomplete and unbalanced view of the ways it can be actually experienced (French 1994d). Much of the discourse surrounding grief is borrowed from the field of traditional psychology and supposes that it occurs due to the 'introduction' of impairment and as a result of internal anguish that is assumed to sprout from within on account of maladjustment of self. Reports taking this approach reinforce professional perspectives and do little to promote those of parents or, the facilitation of 'shared understandings' (Hornby 1992, French 1994d, Abberley 2004).

Parents have revealed that terms synonymous with the bereavement process such as 'acceptance' do not rigidly apply to their experience given that, in this instance it

implies an agreeable moment has been reached (Ho & Keiley 2003). At least two issues can be seen to arise from this assumption: firstly, if parents wish to reject their baby, they may be considered to have 'simply' not reached a point of 'acceptance' and thus be encouraged to carry on until they do. This is incongruent with the notion of individual will in that parents may be quite clear that they do not want the baby (Roll-Petterson 2001, Hubbard 2006, McCoyd 2008). Secondly, 'acceptance' also implies that parents 'recover' in some way from 'what happened' and are thus able to put the event behind them and 'move on' yet for parents, the experience is *ever* present; life continues bringing with it all that entails (Golden 2001).

It is also noted that after initial attempts to simplify the issues, some studies are exposing more of the confusion that parents feel (Kingston 2007) and, it appears that researchers are more recently beginning to question (at last) the clearly predetermined notion that 'being a parent' is *all* bad (Hastings et al 2002, Heiman 2002, Gardner & Harman 2003). The development in recognising the importance of understanding emotion is a potentially useful direction for parents who look for 'guidance' but may not feel they 'fit' a particular model. In line with Roll-Petterson (2001) who also questions the use of the 'mourning model' as an adequate descriptor for experience, a suggested avenue for exploration to find possible alternatives might be found in the arena of 'emotion management' as briefly explained at the beginning of this chapter (Bardill 2000, Hoeksma et al 2002, Trute 2010, Hochschild 1997).

In this, I am not suggesting that parents do not feel depths of sadness, disappointment and pain associated with grief, many reportedly do. What I propose is that what they feel is not grief per se, *no one has died* and in fact, the implications for the disabled population of expressing emotion in such a way when a child is born with impairment is quite grim (French 1994d). Furthermore, (and unfortunately, no better for those with impairment), in reality, parents may *wish* for death, the exact opposite of actual loss (McGill-Smith 1993). In light of past histories, it does not seem an unnatural or unlikely human reaction to receiving a seemingly imperfect baby (Leyser 1995, Forna 1998, Smart 1996, Dally 1992). As such, I suggest the 'loss' parents may feel ought to be (re)framed in the context of 'what happened' not, as is current practice, by assimilation to other human experiences.

As I hope to have explained here, many parents may feel confused by feelings which may relate to a myriad of different things, they may find it difficult to understand, awkward to describe and frightened by feeling alone in this way (Ho & Keiley 2003, Hall 2005). In essence, helping parents to understand, 'manage' their emotions and express those as natural human behaviours may be a more appropriate paradigm to adopt than simply referring to and treating their 'condition' as 'grief' (Maxwell & Barr 2003). A more flexible conceptual approach might make way for parents to be able to talk about the range of feelings they undergo and one such area that remains relatively unexplored in the field of disability is '*love*' (Toye 2010, Donaldson & Prendergast 2011, Chrisman 2011).

*An exploratory focus*: 'Love'

According to Toye (2010), of all emotions, 'love' has received the least attention in any academic research field believing this to be on the basis that it falls within 'unstable ethical grounds'. 'Love' has long been associated with femininity and (in a return to Aristotle and thus ancient understandings) has predominantly and consistently been associated with weakness (Toye 2010). The subsidiary effect has been that 'love' has not been taken seriously in the traditional (scientific) academic arena. As stated earlier and in concord with recent advocates of this subject, I take issue with this position (Donaldson & Prendergast 2011, Chrisman 2011). Having encountered 'motherly love' as an oft cited essential that situates parental experience within social history, the importance of 'love' has been made apparent (Ouspensky & Lossky 1982, Jochens 1999, Phillipson et al 2002). It emerges as an indubitably central and possibly, underlying guiding component of experience thus, the presence of 'love' cannot be ignored. In order to understand it from the perspective of 'other', I believe ways to communicate it through an educational and social science academic context must be explored.

Writing about all mothers, Stadlen (2004) describes motherly love as a complete and protective, powerful force where she notes it has been traditionally considered to be the *"gold standard"* (p. 147) for love. Possibly as a consequence of such a perception, fathers' love has by comparison been neglected and in contrast, with the wellbeing of the child in mind, fathers have often been approached in terms of being perceived as an apparent threat (Moss 1995, Torr 2003). As such, fathers may feel guarded towards the

loving feelings they have for their offspring where this behaviour may also manifest as a result of social pressures in relation to expected ways of being (Williams 2009, Miller 2011). However, through recent in-depth interviews, Williams (2009) found that his male participants willingly volunteered discussion surrounding the affection, fondness and love they felt for their (non-impaired) children. His study also supports the findings reported by Henwood and Procter (2003) whose participant fathers spoke of the benefits they felt through spending time with their (non-impaired) child and their expectations of bonding and forming relationships with them. It follows that fathers who have a baby with impairment may have similar expectations if not experiences of this perceived closeness (Pelchat et al 2003, Beatty and King 2008).

Historical behavioural experts such as Nancy Chodorow and John Bowlby have underpinned much of the research carried out in relation to the process of human 'bonding' and 'attachment' as ways of considering the possible 'mechanics' of parental loving. As stated previously, mothers are usually considered to be the carer of an infant and as a consequence, behavioural research (since 1940s) has privileged mothers over fathers in this specific area (Lupton & Barclay 1997, Neufeld 2008). In transference to the field of disability, 'bonding' has been 'unpicked' and largely explored in terms of elementary 'adaptation' and 'coping' (Serpa Pimentel & Meneres 2003, Grant & Whittell 2000, Heiman 2002). Stadlen (2004) aptly notes how inappropriate this way of describing feelings toward their baby sounds for *any* mother:

> *"Surely no mother ever invented pseudo-scientific terms like 'bonding' or 'attachment parenting' or 'entrainment'. Mothers talk about love"* (p.22)

The implication (by omission) is that parents (and in particular, mothers) may not love their impaired infant and as such, indicators may be monitored to ensure they do not 'mal-adjust' or become 'maladaptive' which in turn, may develop into dangerous psychological behaviour (Malacrida 2009).

In fact, Pelchat et al (2003) found that many parents suffered from stress in direct relation to the 'denied' bonding process where fathers were particularly stressed through wanting to gain a sense of closeness to their infant. In addition, Beatty and King (2008) found that fathers who could spend time and engage with their child (*not surprisingly*) fostered close and mutually beneficial relationships. However, this

contrasts with a study by Ricci and Hodapp (2003) who found fathers' behaviours appeared to correlate to their child's (impairment related) characteristics: if the child was not responsive, the father reciprocated. In line with this, Olsson and Hwang (2001) report that *both* parents are likely to react to specific impairment type where parents who have a baby with Down's syndrome are less likely to become depressed than those who have children with other impairment.

Studies such as these do little overall to help parents understand their relationship with their child where researchers seemingly ignore the infant as a person choosing instead to focus on impairment (Goodley 2009, e.g. Eisenhower et al 2005). It is unclear if results of this sort are revealing anything positive: we ought to celebrate that parents are less likely to be depressed yet these findings are reinforcing 'hierarchical' structures around impairment type that lends suggestion to what is 'acceptable' and what is not (Landsman 2005, Hubbard 2006, Priestley 2003, McCoyd 2008, Crandall 2000). It does not need to be spelled out that this has serious implications in relation to genetic modification, devaluing life and undermining the long fought for *"people first"* agenda (Walmsley 1994 p.153). However, in more specific relation to parents per se, it is clear that research results such as these may also alert professionals who may (through lack of funding) prioritise their resources accordingly by attending to those assumed to be most in need of assistance. As previously discussed, the diverse nature of the ways emotions can be experienced between people, over time *and* with differing intensity and within the same person might mean their subsequent mechanisms of 'control' and thus self support (thus avoiding depression, stress etc), could be a more appropriate and useful focus of priority.

Ultimately, the vital issue here is recognising that parents, *just like all parents*, are expecting to love their baby and in spite of approaches in research which stack evidence to suggest that they do not, there is a growing body of research (including this) to support the fact that they *do*. Kingston (2007) reveals that parents who are able to be with and/or hold their baby when matters relating to impairment are being discussed feel calmer and more able to receive any news. I feel this is a really significant finding which supports the notion that parents want to connect with their baby and feel a shared closeness. Changed circumstances are happening to them all as a family and including the baby seems to be an important element of that process from

the beginning. Such behaviours encourage a 'start as we mean to go on' policy, where for many parents, developing a sense of normality and behaving in familiar ways is *incredibly* important (Morse et al 2000, Mason & Pavia 2006, Walsh 1993, McLaughlin & Goodley 2008).

**'Normality'**

As previously established, some parents may undergo feelings of innate upset through undergoing a period(s) of change (Hall 2005). In order to regain a sense of stability and certainty about their situation and thus feel 'normal' parents may strive to create 'new' normalities (Fisher 2001, Freeman 1999, McLaughlin & Goodley 2008). As a process 'driven' by emotion (as illustrated earlier by Bardill's (2000) 'self differentiation' scheme, through 'controlling', 'yearning' and 'valuing') the change in 'self' will clearly vary between individuals (Pelchat et al 2003, Morse et al 2000, Gardner & Harmon 2002). However, as also explained earlier, the development of self according to Gergen (1999) cannot occur without external influence. To this end, perceived social norms will also present alternative 'ways of being' where Lupton & Barclay (1997) suggest that parents take an:

"*active participation in norms for their own ends*" (p 57)

However, their statement appears to highlight some contentious issues where 'participation' is subject to a number of factors:

Firstly, in order to suit an individual's 'own ends', the norm must be desirable (Savelescu & Kahane 2011). In a social environment that places high value on such things as health, beauty and wealth, many norms appear to be formed through both imaginary and personal ideals and can thus be seen as false (Hugger 2009, Titchkosky 2009, Davis 2006a, Patston 2007). In addition, given that such norms are facilitated by intensive mass media propaganda and often supported by excessive wealth, the 'desirability' of idealised norms may become an unrealistic and moving 'goal post' and it follows this may create a continual source of anguish as opposed to pleasure (Henwood & Procter 2003, Golden 2001, Hobson & Morgan 2002, Barnes et al 1999).

Secondly, being *able* to 'fit' the desired model may be an issue for some where for instance, the appealing social norm of having a baby is also influenced by the dominant politically derived 'norms' that place values against what it means to be

human. In most westernised nations this can be perceived to currently run on a criterion of independence and autonomy from a legacy of late twentieth century politics, itself steadfastly developed throughout pre-modern times (Morse et al 2000, Fisher 2007, Levine 2009, Deeley 2002, Walmsley 1994, French 1994d, Drake 1999). As such, having a baby which does not necessarily fit this agenda (by having impairment) at once appears to deny the ability to participate in the related accepted norms (Watermeyer & Swartz 2008).

Thirdly, certain social norms may be expected to appeal where not participating or striving towards them might result in an individual being perceived as, (and/or is helped to feel) a failure. In addition, parents may be 'expected' for instance, to be extensively and intensively engaged with the educational and physical development of their baby with a learning difficulty although this 'active participation' may not suit the parents' 'own ends' and involvement can thus appear to be 'forced' (Malacrida 2009, Kingston 2007, Read 2000, Manthorpe et al 2003).

Fourthly, socially prescribed norms can be conflicting and contradictory which may be seen to present the individual with 'choice' across multiple levels yet, is more likely to induce anxiety. For example, parents may be offered tests to confirm their baby's health (normality) during pregnancy and this activity, (together with the third point above) may spark debate surrounding private and state responsibility which in turn, may leave parents feeling blamed and/or guilty (Esdaile &Greenwood 2003, Ray 2003, Hubbard 2006, Barnes 2007).

These suggested complications to attaining a sense of normality derived from influential 'external' norms are by no means exhaustive but serve to demonstrate Lewis' (2002) argument that a collective normality does not exist yet, as a universal *concept*, (as in the pre-modern era highlighted through chapter one) it cannot be ignored. It appears to be a condition that defines self (feeling 'normal') and lifestyle (ways of being 'normal') and thus what it *means* for an individual to be-in-the-world (Mason & Pavia 2006). As a parent, the 'individual' sense of normality is immediately compromised by living within the family context (Walsh 1993). As such, Mason and Pavia (2006) explain that normality in relation to the family environment has shared and relevant functional properties that take the form of:

> *"patterns of interaction that support the well-being of the family"*
> (p.1012)

These are not necessarily ideal or typical rather, they are 'systematic transactional processes' which foster an air of familiarity whereby the desired outcome (if all runs smoothly) is satisfaction. Mason and Pavia (2006) deliberately adopt this broad view of the normalisation process given their understandings of the complex ways in which individuals experience being a parent. They argue that commonly cited definitions do not seem appropriate for instance:

> *"normalisation is the identification with or adoption of the norms*
> *of a reference group"* (Morse et al 2000 p.672)

Where the:

> *"normal conditions of everyday living should be made available*
> *to everyone"* (Fisher 2007 p.283-4)

Mason and Pavia's (2006) account of 'family normality' acknowledges (in the first instance) that parents may have difficulty in being able to identify with a particular, single set of people or 'reference group'. Parents may feel the dichotomy of being (in relation to this study) able bodied whilst their child has impairment. For instance, their 'worldly desires' may continue in terms of wanting to eat out, enjoy holidays and be seen to be like everyone else where some parents:

> *"don't want to be the family with the little disabled kid"*
> (Mason & Pavia 2006 p. 1025)

As such, parents' 'loyalties' may be divided, they may feel stigmatised by joining support groups and clubs yet, *not* associating with other parents may also induce feelings of guilt and disloyalty towards their child (Goffman 2006, Kingston 2007, Crandall 2000, Cioffi 2000). This dualism is supported by studies conducted by Morse et al (2000) who report the ways in which some parents perceive their lives as being split between 'two worlds'. 'One world' appears as an everyday household lifestyle where parents perceive their family as functioning 'just as any other' (Pelchat et al

2003), whilst the 'second world' is life as it appears and is experienced beyond the family 'parameter' (Reynolds Whyte & Ingstad 1995).

This binary highlights the difficulty parents encounter with the second part of the 'normalising' definition supplied by Fisher (2007) (above) who in fact uses it to explain that having access to the 'normal conditions of everyday life' is dependent upon what those may be and by whose definition. From a disabled person's perspective this can be perplexing:

> *"almost every activity of daily living can take on the dimension of trying to make you less like yourself and more like the able-bodied"* (Mason 1992, cited by French 1994d p.51)

The pressure upon (able-bodied) parents therefore takes on new and further meaning regarding the development of an appropriate 'family system' which is likely to be incongruent with their own desired (socially pressured) way of being. As such, McLaughlin & Goodley (2008) have recognised that parents:

> *"live with the material and the discursive in co-existence"* (p.318)

In the end, 'normal conditions' can become perceived by parents as being inapplicable to the family as a whole and thus exclusive (Reynolds Whyte & Ingstad 1995, Barnes et al 1999). For (simplistic) example: a child's physical development may not follow the expected 'normal' growth rate and they may have different, irregular meal patterns where the social norm of using a knife and fork is unnecessary. As such, impairment of this type may render whole family meal times or eating out together (more social norms) entirely irrelevant (Morse et al 2000).

Parents may thus face a dilemma in ways to achieve a sense of belonging where 'externally' perceived (undesirable) 'abnormality' becomes *their* normality (Canary 2008, Reynolds Whyte & Ingstad 1995). In this, many parents are able to view their children *as* 'normal' where difficulty may only arise when meeting others who clearly do not (Canary 2008, Levine 2009, French 1994d, Hugger 2009). Furthermore, in order to 'fit in', some parents may have to decide what they can and cannot talk about

to others, judging what may be acceptable (interesting/appropriate/comfortable) conversation in relation to their situation (Watermeyer & Swartz 2008). Encounters such as these emphasize the skills that parents (and their children) may need to acquire in order to negotiate their way through life as situate between two very different contextual 'worlds' (Morse et al 2000, McLaughlin & Goodley 2008, Hall 2005). The ways in which parents undertake this process is often labelled as 'coping strategies' where in the literature surprisingly little attention is paid to notions of 'normality'.

Despite developments in research with families such as the *"Family Management Style Framework"* (Knafl and Deatrick 2003 p.232) which attempts to take account of the variety found in family systems and processes of normalisation, much research focuses on *deficit* perspectives of 'coping' where authors site (presumably in their attempts to inform practitioners) such things as: lack of information and advice (Pain 1999, Ellis et al 2002); inadequate support (Taanilla et al 2002, Law et al 2003); inability to adapt and tendency to blame (Hassall & Rose 2005, Lenhard et al 2005, Hall & Marteau 2003). As Morse et al (2000) implore, these attempts to explain parental behaviours rarely adequately portray the delicate interactive aspect of parents' endeavours whereby, having felt (or in continuing to feel) 'derailed', parents may employ a degree of confidence (in meeting others) and an air of 'optimism' when searching for possible ways to 'right' themselves (Heiman 2002, Baker et al 2005, Crown 2009).

Some parents join 'support groups' not only to enjoy the company of other likeminded people so they may feel 'normal' through understandings of shared experience (Kingston 2007, Kerr & Mackintosh 2003, Torr 2003, Soloman et al 2001), they may also attend on the basis that clubs can provide an opportunity to compare their situation to others in a bid to establish 'positive' identity markers that ultimately help them to feel better and thus closer to a sense of what it means to be normal (Landsman 2005, Morse et al 2000, Pelchat et al 2003, Ho & Keiley 2003, Swim & Thomas 2006, Crandall 2000, Cioffi 2000). As such, parents 'operate' at the *"social interface"* where their task of 'finding normality' can be brought to consciousness through meeting and interacting with other people amongst whom some may appear 'normal' whilst others may not and some may represent desired 'ways to be' whilst others may demonstrate the opposite (Dovidio et al 2000 p.21). To this end, feeling normal, being normal, wanting normality, adhering to socially accepted normality and so on, all appear to

'govern' experience (Walsh 1993, Morse et al 2000, Mason & Pavia 2006, Fisher 2007). As a result, the degree to which parents 'find normality' on a personal level appears to be inter-dependent upon socially prescribed and influential factors. The second half of this chapter is devoted to exploring some of the relevant issues.

**'Self' at the 'interface' of society**
Gubrium and Holstein (1997) aid understanding of the phenomenon of 'being-in-the-world' in their metaphor that can be used to describe the 'self' as existing at:

*"the lived border of reality and representation"* (p. 101)

This phrase may shed light upon the ways some authors suggest parents should 'look away' from society implying there exists a crossing point or 'interface' between themselves in actuality and meaningful social reality. In this, they advise avoidance of the 'representational' influences that create pressures associated with ascribing to accepted 'ways of being', claiming these to be 'false' ideals where instead, parents should find 'individual paths' (Hearn 2002, Lupton & Barclay 1997, Hugger 2009). Assuming this could be possible, such advice may not suit everyone. Managing alone and on one's own terms is not always desirable and this has been revealed in studies conducted with single parents and in particular, mothers (Levine 2009, Silva 1996, Grant & Whittell 2000). Some have found for example, single mothers (who do not have a baby with impairment) have less self-esteem and 'sense of mastery' than those who are married (Beach-Copeland & Harbaugh 2010) and single mothers that do have an impaired baby are more likely to suffer from depression (Olssen &Hwang 2001). This is not to de-value the position of single parents or conversely, to suppose that marriage is a better life choice per se rather, it is a point made for those who assume autonomous parenting may be a preferred way of being.

In marriage an individual is immediately placed at the 'interface of society' and at extremely close proximity whereby spouses share in the experience of having a baby not least by way of undergoing the process of changing their 'normal' (usual and familiar) identities (Stueve & Pleck 2001, Golden 2001, Walsh 1993, McLaughlin-Volpe 2006). As with all things connected to a sense of normality, identities are constructed and temporary concepts subject to levels of 'placement' and conformity (Stueve & Pleck 2001, Golden 2001, Rapley 2004, Crandall 2000). However, identities

may also be imposed via 'norms' of society and these are not necessarily agreeable to the individual where a feeling of stigma may ensue (Liu & Hilton 2005, Goffman 2006, Dovidio et al 2000). In this, having more than one social identity is possible and dominant discourses tend to dictate the most 'relevant' where 'new' may not always supersede 'old' (Vernon 2002), for example: despite becoming 'a father', men in the UK are likely to continue to be identified through their work role (Lupton & Barclay 1997, Lewis 2002) and by contrast in Sweden, being defined as 'a father' takes priority over job description (Bergman & Hobson 2002). However, disability discourse and identity can be seen to override the two when an individual becomes the parent of a child with a learning difficulty (Read 2000, Reynolds Whyte & Ingstad 1995, Barnes et al 1999, Rothman 2010).

**Disability**

As previously stated, Disability is a social construct where learning disability per se falls outside the medically and educationally defined boundaries of being 'normal' (Walsh 1993, Reynolds Whyte & Ingstad 1995, French1994d, Walmsley 1994, Goodley 2001). As such, the concept of Disability presents an on-going moral social dilemma where, as previously mentioned in the introduction to this thesis and further explicated in the historical references to 'charity' in chapter two, well meaning inclusive practices can be seen to perpetuate a further sense of isolation and exclusion (Morse et al 2000, Mason & Pavia 2006, Dowling & Dolan 2001, Canary 2008). In this, everyday social behaviours, media, imagery, symbols and signs recognising such things as: access requirements, parking bays, or separate toilet facilities serve to further marginalise those with impairment by simply being there; they *accentuate* difference (Titchkosky 2009, Snyder & Mitchell 2006, Barnes et al 1999, Rothman 2010, Scott-Hill 2004, Abbinett 2003). As a result, Disability is continually brought to consciousness and it is unsurprising therefore, that some parents feel this to be the dominant discourse imposing a new and 'different' 'whole family' identity (Van Hove et al 2009, Reynolds Whyte & Ingstad 1995, Dowling & Dolan 2001, Jenkins 2004). In addition, the societal markers pertaining to Disability do little to improve its reputation as a negative identity as it is associated with inability, dysfunction and deficit (Van Hove et al 2009, Ray 2003, Thomas 2007, Goodley 2009, Watermeyer & Swartz 2008, Lawson 2001, Scott-Hill 2004).

Parents are thus vulnerable in their new found situation where their reported feelings of 'shock' and 'fear' may be compounded by the knowledge that society operates and 'thinks' in detrimental ways (Thomas 2007, Goodley 2009, Watermeyer & Swartz 2008, Scott-Hill 2004). Furthermore, it is possible, that prior to becoming parent, the individual had conformed to these ways of being where (horrifying) realisation of societal feelings may come as a result of continuing to feel the *same* way (Hubbard 2006, McCoyd 2008). With this in mind, fathers are usually first at the 'interface' where their 'job' is to tell family and friends their news and this can be an extremely difficult task under the circumstances. Stadlen (2004) speaks for most new mothers when explaining how 'approval' of the baby by others may be desperately sought after and in light of perceived societal attitudes, it follows that this particular aspect of becoming 'mother' may be all the harder for those who have a baby with a learning difficulty (Hugger 2009). In this situation, mothers may feel this expected cultural norm to be a pointless exercise and in turn, not participating may add to their overall sense of disappointment and feelings of being detached from society (Craib 1994, Mason & Pavia 2006, Bruce & Schultz 2002).

According to Kingston (2007), despite feelings of being marginalised, mothers also perceive themselves to be posited by others firmly at the centre of society, not least as a victim. As such, many mothers are viscerally aware that they are being judged in their role as 'mother' (Read 2000, Hugger 2009) and this finding has been replicated with fathers (Torr 2003) as well as parents researched together (Goodley 2009). Issues surrounding the notion of being perceived as fulfilling societal expectations regarding appropriate and responsible behaviours in relation to being a parent create pressures on most parents (Stadlen 2004, Beach-Copeland & Harbaugh 2010). Yet, for those who have a baby with impairment who may also as a consequence, have regular and continual contact with professionals, there is the likelihood that they may feel as though the 'microscope' is being directed at their every move (Bonner 1998, Barnes et al 1999, Goodley & Tregaskis 2006, Vehkakoski 2007). Subsequently, social norms that influence parent specific behaviours and thus the interactive element of experience per se, becomes all the more focal.

**Socially constructed parental norms**

'Master narratives' provoke the ways people feel, think and respond to expected socially prescribed norms and sometimes these manifest as very clear directives (van Hove et al 2009, Miller 2011, Fairclough 2003, Gee 2005). For instance, the act of 'mothering' has long been associated with being female where it is perceived to be:

> "*a socially constructed set of activities and relationships involved in the nurturing and caring for people*" (Glenn 1994, p.9 cited by Francis-Connolly 1998 p.149)

As such, the actual role of 'being mother' carries great expectations of fulfilling tasks which in turn, are prescribed by societal emphasis on what is considered currently important (Silva 1996). Hearn (2002) argues that 'fathers' are also compelled to conform in similar ways but in particular, they are controlled by the state which he believes has:

> "*through civil, family and property law, population registration and numerous other policy regulations and procedures has, especially and increasingly over the past 200 years, devised, sanctioned, constructed, constrained and determined what fathers are and what a father is*" (p.251)

As such, specific political structures place emphasis upon the roles of males *and* females to encourage adherence to collective values for the purpose of maintaining harmony under a dominant political regime (Everingham 1994). Ideals in 'ways of being' are thus often verified by law for instance, currently in the UK, mothers are favoured in custody trials, fathers are expected to financially support their offspring and, mothers can be seen to be laden with 'responsibilities' whilst fathers have 'rights' (Hearn 2002, Morgan 2002). As highlighted in the history chapter, shifts in systems occur as society progresses through such things as technological development, economic stability and population growth. Movements in these can be viewed through domestic circumstances where, in line with modernity, family structures and functions have altered considerably over the past thirty years (Lupton & Barclay 1997, Mason & Pavia 2006, Green et al 2005, Gunaratnam 2002, Phillipson et al 2002, Miller 2011).

However, as also brought to light in the history chapter, the assumption that parents merely undergo political aspects of their experience on a one way basis of responding to localised issues such as patterns of employment or modifications to their roles

defined by national statute would be naïve. It could be argued that laws are devised to accommodate (or deny) altered behaviours for example; during the 1980's an increase in the divorce rate gave rise to instances of fathers seemingly 'abandoning' their children (Lewis 2002). Enforcement for fathers to provide financial support was deemed necessary (through what became the Child Maintenance and Other Payments Act (2008)) and consequently resulted in fathers being perceived by some as "*walking wallets*" (Gavanas 2002 p.227). Meanwhile, single mothers without support did not escape the 'spotlight' where to a large extent they continue to be perceived by society as a potential drain on welfare resources (Levine 2009, Silva 1996).

As such, expected behaviours based upon 'rights' and 'responsibilities' may induce pressure in relation to conforming to societal norms where failure to comply carries potential additional (financial and legal) consequences to those of possibly feeling blamed, guilty or isolated (Towers 2009, Torr 2004, Goodley 2009). This issue highlights the point that expected social behaviours are likely to differ in experience not only between parents who are single and those who are married, but also those of different sex (Miller 2011, Silva 1996). The implication is that from ancient foundations, gender remains an important aspect within experience and to explore this further, attention is paid to parents as 'males' and 'females' in the following section of this chapter.

*'Males':*

Whilst many authors suggest that fathers have received little attention in the literature, Hearn begs to differ where he suggests that through the medium of feminist, gay and political discourse they have been "*explicit objects of theory and critique*" (2002, p 247). Yet, from this broad arena Gavanas (2002) believes there has been a:

> *"lack of recognition of men's unique and irreplaceable contributions as fathers"* (p.218)

This statement is supported by studies that reveal the ways in which some mothers perceive their husbands as less capable than themselves in matters relating to the home and child rearing (Kingston 2007, Pelchat et al 2003). As such, the difference between mothers and fathers in approaches towards their children and behaviours as 'parent' may be brought to light where:

> *"fathers need to be understood as gendered and as men"* (Hearn 2002 p.245)

The 'gendered' aspect of being a father has deep seated roots throughout history (as explored in the dedicated chapter) (Miller 2011). Given that the ability to care and nurture has continually been strongly linked to maternal practices, the art of 'mothering' implies risk in relation to perceived loss of masculinity (Gavanas 2002, Torr 2003, Doucet & Merla 2007). In this, Hearn (2002) reminds us that 'masculinity' has in the main been shaped by men, for men and moreover, by men who have enjoyed positions of privilege and power on behalf of those who have not. Assumptions based on the lifestyles, possibilities and perspectives of the elite class have thus appeared to set the criteria for 'correct' and appropriate behaviours for other fathers in very different and undoubtedly, more difficult circumstances. Lewis (2002) notices that men, particularly of the lower classes have thus constantly been reviewed as being:

> *"instinctively uncivilised and (...) family responsibility is the only thing that ties them into communal living"* (Lewis 2002 p.132 my brackets)

As such, 'manliness' has been associated with a notion of being 'naturally' distant from the family as well as being synonymous with responsibility in terms of 'financial provider'. As demonstrated earlier, the latter has been a virtually constant historical social expectation. However, it appears that the distance generated between fathers and their families is far from natural. This appears to have arisen from the social construction of a particular (eventually Protestant) work ethic as described for instance, via the ideology of Max Weber (Jones 2003, Craib 1997, Crandall 2000, Hochschild 1997). From the ancient philosophers devising men as 'strong' and 'able', through Dark Age 'carers' and 'educators', Middle Ages 'obedient out-workers' and later, 'respected tradesmen', to pre-modern era 'authoritative businessmen'; 'ways of being' for men have continually undergone development with 'work' as the obvious dominant guiding principle apart from during one noticeable period. The 'uncivilised' pagan era seemingly represents virtually the only time in history where male expectations appeared to follow the natural human activity of caring for and rearing children. It is perhaps unsurprising then that it is the Scandinavian ('original pagan') countries that have continued in this vein (Bergman & Hobson 2002, Race 2007).

The male 'work' legacy in the UK thus stretches in excess of a full millennium, with (as Hearn (2002) pointed out), the last two hundred years seemingly being especially patriarchal. Here, the age of enlightenment and industry was underpinned by systems associated with growth and subsequent expansion on a global scale: strong men were needed to fight wars and work in factories but moreover, produce healthy (white) children (Priestley 2003). The turn of the twentieth century bore witness to a fervent escalation in overt eugenic practices where Nazi Germany was eventually exposed as having taken extreme measures in this direction (Morris 1994b, Hubbard 2006, Synder & Mitchell 2006). However, following World War II, eugenic policies continued in the UK albeit in a more covert fashion through institutionalisation, sterilisation, abortion laws and more recently, through such things as the development of genetic testing and engineering (Oliver 1990, Hubbard 2006, Priestley 2003, Davis 2006b) (for more detail in the specific arena of 20$^{th}$ century eugenics please refer to Shakespeare 1998, Snyder & Mitchell 2006, Stone 2001). Throughout the 'modern' period, influenced by ardent scientific reason (which in turn, had continued to be influenced by classical Greek medical philosophy), men were broadcast as the unemotional sex and were encouraged to believe in themselves as defenders and overriding controllers of their families (Hearn 2002, Lewis 2002, Lupton & Butler 1997).

Whilst expectations to produce a 'healthy' baby remained (in tandem with the 'work ethic') an ever present guiding principle (and thus social pressure), the pattern of assumed masculine 'commanding behaviours' during the latter half of the twentieth century began to show signs of being destabilised (Miller 2011). In times of peace and low employment, male 'authority' and controlling influence was seen to diminish (Moss 1995). Moreover, the rise of second wave feminism in the1970s and 80s appeared to undermine men's confidence as fathers whereby a concurrent surge in accusations of male child abuse left men feeling extremely vulnerable (Hearn 2002, Torr 2003). As such, the social construction of masculinity and fatherhood is currently being perceived (and felt) to be undergoing a period of (global) flux where relatively new identities for men are being explored, described and 'roles' are taking shape (van Hove et al 2009, Hearn 2002, Ostner 2002, Knijn & Selten 2002, Lewis 2002, Combs-Orme & Renkert 2009, Torr 2003, Miller 2011). In this, Williams (2009) suggests that:

> *"mens' stories constantly challenge traditional forms of masculinity" (p.63)* whereby, *"stereotypical assumptions of rigid, unemotional, inexpressive men are inappropriate"* (p.69-70)

Robb (2004) and Gavanas (2002) also warn against treating all men as 'the same' and this is supported by Pelchat et al (2003) and Abril and Romero (2008) who assert that contemporary family roles are no longer gender specific. Yet, Henwood and Procter (2003) cite difficulties in not having a generalised ideal specifically targeted at men. They believe fathers require a sense of direction in understanding 'ways to be' suggesting that the prevailing variety of discourses surrounding fatherhood impose pressure on men to be 'a father' who, for instance: participates and is involved with his children, is a 'breadwinner' and, is an affectionate, supportive husband. The general understanding is that men are undergoing similar experiences to those of women entering the workforce in the late 1970's and early 1980's described by Hochschild (1989, cited by Walsh 1993) as developing 'superwoman syndrome' where mothers felt the burden of societal pressure to be able to 'do it all' (Torr 2003, Miller 2011).

Williams (2009) is clear that masculine 'direction' ought to emerge from gender emphasis disseminated via the public sector where he suggests proactive steps to encourage positive role models should take account of contradictory and changing forms. Abril and Romero (2008) believe responsibility lies with places of work where they suggest companies should:

> *"create a position on their organisational chart which deals exclusively with gender issues, conciliation and diversity from an overall perspective and not just focussed on women"* (p.13)

In addition, Torr (2003) believes the process should not be a one sided affair where, as primary carer for his children, he advocates that:

> *"within the construction of a framework of agreement and partnership that can bring about (such) positive outcomes, women can bring as much to the equation as men"* (p.11)

To this end, studies reveal that fathers who 'care and nurture' want to be understood and valued in that role and furthermore, are willing to work with mothers to find appropriate ways forward (Miller 2011).

Acknowledging these issues in Australia, Beatty and King (2008) have attempted to run sessions specifically for fathers by setting out trial workshops and activity groups with the aim of facilitating networks, giving opportunities to talk about their circumstances as well as spend time with their children. This brings into focus the apparent contrast in male and female behaviours in terms of 'networking' and forming groups (Phillipson et al 2002). Far from organising themselves, Beatty and King (2008) found that fathers needed much encouragement to attend their groups, although once they had, they happily returned. Fathers also enjoyed some pre-designed format or structure yet this only became successful when tailored to suit the individuality within the group. As such, fathers wanted to be recognised for 'fathering' in their own right and on their own terms thus, 'copying' the format of female driven clubs was clearly not the 'answer' (Gavanas 2002, Henwood & Procter 2003, Torr 2003). As Doucet and Merla (2007) implore, fathers are not surrogate or replacement mothers and do not wish to be treated as such.

*'Females'*:

The literature pertaining to being a mother is vast and copious, a historical trend that seemingly exploded in tandem with developments in the printing press: by the middle of the nineteenth century women were apparently inundated with advice and dictum (Lewis 2002). As was highlighted in the history chapter, mothers have been objectified and examined from various perspectives including those of the church, males, other women, medicine, philosophy and psychology with the underlying goal of generating 'healthy' babies and fostering appropriate behaviours towards them (Miller 2011, Silva 1996, Smart 1996, Goodley & Tregaskis 2006). Throughout history fathers have often been 'absent' and women have been expected to care for their infant alone, despite having to work themselves or live under significant financial duress (Matchinske 1998, Silva 1996). Wealthier women have adopted wet-nurses, paid for their child to be sent out to foster homes, employed educators and arranged social contacts to further their (and their husbands') business not least in relation to offspring marriage (Huneycutt 1999, Leyser 1995, Partner 1999, Fleming 2001, Forna 1998). Particular to this

endeavour has been the propensity for women (specifically) to behave as excellent networkers, mediators and diplomats, building on their (other) perceived matriarchal talents of being 'natural' confidantes, counsellors, advisors and organisers (Jochens 1999, Grundy 1999).

However, the literature of the past one hundred years tends *not* to perpetuate these characteristic details, almost being treated as taken-for-granted assumptions and, in similar ways to the early Greek and Roman civilisations, ignored in terms of talent, ability or perspicacity. In addition, feminist writing has all too often been wrapped up in exposing the oppressive treatment of women by men, their downtrodden roles as mothers and undervalued position as wife (Oakley 1979, Everingham & English 1979, Dally 1982, Everingham 1994, Rich 1986, Richardson 1993, Forna 1998, Silva 1996). Other literature, also collaborated by females (yet admittedly, mainly men) has taken an advisory perspective on biological matters pertaining to child birth, breastfeeding, child care and so on (Kingston 2007). There is little here to proclaim the positive traits and perspectives of mothers. In fact, during the period preceding the second world war women (in general) could be perceived as 'feckless' and despite managing through difficult times where men were viewed as 'hero' soldiers returning only to take control of the house (but not the work within or care of its occupants), mothers emerged in the 1950's with a (continued) reputation for needing expert help (Ong-Dean 2005, Lewis 2002, Lupton & Barclay 1997, Hearn 2002, Bonner 1998, Stadlen 2004).

According to Francis-Connolly (1998), this latter phenomenon was not a one sided development as 'experts' did not impose their information, research and advice on mothers; it was created (as today *and* in the distant past) via mutual understandings (Borsay 2005). Mothers (and fathers) look for 'correct' ways to behave, nervous of not being able to care for their baby properly and, in the case of a baby who has impairment the feelings may be all the more intense (Bonner 1998). Mothers may have informal knowledge through having and living with their baby yet, the tendency is to refer back to the 'expert' for advice, approval and guidance (Woodcock & Tregaskis 2008, Case 2001, Ong-Dean 2005, Vehkakoski 2007, Manthorpe et al 2003). The assumption here (in part based on my own experience) is not that mothers are mindless fools rather, it is that 'experts' are expected to *be* experts and thus to have the 'answers' (whatever they may be) (Lupton & Barclay 1997, Francis-Connolly 1998).

As such, it may be supposed that professionals have, in addition to a considerable wealth of literary information, encountered many other parents and babies with similar conditions (Bonner 1998). As a consequence, parents may feel that professionals are placed in a highly advantageous position where, through making helpful judgements, decisions regarding 'appropriate' ways to behave is enabled (Crown 2009, Kingston 2007).

However, difficulties with the parent/professional relationship is well documented in the literature with particular focus on such things as power imbalance, poor communication and lack of understanding (for further details on these issues, please refer to Deeley 2002, Swain & Walker 2003, Carpenter 2000, Todd 2003, Bruce & Schultz 2002, Bonner 1998, Neufeld et al 2008, Vehkakoski 2007, Manthorpe et al 2003, Hasnat & Graves 2000, Mitchell & Sloper 2003, Abberley 2004). The outcome has sometimes left parents feeling terribly deflated, their expectations of finding a much needed 'solution' may not have come into fruition, they may receive conflicting advice, they may not have felt their valuable insight as parent was recognised or they may 'simply' have felt they were not listened to, not least in cases where they felt there was no perceived problem (with for instance, 'adjustment') yet professionals assumed otherwise (Kingston 2007, Crown 2009, Bonner 1998, Sparks 2009, Ho & Keiley 2003). These frustrations are becoming more evident where mothers (and more recently, fathers) are able to report the ways in which they feel they 'know best'. As educated and experienced individuals, they feel they are (or have had to become) 'mini expert' in the 'field' of their child (Pelchat et al 2003, Kingston 2007, Perryman 2005, Levine 2009, Case 2001).

In light of recent evolution in 'partnership' practice, Race (2007) believes the notion of 'expert' is being *"significantly challenged"* (p. 229). Further evidence to support his remark appears where mothers have turned to each other for advice (Hornby 1992, Carpenter 2000, Kerr & MacKintosh 2000, Torr 2003, McConkey 2003). Considering the historical endeavour of females, perhaps not surprisingly over the last few decades, mothers have networked to create social forums where they are able to exchange information and advice on an informal basis (Stadlen 2004, Soloman et al 2001, Kingston 2007). As popular sites to reap mutual benefit (in terms of for example, sharing stories of daily experience, gaining a sense of belonging, framing the extent of

impairment etc) these 'opportunity groups' are more recently seeing a rise in attendance from fathers (Beatty & King 2008, Torr 2003).

Yet, despite the advantages associated with patronising clubs as a 'comfortable' social environment, they may also furnish parents with a sense of *discomfort*, not only through notions of stigma as mentioned earlier, but also via the impact of further conflicting social norms (Torr 2003, Gadamer 1971, Cioffi 2000). The prevailing 'way of being' is magnified through such groups where notions of the demanding (Aristotlean) concept of being a *'good parent'* exist (Henwood & Procter 2003, Lupton & Barclay 1997, Robb 2004, Pelchat et al 2003, Crown 2009).

*'Good Parenting'*:

The notion of what it means to be a 'good' parent is constantly evolving in tandem with changing identities, parental roles and general progress in expert knowledge, media propaganda and research in the field (Bonner 1998, Lupton & Barclay 1997, Combs-Orme & Renkert 2009, Torr 2003, Miller 2011, Silva 1996, Fairclough 2003). Perhaps one of the best people to describe current expectations of what it means to be a 'good parent' is one for whom the tasks involved are brought to consciousness by the difficulties she encounters in 'conformity'. Malacrida (2009) is a Canadian mother and researcher who has impairment and she has noticed that 'ideal mothering' involves being constantly available, active, expert, involved and *natural,* meaning all this should be performed in a seamless and devoted fashion. As such, many parents report a sense of taking second place to their child where they do not see themselves, or work, as a priority (Lupton & Barclay 1997, Henwood & Procter 2003, Williams 2009, Torr 2003, Shearn & Todd 2000). Moreover, specifically fathers often believe that taking a 'back seat' to the whole family in a supporting and helping role is the most appropriate way to parent (Kingston 2007). It is small wonder that 'stay at home' fathers may find this modern psychological concept to be incongruent with their physical status in the family (Doucet & Merla 2007).

Studies show that coupled parents find ways to jointly devise 'good' ways of parenting and as such, are perceived to be coming more interdependent where Golden (2001) suggests parents will look to each other as well as their own parents for guidance. To this end, research of the past decade has revealed the ways in which parents operate in

their roles and behave as a 'team' (Gardner & Harmon 2002, Henwood & Procter 2003, Towers 2009, Abril & Romero 2008). In this, it would appear that the 'trend' for parents' behaviour is gradually returning to ways that appeared to dominate prior to the modern era when the state least 'interfered' in private relationships. Supported by Gavanas (2002) and Kingston (2007), Pelchat et al (2003) revealed that 'team co-operation' is often overseen and thus organised by mothers who appear as 'head of house'. In taking this stance, mothers tend to discourage fathers from taking the care role, (perhaps pressured by their gendered expectations to care) whilst simultaneously encouraging their partner to go out to work (Torr 2003).

However, Pelchat et al (2003) also found that parents differ in respect to the ways in which they view their tasks: men speak about their role as being more involved, sharing care and contributing to child development (Williams 2009, Towers 2009, Beatty & King 2008, Torr 2003, Grant & Whittell 2000). Henwood and Procter (2003) propose this may be due to fathers (in general) wishing to adhere to the current discourse which indicates 'caring' is representative of the 'bigger' more 'macho' man. This suggestion is made alongside Gardner and Harmon's (2002) report that also reveals fathers may feel pressure through their 'innate desires' to create psychological space *away* from the family. In contrast, mothers report a sense of (Aristotlean) self-sacrifice with feelings of not doing enough or, being 'good enough' (Pelchat et al 2003, Kingston 2007, Stadlen 2004, Silva 1996, Shearn & Todd 2000). In turn, these collective behaviours may be interpreted by 'society at large' in ways that depict mothers as 'overprotective' whilst fathers might continue to resemble 'onlookers' (van Hove et al 2009).

**Society at large**

Parents may not only be wary of being watched and judged by others, some are also (painfully) aware that their child is under scrutiny too (Kingston 2007, Stadlen 2004, Canary 2008, Johnson 2000, Hugger 2009). As such, many parents report that making outings can be extremely difficult where they have found that other people stare at 'difference' and disapprove of 'bad' behaviours (Mason & Pavia 2006, Goodley 2009, Eisenhower et al 2005). The latter can prove to be especially difficult when the child does not appear to have impairment: blame is squarely positioned with poor parenting abilities where uninvited comments can be hurtful (Kingston 2007, French 1994a,

Goodley 2009, Rothman 2010). For some, negative attitude becomes a reciprocal affair, where through no longer feeling understood 'everybody' from the 'outside world' appears as an enemy (Hornby 1992). As a consequence, some parents find social interaction in terms of enjoying and maintaining relationships particularly problematic (Mason & Pavia 2006, Ray 2003, Loprest & Davidoff 2004).

This difficulty is often reported with particular focus on the workplace where attitudes of others can appear to be a distillation of those found in society at large (Golden 2001, Bergman & Hobson 2002, Torr 2003). According to Williams (2009) being in work represents a social life, income, friendship and different degrees of stimulation where Henwood and Procter (2003) add that for some fathers, their changed status can have pleasant consequences. The past forty years has witnessed greater female participation in the UK work force, including an increased involvement in careers traditionally associated with men (Silva 1996, Shearn & Todd 2000). Concurrently, job roles have become more flexible where many centres of employment are able to facilitate parents' 'needs' (Golden 2001, Miller 2011). In this, employment law with respect to parental leave and time off has evolved in line with equal opportunity rights and these developments have ostensibly followed policies devised in Scandinavian countries that appear to lead in this field (Hobson & Morgan 2002, Bergman & Hobson 2002, Eriksen 2003, Race 2007, Miller 2011). Yet, there remain certain work roles in the UK which seem unable to accommodate revised 'ways of being' where such things as client responsibility in law firms is perceived to *always* take priority over home life (Golden 2001).

As such, this particular attitude appears to dominate the wider working sphere whereby parents feel the considerable:

> *"weight of social scrutiny and the pressure to be earning"*
> (Doucet & Merla 2007 p.463)

This phenomenon brings about a number of issues:
   i)   Parents may feel stressed through reorganising home life around work and struggling to maintain a happy medium (Fisher 2001, Williams 2009, Towers 2009, Ricci & Hodapp 2003, Abril & Romero 2008, Shearn & Todd 2000)

ii) Parents may suffer the indignity of being perceived in a poor light by co-workers if they take time off (Bergman & Hobson 2002, Abril & Romero 2008)

iii) Parents may be anxious to be 'at home' at a perceived time of crisis whilst receiving little advice in respect of their rights to take time off (Towers 2009, Pelchat et al 2003, Henwood & Procter 2003)

iv) Fathers may be entitled to paternity leave yet feel they cannot afford to take the time off (Miller 2011)

v) Mothers are less likely to be in paid employment where, for single mothers opportunities to work can be especially rare (Barnes et al 1999, Dowling & Dolan 2001, Lewis 2002, Levine 2009, Shearn & Todd 2000)

vi) Parents may be perceived to be a drain on society if not in work at all (Lewis 2002, Levine 2009, Loprest & Davidoff 2004)

And:

vii) Doucet & Merla (2007) suggest that for many fathers:

> "*investment in paid work is still considered an essential component of masculine conceptions of identity*" (p.463)

To this end, work may play a vital role in the lives of many parents' experiences where if it becomes impossible or opportunities fail to be flexible, other pressures may stem from being denied financial resources (Esdaile & Greenwood 2003, Lewis 2002, Silva 1996). Disability has for a long time been associated with the poor and the poor have, for an even longer time, been associated with scrounging and charity (Stiker 1997, Borsay 2005 and see chapter one). Welfare benefits are 'doled out' to those in need, where there is little distinction between the 'deserving' and the 'non-deserving', in spite of attempts made over centuries to somehow separate the two (Digby 1996, Neugebauer 1996). Despite disability related payments being processed alongside old age and war pensions, (to which contributions have been made, hence their elevated status) they continue to be disparagingly perceived.

In the search for alternative, perhaps more appropriate structures, Eriksen (2003) makes a useful appraisal of the Norwegian 'care wage', a system that compensates parents for staying at home to look after their disabled child. His critique centres on the

fact that the 'wage' is not comparable to a working salary and as a consequence, belittles the 'service' parents carry out. It leaves little room for autonomy, whilst removing much responsibility from the local authority and the state. The equivalent payment in the UK is the 'carer's allowance', legislated through the Carers and Disabled Children Act (2000), with recent amendments in relation to 'rights' endorsed through the Equality Act (2010). The UK benefit does not equate to the 'minimum wage' although recipients are permitted to supplement the amount by also taking on part time work. Unlike Norway, the payment was not introduced specifically for parents of disabled children; anyone can collect it as an incentive to support individuals, including the elderly for instance, in their own home. In addition, the UK 'care allowance' is not relevant to the amount or type of 'additional care' required and is thus collected (monthly) at a fixed rate.

In contrast to the UK and Norway, the Danes calculate their payments by means testing which ensures that parents' potential loss of income through caring for their disabled child is supplemented accordingly. Eriksen (2003) argues this is a much fairer approach given that the care role is usually associated with women and linking values to the work role (rather than the care role per se) encourages closure of the oppressive gender role divide. In turn, this highlights the extent to which the UK 'care allowance' remains strongly linked to gender: men struggle to get part-time work (as supplement), women have found it can be difficult to maintain or develop a career on a part-time basis and for some, the caring role often exceeds hours of full-time working (where even part-time can be exhausting) rendering other employment impossible and leaving the carer on a very low income (Shearn & Todd 2000). Bizarrely, (as I found to my cost), parents are not allowed to enter full-time education whilst collecting the allowance thus it discourages training for any return to other work. Not only does this imply a minimal likelihood of landing a skilled position in the workplace, it also suggests the care role is an expected permanent post. As such, the government message overall appears to be one of work and contribution, with disability as 'burden' rather than shared family and state responsibility (Ray 2003, Eriksen 2003, Torr 2003).

However, the question of the role of state welfare is rarely debated with regard to re-centring aims to focus upon *family wellbeing* as opposed to being tied to the general devaluing work ethic or associated with notions of charity (Desai 2000, Ray 2003,

Davis 1994). As it stands, parents appear to have to learn ways in which they can 'work the system' in order to maintain a sense of control, purpose, dignity, and self esteem (Mason & Pavia 2006). In response to this and possibly encouraged to some extent by the increasing numbers of male primary carers who remain at home, over recent years there have been calls to recognise the very difficult and often complicated tasks that being a parent entails (Doucet & Merla 2007, Kingston 2007). This issue returns the discussion surrounding the relationship between society and the individual firmly back to the position of 'self'. The individual endeavour appears to be one that involves carefully treading through life in order to find appropriate paths and satisfactory outcomes, ultimately hoping to (re)grasp a sense of what it means to be 'normal'.

**Conclusion**

In this chapter I have ventured to explore the notion that parents, as 'ordinary' individuals undergo a barrage of 'processes' when they experience the unexpected event of having a baby described as having a learning difficulty. I have thus endeavoured to examine 'cause' of emotional upset taking focus away from the infant per se where I have argued that experience begins with an upset of 'self' through which a surge in emotion may be brought about by inner passions and desires that are paradoxically stirred within the social context. Having briefly introduced the psychological aspects which facilitate understandings in relation to managing 'systems' of the 'self', I have questioned the dearth of literature that describes emotional experience and moreover, specifically objected to the use of bereavement assimilation to describe the ways parents may experience a changed and altered condition of 'self' when they have a baby with impairment. In light of parents' understandings extracted from the literature, I concluded that the 'borrowed' terminology of 'grief' was neither adequate nor appropriate in attempting to facilitate shared perspectives.

In view of parents' emotional expressions of desires to bond and share closeness with their baby, I briefly explored the notion of 'love' within experience which, it appears, other researchers rarely address. Following traditional avenues and avoiding concepts surrounding notions of 'devotion' and 'fondness', studies of the past have approached parents with ideas of categorising and classifying their feelings towards their baby in

terms of 'coping' and 'adapting'. Both of these, by definition, have negative connotations and I believe this research 'attitude' perpetuates the pessimism surrounding parental experience and, it implies that parents may not love their baby.

Having considered the ways in which parents experience multi-dimensional emotions and the difficulties of conveying related meaningful understandings, I argued that individuals undergoing an unexpected event attempt to regain certainty and stability through developing a sense of 'normality'. This 'self management' enterprise (as described by Bardill 2000) can be perceived to be ostensibly underpinned by emotional drive whereby it includes such things as: 'feeling normal' (controlling emotion), being perceived as 'normal' (desires to belong, disassociate) and accepting what is 'normal' (making moral judgements and valuing others). I hoped to show that for parents, this process may be a struggle in terms of traditional understandings of 'normalisation' where reference groups and activities, as defined by an unimpaired population, seem hardly appropriate or adequate.

In this, I wanted to demonstrate that much of experience appears to become a mediation of 'normality' through the antonymous relationship between 'self' and 'society', where finding 'normal values' places parents (as individuals) at the 'interface' of society. In turn, this activity appeared to present parents with a sense of living among two separate worlds, where both seem 'normal' yet both present different 'ways of being'. From this, I explained how this concept may relate to a renewed sense of identity: being perceived by others in association with the whole family and, the negative labels that society appears to constantly attach to the notion of Disability in obvious as well as subliminal ways. In turn, I understood this dilemma to be directly related to the ways in which parents become aware of experiencing feelings associated with marginalisation whilst they are *also* conscious they may be a focal point of attention.

As such, I highlighted the ways in which parents may also undergo relentless pressure presented by society in terms of conforming to expected 'ways of being'. These were shown to possibly result in enforced behaviours that bore relevance to marital status as well as biological sex. I therefore considered gender issues to assume a large influential position in parental experiences and I explored these under the specific

sections entitled 'males' and 'females'. I discussed men in terms of being not only controlled by the state, but also in the context of historical legacies surrounding the 'work ethic' and eugenic practices. I argued that whilst the custom of producing a 'normal' baby remains prevalent amongst western societies, a global change of perceived male role as 'father' appears to have been underway in recent years whereby it continues in flux. I thus drew attention to fathers that are currently voicing the ways in which they would prefer to be perceived as appreciated and valued for their own contributions to parenting, rather than as 'other mothers'.

In light of the volume of research that has already focussed on mothers in the past, I questioned the absence of much heralding of the specific and extraordinary behaviours mothers can be found to have engaged with throughout history (chapter one). I placed this in the context of relationships with professionals, hoping to shed light on the delicate issues of interplay there and also upon the ways mothers have emerged as finding their 'own way'. In social groups designed to foster a sense of belonging, shared knowledge and wellbeing I also highlighted the ways in which these may serve as forums to exchange notions of impairment hierarchy through comparison and the location of identity markers. In searching for 'normality', this aspect of the process brought attention to the belief that 'good' parenting exists.

In turn, I shed light upon the contemporary ways in which parents understand 'good' (normal) parenting behaviours which included prioritising their child. In this, fathers perceive their position to be of *least* importance in the whole family which seems incongruent with being part of a growing body of 'stay at home' primary care-giving fathers. I also described notions of 'good' parenting as being developed primarily through maternal organisation, although fathers did not appear to be aware of, or perturbed by, this possible imbalance of 'team working'. However, these 'good' parenting behaviours could be seen to have external negative consequences in relation to the ways 'mothers' and 'fathers' may be perceived by society overall.

This led to a final exploration of experience pertaining to the work place where, as a concentrate of society per se, I was able to identify generalised attitudes towards parents and associated issues relating to Disability. In describing the ways in which parents may experience a sense of exclusion and difference through working and non-

working practices, I hope to have shown the difficulties parents may undergo in attempting to recover from their position of feeling abnormal. I thus ended the chapter as it began: at the level of the individual parent who aspires to meet the demands on 'self' as imprinted and imposed through being-in-the-world and thus, their understandings of what it means for them to be 'normal'.

Having explored parental experiences from current literature, historical and theoretical perspectives guided by the empirical data that emerged from participants taking part in this study, I now follow with a closer examination of the actual research work I performed in the field. Chapter three thus goes on to describe methodological practices, ethical understandings and the physical methods that I adopted in order to generate the interpreted accounts of modern experience that have informed the thesis so far.

# CHAPTER THREE

# <u>METHODOLOGY, ETHICS and METHODS</u>

**Introduction**

The purpose of this chapter is to discuss methodological assumptions in relation to this research whereby, the complicated process of transferring interpretative paradigm theory into formulaic institutional frameworks provides a platform. In this, I explicate my experience of putting forward a proposal in this vein and the subsequent difficulties I encountered where misunderstandings of research terms amongst members of research ethics committees led to a long and drawn out process. Given the confusion borne out of 'scientific' expectations of such committees, I continue with a detailed exploration of 'ethics' including critique of relevant ethical codes and governance to which this research must adhere. In a bid to expose the on-going 'divide' in research circles I draw attention to customary research design principles that are significant to this study. As such, I examine the ways in which 'scientific' terminology has been assimilated into other qualitative styles of research to detrimental effect. I argue that sharing terminology with assigned inappropriate meanings has contributed to confusion and disguised the 'ethical problem'.

In particular, this enterprise highlights the struggle of not only attempting interpretative research in a positivistic field but also and most importantly, the *everyday* experiences of being a parent. The attitudes and assumptions that present through encounters with other people who themselves have little or no experience are exposed via the impositions and standardised responses to my research. As such, I understand my experience here as adding further important dimensions to the research findings and as a consequence, I feel this detailed explication is both significant and relevant to the overall research endeavour.

In clarifying the issues throughout this chapter I also hope to explicitly convey my 'phenomenological attitude' (Sokolowski 2000) and ways of working in terms of the actions I have taken as well as through the words I have written. The final section of this chapter is devoted to the methods I adopted and as such, is specifically designed to demonstrate the physical experience of conducting the study and in particular, the

analysis. I have attempted to be as explicit as possible understanding that it is often through taken for granted assumptions relating to research behaviours that the reality of creativity and process can appear to be lacking in the finished piece. As such, I have chosen salient examples from the work to illustrate and have included further supporting data in the appendices (4-12 pp.317-353). It is hoped overall that the level of detail and thoroughness will aid reader understanding of the way I have conducted the research and most importantly, the interpreted accounts of participant experience.

## **'METHODOLOGY'**

Having established the 'legitimacy' of adopting the critical hermeneutic phenomenological framework in the work preceding this (Wright 2006), I was immediately faced with a secondary dilemma: explaining a 'methodology'. My understanding of this term is as Wolcott (2001) suggests that:

> *"methodology refers to underlying principles of inquiry rather than to specific techniques"* (p.93)

As such, the methodological route to my chosen way of working *is* phenomenological theory. In other words, the theory presents 'ways of doing': the thinking, the approach and the 'carrying out' is all in the proposed 'phenomenological attitude' (Solokowski 2000, van Manen 1990, Wright 2006). As I mentioned in the introduction, Emilio Betti (1972) had realised that for some scholars this may be somewhat daunting and he laid out a number of canons which represent a (very useful) 'rule book' of terminology and 'ways of thinking' common to most phenomenological thinkers. This helps immediate understanding of the ways in which for instance, the 'object' and 'subject' are included in the research project whereby, once the terminology is oriented, the rest is a matter of personal endeavour (Larkin 2006). The advantage is clear: the researcher is afforded the 'freedom' to explore, investigate, examine and inspect, read copiously, gather data and information in order to substantiate the 'target area', formulate ideas and understandings and thus, develop a knowledge base of 'what happened' (Gadamer 1976). It is intended as a flexible, passionate, expansive experience that appears intrinsic and introvert yet involves engaging with social discourse and societal structures. As a long-established form of philosophical occupation, Billig (1988) advocates:

> *"the approach of the traditional scholar can be considered anti-methodological, in that hunches and specialist knowledge are more important than formally defined procedures"* (p13)

The 'way of doing' is therefore an 'open route' and not prescriptive (Standish 2001, Watson & Girard 2004). Research work of this nature is liberating and incisive yet, it is frowned upon by the research fraternity who ascribe to notions that 'proper', 'right' and seemingly 'only' ways of conducting study exist and this is where my dilemma originates:

> *"Methodology, in short, (...) implies a concern, an overall strategy of constructing specific types of knowledge and is justified by a variety of metatheoretical assumptions. Methodology is thus inevitably prescriptive because it attempts to legitimate the use of particular methods in ways that are consistent with the development of the specific theory in question"* (Morrow & Brown 1994 p.36 my brackets)

As a consequence, I have made attempts to be 'prescriptive' to satisfy my superiors, the university, the funding body and the research site. Unsurprisingly, as a consequence of formally deciding the ways in which the work was to be carried out long before the 'doing', the proposed work not only stifled what might have been but also, became removed from what actually happened (Standish 2001). I realise that in just admitting this much, I am running the risk of being judged as a 'poor researcher' (at best). However, I want to argue that I am not an anarchist and I have not flouted my responsibilities as researcher (Feyeraband 1975). On the contrary, I would like to think that more than most researchers I have given the particular issues pertaining to 'methodology' a great deal of consideration.

Given that the perspectives in relation to the critical hermeneutic phenomenological theory and thus, methodological driving force of this research were explicated in my Masters degree (Wright 2006), I intend to use this space to explain myself and thus 'what happened' in relation to my 'strategic methodology'. In so doing, I hope to enlighten the reader to the trials of doing exploratory research, to the entanglement of methodology with ethical behaviours and the subsequent struggle to keep within stringent scientific 'ethical' guidelines that bear little resemblance to this type of work

(Gadamer 1971). Moreover, I expect illumination of the overall endeavour to poignantly provide a window exposing a particular context of 'lived reality' for parents who regularly face challenges in relation to being understood (Larkin 2006).

*The original plan*:

Once I had conducted my pilot study (Wright 2006), I was sure of the ways in which I ought to proceed: I had spoken to one mother, in depth, through an unstructured 'conversational' style interview and developed a phenomenological way of analysing the data by drawing upon theory and combining ideas from the literature, (none of which alone appeared to satisfy my aims of research). From these beginnings, I made slight alterations to the design for instance; I had asked four predetermined questions of the research which were:

1. *'What was your life like before your baby arrived?'*
2. *'What was your life like when your baby arrived?'*
3. *'What is your life like now?'*
4. *'What are your thoughts about the future?'* (Wright 2006 p.31)

It was clear that even these 'open ended' questions were too prescriptive. The participant did not see her life in chunks of 'before', 'during' and 'after', she was living the experience 'all at once' and in the telling Emma was naturally fleeting, disorganised and oscillating her way through the 'stories' of her life. The lesson learned came in realising that I could ask the questions of the *text* once the interview had been transcribed but moreover, I recognised I could ask the text virtually anything I chose (Ricoeur 1973). For the research to be truly 'exploratory', the predetermined questions needed to be dropped.

On reflection, from the investigations I had done in order to understand 'phenomenology', I realised before I embarked on the pilot study that I did not need any predetermined research questions yet, as a student, for some reason, I absolutely felt they were necessary. I am still unclear as to where this 'invisible' pressure came from, the sub-conscious, my lack of interview experience and related low confidence, the submissiveness and/or, the blatant instruction. I just *knew* I 'had' to do a literature review, a section on 'aims and objectives', state the 'research questions', explain the underlying theory, and reveal the methods and so on (Wolcott 2001, Creswell 2003). These so called 'traditional' formats are found everywhere in the literature, replicated

in the 'how to' books and encouraged (vehemently) by the university who (helpfully) have guidelines for such matters (Glatthorn & Joyner 2005, Marshall & Green 2007, Hart 1998, Punch 2000). Only having completed my work did I realise these were conventional forms of doing research where mine was traditional enquiry in the pursuit of philosophical reasoning (Billig 1988, Habermas 1970). What I was being asked to do was to somehow adhere to notions borne of two hundred year old scientific investigation that have somehow 'piggy-backed' into educational and social research fields, not to be shaken off lightly (Gadamer 1971).

In a bid to understand the significance of this eventuality more fully, in phenomenological 'style', I shall digress here slightly for one moment. The embedded reasoning that underpins modes of current scientific enquiry appears to be traceable to the moral philosophy of the infamous Greek scholar, Plato (Aita & Richer 2005, Brinkman & Kvale 2005, Mattingly 2005). Plato believed the natural world and human behaviour could be tamed and thus controlled through persons adopting a standardised set of rules based on practical reasoning and a priori principles. As such, Plato described knowledge as 'justifiable true belief' and in their hunger to obtain this 'truth', scientists of later centuries developed rules of conduct corresponding to model and process. Their goal was to enable replication which in turn, was believed to substantiate and 'validate' findings (Oppenheim 1992). A key concept pertaining to this endeavour was initially introduced by French philosopher, Rene Descartes (1596–1650) and was subsequently compounded by Wilhelm Dilthey (1833–1911) (Ricoeur 1973). Their notion of remaining 'objective' was based on the understanding that the investigator could 'corrupt' the natural phenomena with bias and prejudice and this was to be unconditionally avoided (Angen 2000).

Adherence to the 'rules' of science meant that knowledge could be treated as 'reliable' and in turn, this appeared to give rise to possible agreement on what constituted 'fact' and 'reality'. These methods were encouraged and endorsed by European scientific academies and the crucial purpose of these establishments was to create a forum that could authenticate and verify findings. Thus, methods in research were confirmed by consensus of opinion coming from a respected body of people, which naturally put the scientific field into a position of power and authority regarding the 'correct' behaviour and approaches to research (Angen 2000, Vessuri 2002). Such has been the gravity of

this 'methodology' those who have sought to embark upon any research over the past two centuries have aspired to 'answer' to these claims for legitimacy (Ehrenreich & English 1979, Gadamer 1971). As a consequence, the goals of 'objectivity' and 'validity' appear to continue to dominate discourse as 'standard' practice in the aims of doing 'good' research (Lather 2004, Reed 2007, Brinkmann & Kvale 2005).

Despite years throughout which qualitative enquiry has gathered pace and volume, I have been naïve in thinking there might be a greater understanding in the new millennium for the 'broader approach' and unfortunately, I feel I have been proved wrong. The following explication of my experience reveals the institutional level of adherence to the scientific endeavour as described above, wherein the humanistic element and in particular, parental understanding appear to be overshadowed by formulaic and standardised practices.

As an Economic and Social Research Council (ESRC) funded project, my original proposal included an MSc year long study and subsequent three year doctoral degree. The content of the proposal was based upon the likelihood of changes being required for the second phase and thus return for specific ESRC approval was not required. However, the renewal did entail submitting a revised proposal to the School of Education (University of Manchester) and, given the work was to be carried out on a National Health Service (NHS) hospital trust site, NHS Research Ethics Committee (REC) approval was also required (Mattingly 2005). For those unfamiliar with this process, the university central research office (URO) is obliged to 'sign off' the extremely lengthy NHS REC proposal application (a forty one pages, 110 questions document), verifying rigour and suitable methodological and ethical intentions in order to officially support the application as sponsor and insurer.

In brief, the application requested the research proposal be submitted in minutia detail and was to be accompanied by any actual paperwork: visual aids, letters, posters or other intended materials that would be used in the research process. Collating and designing this data prior to establishing agreed ways of working with my new contacts at the hospital's child development unit (CDU) led to a forced progression in the relationship where, although warmly welcomed by the team, I initially felt a little intrusive. That aside, once we had devised an agreeable format, I was able to attach: a

(URO led) invitation to take part in the research (cold and uninviting); a (CDU led, but URO amended) information sheet (8 pages long detailing for participants the anticipated format as well as 'answers' to expected possible questions and contact addresses for guidance and advice in taking part) and a standardised (prescriptive) university consent form (please see appendices 2 & 3, p. 315 & 316). This left no room for amendment, what was submitted was to be used and thus, to comply with regulations, before the process had begun, I had to know *exactly* what I was doing and what I wanted to say to participants (Stevenson & Beech 1998, Richardson & McMullan 2007, Truman 2003). For example, the first six questions on the form covered formalities (name, address, research title etc), thereafter, the (many inappropriate) questions began:

**Part A – Section 1**
**A7. What is the principal research question/objective?**
*(Must be in a language comprehensible to a lay person.)*
**A8. What are the secondary research questions/objectives?**
*(If applicable, must be in language comprehensible to a lay person.)*
**A9. What is the scientific justification for the research? What is the background? Why is this an area of importance?**
*(Must be in language comprehensible to a lay person.)*
**A10−1. Give a full summary of the purpose, design and methodology of the planned research, including a brief explanation of the theoretical framework that informs it. It should be clear exactly what will happen to the research participant, how many times and in what order.**
*This section must be completed in language comprehensible to the lay person. It must also be self−standing as it will be replicated in any applications for site−specific assessment on the site−Specific Information Form. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Once I had worked through the form (with my supervisor at the time) it was passed to the university research office (URO) and after several months and several requested amendments (some of which were over the same points yet with a different URO advisor), the form was submitted to the NHS REC. The revisions had restricted the research to certain boundaries that were seen to reduce perceived 'risk' and the proposed study was 'squeezed' so that it fell in line with university research protocol and expected requirements of the NHS REC resembling a proverbial square peg in a round hole (Richardson & McMullan 2007, Reed 2007, Dingwall 2006). In this, for instance, I had to delete my declaration of the ways in which I felt the research participants might benefit from taking part (a request via question A18) and I could not use definitive terminology ('*will*') as I could not know. The latter was an embarrassing mistake I had made in use of language, although I felt it happened as I was obediently

following 'direction' through the questions on the form (for example, see question A10-1 above) (Stevenson & Beech 1998). Although the title remained, rather than an 'exploration', the study had become a tight research agenda that had to adhere to some inappropriate rules (Truman 2003, Reed 2007).

The proposal had begun with an aim to interview a maximum of twelve mothers (this number to 'satisfy' expected numbers for a PhD thesis) of babies under six months old, intending to visit each a number of times over a period of one year. Each interview was to be for a duration dictated by the mothers, at a time and place designated by them. It was originally designed with disability research theory as a core methodological approach in specific relation to the 'interview' element which included: facilitation of working towards a 'partnership' style of research, reducing the power imbalance of the researcher/participant and, as busy mothers giving them autonomy to decide for themselves what might be appropriate for them (Hallowell & Lawton 2006). In addition, as I am a mother myself, the open interview style was to foster a 'shared' and empathetic approach to knowledge and experience (Keen 2006, Eide & Kahn 2008, Rudnick 2001, Watermeyer & Swartz 2008). I had also anticipated that I might engage in focus group work towards the end of the study and as a consequence, I included provisions for this eventuality.

Although three other hospitals had eagerly responded when I initially and informally (through direct visit) requested 'access' to participant mothers, I felt that adding multiple sites to the form appeared to make an already difficult job seemingly impossible (Saunders 2002, Dingwall 2006, Richardson & McMullan 2007). The complications were too great to overcome in a period of time that was already being ground away by the wheels of bureaucracy (Reed 2007). Under the circumstances I was obliged to politely turn the additional sites away once I had chosen the most enthusiastic where the consultant contact believed he knew of participants who would be willing to take part. In perceiving the site members to be research 'partners' I considered their keen attitude to be important. I was also fortunate in being able to choose this site as it happened to be the most local of the four and thus very convenient for developing regular face-to-face working relationships. Through the form filling process I established firm contacts at the site (CDU) and under discussion with those

people and my supervisor, having not engaged with the participants yet it was decided to continue the research proposal involving mothers only.

Under direct influence from the URO, the submitted NHS REC proposal suggested that:

- I was not to declare my position as 'mother' as this was viewed as coercive
- up to six mothers could be introduced to the research via my contact paediatric consultant; he could only give them the letter of invite and was not to discuss the research with participants
- mothers could be interviewed for no longer than two hours at a time
- interviews had to take place at the research site (CDU)
- a member of staff had to stand outside the designated interview room to provide: a) support for the participant if she got upset and/or b) support for me as 'lone' researcher
- interviews and analysis had to be performed under close supervision

The NHS REC who received my application (almost a year after starting to write it) invited me for interview by their local panel. This was comprised of eighteen people some of whom were 'lay persons' from the local community yet most were professionals with medical association or backgrounds. I was grilled for approximately half an hour during which time I was asked such questions as: 'why are you *not* revealing your status as mother?', 'how are you going to remain *objective*?' and 'why are you insisting on interviewing at the hospital?', 'can your supervisor sit in the interviews?' with further insistence that: I provide some evidence of ways in which the participants 'will' benefit from taking part (otherwise why bother doing the study?) and, I was to amend protocol to allow for the supervisor to not only help transcribe but also analyse the data. Dawson (2006) suggests the onus is with the researcher to communicate their plans to the REC yet I found this an intimidating experience where I felt I was defending myself rather than engaging in appropriate research debate. I was not expecting most of the questions as they had already been fully explained on the application form and in responding, I came to realise that I was not actually being heard by a number of ardent positivistic thinkers (Angen 2000). This was confirmed

when I later received written communication from the NHS REC requesting further clarification on the following points:

1. *To ensure validity of the study data, all interviews and focus groups with participants need to be closely supervised by someone who is trained to do this and is able to maintain objectivity. Please advise how this will be achieved.*
2. *The transcription and analysis of the taped interviews and focus groups needs to be carried out by an appropriate second person as well as by you.*
3. *The information sheets should say that the audiotapes will be destroyed at the end of the study.*
4. *Question A30 of the application form has not been answered; please advise which option you select as the answer to this question.*

Despite my own, my supervisor's and the URO's (two advisors) detailed and constant attention to the form, unbelievably a question appeared to have been overlooked. The application experience left me bewildered: many of the queries the NHS REC put forward contradicted points and amendments made by the university, some resonated with my original proposal and some went far beyond even the scope of expectations anticipated by the URO (Richardson & McMullan 2007). I came to understand that my original phenomenological theoretical strategy had been so twisted into another shape it was barely recognisable and thus, was no longer clear yet, the original proposal was not perceived by the URO as being suitable for the NHS REC (despite collaboration with NHS members at the CDU) and it was thus changed on the basis of others' assumptions (Stevenson & Beech 1998). What I came to realise was that the URO and NHS REC understandings of research behaviours were not in concordance and this also applied 'in-house' in the case of the URO (REF 2005, Hallowell & Lawton 2006, Aita & Richer 2005).

As a consequence, my (then) supervisor and I became submissive to the 'powers' in authority and agreed to the conditions and amended application in order to get on with the research (only insisting the supervisor would closely oversee the transcribing and analysis process, which on further application was granted as appropriate). At this juncture, whilst the 'paperwork' was completed the field work became problematic. It was a year on and circumstances had changed at the hospital. Colleagues of my contact consultant paediatrician had left during the year and the project became less prioritised

due to his additional and overbearing workload. He also had time off and recruitment of participants was not forthcoming over the first six months in the field, not surprisingly, the austere letter of invite alone (as per protocol) was not working (appendix 2 p.315) (Mattingly 2005, Truman 2003). The nurse manager with whom I had also developed a good relationship at the CDU offered to help recruit and her regular feedback was that mothers did not have time, she felt guilty asking them to participate (they came to the centre enough without having extra visits) and she too was working with a heavy case load with staff away.

In the meantime, through my participant from my Masters Degree, I was introduced to a new mother who was happy to take part in the research. I was excited given that it had taken over eighteen months to get to this stage however, the mother did not wish to be interviewed at the CDU (Mattingly 2005). I delayed meeting with her, hoping to get other 'official' recruits from the CDU although none came. Having had many discussions with my supervisors, it was decided I would take the 'risk' of interviewing the volunteer mother at her convenience, which meant at her home. Once there, the participant's husband asked if he could take part which, I am ashamed to say, really shocked me; on stereotypical grounds, I (and those helping to devise the research protocol) had not expected that fathers would want to take part (Williams 2009, van Hove et al 2009, Robb 2004).

After several supervisory meetings at the university and the hospital and over a further passing of six months where I had only interviewed the one 'non-recruited' mother, it was decided the CDU nurse manager could introduce me informally to mothers who attended a physiotherapy session. These were mothers of (approximately) twenty eight month old toddlers who ironically were the same mothers who the contact consultant felt may have taken part when their babies were younger at the start of the project. At the session, I met four of the mothers who, once I had chatted about the research were eager to take part although none of them agreed to be interviewed at the hospital. After more meetings and over further passing of time I eventually arranged to meet the ladies individually (at their convenience) at their houses where two more fathers came forward during my visits and requested to participate.

From these interviews, more volunteer parents came forward (friends of the mothers I had seen) and in the end, I interviewed eight mothers and four fathers once each (rather than six mothers, two or three times). The delays in making decisions to wait or 'veer' from protocol had meant over two years of the three year funded period were now complete. At this point the hospital site research office, where I was no longer working but was still registered, made a random selection to monitor my progress. I was delighted to show them my work: twelve transcripts of interactive interviews lasting between one and a half, to two hours each (Green et al 2005). I had dutifully destroyed the audiotapes and was in the process of 'anonymising' the data.

From this moment, the research was suspended pending an investigation into my study involving male participants, interviewing more than six people and interviewing 'off site' as these were not on the original NHS REC protocol (Truman 2003, Saunders 2002). I had been very careful to adhere to the National Research Ethics Service (NRES) guidelines in altering the format, for instance: I (and my supervisors) was clear that making the changes did not constitute a 'substantial amendment' requiring re-application for an altered design, whereby:

> "A substantial amendment is defined as an amendment to the terms of
> the application, or to the protocol or any other supporting documentation,
> that is likely to affect to a significant degree:
>
> 1.  the safety or physical or mental integrity of the subjects of the trial;
> 2.  the scientific value of the trial;
> 3.  the conduct or management of the trial; or
> 4.  the quality or safety of any investigational medicinal product used in
>     the trial".

**National Research Ethics Service Guidelines (2010) available at:**
http://www.nres.npsa.nhs.uk/applications/after-ethical-review/amendments/#amendmentsNonsubstantial

Despite being clinically oriented (for example, see points 2 & 4 and regular language use of 'trial'), overall, the NRES guidelines were extremely helpful yet, the institutions I was working with failed to acknowledge their existence and instead took extreme and heavy handed action. Regardless of my protestations that I had referred to protocol guidelines, I had made considered and supervised decisions ensuring that there was no 'wrong doing' and that I had not breached ethical conduct, a serious investigation went ahead through top university channels. Fortunately, after a lengthy process, I was able to demonstrate my honesty, trustworthiness, integrity and overall 'correctness of

conduct' in both my research activity and personal ability. Unfortunately, by the time I was able to continue, the funding period had lapsed, my experience of fighting my corner 'proving myself' (with much valued support from my supervisors and department) had left me feeling somewhat deflated and I was bitter and jaded from the process. However, inspired by supervisory advice, I chose to explore this avenue of my research experience to find that I am *not alone*.

Orb et al (2000), Boman and Jevne (2000) and Richardson and McMullan (2007) implore that 'research stories' like mine be told in order to expose the inadequacy, inappropriateness and often times, incompetency of research ethics committees. They suggest that reporting critical endeavours such as mine reveal a certain reality in the 'doing' of qualitative research that is otherwise glossed over and forgotten where the pitfalls continue for future unsuspecting researchers. As such, I do not wish to give an impression that I disagree with ethical guidelines per se, or that research should go unchecked. I *absolutely* believe that *all* research should be open to scrutiny and examination by others (Brinkmann & Kvale 2005, Dingwall 2006). The difficulty lies in who is 'marking' the work, authorising the design and exacting pre-organised procedures (Stevenson & Beech 1998, Dawson 2006, Mattingly 2005). If research is being carried out on a phenomenological basis surely, a team of phenomenologists (or at least those familiar with the work) would be best placed to 'judge' the integrity of the researcher and the quality of her engagement (Truman 2003, Angen 2000, Watson & Girard 2004).

As a consequence of this experience, I see how the problem for researchers is twofold: it is not only about having to foretell what will happen in absolute 'scientific' detail it also concerns being *forced* to stick to the plan (Standish 2001, Feyeraband 1975). There is an irony in systems that aim to uphold ethical rigour in 'common' research methodology that in so doing, ultimately encourages unethical behaviours and proposes unethical methods (Dingwall 2006). For example, to have not told my participants that I was a mother would have been to withhold important, relevant data and, to not agree to parents being interviewed at home would have been to deny *their* choice of comfortable, convenient venue (and time). These examples demonstrate that whilst the institutions claim to work on behalf of participants making their 'safeguarding' and 'interests' a priority, the participants' actual perspectives are often ignored (Orb et al 2001, Truman 2003, Hollway & Jefferson 2000).

These issues lead to serious questions about the integrity and value of the research project whereby I believe the hardwired strategy is secondary to these measures (Eide & Kahn 2008, Watson & Girard 2004). The difficulty in being asked to formulate 'strategies' as methodological plans is that what is in fact being asked for is the ethical insight of the research. Yet, despite being named 'research ethics committees', ethical matters are treated as rigid methods and in turn, the 'methodology' they are seeking no longer takes the form of Wolcott's *"underlying principles"* (2001 p.93). Changes to the format, for instance, interviewing twelve people once or six people twice is fairly straightforward until questions are introduced that imply it is more harmful to interview more people once than less people twice. This is further complicated when individuals come forward as volunteer participants having heard about the research from sources 'outside' the official process: should they be disqualified as inadequate subjects? The matter becomes subject to an agreed moral code, if indeed 'one' is possible (Ramcharan and Cutcliffe 2001, Gadamer 1971). In light of these understandings, the following section of this chapter moves from methodology as a research 'strategy' to methodology as an 'ethical endeavour' whereby I believe an examination of 'ethics' in more detail will offer a constructive beginning to understanding this concept.

## <u>ETHICS</u>

Biehl (2005) furnishes us with a useful description of what we might understand 'ethics' to be:

> *"An ethic is a way of living; a general manner, or mode of engagement with the world that finds its expression in our behaviour, our reactions, and in our deployment of evaluative language"* (p.355)

Aita and Richer (2005) cite Berg and Tranøy (1983 p.xiii) who state that ethics in specific relation to research are:

> *"the moral problems encountered in connection with scientific or other academic research, by the researcher, their subjects or their social environment"* (p.119)

In qualitative study, moral dilemmas are highlighted through the activity of (depth) investigation into individual and private lives and the subsequent exposure of these to a public arena (Brinkmann and Kvale 2005, Gubrium & Holstein 1997). As such, perhaps the most important aspect of any study involving people is to consider personal moral obligations and responsibilities corresponding to the ethical implications arising from the potential impact on others who take part (Richardson & McMullan 2007, Aita & Richer 2005, Dingwall 2006). In this respect, initial consideration of one's aims and intentions appear paramount. Putting aside for a moment the notion that actual behaviour may not equate to original intentions (for whatever reason), this initial process is not as straight forward as at first appears. At the outset, there has to be an assumption that one particular way of behaving will supersede all others and if not, uncertainty is assured. Moreover, if a 'correct' way can be identified, it may conflict with other seemingly 'right' options (Gadamer 1971). In this, *any* intended action is likely to present choices that offer alternative ways of doing and each of these is ultimately entrenched in moral principles (Aita & Richer 2005).

It is often noted that within qualitative research paradigms, moral dilemmas will occur seemingly 'out of nowhere'; they can be unforeseen and emergent given that one is operating in real life situations in the field (Reed 2007, Truman 2003, Boman & Jevne 2000). As Gubrium and Holstein (1997) point out:

> *"each ostensible step in the fieldwork process is not isolated, but
> is instead suffused with the prospective or retrospective relevance
> of other steps"* (p.111)

As such, any carefully drawn out plans and proposals for behaving in certain ways can become apparently irrelevant where acting in direct relation to the unfolding events appears most appropriate (Standish 2001). Truman (2003) recalls an example from her own research project where a participant suffered some psychological distress outside of the process. Following her initial designs, it was felt that the participant should withdraw from the study activities at least until he felt better yet this particular participant stressed that he would like to continue on the grounds that he felt taking part would aid his recovery. Truman's dilemma was that her research ethics protocol

excluded the service user from continuing yet, to have let him might have been more helpful to him personally.

In addition, the tension is raised when the research design or methodology cannot account for the ethical issues that it generates for example: the researcher may believe wholeheartedly (and thus will report) that she intends to behave (or has behaved) in a pleasant manner, respecting her participants where, in reality, she may not actually be perceived by participants in this way (Anastas 2004). This type of activity highlights the question of researcher personality as a matter of ethical interest and the onus being upon the researcher to find ways of behaving that suit the research endeavour (Dawson 2006). Orb et al. (2001) further this issue by outlining the importance of "*moral responsibility*" (p. 95) which to a large extent, is necessarily bestowed upon the chief investigator. They use the example of a novice researcher who witnessed bad practice and was unclear how to act because the particular incident was not mentioned in the given ethical guidelines. To this end, Ramcharan and Cutcliffe (2001) remind us that despite being well designed methodologically, not all projects will necessarily turn out to be of sound ethical value.

Thus far, it would appear that the question of 'predetermined ethics' through methodological processes cannot be met with a positive response. However, formal approaches to ethical debate offer 'structural' avenues through which individual researcher behaviours may be channelled to encourage 'standard' practice. I shall afford this brief consideration here as further insight may be gained.

*Formal structures in modern moral philosophy*:
Modern philosophy of moral behaviour tends to belong to one of three divided camps: 'deontological', 'consequential' and 'virtue' ethics. I shall attempt to outline the thought behind each by comparing one against the other.

Deontological ethics is based on Plato's form of practical reasoning, it centres entirely upon behavioural acts and unlike consequentialism the end result is not important: the means of doing justifies the ends. Deontologists such as German philosopher, Immanuel Kant (1724-1804) have argued that people should act (and *will* act) according to an inherent sense of duty and will respond to prescribed notions of what

is 'right' and 'wrong' (Aita & Richer 2005). Furthermore deontologists assume there can be a definitive 'correct' way of doing things and thus a moral absolute (maxim) must exist that can be universally applied. Brinkmann and Kvale (2005) use the infamous story of Plato and his mentor Socrates to demonstrate this point: Plato suggests that if an item has been borrowed, returning it to the rightful owner will *always* be the correct and therefore good thing to do. Socrates queries this thinking with a consequentialist perspective: 'what if the item is a weapon and if in the time you have borrowed it, the lender becomes psychologically unstable?'

Given dilemmas of this sort, Scottish philosopher Sir William David Ross (1877-1971) developed a number of principles by which people might judge a situation in *context* (Small 2001). His seven points of focus, which he termed 'prima facie' duties, included: 'beneficence', 'non-maleficence', 'justice', 'self-improvement', 'reparation', 'gratitude' and 'promise-keeping'. Ross argued that each duty should hold equal merit yet one can be used against or prioritised over another, dependent upon the situation (Small 2001). In weighing up circumstance in this way, deontological ethics can be confused with consequentialism, however, the focus remains with the moral action of the individual not what will occur as a result.

Conversely, in consequential ethics where only the outcome is important, immoral actions are permitted provided they justify a moral end (Armitage 2005). This philosophy is a little less straight forward than deontology as two branches have emerged. The first is utilitarian consequentialism where the moral worth of an action is decided by its overall contribution to 'usefulness'. Therefore, an action is 'right' if the greatest good for the greatest number of people is achieved. If this is not possible, negative utilitarianism may be applied by inflicting the least harm to the least number of people. The second branch is 'teleological consequentialism' where the *overall* 'goodness' of the resulting state of affairs is of primary importance. In this, a 'bad' action may achieve a good end however; if doing the bad act cultivates discomfort (such as lying) the resulting condition cannot be considered to be good *overall*. Given this reference to 'goodness', teleological consequentialism can be confused with 'virtue' ethics.

However, Brinkmann and Kvale (2005) suggest that 'virtue ethics' has little in common with consequentialism per se and even less with deontology as it works on the assumption that the character of the person acting determines whether the behaviour is 'good', 'bad', 'right' or 'wrong'. As such, the focus is centred upon the individual's sense of purpose and growth from experience as well as their emotional condition (Mattingly 2005). Virtue ethics thus supposes that every individual has an inherent sense of 'good will' and always intends to act well if only to satisfy themselves (Rudnick 2000). In this, behaviours are reliant on individual motivation which means that unlike deontological and consequential ethics, virtue ethics can propose no rules or universal principles.

The theory is open to criticism as the foundational aspect of 'virtue' is a socially constructed concept. Given that being virtuous differs between cultures and over time, definitions and understanding of the term must necessarily be determined and agreed prior to 'application' (Biehl 2005). As a consequence, research ethics committees seem to have taken the apparently pragmatic approaches of deontology and consequentialism, rigidly applying principles in the scientific tradition to form standardised 'codes of practice' (Armitage 2005). However, 'ignoring' the idea of virtue may have come as a result of the ways in which ethics governance initially transpired and given my experience as parent researcher in this specific arena, I feel this issue is of significance to my overall thesis.

*Research Governance*:

The first moral coding to appear in official documentation was the Nuremberg Code (1947) produced by the US in response to the exposure of Nazi experiments and War Crimes committed during World War II (Aita & Richer 2005, Dingwall 2006, Drake 1999, Mason 2001, Cohen 2000). As a current referential and globally adopted set of principles, I found a copy attached to US Department of Health and Human Services (DHHS) Office for Human Research Projects (OHRP) Institutional Review Board (IRB) Guidebook (second edition 1993) (US DHHS 1993a). It contains ten principles:

1. *Voluntary consent must be obtained from participants*
2. *Research must be to the overall good and not random*
3. *Animals or other means must be employed before humans*

4. *Physical & mental suffering must be avoided*
5. *Death and disabling injury is forbidden*
6. *The perceived risk must not outweigh the good humanitarian cause*
7. *There must be adequate preparation to avoid harm*
8. *Experiments must be carried out by skilled, qualified scientists*
9. *Participants must be given the right to not take part and the right to withdraw*
10. *If harm is evident the scientist must stop the procedure*

The document is scientifically oriented making the corresponding 'objective' stance 'official' whereby the character of the scientist is not questioned yet they are afforded a position of authority on the basis of having 'appropriate' *technical* skills (Eide & Kahn 2008). The code was clearly developed using deontological and consequential moral theory as 'duty bound ruling' and was not adjusted in any major way until the World Medical Assembly (WMA) devised the 'Declaration of Helsinki' (1964) (US DHHS 1993b, Cohen 2000). The amendments consisted of four additions which together with the original ten points, continue to inform UK legislation appearing in for instance, *'Governance Arrangements for Research Ethics Committees'* (DH 2009). The supplementary points present:

- The need to submit proposed methods to review panels
- The requirement to publish findings (unless principles are not followed correctly)
- The need to obtain <u>informed</u> consent
- The enforced production of a statement of ethical intentions

The language of the revised document maintained its strong scientific focus and perpetuated the notion of authority in research ethics as couched in the medical arena (Lantz 2000, Vessuri 2002). As such, the Declaration has been (voluntarily) adopted by institutions requiring ethical guidance, including educational and social academic fields that possibly feared their research might not prove 'acceptable' unless they complied (Orb et al 2001, Armitage 2005, Ehrenreich & English 1979).

Following a number of notorious research projects exposed in the US for example; The Willowbrook State School Study (1963-1966) and The Jewish Chronic Disease Hospital Study (1963) (cited by Aita & Richer 2005); The Tuskegee Syphillis Study

(1932-1972) (cited by Orb et al 2001) proved to be the catalyst that inspired an apparently altered course in devising ethical codes of practice. The common denominator to the highlighted cases had been lack of respect (to say the least) where the inhuman studies were performed on black, impaired and Jewish members of the population clearly under the assumption that the code of conduct was not felt to be relevant to these groups (Armitage 2005).

Under the influence of Civil Rights campaigns as well as the growth in behavioural sciences, the new US code was established under 'The Belmont Report: ethical principles and guidelines for the protection of human subjects of research' (1979) (US DHHS 1993c). It took a dialectic approach assuming;

> *"Broader ethical principles will provide a basis on which specific rules may be formulated, criticized and interpreted"* (DHHS 1993 p.1)

However, despite the 'open' approach, the report led to further complexities found in language use where distinctions and interpretations between non-scientific and scientific research were not identified (Stevenson & Beech 1998, Lantz 2000). In spite of making no reference to Ross' 'prima facie duties' (as before), the revised code of practice outlining three major benchmarks was remarkably similar (Small 2001):

1. *Respect for persons*: where the relevant 'application' outlined such things as 'informed consent', which in turn covered; information giving, participant comprehension and voluntariness.
2. *Beneficence*: an assessment of risk and benefit to the participants including matters related to anonymity and confidentiality
3. *Justice*: covering aspects in relation to the fairness of the study, for instance, the selection of subjects

Critique of this document has been levelled at the notion of 'protection' where, in a climate of rising consumerism, litigation and compensation, the protection intended for participants appeared to be a front for the real protection of the research fraternity (Lantz 2000, Reed 2007). Furthermore, the 'progress' continued to omit 'researcher character' and without this, it is difficult to see the ways in which the ethics of any research endeavour can begin to be predetermined (Eide & Kahn 2008, Small 2001).

Perhaps not surprisingly, many of the historical standard principles and expectations of ethical behaviour have been incorporated in obvious ways into contemporary guidance. However, when investigating the latter, I *was* surprised to find that high-end governance in theory is more accommodating of qualitative styles of research than I had experienced in practice.

*Current codes of practice relevant to my research*:
The institutions of the University of Manchester (sponsor), the ESRC (funding body) and NHS hospital (intended research site) are the authoritative bodies who must oversee my research. The university has a fundamental requirement to adhere to the 'Department of Health Research Governance Framework for Health and Social Care' (DH 2005) yet the ESRC (another government body) outlines particular principles in their own 'Research Ethics Framework' (ESRC 2005) which states:

> *"Social science is broad and varied, but often involves human beings. Other ethical frameworks for research on human subjects, such as that which addresses biomedical research, may not be appropriate, which is why a framework specific to social science is necessary"* (p.1)

This appears to be a refreshing and promising perspective and, not unlike other documents, the framework continues with some main principles, the first of which reads:

> "*research must be designed, reviewed and undertaken in a way that ensures its integrity and quality*" (ESRC 2005 p.23).

As such, the language of the tenets makes a welcome change to that of scientific enquiry replacing notions of 'validity' and 'reliability' with 'integrity' and 'quality'. The more relaxed genre appears to have been inspired by the Belmont Report (1979) where the points invite contextual discussion (US DHHS 1993c). Responsibility is afforded the researcher who, although advised to confer with their professional ruling body, is offered the suggestion that full ethics panel approval may not always be necessary:

> *"in the first instance, it is the responsibility of the researcher, or research team, guided by their professional standards, to decide*

> *whether a project is ethically sensitive and should be subject to either a 'light touch' review (...) or full REC approval"* (ESRC 2005 p.7)

However, the weakness in the ESRC framework comes from its lack of authority, referring the student back to the institution and so in the end, can only offer social and educational researchers like me, false hope. I *have* to refer to the university and in turn, they to the Department of Health.

The 'Research Governance Framework for Health and Social Care' (RGF) (second edition) (DH 2005) is supported by the 'Health & Social Care (Community Health and Standards) Act' (2003) and is therefore, not only a reference point but it constitutes the *pinnacle* of guidance. In spite of this (alarmingly), I could find no actual definition of 'ethics' on its pages. Under a section marked 'standards' (one of five parts), I found the familiar list of requirements almost replicating the 60 year old Nuremberg Code. I also noted similarities to the WMA (1964) amendments and reflections of Ross' duties previously incorporated into the Belmont Report (1979) (Small 2001, US DHHS 1993a/b/c). Although the RGF (DH 2005) recognises that principles may be applied in different ways depending on context, the language of the document continues to favour the scientific field where it suggests research must be of *"scientific quality"* (DH 2005 p.1).

However, I see no reason why this should not work in the qualitative researcher's *favour*. The fact that it offers flexibility and acknowledges research circumstances can be highly contextual does leave the content open to *any* (not just scientific) interpretation. This activity is the qualitative researchers' naturalistic endeavour and unfortunately, in approaching the 'scientific field' many appear to have assimilated their work to 'fit' the framework (Gadamer 1971). In so doing they have continued to utilise scientific phrases and terms to describe their behaviours, rather than remain faithful to their genre with appropriate terminology (Dawson 2006, Watson & Girard 2004). This is perhaps understandable as the RGF (DH 2005) advocates the development of a *"quality research culture"* (p.15) where the researcher must:

> *"demonstrate **adherence** to this framework"* (DH 2005 p.46 my emphasis)

In practice, I have found the 'researcher' is severely restricted from actually carrying out this task. The system affords many 'gate keepers' and thus, interpretations of the framework appear on many levels. As such, I was unable to have a 'direct relationship' with the RGF (DH 2005) having to be 'guided' instead by supervisory support, the URO, the NHS REC and thus a variety of medical and personal opinions most of which were primarily based on assumptions of what it means to do research from backgrounds entrenched in the 'scientific tradition' (Saunders 2002, Reed 2007, Mattingly 2005). Through this process, I therefore came to understand the 'scientific assimilation' may not come from qualitative researchers themselves but from the myriad of 'authoritative' voices who, through experience that is not necessarily in concord with the genre, make decisions about 'appropriate' research behaviours (Dingwall 2006, Gadamer 1971). To be asked how I aim to remain objective in my phenomenological research is to reveal this gargantuan institutional flaw (Ramcharan & Cutliffe 2001, Larkin 2006, Watson & Girard 2004).

Unfortunately, the anomalies are many and I am not alone in questioning the ethical principles behind a number of presupposed 'taken-for-granted' institutional research activities where Mattingly (2005) suggests:

> *"Addressing the principles and standards of ethics often opens up*
> *a can of worms for further ethical debate"* (2005 p.455)

I believe the 'can' should be opened and 'other' ways of doing quality research ought to be encouraged and upheld. Consequently, I have looked to the literature to seek out congruent support for my 'phenomenological attitude' which promotes an *interpretation* of the RGF (DH 2005) as opposed to mere 'assimilation' (Sokolowski 2000). As such, the following segment explicates some of the differences between assimilated 'scientific' qualitative study and the interpretative paradigm where the additional purpose of this exercise is to combat potential criticism which has been levelled at researchers who fail to expose the rigour in engagement with their phenomenological perspective (Maggs-Rapport 2000, Burke Drauker 1999, Watson & Girard 2004, Lopez & Willis 2004). As such, my aim in what follows is to make explicit my research principles that relate to the ways in which I have aspired to work on the practical research tasks. However, the primary rationale that motivates this

explication is to expose the ways in which the 'scientific' tenets sit uncomfortably with the participants themselves.

## Customary research design principles and practices

*'Truth' and 'Reliability'*

As previously discussed, in the scientific field it is assumed that trials and tests will produce definitive results where an ultimate response can be claimed as the 'truth' (Angen 2000). Oppenheim (1992) suggests that this 'truth' is couched in the validity of findings which in turn can be measured in terms of "*adequate reliability*" (p.159). This way of thinking is incongruent with interpretative paradigms where a fixed and finished 'reliable' product is not the aim as it can never be achieved (Geanellos 1998, Betti 1972, Billig 1988, Brinkmann & Kvale 2000, Watson & Girard 2004, Lindseth & Norberg 2004). In spite of this, Anastas (2006) (for instance) assimilates the notion of reliability (underpinning 'truth') into qualitative enquiry by suggesting the detailed explication of methods will allow others to repeat the study. Replication may be possible, yet, where human interaction is involved, no two results will be identical. Moreover, multiple repeats of the study are more likely to generate wider variety in the findings and this outcome is just as probable if the same person conducts the repeated research (Geanellos 1998, Betti 1972).

'Scientific reliability' also appears to have been considered possible in qualitative modes of research through methods such as 'triangulation' in the form of "*multiple sources of evidence*" (Yin 2003 p.48). Lee (1993) and Stake (1995) suggest family members, official reports and observations may ensure the data is 'reliable' and Miles and Huberman (1984) advise cross checking 'meanings' to enable 'consistency'. In effect, these authors encourage a sense of 'stability' relating to process to achieve 'uniformity' within the end product (Robson 2002). In contrast, as an interpretative researcher, I do not suppose that reliability is found within the process or the product per se, rather; it is located in the character and ability of the researcher in ways akin to 'virtue ethics' (Eide & Kahn 2008, Hollway & Jefferson 2000, Small 2001, Dingwall 2006, Richardson & McMullan 2007, Fleming et al 2003). In congruence, the RGF (DH 2005) advocates a *"quality research culture"* (p.15) that is facilitated by:

*"personal and scientific integrity"* (p.15).

My interpretation of this statement is that in the case of *non*-scientific research (as mine), 'integrity' is *entirely* personal. As such, I do not imagine my study to be forced to appear to *be* scientific and I do not perceive this 'ruling' as conflicting with my intended non-scientific way of working. Instead, I believe the onus is upon me to demonstrate my veracity and show myself as reliable and thus capable of carrying out quality interpretative research (as I managed to do under investigation and hope to continue to be doing here).

As such, I aim to convey my behaviour and approach to the work as that which is consistent and not the detailed content of the generated study data. Interpretative ways of working do not focus upon finding similarity amongst assigned meanings rather, 'meaning' is understood as being intrinsically linked to context and is thus personal and relative to time and space (Larkin 2006, Heidegger 1953). Furthermore and as explored in chapter two (theoretical perspectives) parents cannot (and do not wish to) be understood as single dimensional beings whose perspectives and emotions are 'fixed' or 'proven'. With this understanding, collecting and 'triangulating' data on the basis of providing 'evidence' or 'proof' to support the generated data also becomes irrelevant (Silverman 2001).

Instead, Billig (1988) implores that the carefully honed development of an extensive knowledge base gained through wide and copious reading is that which fosters 'reliability' in the researcher. To this end, the process is not 'triangulation' rather, it is the manufacture of a deeper and broader picture of the research situation (including researcher perspective) and therefore, *not* a more 'certain' one (Ritchie 2003, Gadamer 1965). As a consequence, a specific explication of 'other opinion', externally sourced supporting documentation and to some degree, a contained literature review are not helpful. In fact, the latter may even serve to be a stifling aspect to the study where the work aims to be a continuous expression of cultivated researcher knowledge (Billig 1988, Watson & Girard 2004).

I hope to have followed this way of thinking having (re)produced a variety of developed understandings that relate to the subject matter through examining

alternative routes for 'explanation' surrounding experience, delving into a range of academic disciplines other than my own and exploring avenues of relevant historical and contemporary information. I have aimed to demonstrate these activities throughout the thesis, rather than keep to a specific focus in one area. In addition, I follow other interpretative researchers who choose to expose their ways of working in detail, not to reveal a 'recipe' for others but with the aim of exhibiting researcher trustworthiness (Gubrium and Holstein 1997).

To this end, I have attempted to be as transparent as possible in presenting my work so that the reasoning I employ appears to the reader as both 'obvious' and traceable (Creswell 2003). For example, I have explicated the methods (shown later in this chapter) using a variety of charts and visual representations as well as verbatim passages with rich text in the findings in order to aid this process (White et al 2003, Smith et al 2009). In adopting this way of working, I aim to highlight the analysis as grounded in the data which in turn, is an important exposure given that other interpretations are always possible and I would like my 'conclusion' to be seen as at least plausible (Spencer et al 2003, Lindseth & Norberg 2004, van der Zalm & Bergum 2000). Showing my workings also reveals ways in which I have approached and dealt with the task of handling 'messy' data and in turn, this can be judged in terms of how I have attempted to remain faithful to the elected research paradigm (Creswell 2003, Watson & Girard 2004).

*'Validity'*

Given that 'validity' appears to be the ultimate goal of scientific enquiry where proven legitimacy and authority in the findings seems paramount, many authors from the qualitative field have assimilated this particular meaning into their work. For instance, validity is often proposed through claims of being 'accurate', having work 'authenticated' via peer review and in returning to members for 'precision checks' (Creswell 1998, Hallowell & Lawton 2006, Lee 1993, Miles & Huberman 1984, Stake 1995). Furthermore, as in the scientific arena, qualitative 'validity' is exposed as negotiated through 'internal' and 'external' means where it is assumed 'threats' to these, such as researcher bias, can be addressed and eliminated (Robson 2002, Gerring 2007, Yin 2003, Miles & Huberman 1984).

On the contrary, 'validity' cannot be accepted by the interpretative enquirer in authoritative terms (Silverman 2001). Peer reviews become irrelevant as it is unlikely they would share the depth of specialist knowledge and they are even less likely to have been involved in the particularity of the encounters with participants (Angen 2000). Problems can also be seen to arise from participants being unethically compromised through direct review of themselves as perceived by 'other' given that:

> *"People may seek to leave impressions that are favourable, those*
> *that match the people's view of themselves"* (Cioffi 2000 p.195)

As Merleau-Ponty implores, in the hermeneutic endeavour this 'view' is unlikely to be 'matched' (Moran 2000) which leads to an overall issue: peer *and* member checks in the form of perceived 'correctness' would not make sense in that all interpretations are individually generated (Betti 1972, Geanellos 1998). I therefore propose 'soundness' in the study is more likely to occur when it is carried out by a credible researcher (Silverman 2001). Again, this may be supported on the basis of demonstrated researcher knowledge in relation to the given topic and the surrounding issues (Lather 2004, Billig 1988) although it may also be attained, for instance, through *"substantive validation"* (Angen 2000 p.387) where:

> *"The term validation rather than validity is used deliberately to*
> *emphasize the way in which a judgment of the trustworthiness or*
> *goodness of a piece of research is a continuous process occurring*
> *within a community of researchers"* (Angen 2000 p.387)

In this, the researcher builds trust and respect from their peers through endeavours to continually demonstrate thoroughness as well as honesty in their work (Watson & Girard 2004). *"Honesty"* and *"openness"* are specifically listed as preferred 'quality research' traits in the RGF (DH 2005 p.15). However, in the creation of my proposal, I was deterred by the URO from remaining 'open' about my parental status where I was advised the ethic of coerciveness usurped this attribute. Although the RGF (DH 2005) does not refer to coercive behaviours per se this is an understandable important moral principle where clearly, the URO were working with the flexibility of the RGF:

> *"The same principles apply across health and social care research,*
> *but the way in which the relevant standards are achieved will differ*
> *according to the research type, context and method"* (DH 2005 p.2)

As the ruling body, the URO were able to assert their authority in deciding which 'ethic' took priority in this research however, I believe it is crucial that I make clear my personal preference which is to acknowledge 'honesty' before 'coerciveness'. I feel that in behaving honestly with respect and integrity, the researcher is less likely to manipulate the participants and more importantly, the participants (certainly in my situation) would be less likely to feel duped.

I thus hope to have also established 'credibility' through the open ways I have conducted myself during the research process. In addition to peers and participants, I mostly discussed each turn of my research endeavour with superiors on the basis of revealing perceived problems as well as finding solutions, clarifications and possible enlightenment. Apart from the practicality of this endeavour, I expected supervisors and seniors (from the university and research site) to gauge my activities and monitor my behaviours (Hollway & Jefferson 2000). As such, checks on my progress, ensuring comprehensive working and my continued respect for the participants were forms of appraisal consistent with the phenomenological approach (Watson & Girard 2004).

Throughout this unfolding process, I also gained a heightened awareness of the input of 'self' where Richardson & McMullan (2007) suggest:

> *"confronting ethical issues **is** a confrontation of self"* (p.1117 my emphasis)

This differs (for example) from Miles and Huberman's (1984) 'researcher effects' in terms of 'controlling bias' in that the researcher continually evaluates their own performance, understanding this to be intrinsic to the research outcome, not a measurable or correctable 'effect' (Etherington 2004, Small 2001, Fleming et al 2003, Betti 1972). The most transparent ways in which I conducted this self-assessment came through the analysis of the data where I made copious reflexive notes. Examples of these are exposed in correspondence with the findings (although placed in the appendix (6a-d pp.329-337)) where including all these would be ideal yet totally unrealistic. I have also attempted to include as much of my predetermined 'horizon' as is reasonable and practical throughout the body of this work which in turn, I hope

will give the reader some degree of clarity regarding 'my directive input' (Gadamer 1976).

*'Objectivity' and making judgements:*

I believe the idea of understanding another person's perspective begins with listening attentively to what they have to say whilst being as open minded as possible about their experience as 'other' (Heidegger 1953, Gadamer 1976, Smith et al 2009). If during this process I imagined the speaker to be a robot, emotionless and anodyne, I might reciprocate insensitively, show lack of compassion and appear to them as blunt. From this, I may possibly interpret and reveal their stories (if they agreed to tell them) as grey, inorganic experiences and; by adopting this research attitude, I believe I would be denying the individual their humanity and I would miss much of their perspective (Angen 2000). Conversely, if I understand the person to be human with feelings, sensitivity and passion, to then avoid, ignore or stifle their emotions would be for *me* to behave as automaton and again, I would remain disrespectful whilst also be denied an opportunity to better understand (Eide & Kahn 2008, Keen 2006, RGF 2005). In both cases, my work would not be representative of the quality I wish to achieve and furthermore, I believe I would be *failing myself* (Hollway & Jefferson 2000). As Angen implores:

> *"the move to detach oneself from the lived world through positivist objective practices is to shun our human moral responsibility"* (2000 p.389)

Although some previous research with parents appears to have been conducted within these underlying 'objective' parameters and I was encouraged through my protocol to behave likewise, I do not believe the practices (as described in the examples above) are even possible during human interaction. Both parties, whatever the relationship, are endowed with feelings, pre-understandings and they make judgements yet, researchers rarely reveal these processes (Donaldson & Prendergast 2011, Simon & Lively 2010). It is perhaps assumed that disclosure of this type is unimportant or 'judgements' are genuinely believed to have not occurred (as per my examples in the thesis introduction). However, *"accountability"* is listed in the RGF (DH 2005 p.15) as a further 'quality research' trait and given that the 'chief investigator' is:

> *"The person who takes overall responsibility for the design, conduct and reporting of a study"* (DH 2005 p.21)

I understand this to be inclusive of Angen's (2000) *'human moral responsibility'* whereby, 'accountability' of this type is primarily highlighted during the crucial moments of making judgements (Brinkmann & Kvale 2005, Mason 2001). As such, this activity is relevant throughout the research process, not just at the point of interview. As a continuous process, understanding how 'intrinsic' judgements are made as well as explicating this information sits in concord with the phenomenological (reflexive) endeavour (Betti 1972). As such, in my reflexive notes (appendix 6a-d pp.329-337) I have attempted to share some of the decision making that I carried out during analysis in order to reveal something of my particular style of 'thought processing' (Billig 1988, Fairclough 2003, Etherington 2004, Ezzy 2002).

*'Risk and Harm'*

Dictating a 'scientific' approach that demands a level of 'distanciation' is generally assimilated into qualitative research under the proposed ideal of avoiding upset and thus 'harm' (Ritchie 2003). Whilst I would never condone deliberately upsetting a participant, I would argue that deliberately avoiding potential upset (as per the 'objective' examples above) is entirely inappropriate and unnecessary. Furthermore, I believe the wording of the RGF (DH 2005) does not deter researchers from 'emotional' study rather; it appears to make allowances for my point of view. To further explain, the RGF states:

> *"The dignity, rights, safety and well-being of participants must be the primary consideration in any research study"* (p.7)

And it also acknowledges:

> *"Some research may involve an element of risk to those participating in it. If there are any risks to participants, the risks must be in proportion to the potential benefit. Risks, pain or discomfort must always be kept to a minimum, and explained clearly both to the relevant research ethics committee and to participants."* (DH 2005 p.8)

It is thus made clear that high regard for the participant should be the priority and in this, I believe the participants in this study should have been granted credibility for their *own* understandings of what it might mean for them to take part. Putting the notion of 'informed consent' to one side for a moment (to be dealt with shortly), the parents were being asked to talk about their experiences of 'being a parent'. I believe they knew what this entailed from the simplicity of the initial question and could therefore (superficially) decide whether they were prepared to disclose their related 'information'. Most parents realise that talking about difficult and emotional journeys involving their offspring is likely to invoke surges of relived upset whereby the majority of parents are passionate about their children (McGill Smith 1993, Kingston 2007, Read 2000, Canary 2008). Given this obvious sensitivity surrounding the subject matter, it is possible to interpret the RGF (DH 2005) as accommodating the eventuality of upset as an inevitable and acceptable 'element of risk'.

However, the directive of *telling* the parents they might get upset (as per protocol and RGF (DH 2005) guidance) suggests there was a possibility they could be unaware of being emotionally charged. Unsurprisingly, parents knew they would get upset and often laughing, apologised in advance and asked if *I* would mind. As such, it appeared they were able to readily determine the 'risk' as being in 'proportion' to the perceived 'benefit' (DH 2005). To this end, Hollway and Jefferson (2000) implore that further clarifications should be sought in relation to who is to decide potential 'risk' in specific relation to being upset. They reason that a third party cannot know more about the process of harm in this sense than the researcher and even more so, the participants and, certainly not enough to be able to decide that the situation *will* be harmful beforehand. Watermeyer and Swartz (2008) and Eide and Kahn (2008) support this latter view in proposing that the process of understanding upset, talking about what it means to cry and negotiating conversation describing difficult and painful events through tears can be a cathartic and thus, not harmful experience for the participant.

In this research, most participants did get upset and when (as per protocol) I asked if they would like to stop the interview they all said they wanted to continue with the recording. I did not leave parents until they had regained composure and I later contacted them to confirm their state of mind. I also took the opportunity to ask if they had any further questions or, if they had changed their mind about the recording in any

way. Due to the discussions held with the URO in building the protocol (that implied participants may reach an uncontrollable mental condition) I worried more about what the protocol had to say in terms of what might happen than in paying attention to how the parents actually were; none requested that I withdraw their story and all were perfectly fine.

As the researcher 'in the field' and one who has undergone a similar experience, I believe I was in a position and able to make responsible, relevant judgements based on the situation (Billig 1988, Fairclough 2003, DH 2005). In addition, through having an empathetic manner towards understanding the nature of the upset, the degree of 'pain' and the possible meanings behind the tears, I believe my behaviour was appropriate and respectful (Keen 2006, Hollway & Jefferson 2000). Naturally, I reported all visits to supervisors and discussions surrounded these issues with notions that any research may induce upset through a myriad of unforeseen triggers. Under the circumstances, it was decided I was well placed to conduct this study with the particular group of people who were participating (Ritchie 2003, Aita & Richer 2005).

*Informed consent*
This research activity has necessarily been incorporated into *all* research projects given that obtaining 'informed consent' is the official way of gaining access to participants (Robson 2002) where the RGF states:

> *"informed consent is at the heart of ethical research"* (and review committees are advised to pay)*"particular attention to this process"* (DH 2005 p.7 my brackets)

However, Hollway and Jefferson (2000) suggest obtaining 'informed' consent in relation to taking part in an open ended interview is impossible as the participant cannot know what it feels like until it is underway. Dingwall (2006) also recognises this activity to be a dynamic process given that participants are emotional, thoughtful and independent beings who are able to retract their 'data' from the research at any time. As such, agreeing to fixed details in an 'official' document makes no difference to continued participation and thus signing a form to contribute to qualitative enquiry often appears as an unnecessary 'contract' (Richardson & McMullan 2007, Truman 2003). As depicted earlier, informed consent came into force to prevent medical trials

from being done to participants without them having full understanding of the procedure and without their subsequent agreement. An interactive open interview is not an intentionally intrusive or invasive practice (Armitage 2005) and in this research, as participants had already met me they felt confident enough to invite me 'into' their lives.

I believe their invite was not based upon personal trust given that initial meetings were brief and (as I later discovered) the paperwork I gave them went largely ignored. Instead, I accept Gubrium and Holstein's understanding of how the research relationship at that stage could be described as *"accommodative morality"* (1997 p.68). In this, parents seemed to accept who I was, as researcher and parent and they were prepared to make room in their busy schedule to allow me into their private domain. I saw no reason why the offer of 'moral accommodation' should not have been reciprocal: I was able to assess the 'risk' in context and with background information from the CDU staff who knew the families (Billig 1988, DH 2005). As such, I was engaged in a number of meetings each time I was faced with a fresh situation in order to be clear that what I was doing complied with protocol and was 'safe' (DH 2005).

The RGF (DH 2005) stipulates that:

> *"Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research"* (p.8)

Although I had originally planned to work with participants as 'partners' in my proposal and did include the site staff when developing the information sheets, the URO and NHS REC were ultimately responsible for interpreting the guidance. They had steered protocol away from this direction where the preference was to 'safeguard' both research parties by discouraging 'partnership' behaviours (Armitage 2005). As a consequence, the 'informed consent' procedure became an awkward sticking point in the fieldwork. Participants signed the form because they wanted to take part, not because they agreed to the prescribed form content which covered contentious (non-discussed) design aspects (Truman 2003).

In relation to this, the URO suggested that I offer the parents as much information about the research as possible and although this had originally been approximately three pages long, the ultimate eight page document attached to protocol turned out to be rather over facing for the parents. As per protocol, I asked them to read it and contact me when they were ready to take part and this had to be at least one week later. Some of the parents were flummoxed by the time lapse and I was anxious they may forget or not bother to call back although in the end, I need not have worried. However, on the day of my visit many of the parents announced they had not read the paperwork as they had deemed it unnecessary. In spite of this, I judged that it would be to their benefit if I went through the main points of the information sheets given that some of the detail was closely connected to them agreeing to sign the consent form.

As such, the process of gaining informed consent was initiated and discussed with participants during preliminary discussions whereby developing an appropriate ambiance in relation to informing participants is described later in this chapter (p. 162). Significantly, I felt I should be clear about the research process especially in terms of our participant/researcher relationship: I was not their friend or confidante per se and I could not 'fix' their perceived problems or dilemmas. I therefore wanted them to be fully aware of the way in which their data would be used i.e. I intended to gather information via conversational interview throughout which I would be interpreting their 'story' which in turn meant I would be subsequently analysing their thoughts and feelings through my particular understandings of their circumstances. As a consequence, their data would move from a 'co-construction' towards hermeneutic analysis where using a pseudonym made sense given the transferred 'ownership' of what had been 'found'. Whilst parents were happy to proceed on this basis, the question of understanding the degree of anonymity was more problematic.

*'Anonymity' and 'Confidentiality'*

Many parents realised immediately that given their unique situation they were well known at the hospital. Regardless of taking on pseudonyms and changing place names they understood their stories to be identifiable (Hollway & Jefferson 2000). These circumstances uphold Richardson and McMullan's (2007) claim that only the reader can decide genuine anonymity of data. Furthermore, some parents were clear they did not wish their data to be made anonymous (Mattingly 2005). I discussed these

considerations with supervisors who ultimately took the decision that vehement adherence to protocol was the most appropriate form of action. None of the parents opted to pick their own pseudonym as all thought the process quite unimportant and irrelevant, especially when compared to notions of 'confidentiality'.

The consent form enforced agreement to the participants' consultant being informed of their inclusion in the study and a copy being kept in an official medical file (appendix 3 p. 316). Some parents felt this was a critical issue where most believed this action to be a breach of confidence (Boman & Jeven 2000). Some parents were quizzical as to why anyone 'medical' would need to know that they were being interviewed. When I explained it was a safeguard for them in case of any negative consequences that might occur as a result of taking part in the research, they became *really* concerned. What might I *do* to them to warrant medical services? My response was to explain that research is a serious endeavour and authorities need to make sure it is conducted in appropriate ways (Dawson 2006, Boman & Jevne 2000). In this, I was being open and honest believing, as I stated earlier, that a ruling body should be in place to oversee suitable and relevant ways of working. I also believe a consent form with accompanying, succinct information about the research that is clear about design parameters and confirms agreed specific uses of personal data is a vital part of the study 'toolkit'. However, the difficulty I encountered in the field was that the parents were not fools and *they* had decided the particular practices outlined in the URO consent form were hardly apposite for this research.

*The overall procedure*

Devised from 'scientific' ethical theory and practice, my protocol paperwork in reality left an impression that the study could be potentially far more sinister and hazardous than it actually was. The increased tension encouraged through overzealous authoritative application of ethical principles subsequently led me to consider the ways in which the research protocol had affected me and thus my confidence in carrying out my 'prescribed duties' (Richardson & McMullan 2007). In spite of being told by the URO that the specific protocol was there to assist me, in practice, given the particular detail, I constantly felt it to be an unnecessary, unethical burden and, not only to me, but more importantly, to the participants (Dingwall 2006).

However, in addressing the ethical challenges presented through conducting interpretative study I also feel my work tested current research ethics guidelines (Hollway & Jefferson 2000). Through undergoing this process, I believe the RGF (DH 2005) does accommodate research styles such as mine although, it is clear that authoritative political interpretation operated via institutional practices appears to prevent and forestall research flexibility 'on the ground'. I therefore join a growing number of authors who advocate for more understanding amongst members of research ethics committees of (at least basic) qualitative research methodology and the ways this relates to ethical research principles (Richardson & McMullan 2007, Mattingly 2005, Truman 2003, Reed 2007, Dingwall 2006, Vessuri 2002). I propose that this cannot be achieved through research projects which merely assimilate 'scientific' practices into strategic or ethical methodology (Gadamer 1971). Misunderstandings between the disciplines of scientific and non-scientific research has been exacerbated in the past through terminology being 'disguised' or 'language difficulties' ignored once overcome (Watson & Girard 2004). Through exposing this aspect of my exploratory research experience I have highlighted some of the *"pettifogging obstacles"* (Dingwall 2006 p.57) that I encountered and from this, I hope others will be encouraged to remain faithful to their interpretative paradigm.

Thus far I have explained my approach in terms of a proposal, strategy, moral endeavour, study preparation, expected behaviours and major underlying principles which taken together have contributed to the overall methodology and the practical ethics I have applied in direct relation to certain elements of the fieldwork. Prior to presenting the findings which appear in the following chapter (four), the remaining task here is to explicate the methods I have utilised with related study detail.

## **METHODS and STUDY detail**

The methods I chose to deploy within this study are advocated by Smith, Flowers and Larkin (2009) whose book '*Interpretative Phenomenological Analysis; theory, method and research*' (IPA) I have used as a constant source of inspiration for this purpose. By remarkable coincidence, their chosen 'phenomenological route' is virtually identical to that which I described in my Masters Degree thesis and have continued to assimilate in

this extended work (Wright 2006). Smith et al (2009) refer to the works of the same phenomenological thinkers (adding Jean-Paul Sartre (1905-1980) to my original 'five') to support the use of particular methods and more specifically in making direct links to the analysis process. Although not prescriptive, their suggested mode of analysis is perhaps a little more straightforward than the one I devised where ultimately, both methods encourage full engagement with the text. As a consequence of the 'perfect fit' and their approach having been repeatedly tried and tested through a number of research projects, I consider theirs to stand in superior vein to mine (which has only been used once before) and as such, I have adopted their 'system'. Prior to explaining the analysis in more detail, I outline the methods leading up to this process.

**Interviews:**
The open ended interview is the ideal method of exploring experience as it sits so well with phenomenological thinking (Wimpenny & Gass 2000). Informed by this philosophy and the methods used in my pilot work, I continued with open interviews where Smith et al (2009) advocate:

> *"the most important thing at the beginning of the interview is to establish a rapport with the participant"* (p.64)

I felt I was able to do this by telling parents that my motivation for the research came from my own experience of having a child with impairment and that I was eager to hear what they had to say about 'what happened' for them, in their terms. The parents were pleased to be able to talk about their experiences where most said they felt other people they encountered were not interested in *really* listening (Maxwell & Barr 2003). By employing the open interview method my intention was to facilitate an environment of prioritising (and respecting) the participant, understanding that parents do not want to be treated with sympathy or pity, but as valued individuals (Carpenter 2000). Together with being in a familiar and comfortable environment, I believe encouraging parents to feel they were 'of interest' helped to create a relaxed atmosphere where rapport was initiated from having something in common that we both considered important.

From the outset, I was mindful not to go into detail about my own experience given that some parents may have felt urges to compare their situation to mine or be competitive in 'proving' their own (Smith et al 2009). In addition, I made it clear that I

did not want parents to feel I might judge their experiences or *them* (negatively), given that I may have appeared to them to have already 'passed through' their current situation and thus be in an 'advantageous' position. Concurrently, I did not want parents to think they were divulging their private life unfairly and thus, to create balance I reciprocated where it felt appropriate (Etherington 2004). As a possible consequence of encouraging this climate of shared understanding the parents felt able to reveal intimate emotions in the telling of their experience (Keen 2006, Eide & Kahn 2008, Green et al 2005).

I aimed for the interview process to be dynamic and unfolding, where I hoped to facilitate participant conversation rather than control their direction. In order to illustrate this, I have extracted four such comments from one transcript page where I encouraged the participant to give a little more detail as he related his experience:

> *Me: and were you left in the corridor then, sort of waiting for that*
> *minute (J: yeah) and your thoughts? (J3:9-10)*
> *Me: did you get a proper look at her? (J3:26)*
> *Me: was that hard to say? (J3:44)*
> *Me: ah, so did you already know about that, from prenatal classes*
> *or whatever? (J3:48-49)*

I found this open approach allowed participants to speak about their experience through stories, events and interactions that were important to them and in ways that they felt most comfortable (Etherington 2004). Green et al (2005) combat criticism of this conversational, open interview style that generates a form of shared knowledge through common experience when they suggest that the unique research relationship can reveal particular understandings, otherwise impossible to obtain. As one participant suggested:

> *H: that's what's happening to me at the moment, (me:mm) why am*
> *I holding sort of this bit back at the moment? but I wouldn't like to*
> *say that to another parent with children* (H15:43-44)

I did feel that the interview was less 'expert' oriented given that we (both parties) essentially belonged to the same stigmatised group and in turn, I hope these particular interaction(s) opened a window into the 'world' of a (our) specific way of being in relation to parenting (Green at al 2005).

Once a 'settling in' period had passed which usually lasted approximately fifteen minutes I began the interview(s) by suggesting I switch the recorder on. At this point I asked all the participants the same question, *"what happened? Where did it start for you?"* This prompt seemed to work for most, although the action of stopping an introductory conversation and 'announcing' the start of the recorder, followed by the questions did stall some parents, for instance:

> *Me: so, the only question I've got is where does it start for you?*
> *C: where does it start? Well…mm, where does it start? Bloody 'ell,*
> *right er wife, well me wife, we went away to France and we (…)*
> (C1:9-11)

Although some did not naturally see their experience as having a 'start' per se, I decided to continue with this prompt with other parents as I simply wanted to encourage them to 'begin' somewhere in the focus of the topic and this question seemed to have a lot of 'mileage' (Smith et al 2009). Most parents had a story to tell about the pregnancy and circumstances surrounding the birth and in finding this ground (and thus their confidence) relatively quickly, I felt I only needed to ask further questions when clarification was required or I wanted to go back to a point from which they had digressed or to probe for more detail.

**Selection of participants:**

*Criterion and number:*

Twelve participants volunteered to be interviewed and all came from a 'white British' background. Whilst I acknowledge this may attract potential criticism in that I am perpetuating the ethnic 'standard' as typical of disability research, I feel I can justify this eventuality (Ong-Dean 2005, Bell 2006). I had not expected any other groups to come forward as the cultural mix in the geographical area, whilst diverse, is not common. As such, in pre-designing the methods of the research for protocol, I elected to state that I would not be complicating the project by including parents from diverse cultures or those who may have a learning difficulty themselves. I suggested this to be fair on the grounds there may be additional vulnerability in terms of potential language and meaning difference and in conveyance and shared understanding of sensitive issues (Bywaters et al 2003).

I recognise this area could have been addressed with additional effort yet unfortunately, I believe achieving this was beyond my scope. I was already stretched with the named group apparently presenting contentious issues which placed me under considerable pressure in relation to obtaining access to them via the NHS REC process (Orb et al 2001, Truman 2003, Dingwall 2006). In addition, once the research was underway, I was not made aware of any local parents who had impairment (through the CDU) and none of the participants disclosed this to be the case during the research process. Malacrida (2009) suggests that parenting experiences are magnified for people who have physical impairment in ways that are specific to their condition, adding particular dimensions to their experience. Given the lack of exposure in this area, I would have included this data had it come to light.

The parents who did take part came forward once word of my research had reached the parent groups where a volunteer 'snowball' sample emerged (Oppenheim 1992). The group consisted of four married heterosexual couples, a single mother and three married mothers and they all had children under the age of three who could be described as having a learning difficulty. Using IPA, I had intended to work with the entire group, conducting a less detailed form of analysis aimed at searching out 'whole group emergent themes' (Smith et al 2009). However, when analysing the first transcript, I felt uncomfortable with not being as immersed in the data as I would have liked and the work consequently felt lacking and sloppy. I therefore decided to remain faithful to my phenomenological endeavour in being as thorough as I could with the text (Ricoeur 1973).

I knew that including the data from all twelve participants would be impossible with this level of analysis and I thus needed to consider selection options. I discussed the issues with my supervisors where ideas were muted for using four or five participants' data in depth or a single data set with contrasting and supporting information from the remaining eleven. Given the interesting variation between the accounts, I felt that highlighting snippets of parental voice would not do justice to their individual experience and worse, their contribution might appear to be of lesser value than the 'main character' (Gerring 2007). As a consequence, I reluctantly chose a purposeful sample of four from the twelve accounts making a clear case to justify the inclusion of each.

*Criteria in sample reduction*:

My first criterion was 'variation' to demonstrate the differences found between individuals in a small sample size, choosing them:

> *"because they are representative* and *they are unique"*
> (Matchinske 1998 p.162 reverse italics).

I also wanted to identify apparently 'non-typical' cases in response to the myriad of 'similarity' found amongst contemporary research (Towers 2009, Carpenter 2000). I wanted to be equally representative of males and females given that both had taken the time and trouble to talk to me. In particular, I determined to work with the fathers' data specifically to counter studies which depict the role of 'father' as being a *"universal category"* and not therefore, as individual men in their own right (Lupton & Barclay 1997 p.47, Gavanas 2002, Miller 2011). As a result, I aimed to pick two participants of each sex with the further specification (from protocol) that they must be amongst those who had fully agreed to their data being made as anonymous as possible. In turn, this provision meant that I had to 'reject' those whose baby had been diagnosed with a rare condition where their 'stories' could be very easily identified.

*The selected participants*:

Given the dearth of research with single mothers (Levine 2009), I chose the only one who came forward and, as research with mothers mostly includes those who adopt the primary care role (Kingston 2007), I chose a married mother who has her own business. It appeared fitting to also include her husband who had elected to care for their daughters at home as he is part of a growing body of men who have become engaged in this activity (Miller 2011, Torr 2003, Doucet & Merla 2007). The marital combination also presented an opportunity to hear individual perspectives coming from the confines of a close relationship and shared experience where each offers unique insight to their joint circumstances (Pelchat et al 2003). The second male participant appeared to have an outlook that stood in stark contrast to the other three contributors although it did resonate with mine and others in the whole group. I wanted to include his data to reflect this parental viewpoint. Although in full-time employment and therefore very typical of men who appear in studies (albeit rarely in this style) this particular father held a managerial position and in light of research which suggests added responsibility of this kind may affect experience, I also hoped to enhance the

knowledge base in this arena (Abril & Romero 2008, Towers 2009, Williams 2009, Robb 2004). Figure 1. simplifies this data and introduces the participants' by name.

Fig. 1 – Table depicting contributing research participants

| Participant: | Description for research purposes: |
| --- | --- |
| *Maggie* | *Single mother, stays at home.* |
| *Hannah* | *Married mother (to Colin), runs a hairdressing business* |
| *Colin* | *Married father (to Hannah), stays at home* |
| *Jonathan* | *Married father, manager of a local supermarket* |

**Data Analysis:**

Once interviewed, I transcribed the data verbatim where example pages from these can be found in the appendices (4a-d pp.317-320). Phenomenologists espouse that being immersed in the data is vital to the analysis process and in the past, I have chosen to hand write the transcript from the audio tape, then type it whilst listening to the tape again and then re-read to a point where I felt I was skipping sections due to over familiarity. However, given the original number of twelve participants, I did not see this as a feasible or practical activity and instead typed each whilst listening to the audio file. At this juncture the research process was suspended and the stoppage lasted approximately twelve months. When I returned to the transcripts I considered re-typing them in order to 're-engage' with the data however, when I read the first interview I was delighted to be 'transported' back into the conversation, remembering expressions very clearly and sequences of dialogue. As a consequence, I decided that re-typing was unnecessary and having been engrossed in Smith et al's (2009) IPA 'guide book', I was eager to get going on their depicted 'steps' of analysis.

In order to complete these some preparation work was necessary: I created a wide margin on the left side of the transcript page, numbered the lines and pages and printed the whole document on A4 sheets. I elected to glue a blank sheet to the right side of each leaf in order to create 'work space' directly alongside the data. I could then work through individual transcripts using a different coloured pen to represent the 'style' of notation I was making. That way, as I worked back and forth through the sheets within

the document comments were readily identifiable for their 'purpose'. I remained working with the participant under scrutiny until the individual analysis process was complete. For each participant, I took at least one week to develop my interpretative notes and a further seven days (minimum) were dedicated to the individual's follow up stages.

In IPA the first step involves reading the transcript over, slowly and steadily making notes as asides that can be revisited at a later stage. I elected to adapt this process slightly by adding from my original method of analysis the idea of composing a 'naïve summary' (appendices 5a-d pp.321-327). This entailed reading the transcript through and afterwards, composing a passage of initial thoughts and impressions from the text as a 'whole' (van Manen 1990). As such, the thinking behind this strongly relates to Gadamer's hermeneutic circle ('parts' and 'whole') and is where Husserl's 'essence' begins. The initial summary essentially reveals my prejudices in what was 'obvious' to me in the data given that these details first attracted my attention. It is thus an exposure of the *likely* routes of analysis and although it is not used for directive purpose I feel it marks the beginning of a 'programmed' focus. Later, having created a concise summary in relation to the findings, I found the naïve summary to be an interesting point of reference against which I could gauge my progression of thinking. Given that this data is peripheral to the findings per se I have placed the participant's 'naïve' and 'complete' summaries in 'pairs' in the appendices (5a-d pp. 321-327).

Once familiar with the 'whole' transcript data, the next steps of the IPA process involved taking a 'line by line' approach, examining the 'whole' via the constituent 'parts'. Interpretation is developed through a tri-fold 'scaffolding' effect where the first of these three readings encourages the researcher to think about 'what happened' at the most basic level. To this end, Smith et al (2009) advise making descriptive notes alongside each line of the text, as with this example from Jonathan's data:

| Text | My descriptive comment |
|---|---|
| *J: Jemma had had the baby you know (me: yeah) sort of one of my jobs was to report the news (sniff) and er… I phoned the first one, Jemma's best* (J5:19-20) | *'his 'job' to phone & tell people'* <br><br> *'told wife's best friend'* |

Through this process, I became deeply aware of the 'parts' within the text: where they were situated and the ways in which they may have related to each other. The breakdown also presented opportunities to think about what the 'incidents' might mean to the participant and why they may have been voiced in particular ways.

As such, the secondary notation developed from the first, entailed paying attention to language use and making possible links between the identified 'parts' in a move toward processing interpretative understandings. For example, noting metaphors that were used to describe, in Colin's case, his child as *"angelic"* (C10:12) and elsewhere in the text, *"monster"* (C5:31) generated ideas about the meaning of these apparently opposite concepts and why they were specifically brought to mind. As such, I considered further interpretations such as: a love/hate relationship with his child; how these might transpire as feelings relating to 'self'; the child as 'angel' and the disability as 'monster' and; 'angel' in the context of the child being 'appropriate' (making life easier) and 'monster' as 'inappropriate' (life more difficult).

I also looked for repetition, triggers of emotion and data that was 'absent' or unfinished perceiving these to be significant where I felt piecing them together aided the process of understanding on a deeper level (this process specifically relates to the work of Merleau Ponty and Sartre). For example, Hannah described how her baby started out quite poorly and her voice trails off, then later in the interview she breaks off when describing her current life and again in latterly thinking about having set a regime:

> *H: er and she never seemed to sort of get…any better from that point…* (H3:3)
> *H: you know, we do find it sort of har'…* (H10:15)
> *H: active as possible and the diet and everything an'… you know I just erm… I found that a hard …* (H18:43-44)

When regarded alone, each comment implies that Hannah finds it difficult to express the way she feels about the given situation where this has resulted in her being apathetic in her attempts to find suitable further description. A developed understanding from these and other instances in the text led me to believe that Hannah viewed her daughter as not ever having recovered from difficult beginnings. I felt the apathy in her voice that occurred whenever talking about her daughter and her own life

in terms of being 'hard' signified that she related the initial feelings of resignation towards her daughter's condition to the continuation of an unwelcome changed and on-going lifestyle. Hannah's voice trailing off also came across as wistful as well as submissive and this strongly indicated an air of defeat and a sense of feeling somewhat trapped. From this juncture and with other clues, I additionally surmised that she had lost interest in explaining herself and her daughter through her previous experiences of communicating and subsequently feeling misunderstood by other people.

Participants' delivery of speech was noticeable as it often came through the text via remembered conversation. I was also aware that due to the eventuality of Heidegger's *"dasein"* ('being there' 1953 p.115) these nuances would be particular to me. I thus realised I was interpreting these signals according to the ways in which *I* received them and these highlighted (for me) the very personal elements of my interpretation: not everybody will have noticed, or 'read' the intentions the same way I did. In making reflexive comments on the transcripts and offering the reader explanations to my approach (such as the example above and in my reflexive notes in the appendix 6a-d pp. 329-337) I hope to expose some of these considerations.

Having completed the second step, Smith et al (2009) encourage a third foray into the text this time working through further possibilities drawing upon the textual data and the notes from the previous two stages. Here, the interpretative endeavour becomes more creative involving researcher intuition through which claims cannot be made to 'know more' than the participants, although:

> *"it does allow us to see how our analyses might offer meaningful insights which exceed and subsume the* explicit *claims of our participants"* (Smith et al 2009 p. 23 reverse italics)

As such, during the 'conceptual' stage I was not attempting to 'become' the participant by relating to events as if from the participant's point of view (MacKenzie & Scully 2007) rather, the 'fusion of horizons' that had begun initially through the interview and subsequently developed via textual analysis meant the interpretation(s) contained my inescapable *"added value"* (Smith et al 2009 p. 23, Ricoeur 1973, Moran 2000). To continue with the angel/monster metaphor from above: my line of thinking would be to consider that extreme descriptions were used by Colin not only to exaggerate

actualities of childhood behaviours that hold shared meaning in parent conversation but also for Colin to convey the extent of his personal emotional desperation in struggling to understand his daughter in terms of being 'reliable' and 'known'. In turn, this appeared to foster the inability for him to develop a 'constant' relationship through which he could assume 'normal' parental control. My interpretation would go further to suggest this inconsistency rocked his foundations of taken-for-granted assumptions surrounding his developed sense of security in knowing how to parent and moreover, how to love his child which no longer seemed to be a subconscious activity.

As a result of making interpretations in this way, by the time I made the third set of notes, the transcript had increased considerably in volume. Much of this latter stage involved thinking about and processing ideas where working with the text became a really intense process feeling as though *all* the data and related ideas were buzzing in my head at once. I had to control the information and stay focussed, noting considerations that I felt were most relevant as opposed to making an over active outpouring of the whole calculated (internal) endeavour. I was mindful not to over complicate the physical data set with erratic thoughts knowing this may leave a trail of puzzling scribbles rather than traceable comments. In addition to remaining open to examination, this transparent way of working aids the continuing analysis process. Figure 2. is an example page of transcript (Maggie p.19) showing the interpretative work as described above as well as the later development of emergent themes filling the left hand margin.

Fig. 2. – Example page of working transcript (Maggie p.19)
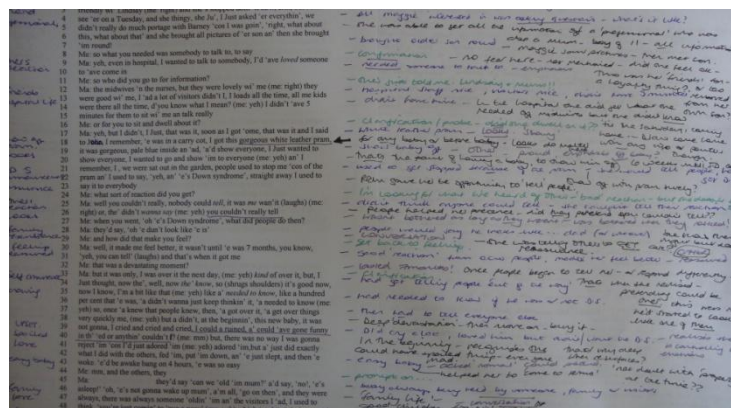


Prior to moving onto the next IPA step I worked back through the transcript in order to focus momentarily upon making any further reflexive comments that I had not already

made (Gouldner 1972, Etherington 2004, Ezzy 2002). I looked specifically at the ways in which I had interacted with the participant, may have influenced the interview and, for evaluative purposes, where I might have behaved differently and thus hope to have learned from such incidences. Unfortunately, I could pick from a number of examples showing room for improvement and therefore, I have chosen one (below) that epitomises the general mode of my mistakes. To place this particular incidence in context: Jonathan has an uncle who has learning difficulties and I encourage him to talk about this relationship:

> *Me: so did you know your uncle quite well really?*
> *J: yeah, I did*
> *Me: and did that have any bearing on how you feel about Harriet?*
> *J: mm…no..not really 'cause…knowing some of it, knowing some of its*
> *quite different…(..)* (J13:32-36)

Clearly, my second question was entirely inappropriate and although Jonathan's response was helpful as it supported data elsewhere in the text, there were plenty of other parts of the interview which presented this 'evidence'. I do not know if at the time I expected a 'suitable answer' directly from Jonathan or whether I was more 'thinking aloud' in the relaxed conversation (an ostensible drawback of this method). Either way, when investigating other patterns of interpretative data from the transcript, sufficient information 'naturally' surfaced to render the question totally irrelevant.

I have placed many further examples of my reflexive behaviours in the appendix which have also been signposted at the end of each participant's interpreted account (findings, chapter four). Although the comments cover instances relating to specific individuals as they were most prominent to these, they are relevant to the whole research process as exposure of my underlying phenomenological attitude. As such, the reflexive notes are revealed in the following ways from:

i. Colin: making judgements using the textual data (appendix 6a p.329)
ii. Hannah: the researcher/participant relationship in terms of my position as 'empathetic mother' (appendix 6b p.332)
iii. Jonathan: the researcher/participant relationship in terms of 'power' and personal judgement (of each other) and the use of 'absent' data (appendix 6c p.334)

iv. Maggie: my personal input in terms of researcher bias, pre-judgement and 'horizon' (appendix 6d p.337)

Having expanded the analysis thus far, I moved to the next step in the IPA process where the aim is to reduce the voluminous participant data into organised 'emergent themes' (Smith et al 2009). This involved working primarily with the comments I had made rather than the actual interview text where:

> *"the main task in turning notes into themes involves an attempt to produce a concise and pithy statement of what was important in the various comments attached to a piece of transcript"* (Smith et al 2009 p.92)

I thus used the enlarged left margin of the transcript to work my way down each page thinking carefully about creating short phrases which I felt would capture the essence of the notes I had made (fig. 2 'Maggie (p.19)' above illustrates). However, given the interpretative development most 'themes' were not straight forward. When relating back to the transcript I found this meant even short bursts of textual data had created a variety of interpretations and thus, a number of corresponding emergent themes, for example; when Maggie recalls thinking:

> *"oh my god, my baby's gonna be a freak!"* (M26:30)

From the 'descriptive' notes, talking about her baby generated an emergent theme of '*mothering*'; from 'language' analysis, I had noted that using '*freak*' highlighted Maggie's underlying assumptions corresponding to 'disability' thus, I created an emergent theme of 'Down's syndrome' and; from 'conceptual', '*gonna be a freak*' seemed to represent the enormity of the parenting task ahead to which I attached an emergent theme of 'panic'. Maggie's comment taken as a whole instilled an overall sense of emotional disturbance through 'horror' and as such, I also added a theme of 'upset' in relation to my notes. The actual remark also supported other interpretations elsewhere in my comments regarding her fears for the future.

Once this exercise was completed, the themes appeared as a chronological list in the left margin. I typed these into a separate document in readiness for 'sorting'. I labelled each emergent theme title with the participant's pseudonym initial, a page and line

number(s) as a reference point. In order to keep the essence of the theme clear I also wrote a little caption from my notes, sometimes including a verbatim quote from the transcript. The extract from Hannah's data given below illustrates the way the finished list appeared (for the whole page example, please see appendix 7 p.340):

> MOTHERING (H15:12) – being practical, don't let emotion get in the way, harden up to solve problems that are bound to arise in the future
> FUTURE (H15:13) – she knows problems are imminent with daughter
> OTHERs perceptions (H15:14) – 'sounds terrible that' she knows she would feel that before having this daughter

Smith et al (2009) suggest the data may be moved directly from the list into groups via computation however I preferred the 'hands on' approach (having tried computing). Although this was a much longer and drawn out process, I believe it is precisely this which encourages a closer relationship to the data. As such, I printed the list and cut each theme into a 'data strip' and taking each one, I began to place them into piles. I put the 'data strips' together where I felt there was a connection and to one side until more 'partners' emerged. Carrying out the task was enjoyable where the data appeared to gravitate almost naturally into groups. It became clear that once grouped, links could be made to other groups and as such, these belonged together as 'sets'. I kept the process going until a minimum number of sets emerged (two, three or four) and these developed into the 'super-ordinate themes' particular to the individual participant as shown in the table in figure 3.

Fig. 3. – Table of participant super-ordinate themes

|  | Super-ordinate themes: |  |  |  |
|---|---|---|---|---|
| Colin | *Other* | *Self* | *Being a parent* | *Life* |
| Maggie | *Being a mother* | *Physicality* | *Emotional mothering* |  |
| Jonathan | *Family man* | *Disability* |  |  |
| Hannah | *Emotions* | *Mothering* |  |  |

Working with a super-ordinate theme, I arranged the sets of grouped 'emergent themes' found within it, in ways that enabled me to explore the relationships between the data. Having the little piles of 'data strips' meant I could readily examine the content of the grouped data and place these adjacent to appropriate neighbours or treat

them as a 'connector' between neighbouring piles. I moved the data around until I felt a pattern or 'story' emerge and when established, I called this a 'data map'. Figure 4. (below) illustrates my working towards completing a 'data map' of Colin's super-ordinate theme of 'other'. I made notes as I worked and used a whiteboard to create a complementary visual image to further understand the ways in which the 'data map' I had created made sense.

(For further pictorial evidence of 'workings' relating to all participants please see appendix 8 p.341).

Fig. 4. – Creating a 'data-map' using Colin's super-ordinate theme data, 'other'



From this expansive way of working I condensed the information by creating a computer graphic of the super-ordinate 'data map' and a corresponding 'data table' by cutting and pasting from the earlier chronological list of emergent themes. This ensured the data was captured in the way I had creatively organised it whilst being represented in a more accessible format (please see appendices 9a-d pp. 342-348 for an example finished 'data map' and corresponding 'data table' from each participant).

Using the maps and tables I began the final step according to IPA guidance: 'weave' the data to produce the 'findings'. During this process, the flow of writing gave rise to some changes in the arranged 'data table' order however, the usefulness of the graphics meant that I could identify the 'parts' and revise what was included or omitted in the 'whole'. I could also immediately refer to poignant quotes and with the transcript references I was able to easily return to the original text if required. The finished interpretation at this level signals the completion of the IPA analysis process and as such, these are presented as findings in chapter four.

However as I understand it, the foundations of phenomenology essentially drive the researcher towards a final 'tight' summary to represent the 'essence' of the experience

(van Manen 1990). I decided to follow this through in order to create a thorough finish although this 'end product' does conceal much of the detail such as verbatim participants' quotes which ultimately aid readers' understandings. As a consequence (and as I stated earlier), I have placed the concise summaries belonging to each individual together with their corresponding naive summaries in the appendix (5a-d pp.321-327). I hope this adds to the transparency of my work, where the reader may detect the difference in quality of writing whilst also identifying origins of my thoughts.

*Further preparation in support of discussion:*

Once the participant findings were complete I wanted to devise a way of sorting the four individual sets of data to define areas requiring further research in preparation for subsequent discussion and other chapter contents. So far I had analysed the data by identifying 'themes' within cases. I now needed to work almost in reverse by bringing the themes to the forefront and considering the ways in which the cases sat within these (Smith et al 2009). For this, I chose a simplistic formula of writing each participant's emergent themes into a single list and in order to identify the relevance of the theme to each participant, I adopted a crude marking system. I awarded five points to themes that I felt were strongly significant and this meant all emergent themes generated by a particular participant would receive five points. For illustrative purposes, figure 5. is an extract from the top of this list where Colin is highlighted in red as it begins with his themes (for the full listing, please refer to appendix 10 p. 350).

Fig. 5. – Table extract from top of emergent theme list

| 'OTHER' | COLIN | HANNAH | JONATHAN | MAGGIE |
|---|---|---|---|---|
| Forced to belong | ◊◊◊◊◊ | ◊◊◊ | | ◊◊◊◊◊ |
| Excluded | ◊◊◊◊◊ | ◊◊◊◊◊ | | |
| Other - Lack shared understanding | ◊◊◊◊◊ | ◊◊◊◊◊ | | ◊◊◊◊◊ |

To further explain the table (fig. 5 above): Colin's list began with his super-ordinate theme of *'Other'* where the first emergent theme in this category was '*forced to belong*'. Working across the table, I awarded 'scores' to all the participants on the

following basis: Colin had the maximum of five points as it was his theme; I also gave Maggie 'five' as the meaning behind this theme also featured strongly in her experience; I scored Hannah 'three' as I felt this was relevant to her although was not as significant in her experience as it was for the other two and I left Jonathan blank; I did not understand any part of his experience as him feeling pressure to belong to any particular group (in the given sense). Once the entire list was complete, each theme had been allocated four sets of marks and I added these to give a score against the theme. A full score of 'twenty' indicated a 'strong' theme being significant to all four participants and a minimum score of 'five' meant the theme was only particular to a single individual.

For continued traceability, I colour coded the themes according to 'popularity' whilst maintaining the link with the participant from whom the theme originally emerged (appendix 11 p. 352). From here, I created a 'league table' depicting the significance of each theme across the four experiences (appendix 12 p.353). This method ensured the inclusion of particular detail, that it remained visible in the combining of the voluminous themed data and that all themes remained traceable to individuals. Being placed together in this way, the charted indicators were sufficient to allow me an overview of *all* the themed data and thus, I was in a position to consider the relationships between the themes and how I might write about what I had found. Furnished with this organised information I had a developed sense of satisfaction in my work and this facilitated confidence in going forward to conduct further exploration into relevant areas of literature in preparation to begin the written work.

**Conclusion**

In this chapter I have endeavoured to expose the underlying principles as well as the practical application to the working of this research enterprise through examination of the 'methodology', 'ethics' and 'methods' involved. Initially I addressed matters pertaining to methodology whereby I argued that phenomenological research theory is representative of ways of working that are not prescriptive or rule bound. As an exploratory and expansive endeavour, predictable methodological techniques that aim to harness the process can be perceived as restrictive and suppressive. In explaining my experience of making attempts to adhere to conventional formats, I revealed the ways in which 'methodology' as fundamental assumptions that relate to research

conduct have become entangled in the web of scientific convention. Moreover, the 'story' of my research experience served to illustrate the on-going context of a reality in which parents continually find themselves (Larkin 2006). Voices of authority often overshadow experience in decisions surrounding what constitutes 'best practice' where parents' views are undervalued and even ignored (Torr 2003). As such, the challenges I met highlighted the nature of the difficulties parents face in gaining understanding from others who are not parents themselves and in turn, this has much to add to the subject of this study.

I continued my 'exploration' by examining the foundations of ethical research behaviours through contemporary theory and followed through with subsequent critique of historical and current research ethics governance. From this, I gained a more thorough (phenomenological) understanding of how and why ethical codes have been put in place and the ways in which they relate specifically to my work. However, I remained convinced that ethical behaviours are not static and as such they cannot be pre-determined; they are value laden and interconnected as well as emergent and unpredictable (Fleming et al 2003, Biehl 2005, Lantz 2000).

In light of this, I went on to consider the ways in which scientifically founded ethical standards have been assimilated into qualitative styles of enquiry that perpetuate the use of customary research principles and practices. This activity served five purposes: firstly, I aimed to reveal the ways in which this blending with scientific notions may have contributed to confusion in terminology and understandings amongst research ethics committee members; secondly, to expose the ways in which these ideals are inappropriate to an interpretative design; thirdly, to explore the ways in which high governance *is* adaptable to flexible styles of research; fourthly, I used the explication to expose my own way of working and; finally and most importantly, to expose the ways in which conventions impacted upon the parents as participants.

Throughout the revelations, I hope to have demonstrated an alternative to 'conventional' measures in that researcher characteristics including integrity, trustworthiness, understanding of moral obligations and the ability to make moral judgements, assessed via appropriate supervision and monitoring of the productive activities of the study appear to be the most suitable ways of conducting research that

has a sound ethical foundation (Eide & Kahn 2008, Dingwall 2006, Richardson & McMullan 2007, Fairclough 2003, Brinkmann & Kvale 2005, Aita & Richer 2005).

In aiming to work in appropriate ways, I attempted to make clear some of my personal principles not least in terms of disclosing practices that I have undergone through conducting this research. In so doing, I expect the act of my explaining to convey more of my phenomenological 'attitude' than has been simply expressed in the text alone.

To this end, I finished the chapter with a detailed description of the methods I employed where I attempted to be as explicit as I could to afford the reader as much insight as is possible under the restrictions of limited space. From this, I hope the reader has gleaned rich information which was intended to not only expose the way I have worked but more importantly, facilitate understanding of the four participants' interpreted data which appears in the subsequent chapter.

## CHAPTER FOUR

## <u>THE FINDINGS</u>

**Introduction**

This chapter is devoted to the interpreted accounts of experience of the four participants included in this study. In presenting this work, ahead of each section, I have written a short passage to introduce the reader to the individual and to set the context of the interview. At the end of each account I point the reader to the appendix location where the completed summary has been logged together with the corresponding 'naïve summary' that they may benefit from the full extent of the interpreted information. I also signpost where the reflexive notes made in relation to each account can be found amongst the appendix. The reflexive comments are relevant to particular data and thus highlight different issues that surfaced in relation to each participant. As such, I have not standardised the notes into a formal, single body of writing or in ways that address similar issues pertaining to each account.

Instead, I have attempted to choose reflexive notation from the array of comments which cover a range of thoughts and considerations with the intention of exposing as much of my way of working and 'horizon' as is reasonably possible. Some of this naturally attends to the various deliberations over judgements that I made and regards questions that arose through completing various aspects of the research process. I hope this way of working functions in a way that inspires the reader to also ask questions of the data (and themselves) in their own quest to understand what it might be like to be a parent of a baby described as having a learning difficulty.

The participant accounts are presented here in no particular order, although Hannah immediately follows Colin (who begins) as they are linked by marriage. Jonathan precedes Maggie and she completes the chapter as I have not drawn a conclusion due to full discussion made in relation to the four accounts fulfilling the subsequent chapter. The participants' data is arranged to include quotes that are referenced to enable traceability to their original position in the transcript. I have written their statements as they sounded (e.g. dropped 't') to foster authenticity and ambience although I have not included my voice (e.g. 'mm', 'yeh') to allow for continuity.

*KEY to participant quotations: '(…)' = text omitted and '…..' = pause in speech*

## <u>COLIN</u>

When I initially spoke with Colin over the telephone he sounded cheery and easygoing and he seemed very intrigued by the study. Under the circumstances at that time I had to explain that the research may remain focussed on mothers' experiences only whereby he quickly replied that he was *like* a mother. Colin was staying at home as the full-time carer for his children whilst his wife Hannah continued to go out to work. They had three daughters, the oldest of whom had recently started school and the other girls were two year old twins. They had been born prematurely and one of them, Helena, was diagnosed as having Prader Willi syndrome. Prior to having their first daughter, the couple had struggled to have any children, undergoing a series of IVF treatments with no success. It is perhaps unsurprising therefore that Colin succinctly describes his experience of being a parent as a *"privilege"* (C24:43).

I went to interview Colin on a sunny afternoon where I was greeted by Hannah and all of their children at the front door. I was welcomed into the kitchen where Hannah asked me about the research and when I explained, she expressed that she would like to take part. Once we had made arrangements for this to happen she took care of the children and I gave my full attention to Colin. We sat in their lounge and were undisturbed apart from the loud noises of the frequent low aeroplanes coming in to land at the nearby airport. Fortunately, these did not have a huge impact on the recorded interview where there were few obstacles to transcribing the data verbatim.

During the analysis process, Colin's data gravitated into four super-ordinate themes: *'Life'*, in which Colin appears to make sense of his 'being-in-the-world' through understandings of 'what happened' in relation to notions of 'normality'; *'Other'*, where Colin is seen to portray himself as developing a sense of belonging in the social context and thus, as (re)negotiating his societal position; *'Self'* includes Colin's apparent understanding of his experience through recognition of an altered self and; *'Being a parent';* in which Colin's taken for granted assumptions of parenting tasks are brought to consciousness through his experience and these help to define what it means for him to *be* a parent of a child with impairment.

# LIFE

***"you've been dealt the shitty card, you know, you've got a kiddie
that's not right"*** (C11:31-32)

Colin talks about his life as if it were somehow straight forward and uncomplicated although it is clear that this conveyance of his way of 'being in the world' is at odds with his actual lived experience. At first he seems to be very clear about his situation as he says things with such conviction and he has little regard for whether he has contradicted himself or not; *he* believes what he is saying, as he says it. It is his way of communicating his reality where he feels life happens *to* him. In this, Colin believes there is a 'right' way of being and this falls within his predetermined notions of what is acceptably correct which in turn, constitutes his invoked sense of 'normality'. However, he feels that he can no longer access this and with an almost bitter outlook he can see others continue to enjoy what he once had:

> *"...as you talk to people who've got normal kids, who're just going
> through the normal day to day routines you know, they'll sit and
> listen and then they'll go off to their nice little lifestyle again, you
> know"* (C13:35-36)

Colin's process of making meaning of his perspective of 'normality' and his consequent sense of abnormality is brought to light through his 'work ethic'. He appreciates such things as routine, keeping busy and employment whereby he views his daughter's expected 'laziness' and potentially 'objectionable' behaviour as a tormenting abnormality. Moreover, his work ethic is also challenged by his need to claim welfare benefits. In order for Colin to feel that he can 'correct' the situation he has come to regard these as a form of payment which he can use to cover his expenses as well as perceiving them to be a deserved reward for doing his 'job':

> *"I get that money to do the best for my kids o.k. and that's another
> reason why I don't sit in for an afternoon and watch TV while the
> kids are messing about in the conservatory, you know, I get out
> there, get 'em socialising you know, an' all that, and stimulate
> them, that is my job"* (C14:37-41)

Colin appears to see his life as a series of events throughout which fortune has played a dominant part. This 'game of life' is apparently dependent upon what chance has placed at his door and he conveys considerable discomfort with this notion of

unexpectedness. Through already feeling he has been cheated, Colin suggests he could yet be 'caught out'. As such, he turns to statistics and probabilities in order to give himself a reasonable idea of how his life is likely to turn out. To this end, he travels along a life path within his own 'micro-world' which is materialised in his immediate environment of family and home. He considers this to be his safe haven where terrible things are not meant to happen to him (or *us*). However, an altered life course appears to have been conjured by the 'chance' occurrence of Disability which subsequently triggered Colin into feeling a tremendous sense of shame. When speaking about this, he imparts meaningful impressions of sorrow, dejection and despair which he has felt as intense, potent and crushing.

> *"things were bad, I thought my life had ended I really did (...)*
> *thought my, my world had ended, nobody else's, <u>my</u> world"*
> (C19:5 & 8)

The powerful sensations Colin underwent appear as 'macro-emotions' that have left him with an aura of aftermath whereby the feelings seem to have transcended the ordinary in line with his continuing extraordinary experience. Colin's run of stories lend clarity to the multi-dimensional nature of 'what happened' in that he denotes multiple 'beginnings'. His accounts emerge as being his way of recognising the contributory factors that have shaped the person he has become. He makes comparisons to think about what his life was like 'then' and 'now' and this leads him into a 'dream world' where he considers alternatives of how life might have been. In dreaming about the future, his forecasting of chance comes into play where he sees himself in scenarios aimed at combating unexpectedness.

> *"...they become so objectionable as, you know, adolescents and*
> *they seem to thrive in certain environments and the reality is, we,*
> *we might not be able to offer that environment and to drive a kid, I*
> *think the nearest one is... Norfolk..er, I think its Norfolk, erm,*
> *anyway to, you know and drop her off there, if she's happy, I'll*
> *leave her"* (C16:50-17:3)

His 'life' experience thus seems to be one of negotiating his sense of settled 'normality' and the extent to which this is still possible or indeed, desirable, given that his reality is such that his daughter's impairment makes his life apparently 'not normal'. However, what is happening in his experience 'now' is becoming 'usual' and

familiar to him to the extent where Colin is establishing a fresh sense of normality by finding meaning in *ab*normality:

**"*I wouldn't have liked to go down a normal route now*"** (C22:36)

## OTHER

**"..*she* (a stranger) *said to me, 'you're in a unique club now' (..) and since time's gone on (...) how right she was and you are, you're part of a unique club you know*"** (C24:35-39)

Colin experiences a degree of enforcement to belong with others whilst concurrently he suffers from the divergent impact of feeling excluded. Although not mutually exclusive, Colin makes these rival positions clear through his claiming disability benefits where this 'belonging' occurs via the combination of canons of localised culture and biological fact and; through his apparent belief that his situation is misunderstood and largely ignored by the majority of whom he was once a part and now feels very much removed. This dualistic reality also appears prominent in Colin's day to day life where the ordinariness of fitting in with a group who share common ground is spoiled by underlying social conventions that spur exclusive practices.

*"its nice to speak to same sex you know, 'cause i', in the two and a half years I've never been invited to a coffee morning you know"*
(C22:4-5)

Colin's desire to 'normalise' his position leads him to ponder his new 'place' in society where he questions who he is 'the same as' and from whom he differs. This is clearly a difficult process given that Colin has taken the primary care role in his family which was an unexpected and staggering change from his previously recognisable, normal role of 'bread winner'; he navigates social environments normally associated with females and; his face to face relationships with others in the way he feels he is perceived, as well as how he now perceives them, has significantly altered from his norm. Colin's feelings of disconnection are highlighted when others articulate their lack of understanding by suggesting that he might have been especially selected, singled out or even 'lucky'. He makes it clear that he does not wish to be 'the chosen one' where his irritation stems from his belief that the 'other' in question would feel the same way. To this end, Colin naturally gravitates towards those who appear to offer a potential shared understanding of what his life feels like.

> *"the people I've met with kids with disabilities are all salt of the earth, they'll do anything for you, sit there and listen, they know where you're coming from"* (C13:32-34)

Colin thus chooses to spend time amongst people who attend clubs and groups specifically aimed at families touched by impairment. He reveals these assemblies of 'other' people to be forums which present opportunities for him to not only be somewhere, but also to feel appropriate and worthwhile. The clubs are also alternative 'safe' environments (from home) where he can assess his feelings about his situation and be relatively reassured. This is enabled when he observes others and makes comparisons which he carries out over many levels. To this end, Colin's experience alongside 'other' appears to be one of dichotomy. He is consoled by ideas of belonging to a group of people he admires (other parents) whilst he also views the same group as 'other' given that he understands Disability to be intrinsically linked to 'otherness'.

> *"...when you go to like Howville Manor, it's like the kick up the arse that you need, because you see kids that are really messed up, you know, and you think like f'king hell, here's me like feeling sorry for meself all piggin' week, just been to Howville Manor and I haven't got to cope with wipin' a kiddie's arse at 12 and stuff like that..."* (C9:23-29)

For Colin, Disability symbolises difference in terms of being strange and unfamiliar, alien and at times, grotesque. This has impacted upon his experience of becoming a father in ways which mean he is still coming to terms with wishing his daughter had passed away and believing he was bringing home *"damaged goods"* (C12:30) from the hospital. Colin continues his disparaging vision of Disability in blaming 'it' for Helena's behavioural problems whilst perceiving her as an unfortunate victim.

> *"...you start shoutin' at her and then you, you sit back, you think well f'king hell, it's not her fault you know..."* (C10:9-10)

Together with believing that Disability spoils what would otherwise be his (and her) pleasant life, this arrangement 'allows' Colin to perceive and love his daughter as a struggling human being thwarted by her impairment rather than continuing his original concept of her being the *"monster"* (C5:36) and *"freak"* (C8:27) he believes he had created. Colin has also consciously forced himself to feel more comfortable with Disability by 'desensitising' himself to the 'disturbing issues'. This process apparently

began when he proactively researched and sourced information which meant that prior to him receiving an 'official' diagnosis he had already collected 'horrifying' images of his daughter's suspected condition.

> *"I mean you see the worst case scenarios you see er, er, the, the, take the kid gloves off, you know the, the kids are pig ugly that you see on these, it's the worse case scenarios, they're dribbling, their backs are all knackered and you know and I'm thinking Christ, what's going on here"* (C5:5-8)

Rather than feeling devastated on receiving confirmation of Helena's impairment he remembers enjoying a sense of absolute relief.

> *"as soon as I'd got the diagnosis you know, that was it, you know, I could tell people, I knew what it was, I could put me finger on it, it was great"* (C11:1-3)

The diagnosis also appears to have given Colin a foundation for reaping further practical knowledge and this helps him to understand his daughter *and* facilitate his communication in being able to explain and mediate his (and her) position to others. Yet, gaining insight into his daughter's condition is simultaneously a negative endeavour for which he feels a 'brave face' is required. In constantly reminding himself of *what* she is like (and not like), he explores his understandings of what he finds acceptable (or not) and thus Helena's overall desirability in the social context.

> *"you're always comparing with other kids and when we've looked at her in comparison with other Prader Willi children…we would say she's ahead in everything apart from the speech"* (C14:38-40)

As a result, Colin feels most comfortable with parents of children he considers to be 'similar' and 'worse off' than his daughter.

> *"I suppose you start to compare yourself don't you? And I think…I don't think it now, but I used to think it then, you know, it could be worse, I could have had a kid with Cerebral Palsy you know, I could have had a kid with Down's because everyone knows you know what Down's is like erm, and the, the truth of it is and its probably only, the past twelve months that I realised this, that... you're all in the same boat, Disability"* (C8:36-42)

He has apparently assumed his place to be nested amongst hierarchies of 'type' (impairment, children, mothers, parents) where he is yet to feel entirely comfortable in his new territory. In this, Colin understands his life now as evolving into something else as well as feeling that he is becoming somebody else. The impact of 'other' within his experience has thus been obviously profound where he now feels he is becoming 'one of *them*', whilst 'other' is rapidly becoming someone he recognises as his *old self*.

**"I knew my life had changed, you know, what a difference, what I didn't know was that it had changed for the better"** (C7:39-40)

## SELF

**"your expectation is though is you, you'll just have kids, you'll grow up, you go to school and all that and to sort of like, have a kiddie that's got the Disability, you sort of like take that different view, I think is, I, I'm glad I've had me eyes opened"** (C22:32-35)

To a large extent Colin reflects upon his developing sense of 'new self' through his understandings of being with 'other'. He is able to identify what he gains from whom and in physically directing the closeness of people he is able to control his emotions. In the process, Colin appears to be (re)fixing the proximity of his relationships with 'other' where notably: he yearned to bond with his daughter; he engineered 'escape' from his 'over bearing' mother; he cited the speciality of rare embrace from his brother; he kept his friends at bay via the telephone and he launched himself into meeting other potentially like minded parents. In this navigation of his developing self, Colin considers the ways in which he now lives amongst other parents and amongst Disability.

*"you know to suddenly have a kiddie with special needs, to meet other people who've got kids with special needs, and do I, do I feel sorry for them? No, I don't. Do I pity them? No. Do I know that they're challenged? Yes, erm, would I swap what I've got? No, I wouldn't erm... I, I believe that they, the challenges of Cerebral Palsy and... things that are worse... could be considered worse than Prader-Willi..."* (C9:14-19)

He muses over perceived burdens of responsibility and by comparing himself to them and their child to his he seems able to gauge his own status and sense of well being. In his deliberations, he does not wish to describe others as requiring pity as he is the same

as them and he does not require pity. Instead, he wants others to recognise his difficult position and be honest about how they might feel in his situation. As such, he has a frank approach in telling other parents of disabled children how 'life is' and in this, he confirms their status in his perceived world.

> *"when I've been in conversation like I've been with you today, it, you know, don't ever forget, you, you, you have been dealt a shit blow and it is and that's the reality of it"* (C24:24-26)

To this end, Colin reassures himself he is not alone and the most significant person 'sharing' his experience appears to be his wife Hannah. Given her unprecedented level of closeness, he often makes references of '*we*' throughout the telling of his experience and in this respect Hannah appears to provide him with valuable, unspoken support in his everyday life. Colin portrays her as being a mighty, coping force against his weak, collapsing self, given that to him, she did not appear to falter under the pressures of change.

> *"she's like a Trojan my missus, you know, she'll work through anythin'"* (C2:2-3)

As a consequence, in spite of their intimate connection his difference from her is clearly brought to consciousness.

> *"I'm sure, I'm sure Hannah will put a different spin on it"* (C21:41)

Colin realises she will have experienced different emotions to those he has felt and she will thus have a different 'story' to tell and in this, he reveals his feelings of supreme difference and the extent to which he ultimately feels alone. Nonetheless, he appears determined to maintain a positive front: he consciously portrays himself as lucky, a good communicator and a good husband and father. He also regards himself as compassionate and open with an optimistic outlook. In telling the stories which carry these details, he sounds happy and convinces himself (as much as anyone) that: this is who he is. However, Colin claims that he is often misunderstood and this might be closely related to the contradictory ways in which he portrays himself. His self-assurance is readily exposed as flawed when alternative stories bring to light contra-indications which also belie his altruistic air. To this end, his positivity is placed in perspective when he declares his misfortune or reveals self-centredness. Through his

contrariness Colin continues to determine the ways in which he now feels 'different' and this is made transparent for him when he spies 'newcomers' to his situation.

> *"...and erm this, this bloke was in bits, absolutely in bits and I could see that he was like I, perhaps not as bad as I was, but he was along those lines"* (C13:18-19)

Colin remembers how life was when his daughter was born as a time shrouded by emotional turmoil where he experienced feelings which he describes overall as 'grief'. Engulfed by self-pity, he seemed to be unable to find a way to regain his dignity and self-control and thus his 'normality of self'.

> *"...so I remember going off on the sick, spent me time going down to see the kids and sort of like wrapped meself up with that..."* (C6:39-41)

Colin refers to his return to feeling more 'normal' as being a very gradual and continual progression and within this apparently slow endeavour, he seemed to undergo a series of 'awakenings'. These appear to have been triggered by events, encounters and interactions through which he felt the changes in himself occur.

> *"there's a lad there (...) and he's got cerebral palsy, an' I'm talkin' cerebral palsy as much as, all he'll do, he, he can't acknowledge you (...) and d'you know some'at, over the summer period, I missed that kid (...) when he wasn't there, I missed him, I mean, ah, erm, would I have him as me own?... yeah, I, I probably would and I'd be proud to"* (C8:45-C9:6)

Colin's stories in his experience thus reveal *what* changed: his values, skills and abilities, concept of self, as well as his expected and actual roles of 'parent' and 'job' were all brought to light as having been transformed. He also understands that he *is* now different from whom he was 'before', to other people, to his wife and family and especially to his daughter who has impairment where she has perhaps presented him with a sense of *unknowable* difference. These combined elements rouse his feeling of unsettled discomfort not helped by his awareness of being a man amid groups of women. As such, Colin finds himself looking for male company, believing men will share a closer insight to his own experience given that he understands his experience to be particular to him being a man.

*"...from, from a bloke point of view and it is totally sexist here, and I'm not a sexist person but you know for, for it to happen to, to me, its the end of my world, do you know what I mean? What have I produced? This little monster..."* (C5:28-32)

Colin displays characteristics that are often associated with 'manliness' not least with his attempts to conceal and contain his emotions. He delivers his stories with a tone of shocking bluntness in a bid to avoid internal stirrings of his 'macro-emotion' and when listening to him this is revealed as an obvious struggle. As such, Colin seems to be exploring the limits of his changed self where he appears to push himself so that he can *feel* how far he has journeyed, whilst he also tests how far he thinks he could go. In turn, this apparently makes a positive contribution to Colin's understandings in relation to his feeling 'comfortable' whereby he does seem to be gaining ground.

**"I'm getting my life back now, I, I've never been to the pub so much in me life, it's brill"** (C14:25-26)

### *BEING A PARENT*

**"..woke up and it was 10 o'clock and I was in tears and I had to get up and was thinking 'Shit!' you know, what's happened here you know, it was so, now wha', you know and it's all going round, me life's changed, we can't do this, we can't do that"** (C6:7-10)

Colin describes parenting as being a *"privilege"* (C16:40) and thus many of the actions, thoughts and feelings that he has experienced most recently do not marry with his precedent understandings where instead, he has felt the full force of being *"dealt a shit blow"* (C24:18-19). He pays homage to socially accepted assumptions when he frequently glosses over detail as he clearly feels the difficulties of such things as balancing work, life and family are the same for everyone, not just him. However, by bringing these issues to consciousness, he provides a basis for revealing the ways in which his parenting role *is* made harder, worse or pleasant in abnormal ways.

*"...it was great what the hospital did but it was the bit that where they sort of like went over the top, you know, all the nurses come out to see you, you know, 'cos you've been there such a long time, I would've like to have just slipped through (...) f', for everyone sort of like you know, oah, 'you're going today', you know, 'brilliant', you're thinking f'kin' aaargghhh its horrible..."* (C12:35-47)

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As such, Colin's experience appears to transcend the socially accepted realms of 'usual' parenting whereby he underwent extended stays at a number of hospitals during which time his babies were cared for by others. He describes the ways in which he suffered feelings of abject grief for his baby that had not died and how his expectations of being joyous were replaced by feeling utterly deflated and depressed. As a consequence, Colin's 'father and daughter' relationship with Helena clearly began in an unpleasant way, under shocking circumstances in an apparently hostile environment.

> *"...cross my heart, within 45 seconds right, the room the size of this, it was empty (....) they weren't interested in me, you know, piss off kind of thing, dumf, that was it, rushed us straight down to theatre, I'm trying to find out what's going on..."* (C3:23-28)

Colin explains that Hannah was sped to emergency theatre in premature labour where he witnessed his babies being 'dragged out' and subsequently whisked off to intensive care. Spending hours at the hospital he was clearly desperate to forge a connection with his poorly daughter.

> *"all she did was just open her eye, one eye it was, wide open, sort of like focussed on them for about 5 seconds and I said, 'its like winning the lottery!' and after all them weeks and I still maintain that's one of the things why I couldn't bond with her"* (C4:24-26)

Colin appears to have since struggled to find a comfortable bond with Helena, whereby throughout the telling of his experience he seems to be looking for a 'way in' to reach the level of understanding that he feels he has attained with his other two daughters. Given that Helena is one of twins his route appears to be obscured by her unpredictable behaviours which he believes stem from Disability.

> *"I, there's certain thi', I still don't know... certain reactions that she will have, knowing her as a 2 year old, whereas Rebecca she is totally, I, I can read her like a book you know, whereas Helena's just Helena, she can go one way or the other"* (C10:14-17)

He sees Disability as preventing him from being the parent he wants to be whilst he also believes 'it' has ruined his opportunities to 'simply' enjoy having twins and his

expectations of family life in general. In this respect, he has experienced a sense of being bound and restricted by his disabled child. This feeling is exacerbated by the additional expense as well as the practicalities of looking after an 'awkward' baby where Colin cites this combination as resulting in hard work and mental exhaustion. However, he pacifies himself in believing that, given her particular condition, Helena could eventually move far away. Besides possibly contributing to his difficulty in bonding with her, Colin 'normalises' this apparently 'abnormal' feeling by suggesting that he is being a good parent in doing what will be the best outcome for Helena. In fact, he regularly reassures himself with such 'normalisations' and perhaps most significantly when he wished his daughter had passed away as a baby. He understands this to be an abnormal feeling for any new parent, yet, in the context of seeing her struggle *and* knowing his wife was in agreement, as well as telling others, looking for and receiving sympathetic reactions, he readily convinces himself that *anybody* would feel the same way.

Colin's 'abnormal' experience also illustrates how 'normal' parenting behaviours can appear magnified and damaging.

> *"I mean, like now, we get with the parents you know, 'isn't she doing well', you know, 'she's doing absolu'', you think 'will you just shut up!' you know, it's as if they're tryin' to make you feel better"* (C7:29-32)

He clearly expects and needs his parents to understand how he feels yet he is apparently annoyed that they are (naturally) protective and reassuring. Instead, for them to show that they do understand, Colin wants them to be 'realistic' and forthright on his terms. In this spirit, he is prepared to be candid and suggest to other parents who have undergone a similar experience that they too have been extremely unlucky. This facilitates Colin's impression of their collective identity and promotes his self-assertion in this manufactured form of solidarity. However, in the turnaround of associating with other parents at specialised groups, Colin is presented with contrast and this helps him to recognise the ways in which he is able to continue his parenting life as ordinary.

> *"I'm like any other parent"* (C16:29)

As such, his experience exposes his 'normal' parenting behaviours to include nurturing and caring for his daughters, educating and teaching them 'morals and manners' as well as contemplating what their futures may hold and; he has a robust sense of parental achievement and pride through keeping them busy and 'stimulated'. In this, Colin portrays himself as a father who is doing 'his best' (against the odds) and as a consequence, one who *is being* his perceived ideal of what it means to be a 'good parent'. This developed sense of 'proper' parenting works in tandem with his receipt of welfare benefits in facilitating thoughts of his full time role of parent as his 'job of work'. As such, from origins of feeling hopeless, helpless and distant Colin does appear to currently have a strong sense of what *kind* of parent he is through him choosing to access a myriad of clubs and groups where he can meet and be amongst other, like minded parents.

> *"I might be wrong, I might be right, but I know which set of*
> *parents I prefer, you know and I, I enjoy going to me opportunity*
> *groups, I enjoy the people I meet and, I won't even say it's a wake*
> *up call now, because we, we're all, like I've said to you, this past*
> *12 months, I believe we're all in the same level"* (C13:37-40)

Being part of the 'opportunity groups' has provided Colin with a platform upon which to feel *confident*. Despite graphic description of difficulty and surges of emotion throughout the telling of his experience, Colin is able to finally reflect upon and summarise his experience overall as having been *easy*. This curious 'reversal', no doubt made possible with hindsight, seems to relate to his regained sense of 'normality' as well as his resilient outlook where he supposes:

> **"I know I've been dealt a, a shit lot of cards, but its how you play**
> **those cards in it?"** (C24:27-28)

Please find Colin's completed summary with corresponding 'naïve summary' in appendix 5a (p.321) and relevant reflexive notes in appendix 6a (p.329).

# HANNAH

Hannah was my last interviewed participant in the study and when I first met her at her house when I interviewed Colin, she appeared confident, pleasant and composed; she was very interested in the research. I learned from this initial visit that through their changed family circumstances Hannah had maintained her role of working mother, running her own hairdressing business whilst Colin became 'house husband'. I returned two weeks later to conduct the interview and Hannah once again greeted me with her children at the front door. It was a very warm day and once we had chatted for a short time with Colin in the kitchen we took a drink into the lounge. The windows were open which meant the overhead planes were even louder than they had been on my previous visit and the little girls stayed at home for the first half of the interview and played in the back garden having just had their lunch. Fortunately, none of these things spoiled the recording and overall the room was actually very quiet: it was peaceful and relaxing with a breeze occasionally catching the curtains, wafting cool air into the room with the children's play chat and laughter in the background.

Once we began talking, it became clear almost straight away that Hannah did not often (ever) talk about her experience, when alone with me she spoke quietly and slowly. Almost immediately Hannah became emotional as she began to unpick her feelings and share her thoughts about her experience. The gentle atmosphere of calm in the room, her being aware of my understandings through my experience, as well as her own timing of feeling she might be ready to talk, I feel combined to create a powerful stimulant which overwhelmed her suppressed emotions. I asked if she wanted to stop when tears welled in her eyes, but armed with tissues she had placed by the side of her chair, she said she was happy to continue. I could see that she was comfortable but moreover, that she wanted to talk through her tears and sadness generated by 'what happened' and how she had felt at that time which she was able to do throughout our conversation.

The burdening emotion released during Hannah's interview was exposed in the analysis process as '*pressure*': the sensation she portrayed throughout her experience as feeling crushed by the strain of living her life. The data thus revealed 'pressure' as an overriding factor to two super-ordinate themes: *'Mothering'* and *'Emotion'*.

# MOTHERING

*"... it was just the trips up and down to the hospital and that's where one day, just, I can't remember how many weeks it was because everything, the days seemed, I can't remember one day, 'cause one day is the same"* (H4:21-24)

Hannah does not have a practised 'story' to tell about her 'mothering experience'; she has lived the experience day by day and as such, the early days of having her twins have become blurred recollections of indiscriminate lengths of time. She felt she was going through the motions of life at the mercy of what was happening to her at the time, only staying in tune with her senses and feelings within. From this, Hannah has thought hard about how and what she would be able to talk to me about: her experience has 'simply' been a patchwork of controlled emotion, where events have become barely distinguishable. It is only as she speaks that Hannah recognises the various times throughout her experience where she was able to determine what to do and how to be. Through this, it becomes clear that her way of dealing with her perceived mothering problems is to keep focussing on what is ahead, even though this activity often manifests as the 'problem':

> *"it wa', it was, it was extremely frightening really when, when I look back, I never really thought of it like that before but it was, it was really frightening to think what would be, what would happen in the future" (H7:19-21)*

This 'forward looking' approach, together with her previous experience of failed attempts at becoming a mother gives her reason to believe in herself as a strong person. Through having this developed understanding of what it means to be a mother she feels bonded to womankind. In this, Hannah believes the concomitant feelings and heightened senses that she has experienced are naturalistic to her being female and it these factors that she feels have 'driven' her experience. In light of this, Hannah's intuitive apprehension that she was going to have a poorly baby was so palpable that she arranged additional scans and appointments to see doctors who could look for confirmation of abnormality. When nothing could be reported Hannah felt it was important that her instincts were later 'proved': her babies were born prematurely and this was eventually followed with an official diagnosis. At this point, she remembers feeling compelled to appear optimistic, not least, for her husband's sake.

> *"I think really, because I think maybe I hid what I really felt*
> *because I knew that he was, because you can't have two of you,*
> *can you?"* (H7: 1-3)

As 'wife', Hannah assumes they both take a shared approach to the values of parenting: she believes they think the same way about most things. To this end, she is very clear that Colin was not failing her at the time, she could see why he broke down, it was a very difficult period. She could also see that somebody needed to stay 'strong' for the family and she felt she was the only one who was both capable and well placed to do so. In taking this 'commanding' role, Hannah became detached, where in a sense, she removed herself from the centre of crisis and organised from an 'external' position. By remaining single minded, she was able to re-focus her active maternal role away from her new born twins and instead, by appearing positive and 'normal', ensure her husband and older daughter were helped to feel assured and thus protected from the trauma as much as possible.

By taking this deliberately matriarchal stance Hannah is now able to reflect upon how she feels she has had to make an ultimate sacrifice, losing her 'old self' to profound change both in the ways she thinks and feels as well as in her relationship with her husband. Hannah also sees that coming through the difficult experience has intensified her understandings of others who can now appear to her as unknowing, shallow and narrow minded. Such people can sometimes remind her of her 'former' self: *she* used to think as they did and she ruefully understands why they may think badly of her, say hurtful things or behave in certain ways.

> *"...that sounds terrible that, holding, if somebody said, if you said*
> *to somebody that you were holding back and not loving your child,*
> *I'd take that as something else prior to Helena I think, oh God,*
> *that's disgusting, that's terrible, how can somebody be like that..."*
> (H15:13-17)

As such, throughout the telling of her experience Hannah judges her own actions when she describes them as if through the eyes of other mothers and always in a bad way. Hannah is thus faced with the dilemma of doing what she feels she has to do, 'knowing' that she will be viewed in a negative light. In addition, Hannah also feels the frustration of being able to understand her experience from alternative perspectives beyond her own, whilst nobody appears to take the trouble to listen, see or understand

her seemingly impossible situation. She feels entirely misunderstood by most of the people she meets.

> *"...maybe you've got to be in a situation yourself to be able to understand a certain amount of feelings about other people's lives"* (H19:13-14)

To this end, Hannah takes the extreme action of starving herself to understand *properly* how her daughter may feel and she believes that only other mothers who have children diagnosed with Prader Willi Syndrome will have any idea of the maternal difficulty that ensues. However, whilst Hannah shows compassion for these parents, it is at a distance; she uses their experience to glean knowledge and she learns from their mothering techniques in order to develop her own.

> *"... I kind of like, pick it all out and think, well maybe I should, I won't throw the word 'active' into things, d'you know, we'll do it another way, we'll have animals, we'll go for walks..."* (H22:19-21)

In this process, Hannah feels she is under pressure to maintain her family as a close and bonded 'unit', a dire imperative as she knows, having seen others, that her daughter will suffer in later life if she fails at this. Yet, in striving to do the best for her daughter (another maternal pressure) an opposing issue arises: she feels she *must* treat Helena differently to her sisters because she understands her to have different needs. As a result, she is faced with incongruous mothering issues and given the ostensible glare from the 'public eye', she feels trapped in the inevitable roles of 'nasty mummy' and 'bad mother'. These roles are highlighted for Hannah when she experiences other people physically intervening with her child's welfare. Their actions unwittingly confirm Hannah's sense of knowing how she is being perceived.

> *"... 'cause you always get somebody who says, 'oh, go on mum, let her have a little bit of cream cake' and I say, 'no, no, she can't have it', 'oh, it won't do her any harm', you get an awful lot of that and it's so hard..."* (H20:9-11)

This also brings to light the degree to which Hannah has experienced the struggle of literally being able to mother to her daughter. Hannah's sense of what motherhood meant to her before her daughter was born surrounded such elements as giving birth, feeding, nurturing and enjoying spending time with her children. She understood the

role to dovetail with being a working woman, where her older daughter attended day nurseries and now school. Her ideal is inconsistent with her lived experience with Helena. When the twins arrived, nurses and neo-natal staff took the primary care role placing Hannah's mothering as subsidiary to theirs. Realising there was nothing she could do to change her baby's condition and under the pressure of circumstance, Hannah felt she should return to work which resulted in Colin taking the traditional 'mothering' role of all her children.

However, given that her daughter has impairment, Hannah feels that her 'job role' within the context of mothering has somewhat intensified: helping Helena to achieve socially acceptable behaviours is her current mission. Her motivation for this is borne out of her own sense of social placement in relation to image. For Hannah, looks matter and the closely related issues of health and fitness which help to create her 'ideal image' are at the heart of her objective.

> *"...we've put so much into her (...), you know, I've, I've seen, erm, a couple of children, same age as Helena is now and erm, and Helena's the fastest Prader Willi kid I've ever seen you know (laugh) she moves so fast whereas other children, they just sit there and they don't move very much, they're very slow in their movements erm..."* (H18:17-22)

Despite feeling this current accomplishment as parent, Hannah's recent challenge focuses upon the difficulty of her daughter apparently looking 'normal'. Far from being ideal, this contradicts Hannah's *impression* of who her daughter is (certainly *not* the angel she appears) *and* it portrays a 'false' image to others. This is further complicated by the fact that Helena is a twin but she very much appears to be a younger, 'cute' baby sister and thus, the image of her family is askew. Hannah wants others to see that Helena has impairment as she believes this will pre-empt having to painfully explain and mediate their situation through awkward and upsetting moments of enforced diplomacy. Looking impaired would also justify her feeling as fearful as she does with her absolute dread of Disability.

> *"...we're not just dealing with a baby that's tryin' to get in the damn cupboard or screaming and throwing their selves around for food you know which happens now, we're dealing with an 18 year old and they haven't just got the food bit, they've got, you know,*

> *God, does this kid want a baby?, has she got a boyfriend?,  and*
> *you know, its all that..."* (H13:8-12)

Hannah's big issue *now* surrounds notions of what Helena will 'look' like in the future, desperately frightened by the horrifying graphic image that she has depicted and established in her mind. This impending doom is amplified when she meets older children who have Prader Willi syndrome who appear to be giant size versions of 'what' her daughter is and they represent a likely undesirable future lifestyle. Whilst she finds this most unacceptable, Hannah does not see other parents as failures, she understands their struggle. She knows that Prader Willi Syndrome is relatively uncommon and as a form of impairment, it is very low on *any* agenda; she thus sees it as being disregarded by 'experts'. As a consequence, Hannah has decided that besides not having any *real* understanding, professionals are in no position to offer any guidance or assistance. As such, Hannah perceives other parents to be coping well in that they appear happy and are doing what they think is best under difficult circumstances.

Hannah feels the full might of her 'task' ahead when finding Helena displaying 'unattractive' behaviours associated with her particular impairment. Wanting to eat all the time, to a point where she will consume dog food challenges Hannah's healthy (and normal) image ideal: she is repulsed by what she sees. Hannah manages to pacify herself with the idea that this is not her daughter, it is the horror of the Disability which causes this behaviour and she feels 'it' must *not* be ignored. Hannah has seen how the 'food cravings' can lead to more serious behaviours such as being devious and stealing and already, Hannah is becoming wary of taking her daughter out and to the shops. She is currently dealing with unpredictable behaviours but with these at least, she feels partially consoled by comparing her difficulty to other mothers: their issues pale to insignificance in light of her own and this gives her a sense of understanding of the ordeal that she undergoes every day.

> *"... a little girl started screaming and I could tell by the mother's*
> *face that this, this wasn't, this wasn't the done thing and it*
> *suddenly occurred to me that this happens to me all the time (....) I*
> *think I notice things like that sometimes because your situation,*
> *you're just so.. it's the norm isn't it?  you know, and all of a*
> *sudden, somebody does something and you think, 'oh right, this*
> *happens to us all the time'..."* (H24:49-H25:8)

These occurrences foster feelings of having a very different experience to other mothers and Hannah has been all too aware of this from the beginning. The prolonged relationship with hospitals brought about initial 'numbing' to her sense of motherhood: she behaved as automaton by expressing breast milk, freezing it, handing it to nurses, travelling back and forth, going to work, being 'false' with clients and having no real, significant soft interaction with her baby that she recalls. Having to be shown how to tube feed and inject the infant created a further sense of distance between them where she could only view Helena in terms of 'other'.

> *"I, I know it's a baby and you've got a baby and it's a fine baby and again, that's 'what do I do?' but this is just, this is a one off, this is completely different, why have I been dealt this? What the hell am I gonna do with it? That's quite frightening..."* (H17:25-28)

The void that was formed at that time continues to present day where Hannah feels she still cannot love her baby properly. This sense of betrayal is deepened when Hannah realises her tactical diplomacy with outsiders is in fact another form of her simply being disloyal to Helena. Hannah also feels she must deliberately create 'conspiracies' *against* Helena so that her food can be controlled and this leads to her instigating the whole family into treating her as different. As a result, Helena is continually maintained in her position as 'outsider' and although Hannah is aware of this, she feels justified given her incessant maternal drive which relates to her other children:

> *"...it will affect my other two children, like you're just giving them a bag of Maltesers, you go (whispers) 'come in here, come here, go and eat them in there so that Helena can't see them', and we can do that now, at this period, but when are we gonna have to stop that and the other two'll get affected by it more..."* (H19:21-25)

As such, Hannah maintains her original innate and sickened sense that Helena is and always will be a burden in their family. This feeling stems from the time of diagnosis when, although she was already a mother, she felt that the mothering of *this* child placed unwelcome emphasis on the need for extreme and prolonged care. At that time, the burden felt so great that Hannah longed for Helena to die and wished to be transported to the future where she would 'only' have to deal with the grief of losing

her baby. Significantly during this period Hannah felt the onus of her feelings towards Helena could not be shared with those closest to her: her husband was weighed down by his own immense sense of grief, her mother showed no understanding of her problems and she knew that her situation was her best friend's 'worst nightmare'. Under this degree of pressure, Hannah felt her only 'mothering solution' was for her to *"switch off"* (H12:17) from the trauma and keep her emotions under control.

> ***"... so maybe I was on automatic pilot for weeks and weeks and weeks just er... and eventually I just knew this would pass and that's why I wished two years would go of me life and then I knew where I'd be and that I could be normal and natural and be dealing with what I knew I could deal with..."*** (H7:11-14)

### EMOTIONS

> ***"...I, I do, I do think that sometimes other people think I'm a bit, a bit hard or indifferent you know, in the way maybe I do deal, treat with things, but again, I suppose I try and balance things....I'm quite practical maybe, a bit too practical sometimes er just in the way I manage, manage me emotions really..."*** (H10:48-11:1)

> *"....and she said, 'I've got the diagnosis d'you want to come in the room'...(...) that's when they told me that, erm... and either it was a relief or I was, I was devastated, but I just tried to sort of hold back, yeah, hold back the tears in there and then it just went quiet for a minute, hold back the tears and then just said, 'right ok', I think by the time I got out of there, I got me head round, yeah..."* (H14:24-30)

Hannah depicts two significant moments in her experience of 'being a mother' which appear to underpin her condition of feeling the need to consciously and deliberately take control of her emotions throughout. The first was 'the diagnosis' where on receiving this official information Hannah felt she could really *know* what she was dealing with. Her worst fears had come to light, she had thought something was wrong and being told merely confirmed this, hence her initial sense of relief. However, what she was told also meant that she had to become even more resourceful in hiding her true feelings, the 'devastation' set in: Hannah realised that she was no longer hiding her emotions on a temporary basis; she was going to have to hide them for good.

Hannah was shocked into taking 'direct action' over her emotions at a second noteworthy moment in her experience when she met older children who had Prader Willi syndrome. Hannah was extremely alarmed by seeing clearly that her daughter's specific impairment challenged her core principles in life. It was a discovery that instilled a sense of panic and urgency to begin 'work' on Helena and *"it was like the start then"* (H19:38) to her rooted determination to control her emotions. By keeping a strict regime and control over Helena's diet, Hannah has a focus to direct her sense of 'doing the right thing' as a mother. It also serves the important purpose of creating a tangible 'front' to her inner emotional turmoil. It is something onto which she can 'grasp' with the anticipation of making visible constructive progress as Helena grows. The desperation comes from Hannah being painfully aware that she is fighting a potentially 'lost' cause where her daughter may resort to eating anything.

> *"...as she gets older it will get worse and worse and worse for her and I actually have known someone who's eaten goldfish..."*
> (H19:19-20)

'Emotional triggers' such as these remind Hannah that she is constantly struggling to keep control of her surging feelings of hopelessness, anguish and exasperation. These, together with fear, isolation, anger and hurt regularly feature throughout her experience. Hannah portrays the effort of keeping these emotions at bay as being a physical and deliberate task where in her mind she has felt the need to 'harden up', 'hold back', 'put' things to the 'back of her mind', 'step to the side', 'get a grip', 'move on'; all in a bid to convince herself to keep going:

> *"... you put the bridges in yourself as you deal with things..."*
> (H15:27)

With the aim of gathering strength, Hannah reminds herself of her fortune as a mother given that at one time she was unable to have any children. However, this reinforcement results in further negativity where she feels obliged to be grateful. She cannot allow herself to complain given that she willed these children, bringing Helena, into her life. As such, she has an enormous sense of self endowed strain where she feels she ought to put forward a brave face. Taken with the demands of running her business, facing the 'public', maintaining stability as well as an optimistic air for her family *and* having to accept a 'repulsive' form of disability in her life, she felt her only

option was to take the dogmatic stance of apparently ignoring the detail of her circumstances.

> *"...it's almost like erm, you sort of like, pretending you haven't got a situation to try and get past things..."* (H8:28-29)

In controlling her emotions in this way, Hannah exudes an essence of calm which manifests as diplomacy with others and austere mothering with her daughter. In earlier days, she reveals that she was able to develop this calculated approach by using her return to work as a form of escape: this gave her the physical space she needed to be away from her family, her husband *and* Disability.

> *"I used to go into work and there was nobody around, just put the Bay City Rollers on (both laugh) yeah, just like, I just like (voice breaks) you know like, get it out your system (fighting tears)....and when anyone came in, it was just like, you know, you had your automatic face on then.... so that's what it was... and I was away from Colin so he didn't see I was struggling with it as I really was (tears)"* (H4:11-16)

Already feeling guilty for not being at the hospital, Hannah was also able to use her business as a form of self-justification for her apparent 'socially abnormal' mothering behaviour: she was clear that she *had* to return to work and as a 'business woman', she felt she could not be emotional. Moreover, by limiting herself to only short periods where she could be entirely alone, Hannah developed 'controlled thinking' time; she never let herself overly dwell on her experience as it was happening. As such, Hannah's ability to pretend her life could carry on 'as it should be' allowed her to gradually cultivate a sense of comforting normality. In the twist of her imagination, her 'reality' appears as the abnormal: a frightening "*here and now*" (H5:21) brought about by Disability.

> *"...it's just not normal and I think when you see that with her as well, you think (sigh) you know, sometimes like your stomach churns over and your head (...) we have got something that's a little bit different here, that's just a bit, e's, I mean, every now and again, you get one of them, a reality shock..."* (H13:29-33)

Hannah's perspectives are thus divided: she has her own 'world of pretence' where *her* reality is her difficult struggle and she also sees "*how life is really*" (H5:34) which is

the non-disabled world of how she used to be. Hannah sees everyone else continuing in their aims to achieve success; they strive to move on to bigger and better things as she once did. To convince herself that the 'sacrifice' has been worthwhile Hannah tries to see that her life has now become more meaningful. She feels that she is less driven towards materialistic gain and as such, she has less interest in established general societal values and activities. However, she also believes that she has had no choice in this changed state of affairs given that Disability was forced upon her. As a consequence, she knows her lack of interest in 'the other world' comes as a result of her feeling unable to do anything about it. She has, therefore, had to develop a sense of apathy about the matter to prevent herself from distraught collapse.

Hannah is painfully reminded of her situation through her close relationships. She sees her brother continuing to subscribe to the old ways of being and to counter her feelings of resentment, she tells herself it is he who is 'missing out'. Hannah is further confused and angered by her parents who appear to be living in their own world. They are oblivious to her dilemma which is most upsetting as she compares them to other parents who seem to effectively understand and support their daughter. Together with her best friend being "*like anybody else out there*" (H25:35) this has contributed to Hannah's developed sense of being alone where, in ultimate defiance; she proclaims that she *really* does not care. Hannah deals with this 'naturalistic exclusion' by further isolating herself: she makes time to go running and to the gym where she can block out her thoughts with music. Being in her 'own world' has a stabilising influence on her emotions so that when 'reality' does tap her on the shoulder, she is able to calmly mediate:

> "*one mum said to me, 'you've got erm, a child that's backward haven't you?' (...) I go a bit dumbstruck really (...) I just said, 'actually it isn't that, I think if you said that to anybody else, they might be a bit upset about that...'*" (H8:45-9:4)

Mediating is a necessary activity in Hannah's current experience, carefully honing what she says to others she feels immense pressure to get her message across and defeated when she fails. This is due to her experience ever being guided by what she feels will happen in the future, a 'battle' lost now, equates to a worse future to come. In this, Hannah is still driven by a will to fast forward her life, to know what it will be like, believing the struggle will not be any less but that she will have learned how to

manage her emotions more effectively by then. For now, when she looks to older children with Prader Willi Syndrome for clues of what the future holds, she is frightened by what she sees. She is frightened by the life she will have to lead in *getting to* the 'future', (which for her is any point in time ahead) and she is frightened by how she imagines life might be when she reaches that point.

> *"...it, it frightens me how things are gonna transpire in the future for Helena and if I'm gonna be strong enough for other parents like, children are not gonna invite her to birthday parties (...) especially if it's a friend of yours maybe it, or you thought they were..."* (H9:8-12)

To this end, Hannah is worried about how she will find ways to negotiate her family's position alongside others who reveal themselves as unable to understand and faithless. Through her own sense of exclusion, Hannah can see how being different 'will' eventually impact upon the whole family. As mother, Hannah is particularly anxious for her other children as she can see how they are *already* affected and most hurtfully, this is via her own parents. It appears bizarre and neglectful to Hannah that her parents single out Helena for special treatment where, by doting on her in this way, they are not being fair to her other girls. In compensating for this, Hannah consciously makes an effort to spend time with her other daughters whom she feels will grow up to be like her, eventually becoming independent and leaving her alone with Helena.

> *"I kind of like, I, I hold, I don't love her any less...but I sometimes hold a bit back from her somehow because I know in some ways I'm gonna have to be a bit more practical in approaching what problems are gonna be arising in the future.."* (H15:10-13)

Hannah accepts that she holds back from demonstrably loving Helena: she cannot feel affection for her daughter who is so unfamiliar and, from her understandings of older people with Prader Willi Syndrome, Hannah is expecting that Helena will later even despise herself. As such, Hannah feels she can justify her emotional detachment which she further verifies by considering it to be a form of self-defence and protection against what might yet happen.

> *"... it's almost like you're just waiting for the next blow up or....or something to go wrong..."* (H15:17-18)

She is all too aware of the unpredictable nature of pointed reminders from others and jabbing evidence of her daughter's behaviour which directly reflect her situation and how these moments can cut through to her core. Hannah therefore chooses to continue to live her life avoiding unexpectedness where she can. She is able to do this by effectively shielding herself and hiding in her 'own world'. By sticking to her routine, keeping busy with eyes 'fixed forward', ignoring the detail, she can shut off, *be* indifferent and simply 'carry on' as if everything is *just fine*.

> **"...if you were over the other side of the fence looking over you, you'd like to stay on that side you know, but with, prior to it, but once you've got over that fence, you know and you've been there a while sat in the long grass, you, you're not bothered are you?"**
> (H25:37-40)

Please find Hannah's completed summary with corresponding 'naïve summary' in appendix 5b (p. 323) and relevant reflexive notes in appendix 6b (p.332).

# JONATHAN

Jonathan lives with his wife Jemma and their two daughters the youngest of whom is Harriet at two years old and has been diagnosed as having Down's syndrome. I had already interviewed Jemma and this is how Jonathan came to learn about the research. He was keen to take part as he felt it important to add male voices to the myriad of experiences of women and when I heard his 'story' I realised more about why this might be important to him. He is the manager of a local supermarket and he has struggled to balance his home and work life where his experience exposes this as being 'the issue'.

When I arrived on the day of interview, Jonathan greeted me, smiling and showed me into the toy scattered lounge with Harriet toddling through with us; her older sister was at primary school. As Jemma was not going out, we arranged that she would 'entertain' Harriet whilst I chatted with Jonathan in the more peaceful conservatory. Jemma made us a cup of tea and chatting to Jonathan while we waited I found he was a

gentle natured person who spoke softly and carefully. This factor did worry me a little as I began to think about the recording although I had no need, it worked well and we were left undisturbed for just over an hour.

Both at interview and through analysis of the data, it became clear to me that Jonathan was a vehement advocate of 'family', with potent values of his being a 'close unit' as well as a 'place' to belong. In describing the ways he perceives and feels about the members of his family, both young and old, he portrays a man who is supportive and loyal whereby, he holds an inclusive perspective of Disability. As a consequence of these factors it was perhaps unsurprising that two super-ordinate themes emerged: *'Disability'* and *'Family man'*.

## DISABILITY

> ***"...but yeah... kinda hold... well not so much 'holding it together', but more... well it's happened... just... there's nothing we can do about it so... we, we... it's a sort o' whole new path in life..."*** (J4:36-39)

Jonathan takes time to think about what he is saying and his attention to detail is quite remarkable, picking through terminology and revising sentences in order to get the exact detail he wants. It becomes clear that this is his way of making sure that he portrays himself in a particular way where he does not wish to be misunderstood. For Jonathan, this is not about his 'audience', their potential reactions, thoughts and feelings to what he says are of small significance. He does not feel like he is mediating his position with a view to being accepted or even admired by others, instead, he is mindful of being 'true' to himself *and* his family. By giving detail and being 'correct' which for Jonathan means not exaggerating or giving 'false' information, he demonstrates that he was *there*; this is what actually happened in so far as this is his 'truth'. Giving detail is also Jonathan's way of being respectful to the subject matter within his experience and this generally includes the people he meets, his relationships and Disability.

In order to convey 'what happened' Jonathan reports a chronological understanding of events where his 'story' in the main, is 'guided' by conversation. In recalling what was said, Jonathan represents interactions he had with key people and this is his preferred way of being able to describe situations. These encounters are significant because they

represent the core meanings of his experience and he shows this through the detail he picked up from others during the process.

> *"...if she'd have said, 'paediatricians are just checking her over and you can see her in a few minutes', I don't think it would have twig', but, the fact that she said, 'they'll be out to speak to you in a few minutes'"* (J2:25-27)

By remembering these conversations, he is able to return to the event; how he felt at the time and what was going through his mind, if there was anything at all. Very often, he feels his mind went blank; he remembers he did not know what to think or how to think. This happened at times when he felt overwhelmed by emotion and had no control of what was happening around him. Each conversation therefore acts as a trigger to a memory and as such, they can appear as an isolated pocket of his experience in being a detailed 'snapshot' of the moment.

> *"...she (Jemma) did sort of say to me, 'where is she?' and I said, 'they've taken her downstairs to neo-natal, they're just a bit worried about her oxygen levels'"* (J3:42-43)

The 'beginning' of Jonathan's relationship with his daughter was fraught with action followed by a vacant and then bewildering calm: he recalls the panic and rush of his wife being sped away for surgery and the contrast of then being left alone in a stark and empty corridor where time, for him, seemed to lose it's place to eternity. When 'finally' a midwife appeared, he remembers the etiquette; she apologised for leaving him outside and he was reassured to hear there had not been a death. This dreaded thought had crossed his mind yet, when he became wary that all may not be entirely well, he does not believe that Disability entered his thoughts. The midwife was followed by a consultant paediatrician whose conversation was short and Jonathan was left to make an educated guess as to what the doctor meant by what he was saying.

> *" ...he's a, a Kenyan doctor with a very, quite a thick, heavy accent and he didn't mention Down's syndrome... he mentioned the fact that she had a chromosomal disorder..."* (J2:39-42)

Jonathan doesn't remember how he felt at the time in relation to the news that his daughter may have impairment, this was a 'blank' moment. Instead, he recalls the detail, the words that were used and how they were said. He remembers being puzzled

by the doctor who he has since come to know as *"absolutely fantastic"* (J2:38) as to why he might complicate or 'hide' what Jonathan could see to be relatively 'simple' news. After this encounter, he was left alone with Jemma who had begun to waken more fully from her anaesthetic. He describes feeling worried at the time as he needed to find adequate words and the right timing to divulge the situation to his semi-conscious and thus vulnerable wife who had begun to ask him questions. As a consequence of being caught in the moment, being more concerned for his wife's welfare than his own, it was not until later that he was able to contemplate the implications of having a baby diagnosed with Down's syndrome.

> *"...it's just this shock to the system knowing that, it's just not going to be like that with Harriet, it's just going to be completely different..."* (J14:17-18)

Jonathan understands his feeling to have come from the impact of realisation that his expectations had been shattered. These were the many taken for granted assumptions about how his daughter would likely develop which he had primarily built from his knowledge of parenting his older daughter. Despite feeling that similar accomplishments were now unlikely for his baby he is clear that his 'shock' did not happen as a direct result of her being per se; he believed this was *his* issue underpinned by him needing to get used to a *"whole new path in life"* (J4:39).

In light of this, Jonathan physically modified his mind set where he reconsidered his traditional expectations in relation to ability and achievement and instead embraced originality. In this, he reviewed the situation, looking again at his daughter using a different 'barometer' and now understands that her development milestones are relative to her individuality:

> *"... you just think, 'God Harriet, you can achieve'"* (J14:21-22)

This positive outlook reflects Jonathan's already established understandings of human diversity and in tandem with this, his positive attitude towards Disability. His innate feelings on the matter led to him being perplexed by the treatment of his daughter from the outset:

> *"...they apply the same set of rules to every child in neo-natal and yet, Harriet was almost full term, where as some of them in there are born at 20 odd weeks..."* (J8:17-19)

Accordingly, Jonathan cannot identify a period of 'adjustment' to Disability, rather, he views the initial stages of his experience as needing the 'space' to spend time with his new born, getting to know her. Jonathan's understandings of Disability prior to Harriet's arrival may have possibly contributed to the positive development of his thinking: he had witnessed and admired his grandmother raising his uncle who has impairment, his wife works with children who have impairment and together with his wife he took the deliberate action of not having any pre-natal screening. Besides satisfying his integrity by 'standing by' this decision, Jonathan also began to realise fairly quickly that his baby, as the newest member of his family, deserved his allegiance. Feeling uncomfortable with announcing Harriet's arrival as if she was an unwanted dilemma, he determined that she should be welcomed into the world as a person, not as a 'problem baby':

> *"...so it was, 'yeah, we've had a little girl, she's, she's well, she's been taken to neonatal because she's suffering with her oxygen like, but, the, they're hopeful that she's on the mend from that, sort of, now, so... and, we had an extra little surprise, she's got Down's syndrome'..."* (J5:34-37)

In this, Jonathan does not remember people's reactions as they were not the issue, he needed to feel he had got the detail just right where he wanted to be clear that he was not imparting bad news. As such, he was careful to announce Harriet's arrival conveying the message that she did have a little difficulty but it was nothing serious. Using his school based understandings of 'Down's syndrome' to mean a person born with an *"extra chromosome"* (J2:47), he described his daughter's condition to others as something 'additional' and, although unexpected, he said it to them in the context of it being a bonus.

Fascinated by his new baby with an 'added extra', Jonathan remembers looking for apparent 'signs' of Down's syndrome when holding her and he tells this as if almost excited by finding confirmation of what he had been told:

> *"...when you did look at her from some angles, you couldn't tell she had Down's, from other angles it was as obvious as the nose on*

*your face and so, just, you know, when you're holding her like that,*
*then, just adjust her, and then, yeah! Yeah!   you can see her ,*
*there!..."* (J3:29-33)

Coupled with his knowledge of the condition not being a disease for which there is a cure, Jonathan accepts the notion that Down's syndrome and his daughter are inseparable. As a consequence for Jonathan, Down's syndrome cannot be a bad thing; 'it' *is* his daughter.

*"...every child is different anyway and every disability is different,*
*but er.... we just see Harriet as Harriet... she is who she is"*
(J13:36-38)

As such, Jonathan does not view Harriet as a 'burden'; he rapidly corrects himself from using this term, preferring to describe his feelings towards her as:

*"a responsibility that we're gonna have for the rest of our lives"*
(J14:46-47).

In this, he embraces the notion that she will always be his daughter bringing different and interesting aspects into their lives, not unlike his other daughter. Jonathan's understandings of Disability permits him to muse over ideas that both of his daughters may fulfil socially accepted adult roles, even if, he believes, some people with Down's syndrome may need a little assistance along the way. His perception of this comes in part, from witnessing adults accompanied by their parents when out shopping. From this, he can see how his life may turn out, but he stresses, it is by no means a foregone conclusion. When Jonathan read about other peoples' experiences on the internet, he realised the plethora of possibilities.

*"...I was doing it for about ten, fifteen minutes, and I thought, oh*
*you know, 'cause there's that many widely differing views and*
*opinions (...) there's that wide an extreme ..."* (J10:41-42&46)

Searching attitudes and perspectives from other's experiences, rather than finding medical information per se, is typical of Jonathan's relationship with 'other' where interaction and understanding through conversation is important to him. Tapping into internet forums allowed him to access opinion yet Jonathan also shows that for him, just being amongst or simply in view of people can constitute sufficient 'contact' with

'other'. In enjoyment of the physical company of others, Jonathan endeavours to attend various groups available to parents:

> *"...to hear other people's take on things and what they're up to and so on er... just trying to think, I suppose there's not that many dads that go along to these things but to me its somebody to talk to..."*
> (J11:26-28)

As such, Jonathan is a social being and comes across as being a compassionate, thoughtful man: when he received the 'complicated' diagnosis he worried about other parents who may not have 'even his' limited knowledge and having spent a fortnight going to and from the hospital, he remembers thinking about other parents who had longer stays. Whilst thoughts of this nature might have enabled him to put his own situation into perspective, he does not appear to perceive things from this comparative angle. Rather, Jonathan literally processes his thoughts with regard to him attempting to understand 'other', he thinks about how he feels (or might feel) and transfers this onto 'other'.

As such, Jonathan takes care to try and convey positive aspects about other's characters to ensure a balance is struck before he has something negative to say and even then, it will only be slight. If someone does happen to make a potentially hurtful remark towards him Jonathan believes it is likely due to their lack of understanding. He is therefore able to discount their comment and retain his sense of contentment. This behaviour directly relates back to Jonathan's appreciation of human diversity in that people are bound to have differing personalities and approaches to life. In this, he recognises that his own daughters' characters are like *"chalk and cheese"* (J14:8) and in deciding that no two people are alike, Jonathan believes that others 'stories' can be of little relevance to him or his daughter.

> *"... I thought this is crazy 'cause, it, I'm not gonna particularly get anything out of it now, other than to read various peoples' individual experiences, which might have relation to Harriet or might have absolutely no sort of correlation about how she's gonna be whatsoever..."* (J10:47-11:2)

As a consequence, Jonathan does not look to others' experiences for 'inspiration' and he does not attempt to second guess the future from what he observes. Instead, he is happy with Harriet making her own steps towards achievement at whatever pace that

may take. Here, Jonathan's confidence is fortified in the knowledge that Harriet remains under the supervised gaze of practitioners. Since the time of her birth, her development has necessitated his involvement with a number of professionals and, from his initial contact with hospital staff Jonathan placed his trust in their capabilities and expertise. He makes clear his admiration and appreciation of this group where he believes, possibly from his managerial perspective, that he understands something of their roles and the difficulties they undergo in carrying out their duties.

As such, Jonathan felt it was totally acceptable that he was left outside the operating theatre and despite being given an 'indirect' diagnosis he understands how hard it must have been for the doctor to impart the unexpected news. However, whilst Jonathan is content to bow to 'professional authority', he also appreciates reciprocal recognition of his merit. As such, he feels that Harriet's current paediatrician communicates in the most appropriate way:

> *" ...(she is) thorough with what she's, and straightforward with what she's telling you as well, she's not, she doesn't sort of try and baffle you with science and make out you don't need to know but at the same token, she doesn't over simplify and you know, talk to you like you're an idiot..."* (J11:6-10)

Jonathan's positive impression of professionals carries through to the National Health Service as a whole and this may be due to some extent to him feeling that he has received unquestioned support at a time when it was most needed for him *and* his family. His GP was able to sign him off work shortly after he had returned to his job given that he felt he had come under considerable pressure. As the manager of a supermarket undergoing refurbishment and approaching a very busy time of year, all Jonathan could think about was his family who he believed required his undivided attention.

> **"...it was just like a boiling pot and the one that had to give was work really at the time, because, well, family life is just too much, too important for that"** (J7:8-10)

# FAMILY MAN

***"I sort of soldiered on for a couple of weeks and then it just came to a,
a point where I thought, 'Oh no, I need to get out of this situation, this
moment'..."*** (J6:21-23)

Overall, Jonathan appears to have a practical approach to life, he enjoys 'uncomplicated' relationships and he prefers to deal with situations systematically. When his daughter arrived he was aware that he was applying his philosophy with some degree of efficiency. He felt he could manage the visits to the hospital, help his wife recover from the operation and although exhausting, enjoy the feeling of being supportive to his new family dynamic. However, when he returned to work, he felt it had a severe and damaging effect upon his wellbeing, he remembers feeling totally overwhelmed.

> *"...I'd gone back into the middle of a refit, hectic, the whole lot is just
> completely thrown into sixes and sevens..."* (J6:8-9)

Having a breakdown at work, Jonathan went to his GP to explain the stresses he felt from the combination of his work and home life. He remembers speaking to his doctor about having a new baby diagnosed with Down's syndrome in the context of feeling desperate that, as the *"man of the family"* (J4:36) he needed to be at home, providing support. Jonathan's issues were that his older daughter had only just started primary school and his working day covered unsociable hours; he felt this may be detrimental to her wellbeing at such a vulnerable time. Jonathan also felt he had been *"cheated"* (J6:12) out of his paternity leave as this had been spent whilst Harriet was hospitalised. As a result, he saw work as an obstacle, hindering his ability to fulfil his role as 'family man' and the level of importance Jonathan placed upon this role outweighs any other:

> *"...I wasn't spending enough time with Harriet and dealing with what
> she'd brought into our lives but also that, you know, from a, from a
> family point of view that there was too much on Jemma as well at the
> same time that you know... I wasn't there for her"* (J12:10-14)

As such, he exudes a developed and strong sense of belonging to his family. In this, Jonathan talks about the members with pride and with ultimate fondness; he *loves* them. Moreover, he appears to love his family life, where he wants to be involved and know what each member is doing. Work for Jonathan is a means to an end where he has managed to engineer one day off each week to enable him to visit parent groups

with Harriet, attend appointments and take both of his daughters for days out. He is not interested in forecasting the future as he is not curious about 'moving on', Jonathan understands he has a 'lifetime' with his wife and daughters and is in no hurry to think about altering the status quo.

In this, Jonathan appears to have readily merged the changes he feels that Harriet 'brought into their lives' with his preconceived and idealised assumptions of his 'ordinary' family life. He reflects upon his experience as a matter of fact occurrence, where the telling of his 'story' could relate to any parent and baby who may have undergone minor complications. As a result, Jonathan's experience does not correspond to notions of 'trauma' with regard to his daughter, instead, he talks about family life and family events, where he can recognise the ways in which Harriet has made a slight impact. In the first week of being in hospital, there was a family wedding where they would have spent the weekend with relatives, but most importantly, his older daughter would be bridesmaid. Jonathan's allegiance was torn between feelings of responsibility towards his newborn whilst wanting to honour the other members of his family. He was able to find justification to leave Harriet when her consultant helped him to feel encouraged against a backdrop of support.

> *"...if you'd have had the baby naturally and wasn't in neo-natal, you'd be taking the baby with you and (laughs) it would have been absolutely battling, so, you should make use of the free baby sitting service and you know, go and enjoy yourself"* (J9:28-32)

Aside from being amused by recognising an unlikely positive arising from a seemingly negative scenario, Jonathan does not see his parenting experience in terms of needing support. He sees himself as the provider and the support giver. However, through his explication of encounters with professionals he unwittingly reveals much of the type of support he did in fact receive. Unintentionally, he also makes clear that his and his wife's parents are supportive, being an integral part of the wider context of his family they were the first people the couple contacted to disseminate the 'news'. Again, it was the message given, not their parent's reactions that has stayed with Jonathan in recalling his experience. In this, he gives a strong sense of his whole family being bonded by shared family values where he has no need to report their behaviours as they are so imprinted as a 'known' and thus normal part of his life. His love of this

'ordinary' family life becomes clear as he relishes the opportunity to talk in detail (and at length) about how all the grandparents found their new identities within the family:

> *"...my mum doesn't like 'grandma' with a 'd', so she's 'granma',*
> *its sort of how you say it almost, but she doesn't want to be a*
> *'grand ma', or doesn't want to be 'granny', definitely not 'granny'*
> *and Jemma's mum is 'nanny'..."* (J13:10-12)

Jonathan's pride in his sense of family belonging is most evident when he talks about his own grandmother whom he greatly admires. He remembers his concern and upset at having to tell her they had a baby diagnosed as having Down's syndrome given that she had struggled in her life to bring up her own disabled son, Jonathan's uncle.

> *"...she sort of fought for, to keep him at home, and...erm.. but just*
> *yeah, to tell her that, knowing what she'd been through, and*
> *knowing how hard, she'd probably found it... going through all*
> *that, that...ahhh... for no reason, I don't know, I just felt like it was*
> *a hard thing to tell her"* (J12:47-13:1)

Jonathan recalls that his desire to 'protect' his Grandmother from the news was unnecessary, she did not show any signs of upset and for Jonathan, her behaviour demonstrated her strength of character and good will which, it appears, he aspires to assimilate. Jonathan also recalls the agony of giving his wife the news that their daughter was diagnosed with Down's syndrome although he felt that under 'normal' circumstances Jemma would be *"rational"* (J4:22) as she, of all people:

> *"was gonna be good with a child that had problems"* (J5:48)

However, this was the early hours of the morning after a long and difficult time spent in the hospital. Jonathan was certain that his wife would be feeling emotional and anxious having just given birth and still being under the influence of the anaesthetic, he knew she was vulnerable. Jemma began asking him questions and at this point Jonathan felt he was in an impossible and thus extremely uncomfortable position: he did not want to upset her, but he knew she would be upset later if he kept the information from her now. As a consequence, he decided to be straight forward in giving her the news having prepared himself to 'absorb' her inevitable outpouring of tears.

*"I, I'd like to think that I was quite matter of fact, sort of trying to
stay positive about it erm, you know, staying strong"* (J4:33-34)

Being stalwart underpins Jonathan's relationship with his wife where he prefers to portray himself as taking a secondary role to hers. He believes the experience of having the baby *"all happened to Jemma"* (J1:42) and as a consequence, he felt he should help her as much as he could. As such, Jonathan understands his experience to be very much shared with his wife referring throughout to most of his explications as '*we*'. He takes this perspective to its threshold when telling the sequence of events in the hospital where he used his wife's perspective as she had described it to him to best explain the rush to surgery. Furthermore, he extends his perspective of being subordinate in Jemma's experience to suggest that ultimately, he is the least important member of all his immediate family:

*"well you're the bottom priority, you stand back"* (J10:30)

Despite portraying himself as someone who withdrew, in his role of being 'father' it appears he did not remain in the background as a 'safety net' of support. After two weeks of being in the hospital, he was entirely familiar with the hospital jargon, of procedures, equipment and routine. He explains in detail the daily changeovers and the logistics of getting to and being at the hospital as well as, the waiting when Harriet was asleep. Although he describes these visits as being difficult and at times boring, he makes it clear that he was actively involved in Harriet's care plan. This appears to have begun from the very first moments of him seeing her where Jonathan feels he was privileged in being given Harriet to hold first, which in turn, fostered a sense of proud 'fatherly' emotion. Given that his wife was drowsy, he was also able to have a first try at feeding Harriet and although she was taken off to the neo-natal unit, Jonathan feels this initial time spent with his daughter was very special.

As such, Jonathan recalls many other issues that arose within his experience of having a second daughter as very different from his first. Leaving Harriet at the hospital overnight became 'normal' where he felt proud that midwives were eager to care for his baby as Harriet could be cuddled whereas other babies were too small or poorly. Leaving her as a baby also meant that three months later when she required additional time in hospital, 'unnaturally' as parents, they were relaxed about Harriet staying away unaccompanied. He remembers how handing over the responsibility of care for his

daughter felt strange as he was obliged to report to the neo-natal nurses such things as how much and when, his baby had eaten. Jonathan reflects upon this activity as being significant in the process of coming to understand Harriet's potential levels of achievement in the adjustment of his own 'familiar' expectations.

> *"...you can have expectations I suppose, its... its like the first time*
> *she took a full bottle, we were still in the hospital and we went*
> *running down the corridor to show the nurse..."* (J14:25-26)

Despite feeling that he has lowered his expectations to compensate for Harriet's different rate of 'progress' he feels encouraged when she does achieve any of her development goals. Being a father who has been readily involved in the upbringing of his children, Jonathan has accumulated knowledge and is in a position to compare the stages of this daughters' advancement. In this, he is able to see how his daughters differ and furthermore, he recognises that Harriet may have developed some characteristics that he feels are more desirable than her sister. Jonathan divulges this information in the context of being a proud father and when he discusses his daughters, he is cautious to be fair to both. To this extent, Jonathan corrects himself as he compares Harriet to her older sibling; he does not wish to be disloyal to his other daughter.

> *"...every milestone that Harriet achieves... just seems to be that*
> *little bit sweeter erm... more reassuring, not necessarily more*
> *rewarding, just really reassuring..."* (J14:19-21)

Throughout the telling of his experience, Jonathan discloses that he has been ever mindful of how his older daughter has faired, feeling guilty that she seems to have been ignored for much of the time once Harriet was born. He felt extremely pressured by his desire to remain faithful to her, whilst Harriet unwittingly demanded most of his attention. As a result, his experience has meant that he has felt the need to make a special effort to set time aside for his older daughter.

> *"...to let her know that we know that she's had to put up with a lot*
> *and... and we try and even things out a bit, like you do when*
> *you're a parent"* (J10:26-28)

In this, Jonathan is aware of the socially accepted 'functions' of parenting. He feels his role as father is a duty, to watch over and care for his children in equal ways, as well as to be their support, providing them with the same sense of security that he derives from

being in a close family. For Jonathan, there has been nothing more important to him than this task, one that has been perhaps magnified given his 'additional' charge. As such, Jonathan has embraced his daughter in to the folds of his family and in thinking about how she has developed and who she is becoming he reconciles the impossible:

> ***"...if someone came along now and said that they could.... cure... Harriet of her Down's syndrome.... don't know.....'cause it's her, it's part of her, it's part of how she is, you know, a lot of her character is built around it, with that, don't know, don't know if we would (...) that's how she is, that's what we, that's what we've got and that's what we're used to"*** (J13:42-47)

Please find Jonathan's completed summary with corresponding 'naïve summary' in appendix 5c (p.325) and relevant reflexive notes in appendix 6c (p.334).

# MAGGIE

I arrived at Maggie's house on a sunny summer afternoon where she greeted me at the front door, happy and smiling. As we walked through her hallway, she proudly showed me a large photograph portrait of her four older sons as she chatted away about who they were and what they all doing that day; a mix of work and college. She explained that her two year old, Barney who has been diagnosed as having Down's syndrome was asleep upstairs, napping after his lunch. Maggie walked me through to the kitchen diner where we sat having cups of tea and remained for the duration of my stay.

I felt welcome and comfortable as Maggie chatted freely and openly, although, in the two and a half hours of my visit, a considerable number of interruptions invaded our conversation: the phone rang twice (one call was quite lengthy, the DLA wanted to go through a form with her), the baby awoke and she brought him down to play and one of her sons came home for lunch. I switched the recorder on and off accordingly, something I was not accustomed to doing and before I left, I discovered that some recorded files were 'full' and this had meant that on three occasions our conversation had cut out prematurely. Maggie kindly offered for me to come back if I felt the need

to go over what she had discussed but, once I got back in the car, I scribbled some notes as reminders to what had been said during the 'gaps'. I added these 'fresh thoughts' to the appropriate places in the transcript between the 'files' of actual dialogue.

As a consequence, I did not feel a return visit was necessary with regard to the data however, it had become clear to me during the interview that Maggie was struggling to come to terms with Barney having Down's syndrome. Of all the interviews, I wished I could to return to Maggie on the basis of being a 'friend' to her, imagining I could persuade her to perhaps see things differently to help her to feel better. It struck me that Maggie's experience is anchored by her *pre*-understandings and she appears to have found it extremely difficult to alter her perspective despite her changed circumstances. As such, three super-ordinate themes emerged through analysis: *'Being a mother'*, which centres upon the familiarity that Maggie associates with this role; *'Emotional mothering'*, describing the torment she has felt of mothering a baby diagnosed as having Down's syndrome and *'Physicality'*, her understandings of Down's syndrome and connected issues.

## BEING A MOTHER

> ***"...I said, ''e will be you know', an' 'e went, ''e won't' and I went, ''e will be', this was 2 minutes before we were told and I went, 'I know 'e will be Gavin and he went, 'I know 'e won't be', so I went right! 'bet you every single money in the world, 'cause I know, just look at 'im, just look at 'im! Are you telling me that baby dun't look like a Down syndrome, 'cause 'e's the spittin' image of a Down syndrome baby', not that I'd ever seen one, but I'd... just knew"***
> (M12:37-43)

Maggie can vividly recall the events surrounding her becoming a mother for the fifth time. She remembers detail and specifically, *times*, where she is able to pinpoint significant moments. Maggie thus makes clear her heightened awareness of what occurred as it happened with examples such as her friend being allowed to visit her in hospital at '5 am' and being promised the results of a blood test at '2pm Saturday'. The events of her experience and her concurrent feelings are brought to light through Maggie's re-enactment of the dialogue she shared with the people who were with her at the time. These illuminating conversations are windows into the 'how' and 'what' of

her experience where she alters her pitch and tone as well as the speed and course in an attempt to accurately emulate the appropriate mood of the moment. In this, she recreates the 'scene', sometimes using the voice of others to give further insight into her own personality.

> *"...she went, 'the only prob'em with you Maggie is your gut feeling, when you have these weird feelings' she said, 'you're usually right'..."* (M8:9-10)

In order to 'reference' her knowledge and understandings, Maggie cites her experience of being a nursery nurse and she naturally draws from her previous experiences of motherhood. For Maggie, what went before constituted what she felt was 'usual' and in turn, this contributed to the development of what to expect. Already having four boys and aware that this baby could be her last, Maggie was hoping for a girl, but moreover, she was looking forward to revisiting special moments and feelings that she associated with having a baby.

As such, Maggie paints a picture of her ideal life and the people within it in terms of her 'normality', this is her known and familiar world and a state in which she feels comfortable and secure. To this end, when her baby was born, Maggie immediately felt something was peculiar given that Barney was apparently not like her other babies. She instantly felt the impact of uncertainty and abnormality flooding through her thoughts and she conveys this repeated 'intrusion' to be the cause of her periodic upset throughout her experience. Maggie's instability therefore appears to be most prevalent when she considers 'who' her son is. Barney was six weeks old when Maggie unexpectedly met three gentlemen who all appeared to have Down's syndrome and her reaction to them was one of abject fear:

> *"I freaked out. I freaked out all weekend and never stopped cryin' sayin', 'a can't do it, a can't do it, a can't do it!' an' a <u>wasn't cryin</u>' for <u>me</u>, I was cryin' for <u>'im</u>, 'e was never gonna, 'e, it's not <u>fair</u> for 'im; 'e won't be able to 'ave <u>babies</u>, 'e won't be able to <u>drive</u>, 'e won't be able to <u>work</u> 'n, what's 'e gonna <u>do</u>? What's 'e gonna <u>do</u>? What <u>is</u> 'e gonna <u>do</u>?!..."* (M22:2-6)

Through her re-enacted panic, Maggie discloses the elements of expected and 'normal' life patterns which she feels are most important. Maggie also reveals the despair she felt in realising that, as far as she was concerned, Barney would not be able to access

these opportunities. In her view, the limits on his life and subsequently hers, imposed by him having Down's syndrome, remain unbearable and unthinkable. As a consequence, Maggie is loathed to equate this condition with her son and she prefers to think of him as 'normal'. In this, she has attempted to maintain a certain level of 'normality' by continuing with her own familiar role of being 'mother'. Appalled by the idea that she may be expected to behave differently to her 'norm', she originally chose to disregard any situation that could threaten her comfortable way of thinking and being:

> *"I'm there to bath 'em and feed 'em an' just, you know, <u>play an'</u> <u>tickle</u> 'em, laugh an' watch telly with them. I don't ever, well, sit and <u>read</u> or, 'right, that's <u>that</u> colour and that's that', I've never really sat and done a load of jigsaws with 'em so for <u>me</u>, I'm just thinkin', I'm really gonna have to work at it' an', an' a just thought, 'if a don't hear it, I'm not... it's just not gonna bother <u>me</u>'..."* (M24:30-35)

Maggie is very clear about what her familiar mothering role entails and she describes the delight she felt in being able to walk out with him in his new pram. She also conveys a sense of achievement and pride in having breastfed Barney and in this, Maggie was determined that her baby having Down's syndrome was not going to *"spoil"* (M15:44) her experience. These activities meant that Maggie could feel as if she had accepted her son's impairment and that she was being 'strong' and getting on with her life. However, interruptions to this nirvana came in the form of hospital appointments which were irritating 'reminders' as well as at the Child Development Unit (CDU) 'mother and baby group' where she felt out of place. Initially she had craved the company of other mothers with whom she might be able to share her feelings yet, she soon realised that she was becoming integrated into a lifestyle where 'Down's syndrome' was uncomfortably prominent.

As a consequence, Maggie hastily left the group where the balancing act of continuing to mother in her 'usual' way against her perceived notion of having to change to being a 'mother of a baby with Down's syndrome' had become increasingly difficult for her to manage. However, when she later saw that Barney was 'abnormally' delayed in his ability to sit up Maggie forced herself to take him back to the group and joined others that were aimed at a variety of young children with special educational needs:

> *"...well I 'ad to go, I had to get it into me 'ed, this is gonna be me
> life from now on, I've gotta mix with them, I've got to..."* (M18:42-
> 43)

As such, Maggie relented to the notion of Barney's condition being permanent and although 'Down's syndrome' remains alien to her, more recently through her sense of duty to her son, she has felt more able to accept his 'difference'.

> *"...I've joined the Down's syndrome Association because I don't
> want to deny him what he is..."* (M12:25-26)

This sense of mothering a baby that is completely different, not only to her but also her other sons, was an agonising concern. Maggie was desperate not to upset her 'normal' family life although she has since witnessed the love her older boys have shown Barney, wanting to share his care with her and spend time with him. As such, they have surprised her in their attitude towards 'Down's syndrome' where, based on her own preconceived ideas, Maggie feared they may reject or make fun of the new baby. These beliefs may have been influenced by her mother who has made it clear to Maggie that she would not have kept the baby.

Given the volatile relationship she shared with Barney's father who is now her ex-partner, Maggie turned to her mother for emotional support throughout her experience. She thus relies on her mother for advice and encouragement and is bolstered by her stories, contacts and the praise she delivers. Maggie also has a close relationship with her best friend to whom she clings in order to maintain her sense of 'normality'. In an emotionally 'safe' way, her friend represents how life is without 'Down's syndrome'. Conversely, Maggie perceives her sister-in-law who has a baby of similar age to Barney as a threat to her happiness. She notices their babies' development as being vastly different where Barney's, for Maggie, is unbearably slow. She recognises that ordinarily the mothers' relationship would have been ideal where she supposes Barney having Down's syndrome has ruined this opportunity. Furthermore, Maggie believes that her son's condition is that which prevents her from finding a new partner:

> *"...how am I gonna find anyone? Got a Down syndrome baby,
> who's gonna want me? So I 'ave got issues me from other people,
> d'you know what I mean? I'm <u>unhappy</u> anyway but a don't know*

> *'ow, sometimes a do sit back an' think ''ow the 'ell am I coping?'..."* (M24:4-8)

Maggie acknowledges that the anxiety she feels is magnified by her being single and she believes this ancillary factor in her life sets her apart from the other mothers she meets. In addition, she is conscious of being older and she knows this incites blame given that her brother has made his feelings clear that she has behaved irresponsibly. In spite of this, Maggie accepts that she has many friends and a good family that want to help her, but she also deems their efforts futile where she believes they have no *real* understanding as they have not felt and cannot feel what she feels. In recognising her frustration brought about by her circumstances, Maggie can identify the ways in which she feels bitter and from this, she appreciates that she can be uncontrollably blunt and caustic.

> ***"...a just said to me friend, 'well would you wannit? It's alright you sittin' 'ere goin', 'it's not <u>that</u> 'ard', a said, 'would <u>you</u> wannit? Would <u>you</u> want Barney? Would <u>you</u> want a <u>Down syndrome</u>?'..."*** (M27:46-48)

## EMOTIONAL MOTHERING

> ***"...35 minutes I was in labour, come out, put 'im on me an' a went, 'what's wrong with 'im?' (...) I said, 'well he's either a Down syndrome or 'e's a dwarf, one or the other'"*** (M3:8-13)

Maggie's first impression of her baby left her shocked and within seconds of seeing him she announced her fears and began internally shaking. Through the days that followed his birth, Maggie continued to writhe in emotional turmoil, not knowing what or who to believe. Everyone but she was convinced her baby did not have Down's syndrome and as a consequence, she remembers these days as being a battle of wills between reassurances she was given that he did not have Down's syndrome, and her doubt where she believed that he did.

> *"I don't know, maybe they <u>didn't</u> think 'e was, I don't know, I really think that the' actually thought 'we're not sure' (in breath) but I was <u>majorly</u> sure that 'e was"* (M6:40-42)

Maggie's feelings initially stemmed from the way her baby looked and realising he might have Down's syndrome, she felt *"Rea-ally <u>sick</u>"* (M3:30). The midwives in attendance tried to reassure her by insisting that Barney looked like his father.

They placed him under blankets and against her skin for warmth and she clearly remembers examining his face, feeling horrified and panicked, praying for him *not* to have Down's syndrome. At the same time, she also remembers feeling an instant love for her baby and given his potential condition, she felt relief that he was not the girl she had been longing for. When a midwife then offered to help her breastfeed Barney and he latched on straight away, Maggie began to relax a little more.

> *"...I thought, 'hang on, maybe Down syndromes can't <u>do that</u>, so <u>maybe</u> 'e isn't!'..."* (M6:29-30)

Yet Maggie remembers the next moments being dreadful. The midwife questioned her initial outburst and this action gave Maggie a signal that she was right to be worried.

> *"...she said, 'you know what you were sayin' before, what did you mean?' I'll never forget 'er sayin' it and me stomach went and a, a could feel me whole face goin' red"* (M6:17-19)

A paediatrician was subsequently called and Maggie assumed this would give her a definitive answer although the wait was agony. Barney's father became angry accusing her of spoiling an otherwise happy event and for his sake, she attempted to remain calm. Late into the night the doctor appeared and to Maggie's relief gave her further reassurances that the baby did resemble his father. Laughing and going over the conversation that happened at that time, Maggie remembers the moment becoming light hearted when it was decided that if the baby had Down's syndrome, then so might her ex-partner. However, Maggie's doubts crept back when she was taken from the delivery ward to a private room.

> *"I wont 'appy about this, 'I'm not 'appy about 'avin' this room', I said, 'they think 'e's Down syndrome'* (M8:1-2)

Maggie also understood her friend being permitted to visit her when she was alone in the early hours of the morning to be *another* plausible reason to believe her son had Down's syndrome. Maggie's mother arrived later and although both women told her the baby looked like his father, she was only able to relax when her mother gave her the reassurance.

Maggie was alone again when she was astounded by the unexpected arrival of a second paediatrician and his entourage who had come to look for 'signs' on her baby. In the desperation of the moment and thinking she might counteract the possibility of the 'dreaded' diagnosis, she offered them the reassurances she had been given that everyone else thought Barney looked like his father who was now absent. To her utter horror, the doctor explained this 'evidence' was irrelevant and all her hopes were crushed in an instant.

> *"then, then I was cryin' me eyes out and it was just me, sat on me*
> *own on the bed, I just couldn't <u>believe</u> it"* (M9:18-19)

For three days whilst waiting for confirmatory blood tests Maggie pretended to her visitors that she was happy whilst secretly she felt miserable, scared and, that she had let everyone down. Eventually, she and her ex-partner were given the conclusive diagnosis in the communal nursery. Other people were present and as a consequence of this, in her distraught state, she also remembers feeling angry and exposed. Desperate to go home, she spent the rest of the day crying however, once *at* home, Maggie believes she was able to accept what she had been told. She thus recalls the evening of her homecoming as being jolly where they had a family party and she felt really happy.

The preliminary undulation of emotions that Maggie underwent in the first few days of having Barney appears to be a continued theme throughout her experience. She describes her feelings towards her baby as a series of sentiments which manifest at times as opposing factors and frequently tormenting thoughts that she struggles to manage:

> *"God, I don't want 'im to look like 'e's got Down syndrome, then I*
> *feel tight 'cause 'e's my flesh and blood and I adore him..."*
> (M12:23-24)

> *"Well you love 'im, then think about things and then you feel*
> *guilty don't you?"* (M28:15-16)

> *"...a was cryin' because a felt, 'who am I? A sh', how selfish am*
> *I? yeah, a could've 'ad some baby that was 100 times worse! So*
> *you do 'ave a hundred and a billion little mixtures of things like*

> *that goin' round and round and round an' it's just...just...*
> *'orrible"* (M25:34-37)

Maggie makes it clear how much she adores Barney but she also admits to the hatred she feels about him having Down's syndrome where ultimately, she feels his condition is a burden.

> *"everyone likes to 'ave kids an' the' grow up and 'ave a family of*
> *their own and the're off your hands. I just kept thinking, 'I'll be a,*
> *I'll never, never be rid of 'im..."* (M11:26-28)

This understanding continues, matched only by her sense of disappointment towards him which peaks when she is confronted with babies who do not have Down's syndrome. Maggie has had to make a conscious effort to stop feeding her desire to know how Barney compares to other children as her jealousy of others developing ahead of him leaves her insides churning in pain.

> *"...and then she'd ring me up 'oh, 'e's walkin', or... that's the*
> *upsettin', deep, cuttin', really, really upsettin'"* (M17:17-18)

Since Barney was born, on seeing pregnant women, Maggie has secretly wished their baby to have Down's syndrome as she wants others to 'properly' know and understand her torment. The early encounter with the three gentlemen that shook Maggie's sense of 'normality' also triggered inconsolable upset in realising her understandings of her own apparently selfish behaviour.

> *"...I was goin', 'oh shu' up', a went, 'jus' shu' up, shu' up, jus'*
> *leave me 'cause I jus' wanna die', an' a kept lookin' at 'im*
> *thinkin', 'oh my God, this poor, poor baby, how tight am I to bring*
> *this baby into this world?' that's when it hit me..."* (M22:10-14)

Only calming down after a lengthy telephone conversation with her mother, she remembers thereafter maximising her level of pretence. She did not want her baby to have Down's syndrome and used strangers to convince herself this was possible. On meeting others her tactic was to immediately announce his condition, fully anticipating their surprised reaction. This response was reassuring and allowed the pretence to continue. However, her charade came to an abrupt halt when Barney was seven months old and a woman noticed he had Down's syndrome *before* Maggie could speak. This incident resulted in her suffering another fraught upset and throughout her experience,

whenever she came across older children or other people who had Down's syndrome, her trauma repeated.

> *"...an' this baby was goin' 'baba, uuhh, uuhh', an' I was like (expression of disgust) 'ooaagghh, oh my God, my baby's gonna be a freak, gonna be a freak, I can't handle it. I can't handle 'im bein' like that'... so I bu-r-st out cryin'"* (M26:29-32)

As a consequence, Maggie's emotional turmoil appears to occur as a backlash to her overall sense of denial: by pretending Barney did not have Down's syndrome and more recently, hoping it is not 'severe', Maggie constantly runs the risk of upset. Whilst she recognises that her emotional condition has improved, she is also aware that she remains vulnerable.

> **"...I feel a lot better now at this stage than I did when 'e was first born, but I've still got loads of worries and feelin's, I'm not, I'm not like, 'oh I'm fine', I'm not, I can't possibly, I don't think I'll ever be fine..."** (M29:35-37)

## PHYSICALITY

> **"...I'd never even met a Down syndrome, and now, I still don't know what it's like sometimes"** *(M28:9)*

When Barney was born the midwives, doctors and paediatricians, alerted by Maggie, paid much attention to his features looking for physical 'signs' that he had Down's syndrome. Maggie had immediately noticed 'flatness' about Barney's face which gave her cause for concern. Later, they all agreed that the baby's hands, fingers, feet, toes and neck were shorter than expected and although his father shared these attributes, Maggie describes them as if unnatural and undesirable. Left alone with her newborn, Maggie also detected that his ears were 'low' and one was 'bent' and the second paediatrician had tested his skin for 'firmness'. For Maggie, this crude introduction to her child confirmed Barney's physical difference and his 'alien' characteristics. She was frightened by the thoughts lingering behind not only what she saw but also, what was being pointed out.

*"she said, 'the, the Down syndrome, the' 'ave a thick line there', which a didn't know but so, ...yeh, she was lookin' for that an' on the feet, a don't know what she was lookin', but maybe there's the same thing on the feet 'cos the toes are smaller"* (M7:34-38)

Within 24 hours of his birth, it seems Maggie had learned most of the typical indicators that practitioners use to identify and diagnose Down's syndrome. She was also made aware of body temperature loss, feeding difficulties, deep creases across the palm, muscle development as well as being told that Down's syndrome can manifest in a number of ways. In her desperation for her baby not to have Down's syndrome, she eagerly picked up this information as she could then (continually) check it against his actual physicality.

*"a kept goin' like that (puts head on one side) and then a kept movin 'im on that side 'cause 'e had a funny bent ear which made it look even worse, I kept goin', 'but 'is ears are dead low' because they 'ave low ears, and I kept lookin' at 'is ears, 'is ear, one ear, one ear, it was drivin' me insane!"* (M8:33-37)

Prior to having Barney, Maggie had very little understanding of Down's syndrome and she can not recall ever speaking to a person with this condition. As such, she coupled the information she received with her worst fears of the 'unknown'. Maggie maintains that it is the 'not knowing' that has made her experience so terrifying yet in parallel with this Maggie also claims that she prefers not to know. Despite hearing encouraging stories and witnessing for herself, independent and able people who have Down's syndrome going about their lives, Maggie struggles to see the positive as they clearly present to her an alarming reality where her perspective and the terminology she adopts highlights her sense of complete 'otherness'.

*"well, if I'm in Asda, I wouldn't go to a Down syndrome, <u>ever</u>, would <u>never</u> 'ave gone over to 'em and asked 'em, 'well can you, where's such a thing?', I feel like people don't talk to 'em, you know, the' don't, an' I'm one of 'em!"* (M22:23-26)

Maggie recognises that she has a clear and static view of what it means to *be* 'normal' and she cannot see how people who are diagnosed with Down's syndrome can possibly satisfy her pre-determined criteria. Moreover, she is repulsed by their 'difference'. Her feelings on this matter are to some degree satiated by her denial

behaviours with Barney yet they are ostensibly underpinned by her attitude towards 'looks' in general.

> *"...'e was jus' beau'iful, 'e is now! I always thought 'e's gonna be a good looking baby anyway. I mean, it's <u>daft</u> to want a good looking baby, but everyone wants a good looking baby don't they?"* (M15:38-41)

In desperation for her son to be as 'good looking' as possible, not least to assist her in carrying out her pretence, Maggie taped Barney's 'bent' ear until it grew in an 'acceptable' way. This behaviour may have been encouraged by her mother who has offered to pay for surgery that will 'correct' Barney's looks. For now, Maggie considers this to be unnecessary as her current focus is Barney's overall image where simultaneously she deliberately and subconsciously obscures 'reality'.

> *"...I mean I even lie about 'is age. (...) because 'e's not walking an' I don't want them to, the, you see, half of you thinks, 'oh, the' don't know the're Down syndrome', 'cause you don't think people can tell, when it's your own, you don't see it as much..."* (M13:10-16)

Whilst Barney appeared to behave as a 'normal baby' Maggie was able to believe in him as such, however, more recently she has begun to suffer great anguish where her pretence has become a 'double bluff'. Maggie understands that through her familiarity and love for Barney she is 'pleasantly prevented' from perceiving him as having Down's syndrome yet now, she is aware that in reality, he *is* developing into her 'worst nightmare' despite her not being able to see it happening.

> *"'cause the're not normal are they? 'cause they're not normal an' a still can't see 'im as bein' <u>not normal</u>, to me 'e's <u>normal</u> (pause) but a'm gonna have to face that when a come to it"* (M22:19-21)

Maggie feels the complication of her internal 'argument' is such that it will have to be resolved at a later date believing a time will come when she will have to accept the 'truth'. However, she also recognises how ignoring her dichotomy has already impacted upon her experience not least in her being able to help Barney. In particular, she remembers perceiving professional intervention as interference rather than the assistance and support she now realises was intended.

*"..I was thinkin', 'oh, you're not treatin' mine, my, 'e's not, there's nothin' wrong with 'im! 'e's normal! 'e dun't need special this an' special that!' (...) I felt like they were interferin' with my baby, there was nothin' really wrong with 'im..."* (M24:14-20)

At the time, Maggie became so upset with feeling 'confronted' by her son's impairment that despite enjoying new friendships she had made with other mothers, she took her own mother's advice which was to break away from the CDU baby group. It was only out of fear through realising that Barney was not physically developing at the 'normal' rate that Maggie rejoined and, she continues to feel it is an 'unnatural' lifestyle which has been forced upon her. Taking Barney to the sessions therefore, only serves to help Maggie feel as though she is doing the 'right thing' yet, she maintains her reservations about the type of support Barney should have. Given her drive towards wanting him to be 'normal', she is loathed that he should adopt what she perceives to be abnormal behaviours.

*"...I didn't know that any Down syndromes 'ad problems with the' talkin' an' that really scared me and it does now. I keep sayin', you're not doin' them signs with 'im, I want 'im to talk but 'e's just picked it up, 'e does 'em! 'e's doin' the 'more' sign now!"* (M29:13-17)

In this, Maggie can see that Barney is capable, but his learnt behaviour is unfamiliar to her and this 'difference' in her child causes her considerable anxiety to the extent that, if it meant he could talk "properly", she would instigate surgery to alter the physicality of his tongue. When she observes other mothers 'joining in' with 'sing and sign' games, going on courses and encouraging their children to sign, Maggie is not only horrified but she is also filled with nerves and self-doubt. She does not want to engage in these activities and, she cannot understand why she feels this way. She feels that her love for Barney *ought* to solve her issues with Down's syndrome but somehow, it does not. Maggie is thus compelled to question what her love for him means in relation to his development.

*"...'e's mentally as good as I 'oped for 'is age now, so I'm quite pleased, but if 'e wasn't (...) would a be different? But a don't think a would because a love 'im, so it, it wouldn't really matter, so why am I beatin' maself up about it? 'cause it wouldn't really matter would it?"* (M27:38-42)

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Maggie conveys this current state of confusion as her being at a 'crossroads'. It seems she is beginning to think differently but she has not quite formulated how she can feel comfortable and thus settled on a daily basis. This might be due to Maggie distinguishing between Barney's mentality and his physicality: she does not seem unduly worried that he may have poor mental ability yet she appears to remain unable to even contemplate 'abnormality' with regard to his bodily appearance.

> *"'cause 'e's normal... 'e will be normal, as normal as well, obviously, physical side, 'e will be normal won't 'e? It's only mental side, mentally as in a bit slower, I don't, I just don't want 'im to go to like a special school, I, I don't think it'll help 'im, I think it'll hold 'im back"* (M22:37-40)

Maggie thus convinces herself (and she attempts to reach out for confirming reassurances) that Barney *will* maintain his development within her acceptable sense of physical 'normality'. Barney's learning difficulties may then become a problem in the future if he is unable to attend a 'normal' school where she feels this will interfere with his otherwise 'normal' progression. In this, Maggie conveys her angst behind the idea that he may need to attend a special school by already presupposing her argument 'against'. It appears that she feels the need to begin an early campaign that will 'head off' any more 'unfamiliar' (and horrifying) territory. As such, it is possible that her continuing 'denial' is a likely form of self-protection against feelings of acute anxiety, worry and dread that Maggie harbours regarding 'Down's syndrome' and the corresponding image that she believes this condition not only portrays, but that her son will 'eventually' assume.

> *"...that's what's worrying me, when e's older, I don't like it, an' I <u>still</u> don't like it. I hate it."* (M26:42-43)

Please find Maggie's completed summary with corresponding 'naïve summary' in appendix 5d (p.327) and relevant reflexive notes in appendix 6d (p.337).

## CHAPTER FIVE

# DISCUSSION

This chapter aims to draw upon the salient issues highlighted by the findings of this study. Underpinned by theoretical perspectives that were brought to light in the earlier chapter (two), this discussion will follow a similar course to that in the way I have chosen to 'order' the data. As such, the chapter begins with and eventually returns to the turmoil found within the 'self' having journeyed through the ways in which social influences appeared to impact upon the parental experiences under analysis.

**The 'Self'**

In working out 'what happened', I was immediately drawn to the reactions of the individual participants and the ways in which they appeared to have managed their surge of emotion in order to control their general wellbeing. It seemed that, having been shaken by an unexpected event, they sought to regain stability through notions of what '*felt* normal'. As such, I explored theories surrounding Bardill's (2000) *"relational systems model"* (p.65), Tappan's (1999) 'moral agency', Freeman's (1999) 'poetic construction' and Hochschild's (1997) 'emotion management' to try to understand the ways in which these parents appeared to organise their feelings. For example Hannah appeared to be particularly conscious of 'self-regulation', (Bardill's label for emotional control and introverted thinking). Incorporating theory described by Tappan (1999) regarding self-determination through self-social dialogue, Hannah spoke of 'building bridges' in her mind in order to manoeuvre between perceived stages of her self-development. In accordance with recent findings from van Hove et al (2009) and Goodley (2009), Hannah used much of this type of (socially derived) metaphor for instance, 'getting a grip' and 'moving on' in order to understand herself as well as to project the ways she felt she might be understood (Cioffi 2000).

Colin's described 'control method' appeared to correspond with the second element of Bardill's (2000) model: 'self-definition' which was the yearning to be amongst and enjoy the company of others or be alone. It seemed he felt he was able to control his emotion by regulating the proximity of others whereby the closer they became the harder he found it to remain composed. As a consequence, he appeared to control his

level of vulnerability before he reached a stage of 'public' upset, allowing himself to be close with some people and not others (Parkinson 1995). Colin also appeared to operationalise Freeman's *"poetic construction"* (p.102) by intensifying his situation in order to understand it better. He created several imaginary and romantic 'what if' scenarios so that he might recognise the 'good' in his lived reality by discounting and writing off other possibilities as not being *that* attractive by comparison. He also appeared to use basic language and blunt description to 'reinforce' his (and other parents') position in his mind so that living 'real life' might not appear so drastic.

Jonathan appeared to 'go beyond' Tappan's (1999) dialogic method of 'moral agency' in almost physically adjusting his mind set. It seemed he had expectations that his new born daughter would be 'the same as' his older daughter and when he perceived that she was likely to have different needs and alternative patterns of development, Jonathan realised his 'traditional' way of thinking was inappropriate. In order to continue with a familiar and thus comfortable, optimistic outlook, he devised a way to 'replace' old with 'new' understandings. This 'process' was portrayed by Jonathan as being a hasty, no fuss eventuality as if very straight forward and simplistic for him to achieve. As such, his method of self-control appeared to also sit comfortably with Bardill's (2000) third element of 'self-differentiation', described as 'self-distinction'. This element relates to beliefs and values systems and Jonathan's behaviour seemed to highlight the theory in the way he organised his thoughts to 'prioritise' his daughter over devaluing possibilities he had contemplated in relation to Disability.

As with Hannah, Maggie's way of stemming an onslaught of unadulterated emotion was to concentrate upon 'staying strong'. Although, *unlike* Hannah, Maggie's chosen form of pretence was primarily developed to protect herself (as opposed to her family) from the way she was feeling. As a consequence, Maggie did not appear to have the constant 'social' pressure of having to remain blinkered and thus composed (Hochschild 1997). Furthermore, her ignorance could not be sustained when faced with direct, sometimes unexpected, triggers that raised her feelings whereby her behaviours became extreme. Maggie told me that at times she became so overwhelmed she had to spend 'whole afternoons' or 'all weekend' sobbing until her turmoil was 'cried out' of her system. It seemed apparent that Maggie did not wish to feel pent up with frustration and hatred of her circumstance at *that* particular time. As such, 'letting go',

shouting out and taking to her bed clearly helped Maggie feel better in the end and, once over with, she felt she had regained the strength to face the world again (Parkinson 1995).

Bardill's (2000) model does not profess to explore the ways in which emotions manifest, his interest lies with the relationships within the 'whole' system of 'self' with the aim of maintaining a balanced sense of individual 'normality'. Freeman (1999) and Tappan (1999) offer suggestion as to the ways in which individuals may undergo this process, understanding their 'self' through their relationship with social reality. In this respect, the combined theories serve a practical purpose of providing a vehicle through which emotional behaviours can be seen to be controlled as well as how the 'self' may be regulated. According to Bruce and Schultz (2002), parents need such models to which they can relate and identify their own emotional turbulence. They suggest parents want to find ways to understand their behaviours and that what is happening to them is not extraordinary, a sign of lunacy or necessarily with them forever.

In this respect the work of Arlie Hochschild may also prove useful. It is possible that her symbolic interaction approach to emotional behaviours may alleviate some of the pressures felt by individuals who are at risk of believing their emotional disturbance is all their own. According to Hochschild (1997), social situations may determine the ways in which emotions are managed where she believes 'the family' is a particularly intense and unique environment that demonstrates this phenomenon. For example, Colin appeared to have fallen into a trap of believing he had 'failed' yet his 'ability' to spiral into depression was likely to have come about through his belief that Hannah was coping (Hochschild 1997): *"she's like a Trojan my missus"* (C2:2). In contrast, Hannah's primary concern was to protect her whole family by assuming a role that created harmony and concord within the household, a position Hochschild (1997) terms *"the third shift"* (p. 51) as it is an additional task 'after' that of work and parenting. Knowing that Colin had become depressed, Hannah suggested that for the sake of her older daughter she stayed upbeat: *"because you can't have two of you can you?"* (H7:2). Colin and Hannah's comments expose their combined recognition and understanding of the circumstances as well as the ways in which the behaviours of their spouse affected their own, private experience.

As such, this raises a query regarding the extent to which social factors may in fact proffer any comfort. It may be that for Hannah, her 'socialised' position prevented her from releasing her tensions and this added to her dilemma yet, on the other hand; Hannah may have latched onto Colin's behaviours in order to justify her own, given her understanding of being amongst a society that may have expected her to have 'collapsed' (not her husband). In addition, an amount of Colin's described self-pity and bemoaning of change and Maggie's outpouring may be what is *personally* needed for some people in order that they may go out and face, and subsequently interact with other people. To this end, the theories available here do present another shortfall: they do not account for the ways in which emotions may surface and what they may *feel* like. Clearly individual behaviours have consequences with regard to how their emotions are received and understood by others. According to Parkinson (1995), Hannah seemed to have 'internalised' hers yet, despite Colin perhaps assuming she was coping, this does not mean she felt the hurt to any lesser degree than for instance Maggie who 'externalised' her upset and let it be known she was at times, feeling great distress.

In academic circles it may be acceptable to discuss 'numbness', 'shock' or 'depression' as these are descriptors associated with mature and staid psychological behaviours. In this, Maggie's behavioural 'descriptors' may be associated with inappropriate aggressive activity if she were male and as a female, dismissed as childishness or madness (Parkinson 1995). Furthermore, (in this case) Bardill, Freeman and Tappan are men who appear to have clearly approached the subject from a male perspective. For instance, whilst Freeman engages with elements of 'poetic romance' underscored by 'passion', he shies away from discussing possible accompanying 'romantic' and zealous behaviours, thus ignoring the flouncing, flailing and sighing that some women do in real life in order to regulate their feelings at times of upset. Hannah utilised music to 'drown out' her negative emotion whilst simultaneously inducing more upbeat, positive feelings. Behaviours such as these are rarely found in the literature yet appear to be effective albeit personal, 'management' processes.

This is not a criticism of Freeman as his task was not to describe 'female emotional reaction'; it is a point to suggest that parents may be helped by understanding not only

the processes of 'self' undergoing change but also the enormous variety in 'what happens' or can happen when unusually strong emotions are brought to the surface. In that way, parents may come to understand that their own unique way of dealing with upset is exactly that, a distinctive set of behaviours peculiar to them as a 'normal' way of being. As such, the opportunity to talk about what these ways are may be a positive direction for parents to hopefully come to understand more about and thus embrace their individuality (Parkinson 1995, Maxwell & Barr 2003).

**Emotions**

In concord with the literature, the upset experienced by the four parents appeared to surround notions of unexpectedness as well as fear of unknown actual and future circumstances and, their consequential feelings of uncertainty and instability (Fisher 2007, McLaughlin & Goodley 2008, Heiman 2002). Each appeared, in one way or another, to aim towards regaining familiar ground where they could hold on to the 'life raft' of recognisable routine and ritual (Mason & Pavia 2006). This effort appeared more difficult for some than others in the telling of their experience whereby, despite citing 'unexpectedness' followed by an emotional breakdown at work, once at home where he felt he was needed, Jonathan appeared to recover his sense of 'normal living' very quickly (Russell 2003, Pollack & Stewart 1997, Hugger 2009). He made it clear that he held both a positive regard towards his daughter as well as an optimistic view of her current wellbeing and future development and these characteristics have been found in the literature to have 'desirable outcomes' for both parent and child (Trute et al 2010, Hastings et al 2002). On the other hand, although it was less simplistic to identify Hannah's optimism per se, it was none the less apparent in such things as her general attitude towards 'fighting' for her daughter to become 'socially acceptable' (a 'positive' goal for Hannah) as well as in her review of the psychological changes and adjusted mind-set she experienced.

I feel this detail in relation to Hannah's account is as important as any other yet I can see how it might be overlooked by others taking only her repeated references to being 'frightened' into account. This may have appealed to other researchers as it was 'obvious' and would have produced seemingly 'appropriate' findings to correlate strongly towards possible predetermined (negative) research questions. To this end, much of Hannah's (other) expressed emotion might have remained 'undiscovered'.

Similarly, Maggie's anxiety appeared to be most prominent through her confusion and difficulty in understanding her love for her baby whilst he also had a 'dreaded' impairment. It would have been simplistic to have focussed upon the idea of Maggie struggling to come to terms with impairment per se, rather than her ideas about what it means for her to love her child. I hope I was able to convey this latter aspect in my interpretation of her account. Of further relevance here, the interviews were conducted as a single instance of the participants' lives where had I returned a week later, the 'issues' that surfaced may no longer have been prioritised by these parents. To this end, I was mindful that specific emotions materialising on the day might have been 'disproportionate' to their experience as a whole and to highlight those above all others may also have represented a distorted view of the account.

All the parents at various junctures of their interview, within differing contexts referred to positive elements of their experience where they felt a sense of achievement, pride in their offspring and a positively developed 'self' (Crown 2009, Larkin 2006, Csank & Conway 2004). However, it is possible that when talking about their experience, they described the negative aspects more fully given that they might have felt this was expected of them, or that, given the rare opportunity to be 'heard' they felt they should prioritise the 'worst bits' to accentuate their perceived 'difference' to 'normal' parenting experience (Smith et al 2009). This notion was brought to mind via Jonathan who told his 'story' *very* carefully, appearing to be mindful to (conversely) not seem disparaging or present a negative image of his situation (Cioffi 2000). In turn, this led me to realise that all the parents, despite some recounting events involving feelings of disgust and repulsion, were extremely loyal towards their infant. If they made a remark that seemingly betrayed their child, parents sought to situate the comment in the broader context which helped to balance what they had said (Larkin 2006). This was also supported by the ways in which they disclosed information and as a consequence, when (for instance) Colin and Hannah independently spoke of the potentially shocking revelation that they wished their baby had died, I was not at all alarmed. This relayed the importance of the many ways in which they contextualised their 'stories' and in this, I felt encouraged by their attempts to facilitate shared understanding.

Being understood appeared to be a primary issue for Hannah as she had clearly struggled in the past with professionals who did not appear to understand hers or her

daughter's situation. As such, one of Hannah's stories exemplifies the frustration that may be created by others that can ultimately compound what might be an already difficult emotional situation: Hannah was worried about Helena's food intake and she was referred to a dietician. However, the issue was not *what* the child was eating, it was the fact that Helena tried to *constantly* eat anything. In this, the professionals' understanding of the practical content of the issue was poor yet did not seem as inconsiderate as the lack of shared perspective that came from ignoring Hannah's feelings through her *"dealing with"* (H5:16) Helena's insatiable appetite. In fact, Hannah was able to convey this to me not just through her words, but from the desperation and apathy in her voice which often trailed off in a sense of (abandoned) defeatism (Johnson 2000). This brought to mind a number of issues when analysing the data in terms of being able to re-convey meaning and more specifically, emotional meaning as I had received it from the participants during our interaction at the time of interview. In this, they had employed a variety of methods in order to communicate their meanings to me, many of which were "*beyond language*" (Frosh 2008 p.37).

*The difficulty of conveying meaning*

In expressing themselves during the interview all four participants naturally emitted their feelings through body language, facial expression, tears and silences as well as through words. They shifted position and sat upright when they revisited feelings of outrage or judgement. At times they all looked longingly at me, perhaps believing in my role as researcher and mother and I interpreted this as them searching for answers, reassurances and at times, praise. As 'interviewer' it was difficult for me to watch the parents struggle as they attempted to find the words they hoped might sufficiently describe their understandings of their situation and circumstances and how they have come to feel. In conversation, one naturally interjects with possible shared meanings and I did this a few times, only to *feel* the frustration and disappointment from the participant when I got it 'wrong'. I also felt their joy and relief when I was 'right' and I took these 'clues' as confirmation of their desperation to be understood. For example, when Hannah explained how she played the Bay City Roller's music loudly as part of her regime to 'stay strong' I instantly recognised her motive and, despite her tears, we *both* laughed. This was an instinctive understanding, based on what *that* action, *that* music, in *those* circumstances could mean and as such, it seems impossible to relate the physical feeling to a third party (the reader) (Parkinson 1995).

Similar inspirational moments appeared in all four interviews and noticeably with the fathers who both conveyed a huge amount of emotion through body language when they spoke of their experience (Arendell 1997, Williams 2009, Robb 2004). For example, Jonathan in terms of pride and love for his daughter where visibly, his face stiffened and his eyes welled with tears and Colin whose chest physically swelled when speaking of his sense of self-development, parental ability and achievements. Their beaming smiles, nodding heads and sweeping arm movements were unrecorded but were invaluable nuances to understanding and interpreting their experiences remembered by me, also no doubt smiling again (and again) as I listened to the audiotape, subsequently transcribed and re-read their interviews. In that sense, I was aware of the 'interaction' continuing.

Being able to reproduce these sensations on paper is a difficult task and under the circumstances, Toye's (2010) plea of turning to inspirational language as associated with literary works, verse and poetry seems terribly inviting. However, even *this* as a methodology may seem inadequate. The difficulty here is made apparent when participants prefer to use their own terminology regarding what and how they feel, for instance, I am unaware of a better statement that could adequately describe Maggie's experience of:

> *"me stomach went and a, a could feel me whole face goin' red"*
> (M6:19)

(this was in relation to her emotional response to being asked by a midwife about her son's potential diagnosis). These described feelings shape events to the extent that they make the experience what it is for the participant, giving it a personal and privately felt intimate and particular meaning (Lupton & Barclay 1997). I can see how other research might need to redefine (or overlook) 'feeling comments' such as Maggie's as they are only really possible to 'knowingly' relate whereas to describe them 'academically' seemingly loses their 'essence'. Also of particular interest from Maggie was her gushing ability to replay her emotional reactions and behaviours. In describing herself demonstrably for example, she rushed forward, eyes popping and almost shouted *"I bu-r-st out cryin'"* (M26:31-32), Maggie was communicating the intensity of what she had felt at the time. Whether she did literally 'cry all weekend' or not, she

facilitated the shared understanding in meaning that the emotional impact had been great (Parkinson 1995).

I gathered the 'intensity' of feeling from Jonathan and Colin for example, in their stories of leaving work. This came via the seriousness with which they conveyed the details as well as through their quieter voices and slower delivery of speech and, I noticed with Jonathan, his eye contact also diminished. They were drawing upon how they had felt at the time, feeling what happened was inescapable and unavoidable. It seemed they felt they had been at the core of a bad event, almost a controversy that appeared to have happened *to* them and they were not proud of the situation as it was a comparatively 'disgraceful episode' in their life yet; they were clear it did not happen as a result of their child or 'impairment' per se. Once they had finished talking about this 'story', their demeanour altered and in talking about their daughters, their sense of pride and parental satisfaction resumed.

Hannah was significantly different from the other three. In the relaxed atmosphere of the room, she became overwhelmed by feelings that she believed she had buried deep inside herself whereby these bubbled to the surface when talking about *"little things"* (H6:1) that hurt her (Parkinson 1995, Brown et al 1993, Johnson 2000). In telling me (and herself) these triggers were unimportant, such as her parents being unhelpful or people remarking on her daughter's behaviour, I could see *and* feel from her that these were being experienced as quite the opposite in terms of *real* meaning. In this, I did not understand Hannah's tears to be a signal of any underlying current distress per se. Her unpractised and thus highly sensitive style of talking about her experience meant that she was drawing on 'past' emotions and as a result of this, Hannah's 'interview behaviour' (more than anyone else's) left me with a sense of having witnessed, felt and shared in some of her experience related emotion.

In turn, this inspired reflective thoughts on the ways in which 'emotionalist research' might be conducted and the possible usefulness of this approach (Gubrium & Holstein 1997, Prendergast 2008, Watermeyer & Swartz 2008). Being with a researcher who is not afraid to 'accept' emotions, participants may be enabled to work through their fears, upset and worries and reveal a 'clearer understanding' and conveyance of meaning to others. Maggie in particular was unclear if her upset was entirely on

account of having a baby with impairment which she initially believed might be the case. As she continued through the interview she revealed that she understood her single status and age to be intermingled with her confused feelings and in the end, having talked about these issues, she concluded the latter were possibly the *most* important aspects in relation to her current emotional condition (Trute et al 2010, van der Veek 2009).

Interestingly, Jonathan and Maggie (and to a lesser degree, Colin and then Hannah), were also able to convey meaning by telling their experience through dialogue and conversation that had occurred at significant times throughout their experience. Narrative analysts suggest this approach offers clues to the ways individuals would like to be perceived as well as how they see themselves (Stueve & Pleck 2001). I believe it also adds personal meaning to participants' emotional state at the time and as such, revisiting conversation appeared to be a way of conveying that previously felt emotion. For example, through the voice of 'authority' (a consultant paediatrician) Jonathan explained how he was able to leave his baby behind in the hospital whilst he went off to enjoy a family wedding. Without describing this behaviour as bizarre for a new parent, he clearly communicated that he felt this was unusual behaviour. In the process of reliving his 'conversation experience' he was able to contextually place 'what happened' (justify his 'abnormal' actions) and show his respect for authority as well as convey his related inexplicable 'weird' feeling (some of which also came from realising he needed 'approval') and thus, his overall emotional attachment to that specific eventuality (Larkin 2006).

In conveying their understandings of their experience through their emotional encounters and in choosing specific 'representative' instances to share in the research, the parents demonstrated the uniqueness of their being. As such, whilst I appreciate there are elements of experience which can be magnified and manipulated to fit general ideologies surrounding parental responses and emotional attachments to experience, it can be seen that each experience tends to demonstrate difference in more ways than it does similarity (McGill-Smith 1993). In turn, this highlights the difficulty of imposing specific applications such as 'theoretical grief' on to experience for the purposes of understanding 'what happened'.

*Grief*

In relation to the corresponding (and earlier featured) notion of 'acceptance' as frequently imposed from the perspective of 'other', the four participants' experiences show how inappropriate such an approach might be:

- Colin was coming to terms with for instance, his sense of masculinity in believing he had produced a *"monster"* (C5:31). As such, approaches to his dilemma with respect to degrees of 'acceptance' would seem ludicrous.

- Hannah conveyed a sense of apathy, being 'trapped' as well as commitment towards her daughter and her situation. To describe her feelings in terms of 'acceptance' would seem irrelevant.

- It is likely that Jonathan would have deemed it patronising (or insulting) if he were to be asked if he 'accepted' impairment, his daughter and/or 'the situation'. Jonathan's perspective is that his daughter has Down's syndrome and Down's syndrome is his daughter and he loves his daughter.

- Maggie stated that she doubted she will ever be 'fine' and in isolation, this could be interpreted as 'not accepting' what happened. Yet, this would be to understand only a small part of the way Maggie actually felt given that she also spoke adoringly of her son, of how she enjoyed the groups she attended (latterly) and the ways in which her son was a 'big part' of her family.

Maggie's situation sheds light on the ways in which parents may feel many things at once, including antonymous and multifaceted emotions (Perryman 2005, van der Veek et al 2009, Hugger 2009, Sparks 2009). As such, it is likely that parents may continue to use the term 'grief' in the absence of another appropriate adjective or, in support of others, to convey the profundity of what they have felt; grief possibly being the worst imaginable emotional scenario that readily communicates the degree of upset. In this, it does seem that using the term 'grief' *is* useful to parents whilst the theory and further implications surrounding how it may manifest is not. If inappropriate understandings of 'grief' continue to be utilised and focussed upon in negative ways via research and practitioners (parent workshops, support groups etc), the problems in relation to perpetuated notions of babies with impairment equating to 'severe loss' and

'bereavement' are likely to continue (Synder and Mitchell 2006). My assumption follows Parkinson (1995) who explains that:

> *"What we say about our emotions can help to produce emotions in ourselves and in others, and, more crucially, can **define** the situation as an emotional one in the first place"* (p.261 my emphasis)

As a consequence, it may be more helpful for parents to be encouraged to talk about the ways in which they *love* their babies, or *not*. Hannah and Colin both experienced feelings of guilt in wishing their baby had died. They both harboured bad feelings about having thought such a 'wicked' and yet tempting 'option'. Yet, in light of what has been revealed through the exploration into parental history (chapter one), 'extermination', 'exposure' and infanticide have all featured prominently stretching over two millennia and furthermore, often including babies that were not impaired (Smart 1996, Dally 1982, Stone 2001, Jenkins 2004). This appears to be a phenomenon that humans have continually attempted to suppress in the name of such things as civilisation, religion and racial progression. It is currently a taboo subject yet the ethics debate surrounding the prevention and killing of foetus and pre-term babies is both fervent and acceptable (McCoyd 2008, Hubbard 2006, Saxton 2006).

To be clear: I am not for one moment suggesting discussion channels should open with regard to exterminating *newborn* babies. What I am saying is that parents need to talk about their true feelings, meaning those that occur naturally, despite them appearing inhuman and descending probably without warning. Nobody knows how an event or experience will feel until it happens. Working out 'what *is* happening' and reflecting upon 'what happened' becomes another way of being reassured through gaining a sense of 'normality' (Walsh 1993, Maxwell & Barr 2003). Both Colin and Hannah revealed this process through telling others (and each other) eventually becoming convinced of their 'normal' reactionary behaviour.

Maggie's introduction' to her baby was also fraught with dilemma although for entirely different reasons to those of Hannah and Colin. In line with study by Lenhard et al (2005) uncertainty and instability surrounding her situation and subsequent emotional condition appeared in conjunction with being given a drawn out, late diagnosis. Moreover, despite seeing his 'difference' immediately, Maggie also

remembered feeling instant love for her infant. As such, it seems the protracted diagnosis began a process of her 'separating' Down's syndrome (and all the connotations that label meant to her) from her son (Hasnat & Graves 2000). Maggie's experience subsequently revealed her prolonged development of the attempts she made to understand the love she felt for her baby. As such, her 'story' aptly illustrated how for some parents this other natural and taken-for-granted emotion can be brought to consciousness.

*Love*

Jonathan's first experience of Harriet was especially sweet for him as he was able to hold her straight away. This finding complements others among the literature as well as fathers' 'yearning to bond' which was apparent in Colin's experience (Williams 2009, Miller 2011, Torr 2003). However, Hannah described a sense of disconnection from Helena as well as feeling she had continued to deliberately 'withdraw' her affection from her. It might be argued that these findings support those of Kingston (2007) who emphasised the importance of parents being with their babies through initial and difficult stages in order to begin a positive relationship with them. However, I believe in Hannah's particular case, her restraint was a deliberate foil in order to prevent herself from acquiring further hurt *and* through being repulsed by Helena's diagnosed condition. Furthermore, I also believe Hannah whole heartedly loved Helena, despite saying she was *"holding back"* (H15:15) as her loyalty and devotion were certainly evident not least through the place and timing of her tears during the telling of her experience.

In addition, although, Maggie was with her son when she was given his diagnosis, she did not easily digest the news that was imparted. She was appalled by the open and public aspect of the nursery where she was told and this suggests parents may not just appreciate having their baby with them, the context in which the news is disclosed is clearly also of immense importance (Larkin 2006, Hasnat & Graves 2000). Most often, the issues of bonding and acceptance are centred on mothers in relation to expectations surrounding 'mother's love' (Stadlen 2004). In this study, it was the men who appeared to foster strong relationships with their babies from the outset. Maggie and Hannah both appeared to be struggling to understand their current feelings yet, this was in light of being frightened of the ways their children might develop and this led to

them being concerned about their love for them at a *later* date. These women were clearly analysing their capacity to love in what they felt was possible for themselves now as well as what might feel 'right' (and therefore, predetermining what life may *feel like*) in the future. Their 'unusual' motherly responses to their children had seemingly brought their emotions to the forefront from where they were not so much questioning their child in terms of disability and difference (Davis 2006a/b) rather, they appeared to be scrutinising their *own* sense of 'abnormality'.

In fact, Stadlen (2004) writes about the range of feelings women have towards their babies in relation to the meaning of an 'all-encompassing love' whereby modern understandings of this often include 'hatred'. An apparent opposite to ideals of fondness and affection, Stadlen (2004) suggests 'hatred' balances the emotive passion underlying love which can rarely be entirely 'one way' or constant. As a consequence, Hannah's 'holding back' and Maggie's separated 'adoration and loathing' appear entirely 'normal' and sadly, it appeared they could not see it that way.

**'Normality'**
In addition to experiencing emotions that induced abnormal, unusual, new and sometimes uncomfortable feelings in response to their situation, all four parents at some point also queried their sense of *being* 'normal'. Colin in particular appeared to have become 'unstuck' with no longer recognising his 'familiar' parameters and benchmarks in life as he had changed both his work role and his parenting role. In this, Colin also moved amongst people he would not have previously encountered. This unsettling process gave rise to him appearing to yearn for a stronger sense of belonging and to this end, his *"active participation in* (social) *norms"* as described by Lupton and Barclay (1997) appeared to be (as they suggest), to satisfy his *"own ends"* (p. 57). However, the negative issues that were discussed in the earlier chapter (two) in relation to this comment are relevant to all the participants in this study, including Colin.

*'Desirability' of social norms*: It seemed (given their prevalence) that aspirations in relation to appearance were more relevant to the women than it was to the men. Maggie and Hannah portrayed their sense of what it means to be 'normal' through their ideals surrounding acceptable presentation in the form of 'looks' and 'health'. These particular 'issues' became prominent possibly because: Maggie was proud to be

having a baby and she wanted to show him off yet she perceived Barney might spoil this by potentially not 'looking the part'. Hannah's perceived 'desirable' norm surrounded notions of being fit and eating healthily which presented a particularly difficult 'issue' with her daughter whose condition is synonymous with having a voracious and insatiable appetite.

Constant social attention devoted to these aesthetics through a barrage of advertisement and magazines, as well as through government campaigns delivered through NHS centres and school policies, all serve as constant (burdening) reminders to these women that their goal is '*real*': to be 'normal' *is* to be 'beautiful', 'slender' and 'wholesome' (Rothman 2010, Synder & Mitchell 2006, Hugger 2009, Davis 2006a). As a consequence, their anxiety in this expected 'fantasy' is experienced as justifiable, 'official' and 'horrifyingly' (for them) 'out of reach'. The outcome appears to be that both Maggie and Hannah are extremely frightened about the future, where they feel that being 'abnormal' is an inevitable permanent, undesirable fixture.

*'Autonomy' as a social norm*: In tandem with 'attractiveness' is the notion of satisfying socially accepted parameters of *ability* and thus independent human being (Davis 2006a). Although not specifically positive, the four participants did not appear to focus on this area in a particularly negative way either. This may have been due to the age of the children whose 'ability' was not much removed from their peers. Although Maggie hated to see other (younger) children progress ahead of Barney, she consoled herself in believing that he would eventually be physically able. Jonathan believed his daughter may require some support and, having done his 'homework' on the internet, Colin was almost relying on the possibility of full residency elsewhere for Helena. Meantime, Hannah was stealing herself for long-term mothering at home having met other families with older children.

The indications from these findings are that these parents have considered their offspring's future needs much as any parent does of their developing child. Whilst Maggie and Hannah both expressed fear for the future in terms of the unknown ('what might happen'), they also both appeared to be quite clear about what they thought would happen and, what they did not want to happen (Csank & Conway 2004). Furthermore, their fears of the future appeared to stem more from picturing how they

would cope rather than their offspring per se (McCoyd 2008). This perspective contrasted to the fathers' who had focused their sense of autonomy on their child and thus appeared less anxious about their own future.

*Expected compliance in social norms*: Attending physiotherapy sessions, hearing tests, clinics and development centres is a societal norm for parents who are encouraged to 'assist' in the development of their babies to be able. (Malacrida 2009, Kingston 2007, Read 2000). This particular norm was most prominent in Maggie's experience in her feeling constant pressure to be involved in a world that originally seemed alien (Hall 2005). In turn, this contributed to her sense of feeling guilty as well as disturbed by her 'new life' (Fisher 2007, Esdaile &Greenwood 2003, Hubbard 2006, Barnes 2007). For Colin, expectations were brought to light through for instance, collecting welfare benefits (Ray 2003, Desai 2000) and for Hannah and Jonathan, in letting others control the care of their babies (Manthorpe et al 2003).

*Conflicting social norms*: Hannah was torn by having to curb Helena's eating habits whilst maintaining 'normal' family activities such as treats for her other daughter's (Morse et al 2000) and Jonathan's conflict was rooted in notions of 'being a father' verses being a 'man at work' (Hochschild 1997). Colin appeared to feel considerable pressure at the groups where his attendance was 'normal' for Helena, yet 'abnormal' for him (feeling inappropriate at times) (Torr 2003, Mason & Pavia 2006). Similarly, this became evident through Maggie's account of not wanting her son to use sign language. She was viscerally aware that other mothers were 'joining in' whereas she was not, believing this to be abnormal behaviour yet concurrently realising, this activity was becoming 'normal' behaviour for Barney. It seems that contradictory issues such as these created confusion for Maggie who, being able bodied herself, attempted to negotiate her child's impairment issues, clearly struggling to find and maintain compliance with her personal sense of what is and is not normal (Mason & Pavia 2006).

Maggie's confusion with these issues centred on how she saw Barney as being 'normal' which is a common phenomenon, particularly amongst single mothers (Levine 2009) although, societal response to behaviour of this type is most often negative. Mothers may be accused of being 'in denial' or will have the impairment

pointed out to them in exaggerated ways to help them 'realise' (Davis 2006a). Yet, when Maggie did 'realise' through meeting older people with Down's syndrome, she became horrified that her son was (in her view) not going to be 'normal'. As far as Maggie was concerned her son was becoming 'somebody else' without her being able to 'see' the developments and, when she could (through his signing), she became even more disturbed. This psychological perception was a clear dilemma for Maggie, understanding her son as 'normal' whilst constantly receiving external and socialised 'messages' that he appears not (Canary 2008, Levine 2009, French 1994d, Hugger 2009).

It is perhaps understandable therefore that many parents organise their sense of 'normality' by seeing their lives as divided between 'two worlds'; 'normal' family life and 'normal' other, outside life (Morse et al 2000). Maggie had 'two worlds' although, she did not seem to make the exact distinction as per the literature; she recognised the 'Down's syndrome world' as being that which was foreign to her 'familiar world'. Whilst Jonathan clearly felt he had no need to make any such distinction, Colin and Hannah both appeared to also live with this phenomenon where Hannah's separation of her 'worlds' seemed rather more complicated than a simple binary divide. Her 'worlds' appeared to be split on many levels although this also seemed to coincide with Helena's presence. At home, behaviours had to alter around Helena to prevent a glimpse of a 'nightmare' world and outside Hannah saw her life as more difficult and thus different if she had Helena with her. This enabled Hannah to experience life without Helena as if she were a 'visitor' to the 'real' world and she consequently displayed a number of corresponding diplomatic skills (Watermeyer & Swartz 2008 Morse et al 2000, McLaughlin & Goodley 2008).

Colin also appeared to see life definitively split, yet he seemed to have three alternatives; his own 'micro world' of family, the 'disability world' and the other, 'social world' upon which, similar to Hannah, he looked out and back as if no longer accessible in real terms. Colin made it clear that he believed people in the 'other' world had their *"nice little lifestyle"* (C13:36) which implied strong contrast with his own whereby, in concord with Calton (2010), his new normality had come to represent what he used to think was abnormality. However, when hearing him describe these changes, the 'contrast' appeared to be undergoing continued development. Colin

attended many groups and clubs and in the process, he appeared to be looking for identity markers in relation to his sense of 'new self' and thus 'new normalities' (Fisher 2007, Landsman 2005, Walsh 1993, Landsman 2005, Morse et al 2000, Pelchat et al 2003, Ho & Keiley 2003, Swim & Thomas 2006, Crandall 2000, Cioffi 2000)

**'Self' at the 'interface' of society**

Maggie's introduction to her new 'normality' through being given Barney's diagnosis in a public space epitomises the concept of being at the 'interface of society' (Dovidio et al 2000). Her private and personal world appeared to her to have been invaded where she was forced to interact whilst concurrently feeling as though she was being watched. She felt exposed and as such, her upset reaction brought to consciousness the otherwise invisible 'divide' between 'self' and 'society' (Cioffi 2000). This was also brought to light through Colin's experience where he appeared to be searching for a sense of belonging and he did this as if crossing a 'border' to enter another world, that of disability (Gubrium and Holstein 1997).

That said, Colin also suggested that he and the parents he met were "*all in the same boat*" (C8:42) implying *all* their lives were similar in *all* being different and segregated from the mainstream. As such, he appeared to be reluctantly submitting to his perceived new social identity as 'parent' (van Hove et al 2009). However, he also continued to compare his situation, his child and himself to others who were on *"the same level"* (C13:40) in order to find a more 'exact fit' (Major 2006). In this, he searched for difference from 'them' (other parents and children) to satisfy his sense of 'able normality' and he appeared to want to avoid notions of (self) stigma by apparently 'elevating' himself beyond 'belonging' in thinking *'I'm not as <u>bad</u> as that'* (Crandall 2000, Cioffi 2000, Miller & Major 2000). Simultaneously, Colin also resettled his sense of normality via continued association, feeling more comfortable as his surroundings became more familiar (Swim & Thomas 2006).

Hannah also created a 'distance' from her potential social identity of 'parent' by maintaining a sense of 'normal identity' through her business and work role (Hochschild 1997). As with Colin, Hannah appeared to 'elevate' her position, although Hannah did this through mediating to clients and being diplomatic to those who appeared blunt with her suggesting that other people ('them') may be hurt if they were

to hear such comments. Maggie also preferred to differentiate from 'being a parent'. Once she realised that spending time with other mothers could mean she might be associated with Disability her response was to flee (Miller & Major 2000). Maggie appeared to be horrified by the prospect of having this 'label' and later, to counter the perceived negative implications (despite enjoying spending time with the other mothers) continued to distance herself from 'them', reinforcing her feelings by sarcastically portraying 'them' to her ('normal') friend. It appears these various behaviours (of Colin, Hannah and Maggie) were 'survival' techniques, dipping their 'toes in the water' of Disability and not wishing to become fully submerged as it might be *too* 'abnormal' (Major 2006).

Jonathan did not appear to respond in the same way as the others. By contrast he seemed proud to be a parent, enjoying seeing his daughter interact with groups and other people (Johnson 2000). Studies have suggested that parents of children who have Down's syndrome are less likely to be stressed claiming that children with Down's syndrome may have 'easier' temperaments than those who have other learning difficulty types (e.g. Ricci & Hodapp 2003, Hall & Marteau 2003, Eisenhower et al 2005). These 'research conditions' may play a part in parents' experience however, in Jonathan's case I strongly believe his perspective came through his 'socialisation' within a supportive and understanding family environment. This 'micro' social level appeared to have dominated Jonathan's life and as a consequence, he took little notice of others' opinion in the wider social sphere and did not appear to engage with any negative social discourse surrounding Disability (Hearn 2002, Lupton & Barclay 1997, Hugger 2009, Fairclough 2003).

Maggie also demonstrated the dominance of her 'micro' social sphere and this appeared to have had entirely the opposite effect upon her. Maggie's mother seemed to be the most significant other person in Maggie's life, offering her advice, consolation and psychological strength. However, despite these admirable qualities, Maggie's mother also appeared to have an extremely negative attitude towards Disability, lending a degree of insight into Maggie's perspective on beauty and 'normality'. As a consequence, these aspects appeared to have overshadowed Maggie's experience whereby she seemed to be living a life drastically opposed to her socialised beliefs and values (Bardill 2000, Britner et al 2003). Rather than coming to embrace 'difference'

as she encountered it, Maggie's doubt and reticence was naturalistically reinforced by her mother's (and additionally, her brother's) principles (Tappan 1999, Hugger 2009).

**Disability**

Maggie had an extremely negative view of Disability whereby she felt 'it' was *not normal*. Moreover, despite seeing her son as beautiful, she understood Down's syndrome (his described condition) to be repulsive. Maggie could not reconcile this antonym to the point that when she was faced with 'reality', she regularly became uncontrollably distressed. The socialisation process, through her mother, her childhood, her (non) experiences, the media, social discourse and everything that Maggie had been exposed to in relation to Disability seemed to have been absorbed by her in a negative way (Tappan 1999, Snyder & Mitchell 2006, Titchkosky 2009, Snyder & Mitchell 2006, Rapley 2004, Rothman 2010). This process appeared to have seeped through her system and become so indelibly inscribed that she could not perceive it any other way despite her son and people she had seen providing 'evidence' to the contrary. Colin also made his 'original' views of Disability very clear: he had produced a *"monster"* (C5:31) and his daughter appeared to him as a *"freak in the pram"* (C8:27). He too was presented with 'evidence' to the contrary as his daughter had Prader Willi syndrome which is not noted for fantastic deformity or dysmorphia. However, Hannah did feel she had verification to support her revulsion; she understood her daughter's behaviours (rather than looks) to be so abnormal they made her *"stomach churn"* (H13:30) (Eisenhower et al 2005).

Chrisman (2011) speaks of inspirational 'role models' and more positive images to promote the status of Disability and thus, attitudes towards the same. No one could doubt this to be a useful way forward however I believe the problem holds more gravity than simply presenting encouraging imagery and 'additional' discourse surrounding the disabled population. The towering strength of the 'opposing alternative' found in celebrity culture and fashionable magazines needs to be addressed and I accept this would be no mean feat (Fairclough 2003, Held 1980). Inspired by Michael Oliver who was not perturbed by the apparent gravitas of the medical arena whereby he turned it to his advantage in arguing for the social model of disability (Shakespeare 2006); this might be approached on a humanitarian basis via moral values (in a return to medieval history) in 'spelling out' what is socially acceptable in

the realm of human desires (Savelescu and Kahane 2011, Kimberlin 2009, Rothman 2010). For instance, through 'green' and 'eco-friendly' campaigns it is no longer agreeable to create unnecessary waste and, in tandem with this, the greed and vulgarity of wealth and fashion is being scooped into the 'social spotlight'. Child workers and slave labour associated with third world and developing countries are undergoing media exposure and the social 'conscious' of realising what is happening is perhaps gathering momentum. My point is that Disability might collaborate with *this* direction of societal impetus in order to be better equipped to 'attack' ingrained negative assumptions.

A moral (re)valuing effort might be usefully employed for those who could not be 'persuaded', (such as Maggie) by any amount of positive 'stories' that illustrate the ways in which Disability may not be unpleasant. Unlike notions of Wolfensberger's (1998) 'Social Role Valorisation' or, 'New Labour's' (2001) directive 'Valuing People', a revaluation of social moral attitude would entail questioning human values per se in a 'back to basics' moral code approach to 'right' and 'wrong' (Savelescu and Kahane 2011, Kimberlin 2009, Mason 2001). As such, the intention would be to place the focus upon society as a whole in terms of understanding notions of diversity (Patston 2007) and *not* the 'valued' individual with impairment per se, where in fact this latter aspect seems more akin to notions of 'saint' or 'sinner' of the past (Rothman 2010, Stiker 1997). I believe this societal approach might also avoid the much feared possibility of returning to a social attitude of 'pity' and 'sympathy' toward the 'appreciably poor soul' (Barnes et al 1999, Chrisman 2011). Furthermore, this level of social movement would likely avoid the trap of 'political correctness' as a 'fashionable' way of thinking where in the past, language has become a minefield of potential insult or offence (Oliver & Barnes 1998, Digby 1996). A developed moral understanding becomes deeper set as it does not have to be consciously deliberated (Kimberlin 2009, Rothman 2010). As such, Jonathan presented an example of how this may work given that his understanding of human being in terms of Patston's (2007) 'diversity' did not subscribe to notions of medicalised 'disability' *or* social barriers as a binary condition of impairment (Rapley 2004). Rather, Jonathan appeared to transcend these paradigms by seeing Harriet for who she is as a person and, he elected to do so from the announcement of her birth.

In this, Jonathan was immediately uncomfortable with 'simply' factually positing that Harriet had Down's syndrome as he recognised that others may not see her the way he did. As such, aside from wanting to embrace her into the folds of his family proudly as his second daughter, Jonathan appeared to respect her and as a consequence of the way he told people about her, he also encouraged others to adopt positive attitudes. In contrast, Colin appeared to be initially ashamed of himself (for 'producing' Helena) and in reporting his position, he clearly induced response which in turn, Colin disliked and moreover, made him feel worse. Colin was blunt about his social status and often publicly announced his 'misfortune', declaring he had been "*dealt the shitty stick*" (C11:30), so much so, that he pre-empted others prospective expected comments with this remark and felt he was giving (and receiving) comfort by suggesting to other parents this was their 'lot'.

Colin's behaviours highlight the fact that parents do not want pity or sympathy, or to be told they are either 'special' or have been 'chosen' (Hugger 2009, Carpenter 2000). However, in many ways, the onus is upon parents to ensure that unwelcome comments are addressed in appropriate ways to help other people understand that they are not well received. Hannah's diplomatic skills at work seemed to aptly demonstrate non-confrontational ways of helping people to realise they may have said something hurtful and it appears she was able to do this by remembering how she might have felt before she had Helena. If parents can find suitable ways to express their feelings through understanding their own situation, other people (society at large) may eventually come to share in the understanding of (that particular dimension of) parents' experiences. However, the type of remarks that may be suitable regarding the offer of well-meant comment clearly must depend upon the individual receiver and this again, highlights Jonathan's seemingly nonchalant attitude (Parkinson 1995). As with Hannah, he attempted to take the other's perspective in assuming they could not understand him as they had not undergone his experience and as a consequence he tolerated 'awkward' comments (Hebl et al 2000).

In spite of some damaging remarks, having a confirmed diagnosis gave both Colin and Hannah something (if not desirable, at least 'tangible') to 'work' with and they both felt a sense of relief in being proven 'right' (Lenhard et al 2005, Hasnat & Graves 2000). In addition, despite turbulent beginnings with obtaining a diagnosis for Barney,

once it had been disclosed, Maggie could at least begin to acknowledge he had Down's syndrome. However, her desire to seek approval of her newborn appeared overwhelming where she would announce that Barney had Down's syndrome in order to hear people doubt that he had (Johnson 2000, Stadlen 2004). This level of societal 'approval' gave her assurances that seemed to help her 'play out' her expectations of being a 'normal' mother.

**Socially constructed parental norms**

Maggie appeared to have relished the pursuit of 'normal' motherhood as she had very clear ideas about what this 'normality' entailed. Conversely, it seems Hannah was denied this opportunity through circumstance, her twins were both poorly and she had to retract whilst nurses attended to the babies' 'mothering' needs (Hall 2005). As such, Hannah became an 'automated wet-nurse' by expressing milk and not feeling a connection with her daughter (Stadlen 2004). However, from this 'removal' Hannah appeared able to assess her whole family situation. Mindful that her business was under threat, her husband was suffering a breakdown and her oldest daughter needed stability, Hannah took the 'other', less celebrated maternal role of 'matriarch' (Rich 1986, O'Day 1994, Shearn & Todd 2000).

In so doing however, Hannah felt she might be judged by others as cold and indifferent towards her children and that she prioritised business and organisation apparently over her family. As such, Hannah's understanding may be an indicator of the contemporary social 'mood' towards women and particularly those who work whereby her experience indicates that mothers can be wrongly portrayed as being 'selfish'. In this, Hannah provides evidence that there exists insufficient appreciation of modern matriarchal skills where at least three issues arise: firstly, Hannah's understanding appears to demonstrate a reinforcement of notions that women *ought* to be at home (or hospital) caring for or watching over their brood. Secondly, the literature informs that social expectations are that mothers care for and nurture their children in 'serious' ways: they organise, network, form-fill, time-table, arrange appointments and so on, whilst fathers take 'quality time', going out for walks and playing games with the children (Abril & Romero 2008, Kingston 2007). Hannah appeared to be engaged in 'serious' mothering yet ostensibly in a way that she felt might be described by others as going literally 'too far' as she did this at a distance. Thirdly, the social pressure that

Hannah felt in relation to the second point above, also brought to light the social expectation that she (as mother) might be the *better* person (as organiser) for the close nurturing of the children and running of the house than her husband (Pelchat et al 2003, Kingston 2007).

To some degree, Hannah may have actually understood this to be the case herself given this comment extracted from Colin's transcript:

> *"my, my missus right, she, she, if she comes back and the house is a shit tip that's it, you know, she sees her arse, blah, blah, blah…"* (C10:29-31)

This off the cuff remark is also in keeping with Colin's portrayed sense of 'all-round' pressure that he conveyed as feeling through having to navigate his own role. Although he experienced his changed role in different ways to Jonathan, social pressures for both men appeared to revolve specifically around the notion of behaving in certain ways to conform to being a 'normal' (typical) father.

Colin appeared to have been extremely troubled by his changed persona rather than by the birth of his daughter per se where the eventuality of him having a baby with impairment conjured self-doubt and self-revulsion. This seemed to lead him to question his masculinity in his role as a man, as husband to his wife and as father to his children. He had previously been proud to be in the position of 'breadwinner', clearly believing this to be a 'comfortable' socially prescribed role and the 'right' (normal *and* correct) way of being (Lewis 2002, Hearn 2002, Henwood and Proctor 2003). This seemingly inscribed doctrine appeared to create a major contribution to his 'downfall'. When Colin began explaining how he had felt about stopping work and collecting benefits and how low he had been at that point he became upset in the interview. It appeared that he felt his 'natural' place was to be earning money and as a consequence, to avoid further anguish, he continued his 'traditional' way of thinking by assuming the welfare benefits he collected to be his 'wages' (Eriksen 2003). In this sense, Colin had psychologically prioritised his 'work ethic' before family in order to 'comply' with the perceived social norm (Bardill 2000, Jones 2003, Craib 1997, Crandall 2000, Hochschild 1997). However, his actions (indirectly) ultimately put the needs of his

family first and in Sweden where this is the expected norm, Colin may not have felt quite as tormented (Bergman & Hobson 2002, Miller 2011).

Furthermore, Colin had additional issues related to the 'work ethic' beyond 'paying his way'. In concord with recent studies, he did not wish to be perceived as indolent or time wasting in being a 'stay at home' father and described many of the skills he felt he had acquired whilst being a 'carer' (Doucet & Merla 2007). He was also adamant that going out and 'stimulating' the children was his current 'job' and as such, this had become his 'raison d'etre' (Torr 2003). His apparent longing to be somewhere and with other people, took him to groups where, in fostering a sense of belonging, he struggled to 'fit in', not only from his notions of hierarchical disability but also from being male in a predominantly female environment (Swim & Thomas 2006). As noted by Beatty and King (2008), attending the groups was likely to have initially taken some courage. Furthermore, Colin's confidence was checked when, despite fostering friendships, women did not appear to fully embrace his belonging whereby he was not invited to join other members for extra activities outside the group sessions.

Torr (2003) explains that some women may feel threatened by the 'unusual' appearance of a man in an expectedly female environment where requesting such things as their children play together can be misinterpreted. Colin's experience highlighted sensitive as well as impractical issues that may arise from being in 'mixed' parenting groups although the potential alternative of groups organised specifically for fathers' would not appear to be feasible either. Given the relatively small number of 'stay at home' fathers, it follows groups for fathers who have a baby with a learning difficulty would be even more scarce (Torr 2003, Doucet & Merla 2007). Colin and Jonathan both remarked that they do occasionally come across other fathers at the groups and although this may have been each other, their understanding is that this is happening more regularly. However, Beatty and King's (2008) study revealed attendance to ('ordinary') fathers' groups was initially low and establishing agreeable activities was difficult (and costly). Combined, these factors appear to suggest that an integrated approach, appreciating men's needs amongst women, would be the most appropriate form of continued development (Torr 2003). Furthermore, despite the obvious benefits of joining other parents at groups, it could also be argued that the

groups' purpose is primarily to support the children, not the 'specificity' of the parents per se (Kerr & Mackintosh 2000, Beatty & King 2008, Ellis et al 2002).

Overall, Colin did make it clear that he enjoyed attending and as such, it seems the benefits both he and Jonathan appeared to reap through meeting people who had undergone similar experiences to their own replicate other findings in the literature (Kerr & MacIntosh 2000, Torr 2003, Soloman et al 2001). When Jonathan had been able to attend groups, it seemed he was able to see past the 'gendered divide' although his purpose could be seen to differ from Colin's. Jonathan attended in order to engage in the company of (any) others and to be with his daughter(s) in family friendly environments for fun. Colin did appreciate this latter aspect yet he had a different underlying approach. He believed his attendance was part of his duty and moreover, his job of being a father. For Colin, the groups seemed to represent his 'going to work' and thus, fostered maintenance of his 'masculine dignity' through this self-induced identity (Williams 2009, Cioffi 2000).

By contrast, Jonathan portrayed these elements of his fathering role as being 'special' where, in tandem with a growing number of men, he had organised his work life to accommodate such occasions (Towers 2009). In this, Jonathan felt his employment role presented an obstacle to his wellbeing. In their Spanish study of the workplace, Abril and Romero (2008) found this to be a common phenomenon amongst fathers who were also managers yet, as a result of their position, they feared taking time off. Jonathan eventually became so disturbed by being at work and unable to fulfil his perceived role as *"family man"* (Hochschild 1997 p.132) that he suffered an emotional breakdown. As such, his 'masculine' identity emerged as being grounded in his family where again, had he been Swedish, his anxious frame of mind might have not only been understandable, it would likely have been expected (Bergman & Hobson 2002, Miller 2011, Race 2007).

Jonathan and Colin's experiences raise some important issues in relation to being male. Much of their torment appeared to come as a result of feeling they were not able to ascribe to the roles they perceived as being important to fulfil. Furthermore, both experiential breakdowns were connected to the workplace yet each father felt pressure for very different reasons. I am therefore surprised that Williams (2009) and Henwood

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and Procter (2003) suggest that male gender roles would benefit from broadcast prescribed ideals. It may be more helpful to consider the ways in which men differ from each other as well as from women in order to facilitate ways of understanding and thus appreciating their uniqueness and perspective towards family life (Hearn 2002, Gavanas 2002).

*Good parenting*

Much of what has been 'lost' in apparently neglected discussion of gender roles and the redefining of 'functional' parenting has been gained by the 'prominence' and perceived importance of the child (Williams 2009, Lupton & Barclay 1997, Henwood & Procter 2003, Malacrida 2009). In concord with the literature, the fathers in this study saw themselves as taking second place to their children, where Jonathan in particular believed he was the lowest priority in his whole family. He felt he should support his wife in rearing the children and, in spite of taking the primary care role, Colin continued to also perceive himself as subordinate to Hannah's overall 'command' and noticeably, both of these relationships correspond with historical accounts of partnership rather than more recent 'gendered' behaviours. Colin often spoke of his own experience using the term 'we' to describe events that had happened, indicating his sense of team work and shared identity with Hannah (Stueve and Pleck 2001, McLaughlin-Volpe 2006). Jonathan went even further in describing his experience from his wife's perspective and this bonded family togetherness was made more conspicuous in view of the contrast found in Maggie's single status.

As previously mentioned, Maggie's 'partner' for support was primarily her mother and this follows Golden's (2001) suggestion that parents naturally turn to their own parents as role models for ideals of 'good' parenting behaviours. In taking this action, Maggie appeared to display many of the traits identified by Beach-Copeland and Harbaugh (2010) who, in their comparison study of single mothers with those who were married, found that single mothers tended to have lower self-esteem and 'sense of mastery' of their situation than married mothers. However, given her previous experiences of being a mother, Maggie *also* showed that she was not a *"powerless victim"* (Levine 2009, p.408). In fact Maggie was in 'control' of her situation much of the time, only to be knocked by her formerly imprinted understandings of Disability.

Levine (2009) usefully points to the ways in which mothers generally tend be the family figurehead where statistics reveal disabled children often live in one parent families and this is most likely to be the mother. She therefore advocates these women are capable decision makers who, in the absence of many resources manage extremely well. Levine (2009) goes on to argue that despite these 'social facts', single mothers are also likely to be closely monitored, judged, possibly deemed 'unfit' and lacking in their parenting skills more than other mothers. Whilst Maggie may not have felt this undermining pressure directly, she made it clear that it was present not least when she showed concern for her ability to make the 'right' choices in comparing her own behaviours to those of other mothers. In her decisions, she did not appear to take 'second place' to Barney and her actions often resulted in self-doubt. In light of this latter aspect, Beach-Copeland and Harbaugh (2010) argue that *all* mothers require reassurances that they are doing a 'good' job of parenting their child and it is not something peculiar to being single.

Unlike Maggie, Hannah did not have a close relationship with her mother and did not feel she could turn to Colin's parents for advice. In fact, Hannah was also reluctant to accept advice from anyone else other than from those parents who had specific experience of having a child born with Prader Willi syndrome. Personal levels of understanding through experience were important to Hannah as these helped her to feel understood (Rosaldo 1989). However, she did not follow others' advice given their 'unacceptable results' rather, she used their experiences as a guide of what *not* to do (Miller & Major 2000, Taanilla et al 2002). As a consequence, Hannah appeared inventive, creating 'alternatives' in order to 'correctly' rear her daughter whilst managing a continuation of her perceived 'good' parenting of her other girls. Her uncomfortable 'path finding' experiences exposed some of the ways in which having to explore new directions appears to be more prominent for those mothering a child with impairment than for those who do not (Crown 2009, Kingston 2007, Hugger 2009). Moreover, Hannah's forthright approach aptly demonstrated the ways in which she was *unable* to directly prioritise her child in a positive way as instead, Helena's impairment had become her focus (Hughes 2009, Shakespeare 2006).

In her endeavour, Hannah did not feel able to turn to professionals for ideas to help her with raising her daughter (Pelchat et al 2003). Professional intervention also appeared

to 'fail' Maggie where she saw physiotherapy and signing as specifically intrusive. Furthermore, it appeared that the fathers, despite voicing gratitude and admiration for the professionals they encountered, also suffered from their apparent lack of parental perspective. For example, when leaving the hospital, Colin was embarrassed and frustrated at the behaviours of the staff who appeared to have 'misread' the situation and, Jonathan was left to make an educated guess when given a vague diagnosis of his daughter's condition in the middle of the night. As such, it was quite clear that the 'experts' featured in the parents' experiences did not attempt to perceive the situation(s) from the parents' perspectives. Many assumptions were made from an unfeeling and 'expected values' route where in Maggie's case in particular, they appeared to be forced through rather than explained (Hasnat & Graves 2000, Abberley 2004).

These findings suggest that professionals' perspectives remain firmly fixed on their own rigid notions of 'good practice' and 'appropriately' directed policy (Todd 2003). Furthermore, and in light of the earlier comments made in relation to 'diagnosis', these 'ideals' appear to be combined with personal awkwardness in speaking to parents about (potential) difficulties with their offspring (Manthorpe et al 2003, Hebl et al 2000, Hasnat & Graves 2000). The raised issues return to the notion of continued poor professional conduct and failed attempts to 'get it right' as discussed earlier in the main introduction and theoretical perspectives in chapter two. It appears from (just) these four accounts there remains a serious shortfall in professionals' understandings which, in concord with Goodley & Tregaskis (2006), I believe could be remedied with consideration and focus placed upon parental perspectives.

Parents are not 'super human' they need and appreciate constructive help. Based on an exemplary encounter with one paediatrician, Jonathan suggested that he appreciated being treated according to the context of what was happening and, to whom (a young family) whereby she did not:

> *"baffle you with science and make out you don't need to know"*
> and not *"over simplify and (…) talk to you like you're an idiot"*
> (J11:6-10)

From Jonathan's point of view, it seems that professionals and practitioners do not necessarily need to know what parents are feeling as much as they need to understand how to approach them (Gunaratnam 2002, Hasnat & Graves 2000). Furthermore, it appears from his example that appreciable respect could be the major underlying factor that might support the process of disseminating information in an appropriate way which in turn, may enable parents to help themselves (Ellis et al 2002, Mitchell & Sloper 2003).

The participants in this study very much appeared to consider themselves to be 'ordinary parents' who were getting along with parenting their children in the best way they knew how (Hugger 2009, Sparks 2009). Their ideals of being a 'good' parent therefore appeared to be underpinned by this perception taken in the context of the wider social sphere (Robb 2004, Larkin 2006). In accord with the literature regarding modern ideals of 'goodness' for example: it was clear that for Jonathan, being protective, supportive and simply with his family equated to 'good' parenting; Colin believed it was his job to teach his girls moral values and Hannah wanted to encourage them to be like her, capable and independent and, Maggie saw 'good' parenting as loving Barney and spending time with him (Francis-Connolly 1998, Beatty & King 2008, Williams 2009, Robb 2004, Malacrida 2009, Henwood & Procter 2003).

Perhaps unsurprisingly the highlighted issues were those that appeared to surround the difficulties in the relationships the parents had with their children. It is therefore likely that these characteristics of 'good' parenting were most prominent as they also appeared to be the most *unobtainable*: Colin and Hannah believed Helena struggled with socially acceptable manners and was unlikely to be autonomous and Maggie (as mentioned earlier) was frightened about how she would be able to keep loving her baby as he grew older. Conversely, it appeared that the 'good' parenting attributes for Jonathan were the most prominent as these were 'done' and 'doable'. However, this did not prevent Jonathan from experiencing parental doubt and upset. In wanting to take a supportive and involved role as parent, he often found he felt guilty through feeling potential neglect of his other daughter after a prolonged time spent with Harriet (Kingston 2007). Hannah explained similar 'sibling' effect where she felt Helena attracted a lot of attention, specifically from grandparents which she felt deflected 'proportionate' affection off her other girls. As a consequence, she reduced her time

spent with Harriet and through her attempts to 'justify' her actions she clearly felt she could be judged by others as a 'bad' parent.

In concord with French (1994), Hannah also felt a sense of double jeopardy as Helena's impairment was invisible to others. Consequently, if Helena misbehaved in front of others Hannah felt her parenting skills appeared questionable and it seemed she pre-empted this possibility by judging herself as she felt others might do (Cioffi 2000). According to Stadlen (2004), this behaviour is common amongst many mothers and particularly those who feel they are not 'good enough'. Unfortunately, Hannah's anguish did not halt there as she had begun to perceive her *whole* family as potentially being 'not good enough' given their developing collective identity as associated with Helena's impairment (van Hove et al 2009, McLaughlin-Volpe 2006). As a result, Hannah had begun to worry about family related social interactions and this particular issue brought to consciousness the full impact of being accepted by society or *not* (Mason & Pavia 2006, Ray 2003). In this, Hannah included the 'faceless' general public as well as the people she knew. Her apparent apathetic attitude seemed to stem from her perceived 'reciprocal' understanding that overall, she judged others with suspicion whilst feeling they judged her in a bad light and moreover, she felt there was nothing she could do about either situation (Swim & Thomas 2006, Hornby 1992).

**Society at large**
Potential societal behaviours and social attitudes were perhaps most obviously 'filtered' through Hannah as she appeared to voice her encounters with 'society at large' more than any of the other participants. As a hairdresser, she was 'locked' into hearing other peoples' stories (from the 'other' reality) and sometimes cornered into mediating hers and her daughter's position (Read 2000). This seemed to create additional pressure for Hannah, although in the beginning her orientation to her work also emerged as her form of 'escape' (Hochschild 1997, Shearn & Todd 2000). In his focus on fathers, Williams (2009) describes 'work' as meaning many different things (income, social life, friendship etc) yet he does not list it as a source of 'refuge' as it appeared to be for Hannah. Certainly, for Jonathan and Colin, the public workplace seemed to create the opposite effect where they needed to get away from it. Through working for organisations they were able to take time off yet this luxury was not available to Hannah and she clearly felt considerable pressure to keep the business

going. In light of this, it is difficult to see how those like Hannah who are self-employed could be alleviated by employment legislation per se. However, as a family, Hannah and Colin's stress in relation to financial matters could have possibly been lifted via Colin's position.

Colin was clearly uncomfortable with the situation of having to 'live off' the welfare state where he appeared to feel stigma from not working and initially perceived the payments to be 'undeserved free money' (Lewis 2002, Levine 2009, Borsay 2005). The difficulty appeared to be the connection Colin made with being 'out of work' where pressure stemmed from his persistent sense of the 'work ethic' (Hochschild 1997, Jones 2003, Craib 1997, Crandall 2000). Colin thus provides a glimpse of the current prevailing attitude towards disability related benefits as discussed in the theoretical perspectives chapter (two) of this thesis. In order to overcome his (socio-) psychological barrier, Colin had created a defensive 'story' in counting his allowances as a justifiable 'wage'. I imagine this to be a well used narrative for Colin as it was an issue which stirred much passion in the telling of his experience.

As stated previously, Scandinavian countries appear to be leading the field in attempting to address this situation although, not without their difficulties (Eriksen 2003). It appears the continued adherence to gendered ideals relating to functional roles may be part of the problem, as well as state approaches to welfare benefits which as Desai succinctly suggests:

> *"undervalues citizens living time and overvalues its own financial savings"* (2000 p.92)

Following this latter line of thinking and returning to a previous thread, I also suggest that neglect of family values, the role of caring and recognition of diversity in human being are at the core of the issue. I (again) propose that a return to moral values surrounding Disability would aid the societal attitude in better understanding the notion of shared human experience and thus responsibilities in the same (Kimberlin 2009, Ray 2003). I understand this is a contentious issue, given there are those who would exterminate and filter out from society others who could be perceived to be a 'burden' (McCoyd 2008, Hubbard 2006, Saxton 2006).

Given the enormity of the ethical issues that abound within this specific topic I do not intend to enter into a debate on modern eugenic practices (certainly not at this late stage of this work), however I will suggest that: as it is unlikely these practices will ever be halted (see the history chapter (one)) ways must be found to accommodate the activity whilst synonymously valuing the increasing number of 'survivors' in meaningful ways (Savelescu and Kahane 2011). Parents clearly make conscious decisions to keep their babies (when tested 'negatively') and many more babies survive premature births developing with associated impairment (as did mine) (Barnes et al 1999). In order for parents to not feel guilty, blamed, stressed, aggrieved, depressed, judged, excluded and generally negative about their *situation*, a unifying (although *not* single) perspective needs to be explored and advocated. I believe I have made a start by seeking out parental perspectives where ideals such as these can be formulated from 'what happened' in their experiences.

**Conclusion**

Through drawing out this discussion, I hope to have highlighted pertinent issues that emerged from the findings of this study to draw attention to significant aspects of modern parenting experience. I shall review those here in a more succinct format prior to closing the thesis with an overall conclusion. Through offering parents space and time to talk about their experience they seemed able to explore their feelings and find ways to describe these to convey their understandings of 'what happened'. In light of other findings which suppose men shy away from sensitive research, it was refreshing to find that fathers came forward and furthermore, appeared to have no difficulty in speaking about their emotional experiences (Csank & Conway 2004, Williams 2009). This may have happened on account of the particular style of this research which in turn, lends some justification to taking a 'relaxed' and open approach.

Of significance was the noticeable management of emotion and self-regulation as all the parents attempted to unpick their experience through a minefield of sensitive issues relevant to what had gone before and the ways in which this affected their present day feelings. It became clear that describing their experiences in context was important whereby 'explaining' circumstances facilitated proportion and moreover, it helped to convey meaning (Larkin 2006). The parents chose to tell stories within their experience and revisit encounters as well as conversations with others. They also used

body language, music and metaphor amongst a variety of other methods to get their meaning of these experiences across. The range of description 'beyond language' highlighted the difficulty for me in representing those emotions 'third hand' and in writing as well as confirmed the importance of using participants' own expressions in delivering the findings.

Although some parents described their feelings as emotional 'grief', their individual experiences belied the ability to 'apply' notions pertaining to grief theory. I suggested that if the association of patterns of bereavement with Disability is to be (ideally) stemmed, parents might be encouraged to talk about their upset in alternative ways. It seems that 'love' and understanding the variety of representative meanings brought about by what *that* feels like, (including negative associations) could be a more useful vehicle through which parents might express their turbulent emotions. Parents want and need to be helped to understand that their individual behaviours in response to overwhelming and unusual emotions are 'normal' (Bruce & Schultz 2002). As such, professionals and practitioners who come into contact with parents might benefit from training in basic counselling skills in order to respond to this level of individuality.

In addition to exploring emotional 'normality', parents also appeared to search for stability in relation to finding 'normal' ways of being. Their experiences revealed the ways in which they were ordinary individuals vulnerable to torment via persistent self and social pressures. They all appeared to notice their own previous (comfortable) ways of being as well as other, unfamiliar (alien) and different (uncomfortable) ways of being (Hall 2005). Pressures appeared to result from self-expectations and from acknowledgement of societal norms thus highlighting the interaction of self with society (being at the 'interface') and the subsequent ways in which parents may live their life between any number of perceived 'worlds'. In this, three of the four parents seemingly attempted to cling onto their 'old' (non-stigmatised) identity, creating a distance of 'us' and 'them' in self-definition of their (elevated) difference.

This brought to consciousness some of the issues surrounding Disability and expectations from parents of what this might mean. I made a brief comparison of Jonathan's beliefs with Maggie's through highlighting their socialisation prior to having their children. I concluded that Jonathan had a developed sense of 'moral code'

based on appreciation of diversity and proposed this to be a useful understanding that could be utilised in 'campaigns' aimed at changing public conscience. I suggested such an approach might be to address social values rather than 'valuing individuals' per se, placing the context of change in the wider social sphere whereby impairment could be considered as part of diverse human eventuality. In contrasting Hannah's and Colin's responses to negative public comment, I proposed that parents, being at the (conscious) interface of society are well placed to at least begin the process.

In turn, I discussed the roles of parents in relation to their perceived gendered identities as 'mother' and 'father'. Hannah's experience could be identified as her taking a traditional 'matriarchal' position and, in briefly exploring the ways in which Hannah's maternal behaviour appeared to simultaneously conform and conflict with societal expectations, I appealed for a return to societal appreciation of associated matriarchal skills. The adapted family behaviours of Hannah had clearly impacted upon Colin's experience and as a consequence I subsequently placed this under the spotlight. Just as Hannah's experience of feeling judged by other mothers appeared as a 'window' into understanding potential societal pressures, Colin's attitude also seemed to offer views on current socially acceptable behaviours in relation to fathers and work. Colin's difficulties appeared to stem from his appreciably strong correlation to a perceived 'work ethic' through which he did not appear to associate welfare benefits with 'deserved income'. As such, Colin felt considerable pressure to justify his being a 'man at home' which in turn, emphasized the continued presence of male associations with being a 'breadwinner' as well as (potential) 'feckless layabouts' (Lupton & Barclay 1997, Lewis 2002).

I contrasted Colin's experience with Jonathan's who, despite also suffering work related trauma, showed his to have arisen from alternative 'masculine' expectations. Jonathan felt that work prevented him from supporting his family. His eventual emotional breakdown appeared to be a drastic outcome shedding light on the potential consequences of a lack of societal recognition of the strong bond that some men feel with their families. As such, I contemplated the fathers' experiences in the context of a more understanding social environment such as that apparently offered in Scandinavian countries, especially Sweden, where it appears through circumstance, emotional breakdown might have been avoided on both accounts.

I also highlighted specifically male experience in terms of the fathers' engagements with parent groups where I determined that more integrated approaches may be required given the small but growing number of fathers attending. Through identifying Colin and Jonathan's different approaches in terms of the ongoing discussion I was led to conclude that prescribing idealised gender roles (as has been espoused in the literature), to be entirely inappropriate. This claim was further supported through exploration of the participants' understandings of 'good parenting' whereby the married participants appeared to work as a 'team'. In being 'partners' the fathers described their role as being subsidiary to their wives, confirming the females' 'controlling' status whilst proposing their own 'natural' (male) position as being 'in support'. Furthermore and in line with modern understandings of being a 'good parent' the fathers also seemed to prioritise their children over themselves. Yet in contrast on both accounts, the mothers did not. The focus on couples' behaviour and family prominence drew attention to Maggie's single status in terms of her perceived ability to be forthright in the decisions she was making, incorporating consideration of the effective contribution of a significant other as partner. I contrasted this with Hannah who believed she needed to find her 'own way' of parenting, exposing the sense of 'pioneering' experience that some parents may undergo.

In all the parents' experiences, it seemed that professional assistance had been disappointing, often lacking foresight and the ability to perceive problems, issues and events from the parents' perspective. In turn, I suggested the parents perceived their roles as being 'ordinary' and these were highlighted by them as being problematic which coincided with them appearing to be most difficult for them to obtain. I focused upon Hannah's specific struggle with her understandings of not being a 'good enough' parent and her extended realisation of the whole family potentially being 'at fault'. In turn, this served to demonstrate the ways in which parents may come to understand the reality of living with notions of social acceptance and rejection, which includes their own 'reciprocal' feelings.

I also pointed to Hannah's situation as presenting an inflexible source of family finance and switched the focus to Colin's circumstances and the perceived difficulties surrounding current welfare state benefits. I used this final point to argue for state

welfare and work ethics to include a better appreciation of family care roles. I again proposed the proactive introduction of social morals that would value human diversity and in this I acknowledged that eugenic practices would need to be addressed. In opening these avenues and not being afraid to talk about the difficult and sensitive, often self-repulsive ways of thinking and being, it may be possible to find new 'normalities' and thus, comfortable ways of being in the diverse social world.

# **CONCLUSION**

Having been exposed to the ways other researchers approached the subject of parenting a child who is described as having a learning difficulty and being a parent myself I was inspired to make further investigations into experiences of being a parent. The outcome of my interest has been to carefully process an exploratory study and subsequently produce this doctoral thesis. I chose to take an 'open' critical hermeneutic phenomenological route in order to embrace notions that parents are ordinary people to whom an interesting event has happened and being a parent myself, I believed they were likely to understand their experience in a multitude of ways and I would need to accommodate this eventuality. As such, I could see that a large portion of parents' experiences were being missed through being captured via conventional forms of investigation: they could be entirely misunderstood through these narrow, one-dimensional extractions. I thus began my written work with an introduction to the issues arising from the literature where I highlighted the main areas of parenting research that I felt required urgent attention.

Given the number of shortcomings it was immediately clear to me that research was not being carried out from the perspective of being a parent and from this, I realised that being an 'inside' researcher may bring some benefits to the project. For instance, I was perhaps able to identify the anomalies in the first place *because* I am a parent where others may have accepted inadequate and sometimes inappropriate modes of research because they are not. Findings and consequent expected actions and understandings may also have been accepted by others given that contrasting alternatives and variety in experience are difficult to retrieve from the existing literature. As a parent, I was puzzled by the lack of 'normal' and individual 'parental activity' portrayed in experience and I was left to assume that others who are not parents themselves perhaps expect these to be lacking. To me, they are essential elements of any parent's life. I determined from these thoughts that if others do not see the problem with current understandings then it may be time to add to what is known.

In taking an exploratory route I began with a general area of interest in parenting experiences, simply wanting to find out 'what happened' and I therefore had no specific research questions per se. As a consequence, the findings revealed a broad

spectrum of current issues pertaining to being a parent and these were discussed in chapter five (p.233) and subsequently outlined as succinctly as possible in the chapter conclusion (p.265). My interpretations of the participants' accounts of experience brought to light the ways in which individuals 'play out' their experience in a multidimensional social environment where the emotional 'self' often appears to be at the mercy of grand social design. As such, this research uncovered detail in relation to individuals experiencing unfamiliar emotions where current literature and theory can be seen to fail to explain parents' understandings of these thoughts and feelings. The study findings identified the ways parents seemingly negotiate their 'new' lives through 'old' ways of being, reinventing themselves, their family and their understandings in an attempt to feel at ease in the social world. Regaining their sense of normality through a barrage of social concepts including perceived right and wrong ways of being in relation to such things as having and rearing children, being male or female and being in close proximity to impairment (or not) all appeared as significant factors in these parents' lives.

Given that these moralistic social issues are generally ignored by others, the matters arising created useful additions to what is already known. As a result, this conclusion serves as a comprehensive reflection on my study and in revisiting the themes, I aim to identify more closely what I believe has been gained through conducting this research and thus, what I feel I have been able to contribute to this field overall.

**Addressing current research shortfalls**

I begin this reflection by revisiting the contentious issues I set out to address as highlighted in the main introduction (p.24&30) I had identified these as areas where current research appeared to be lacking and considered them to be motivational 'technicalities'. They primarily constituted practical tasks pertaining to the field of study and as such, were matters that I felt could be 'simplistically' overcome in terms of taking an alternative research approach to that adopted by the majority of others. The first five points that I identified were made in direct relation to parents as individuals where other research appeared to treat them as distant objects under scrutiny. I followed this with a rationale for understanding parents as living in a social context which revealed a further six issues and together, these yielded a total of eleven

significant factors that supported the conduct of my study in both my chosen style and content.

*Parents as individuals*

I had gleaned from the research that parents were being perceived as suffering trauma as a consequence of having to cope with their child having impairment and furthermore, in a way that depicted the 'problem' as being entirely personal and family bound. I therefore saw my first task as making an attempt to convey the thoughts and feelings of parents as people who were living ordinary lives in a social world, with other children, relatives, friends, work, leisure and a sense of their own being in this busy, shared environment. I attempted to achieve this by being truly open to what the parents had to say about their experience, in allowing them 'space' to talk about what the events meant to them, how they had lived through the instances, including whatever else was happening at the time and giving them a free run to explore their own understanding of 'what happened'. This created a rich picture of their lives which revolved around themselves, their children, their relationships with other people and their feelings of being low and upset as well as their moments of joy and happiness.

Secondly, I wanted to counteract studies that portray parents as having entirely negative experiences. I believe that through assumptions made in this vein, deficit approaches have been taken and this not only perpetuates (mis)understanding of the presumed condition, it also denies parents their right to respect for who they are as people. Parents are often portrayed as victims who are struggling to recover from a stressful situation and, when investigating their wellbeing the child's needs are most often prioritised. As such, parents can be understood to be of lesser importance and I therefore endeavoured to place parents as 'centre stage' in this study. I felt that in order to understand their experience of being a(nother) parent, a beginning to the process was to consider their lives, not in direct relation to 'the child' or Disability per se, but from their own account of being an individual. From this approach, I felt I could learn and pass on what 'these things' might mean to them as well as the ways they navigated life with their particular applied meanings.

This leads to the third point I made in the introduction regarding individuality where I now hope to have added substance to the small body of work that heralds parents'

experiences as being idiosyncratic. In this I wanted to show that parents do not all experience negativity in direct relation to their child and that parents naturally experience fluctuating emotions that are triggered by eventualities and variations in relation to their particular life course. In presenting my findings as interpreted accounts of experience, I wanted to give the reader an opportunity to gather 'what happened' in ways that might inspire further thought and consideration of the 'real life' events. I included contextual detail to invite imagination and aesthetic response as I felt this could facilitate the creation of understanding the unique 'story'. Clearly, interpreted and 'narrative' accounts are not new to this field however they are too few to reasonably complement and balance the myriad of quantitative studies that otherwise abound. As such, I believe my research makes a specific contribution to the qualitative field whilst broadening the overall knowledge base in relation to (individual) parents' experience.

In this respect, the particular research participants also served to respond to the fourth issue as highlighted in the main introduction. I attempted to include experiences that were not stereotypical of the genre (usually non-working, married mothers) and instead chose a single mother and two fathers, one of whom stayed at home as primary carer as well as his wife, a working mother. The four parents interviewed thus offered some insight into 'different' ways of being whilst concurrently they were representative of modern (English speaking) family lifestyles. However, this action also reveals some of the limitations of my study as it was not possible to include parents from ethnic minority backgrounds or those that had learning difficulties or physical impairment and nobody from the gay community stepped forward either. As such, these are areas I believe would benefit from further exploratory research that explicitly intends to consider parents' perspectives against a backdrop of specific cultural and disability related discourses and (re)presentations, which in turn, are set in the context of predominantly white, able bodied, heterosexual cultures, customs and environments.

This brings forward the fifth and final issue I made in connection to previous research with parents as 'contained' individuals and this is possibly the most important: other research appears to be designed to inform policy and practice and yet, despite attempts to claim the contrary, I did not find many that took parents' perspectives properly into account. As a result, I believe this has been key to the ways in which professionals and

practitioners utilise findings and subsequently come to (mis)understand parents. In this research, regardless of being a parent myself, I have attempted to grasp an understanding of the participants' experiences by listening to their accounts and through interpretation of these, I aimed to pass on what I believe the parents thought and felt. With the additional chapters on historical and theoretical perspectives, I hope to have enriched the interpreted experiences with additional foundation and locale. I placed them amongst this broad contextual field in order to aid the readers' understanding of circumstance where this was entirely relevant given the data was inspired from themes derived from the participants themselves. In addition, I hope to have further aided this 'perspectives' approach by explicating my own understandings and the ways I have worked in order to reach my interpretations.

In taking an individualistic approach that ironically does not account for individuality, what is also noticeably missing from current research is acknowledgement that parents undergo their experience in a social, culturally developed environment. Occasionally studies have attempted to identify 'barriers' to inclusive practices yet these are rarely concerned with the daily experience of being a parent and as such, do not enter into examination of what their life might feel like. Instead, studies tend to remain focussed upon structural 'barriers' where this notion immediately continues the implication of 'individual problem'. Issues surrounding access to such things as 'key workers' and 'information' strengthens my point that parents' perspectives are not central; it is the view of the 'expert' looking for ways to improve services that appears to guide the research question. If parents' perspectives were taken into account, I argue that 'access' would not be an issue as the 'key worker' would know where (and how) to be in order to make the parents' lives much easier and relevant and appropriate information would be 'naturally' forthcoming. Moreover, service provision as defined in physical terms of such supply and demand may not even be framed by parents as priority issues for investigation. This study for instance, revealed a requirement for review of professional attitudes and approaches towards parents, giving substantial evidence to the overall case for considering their perspectives as a significant parental need.

As a consequence, I identified five further points in my introduction that I felt my research should incorporate in order to compensate for the lack of social

acknowledgement elsewhere whilst believing that, however proportioned; the contribution to knowledge would be worthwhile.

*Parents experience as a social being*

The first point I made was that parents have been extracted from the social context in research generally yet, when intersectional systems are taken into account these have also been treated as separate entities. For example, research on families often surrounds notions of poverty in relation to Disability whilst issues of gender and race are ignored. I hoped to address this by exploring experiences with minimal assumptions and this allowed the parents to reveal (consciously or subconsciously) the ways in which these socialised classifications might have affected them. This yielded interesting data with particular focus on welfare benefits mixed with gendered roles in relation to caring and participation in the workplace. It would seem naturalistic that these also exposed cultural expectations in relation to being a parent in a particular socio-geographical context, in this instance, the UK.

I made a second point in relation to society that whilst other researchers tend to examine individuals as if unaffected by their social environment and heritage, there is little recognition of this in fact, being impossible. In this research, I hoped to make this position clear by not only acknowledging notions of social influence, I attempted to illustrate the interplay through examining ways in which parents can be manipulated by society whilst also exposing the potential of individual will in the form of human desire and inherent behaviours. I hoped to do this both through 'stories' from history, conceptual theory as well as via the participants' interpreted accounts of their experiences.

This way of working also addressed the third 'social' issue that parents, being in a social environment, may not always realise their situation as being part of the grander scheme of social life. In other words their experience may consist of many taken-for-granted assumptions about what it generally means to 'play out' the parenting role in terms of socially derived rituals and customs. In taking a critical (parental) perspective I aimed to consider some of the ways in which these had impacted upon the participants as well as parents in general. Some ordinary parental assumptions of 'what happens', such as when bringing a baby home from hospital, were exposed as being

taken-for-granted normalities of social life because they did not occur in the expected format or rouse anticipated feelings for these particular parents. Naturalistic ordinariness of life in relation to 'simply' being is rarely brought to light and this research has made attempts to work in this direction.

As a fourth point, I also wanted to expose the publicly devised constraints that some parents may experience in order to address a further gap in current research as this often fails to acknowledge social pressures surrounding idealised concepts such as 'mothering' and 'Disability'. Again, exploring histories surrounding the 'creation' of these concepts as well as various theoretical perspectives and 'corresponding' empirical findings, I believe this research has entered the process of disseminating a broader understanding of the issues and the ways in which these relate to parents. This directly follows through to the fifth issue I raised which was to consider the ways in which parents may be governed by social ways of being to the extent that these may (overall) constitute a sense of desirable social normality.

These 'social' elements of the research enterprise were borne out of issues that were prominent in participants' accounts *and* they constitute a considerable gap in current literature. This aspect in particular created intense motivation to ensure I thoroughly explored 'what happened' with a view to looking beyond the usual routes of parenting research in the quest for deeper understanding of the 'whole' situation. I was also similarly driven by the sixth issue, as an overriding and thus eleventh critical feature of this research and that was to address 'emotion'.

Emotions were a vital part of all the parents' experiences and I wanted to explore these with a view to representing a clearer understanding of parental feelings than was currently available in the literature. By incorporating emotional discourse throughout the text, I hope to have added to the currently scarce amount of research that considers human feelings in aesthetic ways. Perhaps more importantly, I wanted to make inroads towards rectifying an unbalanced and disproportionate image that I believe floods the contemporary field. In this, I also determined to make clear that the onus is not all with the parent in feeling the burden of apparent 'stress' given the negative relationship that society as a whole appears to hold with impairment and the notion of Disability. This was seen most vehemently in parents' own (pre)understandings and through their

stories, particularly relating to those of significant others who appeared to hold considerable influence over parental feelings in both good and bad ways. As a result, I believe this would be a useful avenue to focus further research in terms of identifying social moral values (and related surfacing emotions) in family and close relationship contexts.

In relating parental experiences through interpreted accounts, I hoped to invoke a degree of empathy through which other emotions besides the regularly cited 'grief' and 'stress' that usually 'surface' can be recognised. That being said, I wanted to highlight inappropriate usage of theory with particular reference to 'grief' given the related morbid connotations and often incorrect ('convenient') application which I believe has contributed to (further and moral) misunderstanding in the past. Instead, I introduced the notion of other, more appropriate and alternative ways of discussing feelings of hurt. As all the parents had talked about the ways in which they loved their baby and this rarely appears in other research as *love*, I suggested this may be a starting point for parents and practitioners to discuss feelings of upset within this 'all encompassing' expression of emotion. Although I did not discuss in such detail the range of other emotions that became apparent (only due to limited space), I believe parents may benefit from further research that explores notions of emotional turmoil incorporating *balanced* views of such things as jealousy, fear, pleasure and pride all of which (and more) appeared as equally prominent (to 'grief' and 'love') among the generated data. As a consequence, I believe I have only scratched the surface of what can be known and this is frustrating as I believe it to be an area that could prove extremely helpful.

However, as an exploratory piece of research I am satisfied with my attempts to fulfil my own predetermined criteria that I necessarily set as aims for conducting a more appropriate style of research with parents and which has subsequently appeared to reduce a number of 'technical' gaps in the related field of knowledge. In this I also include the actual mode of research I chose in order to execute the project. Critical hermeneutic phenomenological enquiry is a rarely used research vehicle which I hope to have exposed as being both appropriate *and* worthwhile. The loose framework allowed for an expansive exploration throughout which I felt encouraged to 'chase' what could be known, track down concepts, open up possibilities and formulate understandings. The experience of working in this way has been exciting as well as

absorbing and most importantly I believe it has proffered relevant, useful and informative results. The following section of this conclusion is therefore devoted to reflection of the ways in which these were obtained as this formed the 'productive' body of work.

**The productive body of work**

Having established an appropriate way of working, to complete my 'research attitude' I was eager to find relevant disability theory that sat comfortably with both my understandings of being a parent as well as with modern discourse surrounding others' experience of impairment. I was able to achieve this through drawing attention to three separately proposed models (from seemingly opposite ends of the globe: the UK, US and New Zealand) which incorporated notions of diversity, justice and wellbeing. All of these were underpinned by social moral values and together formed the critical concept underpinning my research endeavour. These theories likely 'came forward' as appealing critical goals as I found them once I had interviewed parents and my prejudices' towards this arena had clearly been set from this activity.

Referring back to the introduction where the models are briefly explained (p.44), I also considered 'bio' and 'cultural' as well as combinational models, subsequently disregarding these believing them to be not entirely suitable. For instance, impairment is not directly of the parent (being able bodied) and therefore 'bio' models seemed inadequate although, one that might have incorporated biological-identity related issues may have been more helpful (had it existed), not only for parents but also siblings and significant others in the family. Exploring the 'mechanics' of these (and other) models helped me to understand more about why finding recognisable routes is important, as shown in detail with the example of the social model, it can form a simplistic yet vital message that aids the process of being understood. As such, I concluded that my attraction to moral values was based upon the ways in which I see that parents are perceived by society as 'others' who are misunderstood and in terms of them receiving unfair 'treatment' given that experience of impairment occurs in a seemingly cruel and unthinking world.

In order to explore this concept more fully, I endeavoured to look at parents and related attitudes, behaviours and understandings from the past. Although I had always

intended to investigate parenting history as part of the project of 'finding out', I had not expected to fulfil a whole chapter. However, I was disenfranchised by the narrow and 'oppressive history' I found in educational and disability fields and I subsequently became engrossed by the developments I discovered through considering alternative areas of study in (for instance) art, religion and social history. Taking a broader perspective, I was afforded the opportunity to expose (the notion of) the myriad of events that happened which appear to have built a cultural heritage through which we live out our modern experiences. I could see events as having unfolded over eras of time and moreover, through the social/individual intercourse that occurred during certain periods which appeared to mirror and perhaps even inform modern day behaviours. I thus came to understand these issues to be of great importance to the 'tradition' of parenting and thus, the foundation of our thoughts in relation to being a parent including 'what can be known'. As a result, I considered a whole chapter (at least) was vital to this exploratory work.

Again, the issues that transpired here were brought to light once I had worked with the parents' data as they were clearly 'stand out' subjects having become familiar with the participants' experiences. For instance, gendered roles, stereotyping, infanticide, cultural representation, conforming to norms, the work ethic and so on were historical routes I felt could not be ignored. However, all of these were entwined with the underlying (research) principle of social moral values (including justice and notions of diversity) and throughout the chapter I was able to examine the ways people, families, impairment and disability have been treated, perceived and understood in these terms.

Interestingly, for instance, Disability became reviled in times of widespread poverty and appeared to be embraced, or at least 'catered for', during more affluent periods. In recognising this 'pattern' from the past, it can be applied to modern day where unprecedented levels of wealth at the turn of the 20th century invited the prolific construction of complex, substantially funded institutions which post-WWII declined rapidly into a state of abusive overcrowding and disrepair. The onlooker is left with the overall impression that Disability is a financial value concept over and above a moralistic one. However, the moral 'high ground' can be seen to be currently used to 'justify' low funding levels as fed by notions of independence and autonomy, ironically sprung from sectors of the disabled population where misunderstandings

appear to abound. Under the circumstances, a perspectives approach seems incredibly important if moral values are to be upheld in appropriate ways.

Having conducted the foray into 'themed' history in this particular way, I believe more of the same is urgently required. Picking out issues such as these brings to consciousness 'what happened' and invokes depth thinking about solutions regarding 'what is happening' in the present. Furthermore, an entire study exploring other issues and understandings may aid the development of a 'balanced' historical foundation that not only forms a 'parenting' history (as nothing specific exists in this capacity that I could find) but might also proffer further insight into 'disability' history. In particular, I recommend penetrative investigation into families caring at home as this appeared to be the popular experience of the past yet I could retrieve very little information with the searches I was able to perform. I would especially recommend coverage of this particular topic to include the already scoured modern industrial era given that current impressions are that the majority of children with impairments were institutionalised. This assumption arises simply due to these being the (obsessive) focus of modern day research and as 'discovered' (and learned) with pagan history, one dimensional versions are hardly appropriate.

Once I had some historical footing, I also worked closely with the parents' data to consider theoretical perspectives. By utilising the comprehensive table of themes that had arisen during analysis of their accounts I could see a pattern emerge and this eventually informed the compilation of the whole thesis in terms of organising, retrieving and presenting data. As such, it was a valuable working tool from which I could see all the parents foremost as emotional beings who were able to adopt differing methods of self-management through which they controlled their feelings, parental expectations and future aspirations. I recognised this was the individualistic element of experience revolving around notions of 'self' where other researchers appear to have been trapped in the concept of negative emotional turmoil on account of 'suffering' the impact of impairment in the family. I took an alternative (parental) perspective: I explored emotions and systems of self in terms of inherent feelings, surfacing as personal and diverse reactions that were triggered by notions of normality as determined by the phenomenon of being-in-the-world.

As a consequence, the theory I explored encompassed 'the self' as a complex individual making sense of feeling and being 'normal' including resetting complicated identities of self and family, considering social ideals, constraints, desires and sacrifices as well as finding a sense of belonging, comfort, stability and security. In journeying through the social world in this way, I returned to the 'inner being' who must negotiate life through the described discourses and concepts of self, Disability, family and impairment and considered these ethereal ideals to be the cause of upset and turmoil, not their child per se. The interworking of the findings and the theory meant that I could relate this 'story' to the four participants' accounts in the discussion chapter and concluded through this driven concept that notions of 'normality' were key. As a consequence, in order for parents to be helped to feel understood, the cause of emotional upset, family wellbeing and particular social pressures may be found through identifying their sense of normality which in turn, may be obtainable from attempts to understand the meaning of being-in-the-world from *their* perspective.

Understanding a fellow human being with attempts to share perspectives, or at least respect them, might be an assumed basic premise of living in the social environment. However, this is theory and as such, naturally appears very simplistic; on paper one can detect what should happen and it is difficult, incredible in fact, to think why this does not actually occur. Yet, the 'difficulty' equates to the 'solution': social interaction, which can appear to be as obtuse as it can compassionate. I encountered clear signals of this humanistic dichotomy during the earlier stages of conducting this research and this interaction created further evidence to support a shared perspectives approach. As such, I move to briefly reflect upon the research process which itself adds substance to the findings and thus, my conclusion.

**Research process and conduct**

The initial difficulty I encountered was the formation of a methodology that could be separated from the theoretical principles I had chosen to deploy. Critical hermeneutic phenomenology is a theory incorporating a particular way of working with underlying principles that assume:

> *"the genuine researcher is motivated by a thirst for knowledge and by nothing else"* (Gadamer 1976 p.152)

However, I recognised this way of working to be incongruent with expected 'scientific' practices found in educational establishments and I therefore conformed to conservative research requirements. In the process of delivering a proposal and following the set protocol throughout the conduct of the research I became viscerally aware of the lack of shared perspectives found amongst the fraternity and authoritative others. This was not simply on account of differences found between quantitative, scientific, qualitative and interpretative styles of research. More importantly, it was through feeling entirely misunderstood as a parent whose perspectives regarding appropriate approaches to study with other parents were counteracted by apparently 'well meaning' actions of others. This activity is hardly new (see the history chapter!), the idea of devising policy, in this instance 'safeguarding', that 'protects' certain individuals or groups becomes bizarre when those being 'guarded' are hardly consulted. I concluded that in fact, it was *un*ethical.

The institution was (as with the state in the previous example re: autonomy) shielding itself with the 'moral high ground' in order to best (financially) protect itself. In this instance, again, perspectives were not really 'required'. My argument therefore continues that in order to *actually* assume moral responsibility, the perspectives of considered others must be taken into account. I explored this most thoroughly in the ethics section of chapter three, examining in particular, a number of research conventions which jarred with participant perspectives. I concluded that these instances were, to a large degree, unnecessary given examples of my appropriate (perspectives based) interpretation (*not* assimilation) of current research governance. Furthermore, through my exploration of the issues, I was able to propose an alternative suitable research approach, not only through the theoretical argument but also with the intention of being evidenced by my actions.

Following the underlying 'theme' of moral responsibility supported by adopting a phenomenological attitude, I have endeavoured to work in ways that showed respect for the participants, my superiors, the subject matter and myself. I hoped to show this through conducting the research in an open manner through which I have attempted to keep a subjective balance by placing tracts of personal comments and related detail in the appendix (6 pp.329-337). As stated earlier, I have endeavoured to position 'other' parents as centre stage in order to maintain the focus of my phenomenological

investigations. Through remaining loyal to the interpretative paradigm and explicating these ways of working in some detail, I hope to have added to the specific method of the genre as well as inspired others to undertake and improve upon this way of working.

For particular advancement I suggest that the mode of analysis should be further developed to better complement this specific style of research. Originally, I had begun this project with analysis based upon extractions from the literature that ensured a close relationship with the phenomenological endeavour. When I discovered Smith et al (2009) had concurrently devised a strikingly similar route, described as Interpretative Phenomenological Analysis (IPA) I was delighted by the prospect of utilising a tried and tested method rather than continuing with my under-developed own. However, during the process and later reinforced with hindsight, I became aware of the limitations of the recently popularised analytical tool. In the first instance, given the complicated and intense nature of phenomenology together with the proposed personal connection with the data, I felt the necessity to still create the 'naïve' and 'concise' summaries absent from prescribed IPA methods. In addition, although IPA suggests the analyst revisit the transcript with three specific purposes in mind, in reality, I felt more comfortable ensuring that my readings took on a much more fluid action where 'finding meanings' flowed more readily between the 'parts' and the 'whole'.

These adaptations highlighted some of the ways in which IPA could at times feel inadequate for its purpose in that rather than attempting an open, effortless almost instinctive movement of data, IPA facilitated a restrictive and regimented approach. This, to some extent, was the problem I had experienced previously with my own '10 stage' method; developing set 'ways of doing' conflicts with the underlying precept of phenomenology yet finding alternatives that satisfy the enterprise of academic research is almost impossible. In order to explicate one's method, there must be a method! The difficulty lies in the notion of being as open as possible in that describing what constitutes a jumble of ideas is far less straightforward than exposing a set pattern of 'trained' thoughts. Well aware of this dichotomy throughout, I chose to (phenomenologically) reveal as much of my personal endeavour via reflexive notation.

Whilst IPA recommends this activity, it was not as strongly advocated in the literature as I believe it should be in order to uphold the phenomenological foundation.

I found the reflexive activity during the process extremely useful as an 'outlet' from the confines of doing IPA and vital in the form of 'revelation' given that IPA encouraged a strong sense of being judgemental. On further exploration of the authors' backgrounds (psycho-analytical), it is unsurprising that a tendency erring towards critical analysis of the individual, as opposed to the phenomenon that is held within the text (as per Ricoeur) begins to emerge when writing up. This confinement to person has serious implications regarding purportedly specific phenomenological analysis and more so when ethical considerations surrounding consensual participation are taken into account.

The participants agreed to take part in this study with the knowledge that their data would be used as interpreted accounts of their understandings, thoughts and feelings, resulting in researcher constructed stories of their experiences. 'Corrections' to this hermeneutic activity via member checking was thus rendered irrelevant whereby, under these conditions, it might also be considered unethical to directly expose the member to the interpreted piece as being 'them'. To the mind of the researcher their work is an accurate representation of 'real life' yet the participant may feel the analyst's 'revision' does not match their own impression or that which they intended to leave (Cioffi 2000). This does not mean that the interpretation is 'wrong', nor does it mean that the participant's own view is 'right'; these are perspectives of a constructed world. For an interpretation to be entirely 'agreeable' therefore, it must remain co-constructed by both parties where textual amendments to the data may have to be revised over a number of meetings until satisfaction by the participant is met (Gadamer's 'fusion of horizons'). The data is not then a single interpretation but a co-constructed idea of 'what happened' and in this, participatory research takes precedence.

Clearly, this latter style would be preferential overall given that ethical dilemmas could be addressed in partnership yet this may only occur where ethical governance allows and in this instance as explained in this thesis in some detail, it did not. As a consequence, it became extremely important for me to be as explicit as possible about

how I had (personally) reached my conclusions. However, returning to the ethical issue of IPA as a vehicle for interpretation, the underlying psycho-analytical approach did appear to take the experience of individual hermeneutics to a tenuous level where the accounts of the participants in this study became almost diagnostic and as such, it is more possible than ever that they may not have enjoyed checking this critically personalised view.

With hindsight and if the work was to be expanded upon, I would choose to follow my original insights regarding analysis development ensuring a much more holistic approach. In this respect, I believe that researchers are in a privileged position in that they may take a 'step back' in order to survey 'what happened' and as such, are able to report on 'being-in-the-world' in ways that may help other people. In my experience of being a parent researcher, I feel it is imperative that we carry out our task by incorporating the perspectives of those under our gaze where taking 'moral responsibility' appears to be an appropriate beginning to this process. Having taken this starting point myself, I have argued in this research that 'moral obligation' (sometimes only made 'real' when the question of funding is removed) and related social values surrounding notions of what it means to have impairment (or be associated with it) would be an advantageous progression if positively developed within the greater social conscience. Ethical understandings are the foundation to our whole sense of being-in-the-world, from ancient scholarly writing to modern (moral) concepts including 'research', 'Disability' and 'parenting'. As such, the ethical implications of 'now' also underpin what these 'ways of being' might mean to us in the future. The eschatological idea of 'good' and 'right' ways of being has been seen to come into fruition (most recently) through 'green' issues and I see no reason why this momentum should not continue in relation to the subjects of this study. With 'moralistic models' springing up around the globe and inspired by the perspectives approaches of our counterparts in Scandinavia, it would seem this directional way of thinking and being *is* possible.

*And finally…*

At the very beginning of this thesis I questioned the likelihood of parents feeling overwhelmed by their baby having impairment. I now feel in a comfortable position to make a final concluding remark in self-response: yes, parents *are* overwhelmed. Yet, I

believe I was right to question. I have found that parents are inundated with life, with upset normalities, relationships, the pressures of social conformity, the desires to be included, the pain of feeling excluded and moreover, with the hurt, satisfaction, joy and personal growth that comes with having children as a major part of that social life. Having made this exploration, I am satisfied that this 'jumble' *is* about the experience of having a baby described as having a learning difficulty and fortunately therefore, in spite of contrary portrayals in the literature, this parental 'utopia' does not appear to be exclusive to me.

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## About the researcher

I left school when I was sixteen (in 1982) because I wanted to earn money and become independent; I felt I was striking out from dull family life. I found a job, moved to the city and enjoyed going out and spending the money I earned. By the time I married my husband in 1990 I had already made successful career moves in the rapidly expanding computer industry of the late 1980s to become a credit control manager for a large company. I ran a department of fifteen people, was responsible for overseeing a valuable financial ledger and wearing my suit and heels, I thought that I was special and important.

In 1991, I had my first baby. He was born prematurely at just over 25 weeks gestation with little chance of survival. We sat by his incubator for weeks, unable to touch him, listening to the frequent sound of pinging monitors warning shut down and only able to watch as nurses and paediatricians came rushing in to resuscitate his frail body. Each time, somehow, he managed to get going again and after repeatedly winning the fight for his life, we decided to name him Daniel. Three months passed before Dan was strong enough to come home although he brought with him a list of 'medical labels' which ensured that he and I were kept very busy: cerebral palsy, hydrocephalus, right sided hemiplegia (later quadriplegia), asthma and anaemia were the initial conditions we both had to learn to negotiate in our own ways. Dan did this in finding ways of doing and I attempted to develop ways of seeing past the worry of what all these conditions appeared to mean.

Mothering Dan coupled with regular visits to various hospitals to meet with an array of doctors, consultants, nurses and practitioners who could monitor, weigh, examine and suggest meant that I did not return to work. With Dan's particular care needs, I knew that unless I found a retired nurse, nobody else could look after him although, if somebody had come along, I do not think I would have let them. I was quite clear I did not want to work; I wanted to be with Dan. Despite not having much knowledge of impairment types or interest in Disability beforehand, I embraced my son in a defensive, protective and forthright way (that even surprised me at the time). I was faced with: neo-natal nurses who joked he may have a 'gammy' arm; doctors who prophesised he would not walk or talk and; one consultant who post-examination looked me coldly in the eye and said curtly; 'you do know he is blind' and another at a later date who announced; 'he is already brain damaged and he now has epilepsy, just so you know, he will only get worse as time goes on'.

Although I cannot say I was happy with the on-going diagnosis, it was not so much what these people were saying that threw me. I could feel myself becoming increasingly aware of their (and others' in general) bizarre attitudes and behaviours. I began to realise that my parental part of 'negotiating' this experience was not about

Dan's impairment, I needed (for both of us) to successfully navigate my way through collective moral values and socialised understandings that appeared to foster widespread rejection of diversity and difference. As time went on and incidents frequently brought further 'social enlightenment' I became so fascinated (and concurrently exasperated with the obviousness of it all) that at the first opportunity (when Dan was eleven years old), I enrolled at the University of Manchester with a view to satisfying my thirst for a better understanding. Here, I was able to complete the Learning Disability Studies Degree course and subsequently, was further encouraged and supported by the department to put forward a proposal for this research.

Meanwhile, Dan has steadfastly continued with his own 'negotiation' of the situation. He has grown into a lovely young man whose character, bodily functionality and spiritual being naturally defines him as Dan, my son whom I love and feel fortunate enough to know so well. Of course, I am his mother and I am bound to say that; it is what most mothers, most of the time, will say if asked to speak about their child and here lies my concern. Through my experience of being-in-the-world, I understand that other people may not recognise that this parental relationship exists for those who are struggling to understand their child through a perceived 'wall' of diagnosis that relates to unexpected and possibly feared impairment. Furthermore, people who are well positioned to be supportive in this instance may make matters worse by failing to understand the 'total' and all encompassing parental perspective.

Through offering this short extract, I aimed to give the reader sufficient information to grasp the basics of 'what happened' regarding my experience of being a parent and from this, I wanted to convey enough of my developed 'world view' to facilitate some understanding of my particular parental perspective. I therefore hope the reader can detect that I feel my life has changed almost beyond recognition since having my son and moreover, that I believe it has changed for the better. After Dan, I had three more (lovely) children and my materialistic beginnings have now faded into the dim and distant past where life goals in relation to being a parent have altered the ways I think and feel about being-in-the-world to the extent that now, I feel I have a much deeper understanding of what it might really mean to be special and important.

## Participant Invitation

**MANCHESTER**
1824

PhD NHS REC 5.2
18.0.08
08/H1012/12

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**NHS**
NHS Foundation Trust

The University
of Manchester

### An invitation to take part in research (Individual participant)
#### Hello!

My name is Louise Wright, I am a PhD student from the University of Manchester.  With the permission of the Child Development Unit (CDU) at ▮▮▮▮▮▮ Hospital, I am carrying out research with some of the Mums who visit the unit. The title of this research is:

*"An exploration of the experiences of Mothers who have a baby described as having a learning difficulty".*

Other researchers have provided information on this subject before, but, I have found that:
1. Other research generally focuses upon Mums who have older children.
2. Quite a lot of information is written about Mums without much contribution coming from the Mothers themselves.

I think it is important to try to add to this previous research by exploring experiences where information is provided by Mums of young children and is taken from their perspective.  I therefore hope to involve Mums who attend the CDU by listening to, and reporting on, what they think are the important issues.  I also want to look at the ways Mums may change their views and opinions as time passes and, how being part of a community can affect experience.

In order to do this, I am inviting Mums to spend some time with me at the CDU where they can chat to me about their experiences. I hope they will find this part of their experience an enjoyable, relaxing activity!

I think there is a need for study like this because it may help other people to better understand what life is like for Mums when their child with a learning difficulty is very young.   At a local level, I hope that the finished work will eventually benefit service users at the CDU: I intend to report to the professional people who work there and they may be able to use potential evidence from this study when they make future plans for possible changes to their service.

I am currently recruiting volunteers and giving out more detailed information. If this research interests you, I would be delighted to hear from you. Please contact me as soon as you can (see attached).
Thank you,

**Louise Wright**

**Research Consent Form**

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## Individual Participant Consent Form

**Title of Project:** An exploration of the experiences of Mothers who have a baby described as having a learning difficulty

**Name of researcher:** Louise Wright

### Participant (volunteer)

Please read this and if you are happy to proceed, initial the boxes and sign in the space below.

1. I confirm that I have read and understood the information sheet dated 8 March 2008 (version no: 5.3a). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.  ☐

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 understand that data collected during this study may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant for these individuals to have access to my records.  ☐

4. I am happy for the data to be used in the ways described  ☐

5. I agree to my consultant being informed of my participation in this study.  ☐

6. I agree to have my conversations with the researcher audio recorded and subsequently made anonymous.  ☐

7. I agree to take part in the above study.  ☐

……………………………………          ……………………………          …………………………………
**Name of service user**          **Date**          **Signature**

…………………………………          …………………………….          …………………………………
**Name of researcher**          **Date**          **Signature**

Copies to: participant and researcher. Original to: medical file.

## Example Pages from Transcript

(Random pick of page 10 from each participant)

## Colin

1    pair of us look forward to our curry every Saturday night you, you know (me: mm) by
2    the time it comes round (me: ours is Friday night laugh) is it Fri', sorry, sor', (me: we
3    have a Friday night – both laugh) but S'Saturday night when that curry com' you
4    know and it is, it's hard, we don't sp' (munching noises) you know and it, it's love-ly
5    and you know, it, we look forward to that but it must be like 24/7 for Helena (me:
6    yeah) all the time, you know, and the, there's times when you know, she goes in there,
7    she's draggin' out the Weetabix and stuff like that, you know and I'll drag her in here
8    an' she'll go back in and you drag her in a little bit harder and erm you know you're
9    like, then you start shoutin' at her and then you, you sit back, you think well f'king
10    hell its not her fault you know (me: I know) and erm, the, the other thing as well is,
11    tha', ways you change Rebecca's nappy you can reason with her, Helena's out in the
12    air, you know, everything she's just, she's angelic but she is hard and we know she's
13    gonna be harder to manage, the tantrums are there, the, things like that she's very…
14    erm.. she's very, I don't know, I, there's certain thi', I still don't know .. certain
15    reactions that she will have, knowing her as a 2 year old (me: mm) whereas Rebecca
16    she is totally I, I can read her like a book (me: mm) you know whereas Helena's just
17    Helena, she can go one way or the other (me: a little bit unpredictable) very (me: you
18    don't know) very (me: which way she's gonna turn or) yeah (me: go) yeah, yeah and
19    we, we have got challenging challenges you know ahead of us,, but erm, you know as,
20    as to what they'll be we don't know but we do try and keep in touch with people
21    who've got kiddies with Prader Willi, we do go to the meetings (me: mm) erm
22    Me: how does that help, what does that do for you, where does, why do you do that?
23    C: why do we do it? Well.. we, we, one thing we did say at the start was, we would
24    put er, erm, like a regime in actually, with Howville Manor at the middle and we said,
25    right we'll stick to Howville Manor (me: mm) right, we'll do this for her, do that for
26    her, do that, now.. I'm just sidetracking here a little bit, but (me: d'ok) bu' one of our
27    problems is, is, not marital problems but… (pulls a face)
28    Me: is that code for it's a marital problem (laugh)
29    C: it probably is actually, it probably is (me: you like to think its not, but it is) my, my
30    missus right, she, she, if she comes back and the house is a shit tip that's it, you know,
31    she sees her arse, blah, blah, blah, (me: mm) so purposely, morning and afternoon I
32    will be out, there'll be something like sing and sign or what have you so I get the kids
33    ready, get them out, dumf , back, dinner out, dum, house is a bit of a shit tip alri', but,
34    we've had a crackin' day (me: mm) the, Helena's had the stimulation that she needs
35    erm, all the kids are worn out you know, blah, blah, blah, (me: mm) that's how it
36    works .. where as if I stayed in for half a day (me: laugh) you know and the house got
37    trashed, you end up bickering, but lu', luckily things have run like clockwork for us
38    Me: when you say luckily, I don'. I'm not sure that's the right word, you seem to have
39    engineered it in (C: we) a sort of blokey way, actually, you're not working, you're
40    feeling fine, I'm gonna get out there (C: well, yeah) and that's just precisely what
41    you've done, you know, you're out there aren't you
42    C: to, to be honest with you, it, it's hard work, it is
43    Me: how did it come about where you thought, right, well actually I'm gonna do this,
44    'cos obviously your wife's working, you've got the kids at home, what made you get
45    out of that front door instead of, apart from the bollockin' you might get at tea time
46    (laugh) but apar', you know
47    C: d'you, d'you know something, its one of those things in it, you, you sink or swim
48    don't you (me: right) its, you know, I know people who, erm.. you know, they are
49    peop', ar' luckily I'm a people person, you know (me: yeah) and er… I'd yeah, I have
50    to get out there, I have to meet people who, an' if somebody does, it, it's funny really

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# Example Pages from Transcript

(Random pick of page 10 from each participant)

## Hannah

1      of tissue, erm (H: sniff) they, they eventually help you to be strong in the end (H:
2      oahh) you have take that barrage of comments (H: yeah) and lots of the time people
3      are only trying to say… what they think will help and they just haven't got a clue and
4      that (H: yeah, I know) that's the difference isn't it
5      H: I know I can see that as well, if somebody says it to Colin I'll probably try and
6      pacify him by saying yehmnmm, yeah a memb and then sort of step back from it a
7      little bit 'cos he's the one thats got to deal with it 'cos it was his situation (me: yeah)
8      to make him (me: yeah) you know (me: mm) get stronger again, you can't… patronise
9      him because its something that's deep (me: yeah) isn't it, (me: very) you know, he's
10     got to deal with his own situation as I would mine erm in that way so
11.    Me: it sounds like you're constantly mediating your situation with other people
12    though, sort of we are a normal family, and we are ok, you know there's no need to
13    (?)
14    H: well I think, I think we do try and put that forward me and Colin, you know like,
15    you know, we do find it erm sort of  har'
16    Me: but its hard though sort of having to justify yourselves and, and the girls
17    H: the easy (?) we don't like to moan well, we don't mo', you know, oh it's a busy
18    life with 3 children 'cos some people can't have children 'cos we've been in that
19    situation as well (me: yeah) you know as well, where we've not been able to have
20    children so
21    Me: and what a joy to have had Imogen (H: mm) and then to find you're having twins
22    (H: and tha', I know) what an absolute joy, and its scary (H: laugh) thinking oh my
23    God what we gonna do with 2 babies and you know how're we gonna cope with
24    Imogen as well
25    H: yeah and then its never, its not
26    Me: and then its not just gone to, even that little plan really
27    H: yeah, but its not been as bad as it first was, was, was thought really as well, its all
28    turned out really, really well, we both consider ourselves very, very lucky with what
29    we've got you know compared to what a lot of other people do have to deal with as
30    well I mean some people can't even have their own children, you know, and won't,
31    won't even adopt or what ever (the other?) far, so I mean that's their choice but you
32    know, we've got (me: you've got your girls) yeah and they are they're lovely (starts to
33    cry again)
34    Me: they are, they're absolutely gorgeous, absolutely gorgeous
35    H: but I do think the business, has tried to sort of like you say, keep you back on (me:
36    mm) maybe if I worked for somebody else, I wouldn't have been the same person
37    (me: no) you know in tryin' erm deal with it, I'd have given up and maybe Colin'd a
38    gone back to work, it might have been a completely different scenario (sniff) but
39    having to just sort of like keep, keep face… sort of like kept it together really for me
40    anyway (me: mm) having to get back and try an
41    Me: well that's, that is really why I just thought your story was so interesting because,
42    9 ti', 99 times out of a hundred more than that in fact lots of the time you know it's, it
43    is .. the woman who (H: sniff) ends up being at home thinking well that's me career
44    gone (H: mm) that's me life gone (H: yeah) and you can think as a woman who's
45    done that, oh it'd be great if I could go back to work (H: sniff) but you're the reality
46    aren't you, you're the person who has had to go back to work (H: yeah, yeah laugh)
47    and its not great either is it
48    H: no, no, 'cos I, I do, I do think that sometimes other people think I'm a bit, a bit
49    hard or a bit indifferent you know, in the way maybe I do deal, treat with things, but
50    again, I suppose I try and balance things… I'm quite practical maybe, a bit too

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**Example Pages from Transcript**

(Random pick of page 10 from each participant)

## Jonathan

1   J: I wouldn't say nagging, it just you know, … seemed strange, that we
2   weren't rushing backwards and forwards for the feeds, there was this sort of
3   like momentary calm, (me: yeah) from all this chaos that's been going on
4   for that few weeks, and then, I suppose that also was strange when in the
5   Jan, the January.. I think it was and Harriet was ill with, she had er,
6   bronchialitis (me: mm) and was taken into hospital and she was.. she was in
7   for 2 weeks then, if I remember rightly, erm, and she was quite ill when she
8   was first taken ill, she was on a C-PAP, breathing (me: ventilation) er, but,
9   … I can remember they were saying to Jemma 'cos, that's right, she was in,
10   in a … oah, a high dependency, the, they'd just built a room in there that
11   was high dependency unit in the Bushels at Stonton Mount, (me: mm) an,
12   and they said to Jemma, and you can't stay, it, its doesn't have a, because
13   its, well the equipment that's in it and the level of illness that they expect a
14   child to go in there with, you, you can't stay with them in there (me: right)
15   and we were like, 'well that's alright, we'll go 'ome', you know, 'cos we'd
16   been that used to her being in hospital (me: yeah) and so leaving her
17   overnight was and one of the, the nurse, she said, I could tell you'd been in
18   neonatal, (both laugh) 'cos see any time that we have a parent that's had a
19   baby in neonatal, they are quite matter of fact about leaving them… so that
20   was a traumatic time, when she in there and again, it fell, it fell over a half
21   term period as well, so it just seemed like every time Cathryn was off
22   school, in that first few months, it was, oh sorry you're off to the hospital
23   (laughs) erm.. which has been, well since then, we've deliberately tried to
24   make sort of special time for Cathryn where we … we do things with her
25   that's specifically orientated towards her so that you know (me: yeah)
26   suppose, to let her know that we know that she have to put up with a lot
27   (me: mm) and.. and we try and even things out a bit like you do when
28   you're a parent (laughs)
29   Me: and then what about you? From the dad perspective?
30   J: well, you're the bottom priority, you stand back
31   Me: did you feel included?
32   J: well….. yeah… erm, pretty much, I s'pose, I did that thing that you do
33   these days, I came home from hospital that day and (cough) you know and
34   came home with the intention of going to bed, (me: mm) but I didn't, I came
35   home and got on the computer and googled 'Down syndrome' (me: yeah)
36   and (me: yeah) you know, didn't, just reading all sorts of things I did that
37   and then it was about ten, fifteen minutes, I thought, this is crazy, 'cos, I've
38   got a whole lifetime to worry about all this sort of stuff
39   Me: why did you do it?
40   J: well, I don't know, to get information I suppose, to help the situation, but
41   then, like I said, I was doing it for about ten, fifteen minutes, and I thought,
42   oh you know, 'cos there's that many widely differing views and opinions
43   and people's (me: right) you know, some people will say, you know, 'my
44   son got Down syndrome and he's done this, this and this and other
45   people'll, 'my daughter's got Down syndrome and she's never walked and
46   talked properly and (me: mm) and you know, there's that wide an extreme
47   that you come across when you do sommat like that er… but.. erm I just
48   remember, I'd looked at it and I thought this is crazy 'cos, it, I'm not gonna
49   particularly get anything out of it now, (me: mm) other than to read various
50   people's individual experiences, which might have relation to Harriet or

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**Example Pages from Transcript**

(Random pick of page 10 from each participant)

## Maggie

1    Me: did they come and visit you?
2    Ma: yeh, the kids came up in the afternoon where I, so on the Thursday, like the
3    first day (me: right) after the, after the paediatrician 'ad been, after Dr Zing 'ad
4    been in (Barney uses the beaker to bang on his tray) that was er, that was
5    'orrible 'cos I'd been, they'd put me off it, with the paediatrician, then, I thought
6    it meself through the nigh' and me friend 'ad come up and me mum 'ad bin, and
7    so I was reassured and then I'd gone back in, so I was up and down like a, like a
8    yoyo (me: mm) but, the' took the bloods and we just 'ad to wai' an' that was it,
9    oh, I gave me mum a phone an' I said, oh no, that was on the Saturday tha', on
10    the Saturday, so the kids come up so I 'ad to act normal (me: right) but 'e was in
11    the incubator it was only in the other ward but (me: yeh) behind the desk, in that
12    room with the glass windas, (me: mm) I could go in any time a wanted, but I
13    didn', but I was cryin' and me son who's 20 said, (sympathy) 'its alright mum,
14    don't cry 'e'll be fine, its only just te get 'is temperature righ', but 'e didn't
15    know really what (me: right) I was really cryin' about 'cos I'd only really just
16    'ad the paediatrician in, Dr Zing, tellin' me that
17    Me: so your emotions are all on (ma: yeh, yeh) feeling
18    Ma: yeh, and your kids comin' along, ye just were.. cryin', yeh but they thought
19    it was 'cos 'e was in the incubtor and all I kept thinking was, 'cos the'd l', all
20    th'were just so excited about this new baby comin'
21    Me: I bet they were, they're all that much older aren't they?
22    Ma: yeh, and Steven's girlfriend lived 'ere, she couldn' wai' an' but you can
23    imagine what I felt like a', I mean you *know* what kids are like about Down
24    syndromes, they call 'em names an' the laugh about 'em an', don't they?
25    Me: so you're thinkin'..
26    Ma: my main concern was how upset the other, bu' (high pitch) what's it gonna
27    do to the family!? That's all I kept thinkin', I mean, I *loved* 'im, so eh,
28    Me: but knowing your lads and one of your son's girlfriend .. aren't they
29    removed from them, that's what *other* kids might think…
30    Ma: no I didn't think (me: …my kids'll be different) no, I just didn't know, I
31    just thought what the hell, what are the' gonna be like (me: mm) an' I was very,
32    very shocked … because the one, Steven, the main, he was the main concern, he
33    was the one that was always concerned and 'ad come up loads to the hospital,
34    John didn't even come up (me: yeh) but Steven come loads, in 'is dinner hour,
35    and 'e'd come after work, an' 'e come at night, 'e come loads an' loads of times
36    (me: is that during the 4 days that you were there?) yeh, an' it hit him, *really*
37    hard (me: right) an' 'e didn't look at 'im, he went, it hit 'im *really, really hard*
38    and its so, 'e's the one now, well 'e's moved
39    Me: and having seen him in the incubator or next to your bed and everything,
40    they didn't notice anything?
41    Ma: no they never said, no, me little one did, Joe. … 'e said, 'e looks lie T, 'e
42    said don't you think they look like Down syndromes…an' I went (wide eyed) …
43    so, 'im now, Ste, he just was a bit, I 'ad to get books out …I 'ad to get stuff out,
44    books an, an', I 'ad to show 'em pictures a', all I was bothered about was me
45    other kids (me: yeh) I 'ad to show 'em pictures an' I used to go around and say,
46    I used to say to Joan Duley, 'ave you got any booklets and pictures?' an', an' me
47    kids'd go (uninterested) 'uoh' an' I'd go, 'uoh, look at that one' 'um', didn't
48    wanna look, I'd say look at the pic', ah, that one, that one dun't even look Down
49    syndrome

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## Naïve and Complete Summaries

# Colin

### Naïve summary

*He's a man 'at odds' with himself & his world. He lives his experience in a chaos of dichotomies, he wants to see his world as black and white, but he knows it isn't that simple. He is frustrated, angry even, trying to organise and replace chaos with order & routine, he can see how it should be, he has a vision. He creates this vision with self convincing imagery, the 'reality' can be very different but if he can ignore that, he can get on and be positive about things. He knows he's pretending, he's testing the floor to see how it goes, one step at a time, future can be 'boxed' as an idealistic dream, sorted, no longer a problem... In his reality/dream world he then faces huge contradictions: is looking after kids hard/easy? Is meeting people good/bad? Is he on his own in the world, isolated, or in unison with his wife, a team player?*

### Complete summary

Colin reflects upon his experience of 'being a parent' by recalling his thoughts and feelings through stories which depict significant events. Throughout the telling of these, Colin reveals his experience as being one where his whole life has undergone great change and as a consequence, he is making sense of 'what happened'. Colin portrays his approach to this as being a basic two dimensional affair; as such, he appears overall to be faced with many 'opposing' factors. In this, Colin's sense of 'normality' has been challenged; his experience has exposed the ways in which he has attempted to embrace abnormality, believing that this appeared on account of a 'chance' happening. Colin originally viewed this as horrendous misfortune specific to his own 'life world' and as a result, remains dented by the enormous weight of emotions he suffered at the time. In order to console himself in his current predicament, he toys with and dismisses ideas of how his life could have been and to protect himself from further unexpected disasters, Colin muses about the future using statistical evidence to underpin his 'dreams'.

Colin perceives the impact of 'Disability' to be that which has dominated his enforced life change and thus has shaken his otherwise stable and comfortable environment. He is easily reminded of this when he interacts with others who do not have a shared understanding of his situation. However, in comparing himself and his daughter to others of perceived similar 'type', he is able to negotiate a renewed sense of belonging in the world. Desensitising himself to Disability by (over) exposure and being amongst other apparently like minded parents, Colin can navigate his new understandings of normality. Moreover, he is able to view his daughter who has impairment as being simply affected by Disability, rather than as 'Disability' per se and thus he feels he can learn to bond with her 'difference'. Knowing his daughter's 'official diagnosis'

continues to play an important role in this process; it also aids in such things as being able to 'predict' her likely behaviours and in mediating his (and her) situation when moving amongst others. Colin finds this less difficult and thus feels most comfortable when nestled in groups of parents and their offspring whose difficulties appear equivalent, or 'worse' than his own.

For Colin, meeting others who have a sense of shared understanding is paramount to his successful negotiation of his being in the world amongst other. He has a significant bond with his wife whom he believes to have been stronger than him: she has not 'collapsed' and been defeated by this event in their lives. Yet, Colin is now able to consciously portray himself as a parent who is doing his best, albeit against destructive odds, as well as one who is optimistic and happy in general terms. Although Colin's told experience reveals the latter to be not entirely the case, he is able to identify how he has felt his changed self materialise and in what ways he has altered. These have been triggered by particular events where in he believes that much of what he has experienced, as he has experienced it, has occurred on account of him being male. In recognising these elements of his experience, Colin is contemplating who he is now in the world and as such, his degree of autonomy, control and responsibility.

To this end, Colin understands his role of 'being a parent' in terms of the differences he notices from the activities and experiences of other parents. He is able to gauge these differences given that he understands his role in the overall context of assumed 'normal' parenting behaviours. In this, he reveals how he finds his experience: upsetting, frustrating, annoying, expensive, mentally challenging and physically hard work. These highlighted elements he believes, are magnified and intensified as a direct result of having a daughter with PWS. Using 'what is normal' as a benchmark adds further heartbreak in light of his parents' seemingly disjointed behaviours, however, it also creates a sense of personal harmony when he strives to 'normalise' his apparently 'abnormal' situation. 'Being a parent' for Colin has enabled him to recognise the job of parenting: the skills and abilities he has gained through this process have given him a foundation for self confidence; he has a knowable aptitude which develops his sense of self (re)assurance.

Ultimately, Colin's preferred way of getting through his experience is to spend time with 'opportunity groups' where he feels 'safe', understood and 'normal'. However, it is these same groups that remind Colin of why he is there, who he has become and what his life means now and forever: he is the parent of a child who has been diagnosed with having Prader-Willi syndrome.

## Naïve and Complete Summaries

# Hannah

### Naïve summary

*A woman in turmoil – scattered reality, routine = easy, out of routine = hard.*
*CONTROL Blocking out reality – what is reality?  living reality, hiding from reality – dualism. Preparing to face reality – people, the world, a scary world where reality is not just the here and now, its the future. What's going to happen in the future, all of it is very frightening, life now is VERY influenced by the future.*
*Keep going, keep busy, brave face, mediate your situation to other, including and more than ever, your husband, support, be strong, stay strong to stay away from the scary stuff. Deal with it by not dealing with it, 'keeping it together'.*
*Wish life away, fast forward; pass this bad bit, but then what? (different to husband, she doesn't wish it hadn't happened, just wishes it over...)*
*Particular feelings of being a mother – letting down, being cold, holding back, hard, protective, not blaming, take others 'on the chin', frightened, aware, extra duties. Woman at odds, job, control, house, health and fitness. Having a daughter (same) is different, very hard, trying to understand her. Lucky having babies after not being able to have them, lucky to have these babies.*
*It's important to be understood, to be heard, yet, she's 'seen the light', the bigger picture, what is important has changed from before, she recognises things wouldn't have changed if it wasn't for H.*

### Complete summary

Hannah's experience of being a mother has been clouded by intense emotion: as events unfolded, she became 'numbed' to what was happening whilst at the same time, she gathered her strength of character, feeling compelled to protect and reassure her husband and older daughter. In this, Hannah believes her experience is grounded in womanhood, living her experience through heightened senses which drove her forward. She considers the changes she has experienced during this part of her life to be the sacrifices she has had to make in being a Mother of a disabled child. Through being changed, Hannah feels she now commands a 'universal' perspective where she is able to view her experience as others might; she once thought like they do still. However, Hannah is saddened in the knowledge that they cannot understand her perspective; they have not undergone her experience and as such, she feels her 'mothering' is likely to be judged in a negative way.

Hannah learns from other parents of children who have Prader Willi syndrome and in desperately trying to fulfil conflicting mothering roles, Hannah feels she is placed in an impossible situation. Furthermore, Hannah believes she has, to a large extent, been unable to be a mother to her disabled daughter: extended hospitalisation and having to

return to work, coupled with having a child that contests her ideal, have all challenged her involvement. Her whole family image is of great importance and when she notices other mothers, she is able to make comparisons and judge her own situation. Hannah can feel how she is different to other mothers, not least in that she carries a constant sense of betrayal of her daughter, as well as, an impression of Helena being an overriding burden.

These issues of her mothering experience have forced Hannah to find strategies to conceal her negative feelings and to control the emotions that stir within. The diagnosis confirmed her worst suspicions of her daughter having PWS, she was thus prompted to gather her moral fibre in order to organise her home life. Later, being frightened by seeing other, older children who have Prader Willi syndrome Hannah was shocked into taking action again. By concentrating her efforts in improving her daughter's potential behaviours Hannah has a tangible front behind which she can 'physically' muster strength. Hannah builds this through being single minded and controlling her thinking time within the limiting environment of her business. Here, Hannah practices her diplomatic skills with others as well as being able to continue the pretence that her life is carrying on in a pleasant way. As such, Hannah's 'pretend world' has become her norm and her 'reality' is the shaken disturbance of her ideal brought about by Disability. In living with this perspective, Hannah believes life elsewhere continues in the context of a different reality that was once her own. This is often confirmed by her relationships and through the people she meets. This has generated feelings of her being alone in her experience but, in knowing she is at the mercy of 'what happened', she isolates herself further and declares an apathetic stance.

Being 'distant', Hannah feels pressure to mediate her daughter's position to others and in believing Helena's behaviour will deteriorate, she is fearful of her ability to succeed in the future. This apprehension leads her to dread the extent to which her whole family will become excluded. For now, she concentrates on building strong relationships with her other two daughters who have her familiar characteristics. She is convinced that she has to reserve love from Helena who is different to her and who she believes will be more needing of her in the future. In this, Hannah wants to feel prepared for what might happen and as such she constantly strives to shield herself from unpredictable emotional triggers. Hannah's primary technique for carrying this out is to keep busy, look ahead and ignore the detail. This way she is able to portray an image of calm indifference to her situation and convince herself that her life is unproblematic.

## Naïve and Complete Summaries
# Jonathan

### Naïve summary

*Jonathan speaks calmly and steadily, giving a 'storied' account of what happened. He recounts the events being careful to correct detail – I don't know if this is because he feels I am a 'professional'? – I need the detail as a true account? Does he want to get it right for himself? His family? His family are so important – he talks about 'we', his wife so connected – what happened through 'her eyes' at times – and his girls are everything – he knows the milestones, he spends time with them, he's proud. He doesn't see disability, he sees diversity in people – that's why he (I think) isn't phased by his daughter having Down's syndrome – his collapse from work was that – a collapse from work – and – work just gets in the way of family – being together so important. He needs social interaction - to see people, not for relationships, he has his family for that – see Gran (his idol?) – but to be amongst. He uses their conversations as 'benchmarks' to relive/feel the situations – that is what happened, through that encounter – tries to remember it precisely to be 'true' to them/it. Especially professionals – trust, admire & respect – can turn to for support/understanding = information. But – is he telling me this because he thinks I am one? mmm....*

### Complete summary

Jonathan takes time to explain his experience, ensuring that he has the detail which will portray his understandings as accurately as possible. In this, he wants to remain true to himself and his family, as well as, be respectful about those he includes in his recollections. Jonathan remembers significant events through his interactions with other and he uses their conversation as a vehicle to convey 'what happened'. As such, Jonathan remembers how he was given the diagnosis of his daughter having Down's syndrome. It was not the news of 'Disability' per se that left him uneasy but it was how he had been told. When Jonathan later considered the implications of the diagnosis, he remembers feeling shocked: his expectations of Harriet's assumed ability had been crushed. To this end, Jonathan proclaims his 'issue' was not with his daughter having Down's syndrome; it was with himself, coping with ideas of difference between his two daughters in their levels of possible achievement.

However, Jonathan was able to draw from his innate positive attitude towards human diversity and his previous understandings of Disability; as a consequence, he came to embrace his daughter's individuality. In also conveying a strong sense of loyalty to Harriet, Jonathan determined that her arrival should be heralded as a positive event where Down's syndrome should not be portrayed as a bad thing. At this point, Jonathan had already searched the internet in an early attempt to discover more about his daughter's condition. This further encouraged and confirmed his views about

diversity and he found such a range and extreme as to conclude that other's stories were not helpful. Jonathan thus believes that attempting to ascertain what the future holds through observing others is a futile endeavour.

Jonathan only recoiled from others in so far as he did not wish to make comparisons. He makes it clear that he enjoys social interaction and particularly parent groups where he can talk. He comes across as a compassionate man, who tries to understand other's perspectives through thinking about how he feels in given situations. As a result, he aims to stay positive when speaking about others and tries to be sympathetic to their circumstance. Jonathan also appreciates the relationships he has encountered with Professionals and he feels most comfortable here when he believes there is reciprocal respect. Jonathan is able to trust practitioners and appears to admire the work they do; his feelings here may stem from the support he has received from this group throughout his experience, as well as, from his understandings of being a manager.

When Jonathan was overwhelmed by the demands of work and home life, he was clear that work was the cause of his stress and it was work that prevented him from fulfilling his role as 'family man'. To this extent, Jonathan conveys a strong sense of him being intrinsically bound to his wife and children; he demonstrably loves his family and his family life. As such, he has managed the small changes that he feels his daughter has brought into their lives by merging them with his familiar understandings of his 'ordinary' family behaviours. This includes the wider context of his family, where grandparents for Jonathan are very much a part of what it means to be a family. In this, Jonathan holds his own grandmother in high esteem and significantly, he found disclosing the diagnosis most difficult with her and his wife; showing great empathy towards both of them, he was at pains to not cause either of them any upset.

Jonathan considers his experience to have been subsidiary to that of his wife's where he assumed a supporting role and the position of 'lowest priority' in his family. However, he also inadvertently describes his assertiveness and acquired skills in becoming knowledgeable with procedures in the hospital as well as having first hand involvement with his newborn daughter's care. Being first to hold Harriet was an emotional moment which he had not experienced with his other daughter. Jonathan was also aware of other differences between his previous and this experience, not least, leaving Harriet in hospital, entrusting practitioners with her welfare and lowering his expectations to encompass her levels of achievement. As a father, Jonathan takes delight in Harriet's progress but he has felt guilt when she has seemingly dominated his time; he feels compelled to be fair to both his daughters. In this, he believes his role is to support their development to enable them both to grow as individuals in the comfort and security of the family environment he endeavours to create. Harriet has become so assimilated into his understandings of this; he cannot imagine how things could be any different.

## <u>Naïve and Complete Summaries</u>

# Maggie

### <u>Naïve summary</u>

*It seems to me that Maggie underwent an initial period of doubt that has never left her actually. She was convinced her baby had problems, had never met or encountered someone with Down's syndrome before, but cited this (or dwarfism) as her instant concern. She <u>had</u> discussed this with her best friend during pregnancy, but not with a view to it becoming a reality. She did not have any tests, not in her nature, wouldn't have terminated – she had already lost a baby.*

*Her doubts are balanced with reassurances – finding comfort from her <u>mum</u>, with whom she has a close relationship and her best friend. Her mum is her ultimate crutch. Her other children are also important in her life; she is proud and still feels protective of them, although, as grown boys, they now appear to be protective of her and the baby. The relationship she has with the baby's father is upsetting to her. She wants closeness, friendship, a relationship; he is too erratically behaved for that. She is suffering, wondering: who else will want her with a baby who has Down's syndrome?*

*She adores her baby, BUT, he has Down's syndrome – he is an alien, Down's syndrome is alien, unfamiliar and ugly. <u>Looks</u> are a big issue, 'fitting in' to society, having friends, relationships is important; despite reassurances from seeing and hearing stories about older and adult people with Down's syndrome achieving 'normality, she is not convinced. In fact she is frightened, frightened of every stage to come, the next stage, the one after that, adulthood. She feels the burden of loving him, mixed, tangible emotion triggered by seeing what will happen via others. She is desperate, can't help feeling this way – feels she always will.*

### <u>Complete summary</u>

Maggie tells of her experience using a series of lively conversations that occurred at the time, picking out detail and nuances that animate 'what happened' in a very precise way. She relates this to her previous experiences which have given her a sense of her own 'normality' through the familiarity of what she has come to know and understand. As such, Maggie attempted to assimilate her new born baby into her expectations of what she believed her role of 'mother' to entail and thus, she made a conscious effort to ignore not only his diagnosis of having Down's syndrome, but also, early professional intervention regarding his development.

From the outset, Maggie was most worried about the potential reaction of her older sons but she was pleasantly surprised to find they did not reject Barney on account of his diagnosis; she believes that they, as well as her best friend, try to be supportive. However, Maggie also feels that family and friends will never be able to help her due to their absolute lack of understanding; they are not in her position. Yet, Maggie will

accept advice and reassurances from her own mother who has regularly shown her influence: her mother would not have had the baby and this helps Maggie to feel 'brave' and, she has offered to pay for cosmetic surgery where Maggie believes this may be a necessary option with regard to Barney's speech. For the moment, Maggie feels that Barney's looks are 'good enough' given that she cannot detect that he has Down's syndrome and she has used this factor to facilitate her pretence which in turn, enables her to avoid facing her fears of this condition.

Maggie had very little information about Down's syndrome before she had Barney, yet, within 24 hours, she had gained enough knowledge to understand the 'qualifying' factors that identify the condition; these added confirmation to Maggie's pre-understandings of Down's syndrome as something strange and abnormal. This resulted in Maggie's experience becoming one of undulating emotion: she loves her baby but hates his condition; she feels the trauma of what he brings into her life and she subsequently feels guilty and selfish. Maggie is currently filled with self doubt where she is attempting to explore her feelings in relation to Barney's development; she wants to feel comfortable in allowing him to progress in his own way. However, she cannot escape being repulsed by what she believes Down's syndrome represents: she cannot bear the thought that her child will develop into the vivid and ghastly image she identifies with older children and adults who have Down's syndrome. She is frightened for her son, that he will not be able to access mainstream activities and become independent and as such, she believes he will be a burden to her forever.

# **Reflexive Notes**

From Colin: Making Judgements

The frustrations of condensing an enormous amount of data into a few short paragraphs came to the surface during the creation of this (first) work. Having explored the raw data in so much detail, having spent hours wrangling with ideas and formulating my understandings in order to produce the interpreted account I was left a little deflated by the seemingly 'obvious' end result. It was only when I returned to my 'naïve summary' (appendix 5a p.319) that I saw how my work had truly developed. I liked being able to refer to this as it helped me to evaluate the extent of my engagement with the data as well as the worth of going to such great lengths. However, I appreciate this personal assessment does not necessarily aid the *reader's* understanding of the *manner* in which I made decisions within the process. As a consequence, I hope to move towards sharing this by elucidating with four salient examples which I believe illustrate the different primary aspects of my thinking behind the way I have worked.

*My 'judgemental attitude'*:
2. *Making Judgements through reactionary feelings*. I examined the ways in which I dealt with my personal reaction of 'shock'' (for example) and two prominent issues arose regarding the inclusion of detail:
   a) *'Non-transparent' data*: Early in the interview, Colin was called to the hospital where Hannah had gone into premature labour and he divulged that he was *"really badly hung over"* (C2:49). This revelation affected my immediate listening skills at the time and I pondered over this information at length during the analysis stage. I became aware that I was in danger of attending more to my feelings of disapproval, inflating the issue into an 'important' point, than to Colin's actual experience. I concluded that being 'hung over' only held minimal relevance to his story as it was simply a 'benchmark' from his memory to enable him to relate the practicalities of events. As such, I felt it would have been disproportionate to include this as 'detail'.
   b) *'Transparent' data*: Conversely, I deemed other data that produced 'shock' reactions from me to have sufficient justification to be detailed in my analysis. Throughout the interview, Colin bluntly described how he felt about his daughter; he described her current as well as anticipated behaviours and gave me subtle indications of his underlying feelings about impairment in general in such statements as: *"a kiddie that's got the Disability"* (C22:33). His 'shocking' revelations such as her being *"a freak in the pram"* (C8:27) and of her apparently foraging for food all painted to me, a rather gruesome image of how he must see his daughter *and* 'disability'. I believe that by talking frankly, Colin was not being

disrespectful per se; he was desensitising himself and testing his own sense of developed understandings borne of his previously established concepts. This thread sat comfortably with the larger theme of 'normality' and underpinned other detail that transpired. As a consequence, I felt my degree of 'shock' was entirely appropriate to the subject matter and thus I included the associated data as relevant in the analysis.

2. *Supporting generalised judgement*: I was not only aware that some judgements I was making were subjective but, I was also making them deliberately. This was an activity readily illustrated in my judgement making regarding Colin being a man. Initially, I prejudged that Colin might feel awkward amongst women for a number of preconceived and predictable reasons, some of which became fairly evident in his stories: coming face to face with 'open' breast feeding is a good example (C20:9-11). However, throughout his experience, I came to believe that he was attempting to justify his being a man and thus his manliness which came across in subtle ways in 'self defence' and self assertion. My assumption for this came in part from some clear remarks he was making (e.g. being hung over) but also through thinking in general about his descriptions of moving amongst women *and* remembering that he was talking to me, a female.

   I could not feel comfortable with why I felt this way in that 'tangible' evidence appeared too candid to pinpoint the subtlety and more importantly to me, I did not want to put forward interpreted data that felt more like my unsupported opinion (again, the hang over incident). I therefore needed to decide if my judgements were sufficiently evidenced to be fair or even 'real'. My resolve lay in returning to the language stage of my analysis where for instance; *"being a bloke"* (C3:14) inspired me to think about why he used the term '*bloke*'. I saw that he often used this to describe himself specifically in female environments and I concluded that this *was* about confirming his difference as a male and thus his maleness. In turn, this led me to understand how the more subtle nuances occurred throughout his experience and I could feel comfortable that my judgement, which began as a 'hunch', *was* rational and that it could be supported by bold statements.

3. *Judgement overriding other perspectives*: One of the most striking things about Colin's experience for me was hearing how he apparently sees the world in terms of black and white, 'either/or', styles. At interview, by the time Colin came to talk about his daughter going away to a residence in Norfolk, I was quite frustrated by his 'all or nothing' perspective (if not a little annoyed in fact by this specific point if I am to be brutally honest). As such, I could not help but suggest there may be other options by the time she grows up; it did not *have* to be so cut and dried. Colin immediately replied, as if in retreat, that it was something he did not know anything about and consequently I felt wretched; for me, for him *and* my research. I could not believe I had been *so* judgemental as it became immediately clear that Colin's way of looking at the world was 'simplistic' for a reason: he needed to see it that way to deal with the confused thoughts and feelings he was experiencing. This

judgement became such a highlighted issue in my mind that I think it carried through into the analysis on that basis as much as from the data itself.

4. *Guided Judgement:* When reflecting upon my interview with Colin and during the course of the analysis, I became increasingly aware (and at times, embarrassed) of how I had been influenced by such things as previous participant experiences and the literature, as well as my own experience. At the time of interview, I was sure I had an 'open mind', believing in the 'unstructured' format and yet, for example I asked Colin not once, but *twice* about 'support'. I think I was expecting him to tell me about his wife, or his friends, or his parents, anything! I clearly had a pre-judged idea of what I *thought* he might say. I do not know why it took two direct questions before I began to realise that he did not consciously perceive his experience in terms of receiving 'support' at any time. He did not choose to talk about it and moreover, he was almost confused when I asked him about it (on both occasions) given that he was so removed from this concept.

Although this is an incident I am loathed to admit, it does highlight a further related issue: I have also experienced how apparently 'guided judgements' have been useful to me in my decision making process. In reviewing the data with this in mind, I was able to reflect upon my 'leads which came to nothing' in order to satisfy and confirm alternative and other lines of thinking. Thus, to follow through with my example above: despite the fact that Colin did *not* appear to consider 'support' in a physical or conscious way, I was charged with the confidence to accept notions of him for instance: seeing his life in terms of a 'micro world'; making comparisons as his frequent 'crutch'; promoting his acquired parenting techniques as being self assurance *and* in all these, showing further possible subtleties of 'manliness'.

In explaining the detail specifically related to Colin's account, I hope to have opened a window that permits the reader to witness this aspect of the way I work. As such, I hope this explication of my judgement making will further aid the reader to further understand my personal approach to the other participants' data.

# <u>Reflexive Notes</u>

From Hannah – Researcher/Participant relationship
'Empathy'

With Hannah's data, I have chosen to share reflexive comments that reveal my whole way of working rather than picking out detailed incidences. This is because I feel that my empathetic response to Hannah's account was felt most strongly and as such, clearly illustrates the way in which who I am (as mother) influenced the generated data and analysis process.

In the interview, I found it very difficult to *not* share my understandings with Hannah and I felt I should interact with her more through her being upset. My aim was to help her to say the things she wanted to, whilst being mindful that she could breakdown uncontrollably if she dwelt on some of the points that she was making. In the moment, I judged this eventuality to be highly unlikely, but clearly, I did not want that to happen and it did not. Later the same day, Hannah reassured me that she was (still) fine yet, I had become anxious. I realised that I might incite criticism from the research community, not just because Hannah had become upset but more for my interview being exactly like a conversation. However, I believe that to arrive at (and remain faithful to) my understandings, I needed to interact with Hannah in a way that was comfortable for us both. I do not believe that Hannah would have carried on unless she wanted to and, as a consequence of this rare 'capture' of emotive perspectives in 'mothering' experience I consider her data to be extremely valuable.

My understandings of Hannah's emotion considerably influenced the way in which I later approached the data. When I came to analyse her transcript, I wrote my 'naïve summary' in a frantic, unstructured way and this reflected the way I felt after the initial reading (appendix 5b p. 321). Vividly remembering my encounter with her, it was a sort of breathless outpouring which fell in direct relation to the way I understood Hannah to feel, yet, *she* had managed to recant her experience slowly and steadily, albeit through tears. From this, I gained reassurance in my belief that although she appeared to have little experience of talking about herself in this way, she did have a strategy and thus, hold over the way she dealt with her life and her emotions.

I immediately detected (ie prior to 'sorting the data') that her emotions were caused by her feeling pulled in all directions through being a working mother and through being a mother of a child with impairment. It seemed to me (and this thought was also inescapable), that the overriding pressure to control her emotions to 'allow' her to carry out her mothering role was immense. From the outset therefore, Hannah's super-ordinate themes were virtually set in stone although, during the analysis process a third super-ordinate theme of 'Future' had formed. When I came to work with the relevant

data, I found the constant inter-play and crossing strands of this theme with the other two made it impossible to somehow keep 'separate'. As a consequence, I deemed the 'future' data should be dispersed and highlighted throughout both 'Mothering' and 'Emotion' to reflect its 'erratic' appearance in the original text.

A final point in relation to Hannah's data concerns my relationship with participants where this particular interaction seemed to draw extraordinary attention to my 'position'. Being a mother myself, I feel 'armed' with profound empathy based on assumptions of shared understanding. In this, we (the participant and I) have expectations that we will share similar thoughts and feelings, eventualities and insights through having undergone our 'similar' experiences. Yet, the extent to which individual experience is particular soon becomes clear as they tell of their experience and this makes it very difficult for anyone else to declare they truly understand. As such, when participants talked to me about their experience and in particular Hannah, I found myself wondering what I understand and if I am able to convey an adequate account to those who begin with little or no understanding. This element of the research sheds light on the enormity of the task of helping others to understand where this is the overriding importance of the study.

# Reflexive Notes

From Jonathan – Researcher/Participant relationship
'Power', Personal judgement & 'Absent' data

The reflexive comments pertaining to Jonathan revolve around the notion of the researcher and participant relationship being bound by judgement of each other and power. I also talk about the physical data and absence of supporting 'facts' as well as my related lines of questioning both in interview and of the data.

When I interviewed Jonathan, I came away wondering if I had captured any 'real' data at all. He spoke slowly and deliberately and although this was the case before I started the recording, I could not help speculating: *why*? His wanting to get detail and description 'correct' was, I thought, too precise to go unquestioned. My main concern was if his behaviour had been due to the way he perceived *me*. Within his experience Jonathan appeared to hold 'professionals' in fairly high regard, apparently fully trusting them and seeing them in many ways as 'authority'. The relationship between 'researcher' and 'researched' is often questioned from this perspective and in particular, of there being a power imbalance; my unease thus centred on this matter with Jonathan. I wondered if he was trying to 'impress' me or even say what he thought was expected of him as a 'nice' person. Either way, he was certainly very keen to make it clear that his daughter's impairment was *not* an issue. This was to the degree that *I* became wary of him in that he was almost 'selling' me an *'unbelievable* idea' for which he felt I might require 'evidence'. As a consequence, I was sceptical of both his motive *and* his integrity in the telling of his experience.

Most interestingly, when I came to transcribe the data, this extreme feeling, although present, became a little weaker; I could see potential indications that Jonathan's account may be 'genuine'. On writing the naïve summary (appendix 5c p.323) I still had concerns that Jonathan was heavily influenced by my 'position' but through the first reading, I had already (unwittingly) found a substantial 'alternative theory': he wanted to get it right for himself and his family. This sentence (below), although not used in my findings, epitomises my point here (Jonathan is talking about letting his Gran know his daughter's diagnosis):

> *"er...one of the hardest ones was, we had, was... my.... Gran...
> erm...my uncle has got quite severe learning difficulties, well not
> quite severe, but severe enough, he's... fif-ty eight now, I think... in
> his late fifties...coming up towards sixty.. er..."* (J12:24-27)

He was at pains to get the detail correct I think out of respect for his Gran, his uncle *and* from his sense of family loyalty. The transcript is littered with these elements and whilst they do not necessarily provide findings per se, they do form the foundation of what has been brought to light. As such, during the process of analysis, I became less and less preoccupied with my worry and more absorbed in Jonathan's experience, his

'life' and who he is, as portrayed in his account. This 'in depth' study allowed for the 'quieter voices' of the research to come forward where I decided these were in fact Jonathan's, whilst the louder ones had been *mine* (interference!). I concluded (as in my findings) that Jonathan is extremely supportive, protective and loyal towards his family and this includes Harriet. As a proud father, he understandably did not want to portray her existence in a bad light and furthermore, he does feel that he has no reason to see Disability as cause for crisis in his family. He was very careful at *every* moment to make sure I understood:

> *"...you know, its never been a, never been a iss'... never been a conversation point..."* (J13:5-6)

By Jonathan picking meaningful terms throughout his account in this way, I am left in no doubt about his integrity and authenticity. Furthermore, this level of loyalty together with him being a positive parent where he did have encouraging things to say, has bearing upon how he perceived *me* in this process. I believe Jonathan regarded my position (of 'power') as one that could offer him the opportunity to assert his opinion and justify his feelings in what he may have seen to be an 'official' way; he could put his perspective 'on record' in this research.

Issues on: 1) physical data 2) absence of 'fact' and 3) asking questions:

1. When I first began working with Jonathan's transcript which is shorter than the others and less 'wordy' within, I did think my findings would also be shorter with less to 'report' so to speak. In fact, I found so much in Jonathan's account I was conscious that I could end up presenting longer findings for him than anyone else. As such, Jonathan provided me with a perfect example of there being ample material in the data if one is prepared to spend time with it. As I have explicated above, I found 'obvious data' can drown out other important detail and data that does not appear in the first instance can materialise through further engagement.

2. Another perspective on having a shorter transcript was the feeling of missing data. At the time of interview Jonathan did not seem to have talked about much and, as he had not given his account as an outpouring of his story or even his thoughts and feelings, I felt there was an 'absence'. Furthermore, during the analysis of the 'short' data I felt I was sensing more than was actually written. For instance, I just 'knew' his and his wife's parents were an integral part of his family but he only actually mentioned them 3 times; twice very briefly and the third to divulge how they decided upon their names when they became grandparents. I did not want to exaggerate (same dilemma as Colin's 'manliness') as such, I did not want to over conceptualise and include what could not be substantiated. However, I believe that it is the connotations that I put upon his small clues that 'drove' his super-ordinate 'family man' theme in the end:

   a. The 'grandparents' names' explication was an 'obvious' link yet it was in the less obvious way that Jonathan spoke and went into minute detail that offered 'real evidence'; *I loved* the way he talked about his extended family like this, with fondness and a strong sense of pride.

   b. He also casually mentioned that his father took his older daughter to the wedding in the telling of that particular story and this small detail told *me* how much his parents are a part of his life, they just 'do things' together.

   c. The first mention of 'parents' was when they were given 'the news': they were the first people told which was perhaps an obvious priority yet when

I asked; *"was it difficult to tell your parents?"* (J5:1) Jonathan's response led to nothing. He replied; *"... er... no... don't think it was...."* (J5:2) and then launched into telling me about a lady who said if they were lucky, a cure might be found for Harriet, which he felt *was* a 'difficult' situation. In other words, Jonathan had an alternative perspective on my question, perhaps thinking; *'she wants to know what was difficult'*. As a consequence, I concluded that I had 'missing data' (e.g. nil direct response to his parents) because he had nothing to report on the basis of there being nothing extraordinary or difficult in relation to what I had asked.

3. As Jonathan did not appear to divulge too much about himself, I found myself asking a lot of questions during the conceptual stages of analysis that unfortunately, I felt were impossible to answer. Some examples following the theme of his parents 'not reacting' to news of the diagnosis were as follows: *'maybe his matter of factness helped his parents??', 'maybe vice versa?' 'is he paternalistic towards them, as with Gran?'* (and many more). I could not know the reasoning relating to these behaviours; as a consequence, I was aware I needed to 'stick with the data' (I was being careful not to enter the realms of 'psychologist' or analyst of that type...).

On the question of asking questions:

I was aware that I had asked Jonathan a number of questions during the interview. These were unplanned yet I felt that Jonathan needed prompts to encourage him to continue talking. As such, I wondered what impact this more 'semi-structured' looking approach to interview might have in my analysis. I felt the main issue was looking closely at my 'influence' given the impromptu nature of the questions.

What I found was that Jonathan very often seemed to pay little attention to what I actually asked. For example, this excerpt (J13:37-42):

> J: *(...) Harriet is Harriet... she is who she is*
> Me: **you mean you don't compare?**
> J: *yeah, she's I mean, we had an interesting conversation a couple of months ago where, where, I forget how we came onto it but it was ... sort of ...well... if someone came along now and said they could cure Harriet of her Down's syndrome (...)*

His answer was to tell me that *if* there *was a cure* for Down's syndrome, he does not know if he would 'cure' Harriet. He then continued to say how her character has developed and what a confident child she is becoming. He then gave a story which compared Harriet to her older sister, but in terms of Harriet being the more confident. Jonathan did not give me a direct or 'simple' answer: I think that he does not muse over comparison per se. For him, comparison is generally futile unless it can be made in a positive way and this was, albeit indirectly, the point he was making here. It was interesting that this sort of thing came out in the analysis given that Jonathan appears to like things to be straight forward preferring a pragmatic approach overall. On reflection, Jonathan did 'pay attention' to the questions I asked, but chose his reply carefully and I think my questions did serve as 'prompts' as intended (in the main) rather than 'directive guides'.

# **Reflexive Notes**

### From Maggie – Researcher 'bias', Prejudgement and 'Horizon'

The comments I have chosen to highlight in relation to Maggie centre around the usefulness of producing a naïve summary and the ways in which it aided my evaluation of my attitude within the overall analysis process. In particular, working with Maggie's data shed light on my biases, prejudices and thus my 'horizon' in relation to (some) ethical practices and moral behaviours. As such, in order to aid reader understanding, I have attempted to explain more about the decisions I made during the research process with this is mind.

When I checked my initial summary (appendix 5d p.325) of Maggie post-analysis, for the first time, I was rather surprised to find that some of the major elements that had struck me from the first reading had not 'come forward' as 'strong' issues through the interpretation process. Two of these in particular were pertinent to triggering further considered thought:

Firstly, despite my initial attention paid to Maggie not having foetal testing and her having previously suffered a miscarriage, this did not 'surface' as a significant issue per se; I merely used this as 'evidence' to uphold interpretation elsewhere in the account. Buried amongst the key examples in the emergent theme data, this detail supports claims of her 'understanding' and 'knowing' pregnancy as well as, her feeling guilty and thus, blamed. In the findings, I felt it more appropriate to cite her brother as someone who had actually pinpointed her as being to blame as this also gave further insight into her family relationships, how she may be treated and why she may think and feel the way she does from a broader context. In addition and quite importantly, I think it is difficult to appear as indifferent or not to be judged when writing about moral decisions a participant has made based upon personally emotive ethical issues such as testing for infant 'defect' in utero. I wonder, would the reader have thought I had included this information because I disapprove? or approve? There is no room in the interpretation per se to add my sentiments or perspective in order to make it clear where I stand on the matter so that the reader may know my intentions and why therefore, I have 'used' this detail. Furthermore, I do not like the idea that the reader may make possible judgements of 'Maggie' that might be disproportionate to (or misinterpreted in) her story where I feel this may have occurred if I had made this detail appear as 'important' as it seems in my naive summary.

Secondly: the second paragraph of my initial summary hones in on Maggie's relationships, something which I do feel is important within her experience and as a consequence, some of this did come to light under deeper analysis. However, despite the raw impact, other data soon 'swamped' the 'relationship' detail. Maggie's struggle

to understand Down's syndrome and her inability to come to terms with her youngest son being diagnosed with this condition thus 'overtook' what initially appeared as a potential super-ordinate theme of *'influential relationships'*. On re-reading my naive summary, I did startle a little; I thought for a moment maybe I *should have* separated this theme and expanded on the notion that there is a strong connection between Maggie's understandings and confusion with her circumstances and the people around her. As a consequence, I have considered three possible reasons why I did not take this route:

a.  I would not have been 'true' to the data or myself where 'forcing' the data was not my intention. Under the analysis break down and subsequent re-grouping I felt the data 'naturally' seemed to 'find itself' during the process as Smith et al (2009) suggest:

> *"some themes will act as magnets, pulling other themes towards them"* (p.96)

I believe this is why I was surprised on re-reading Maggie's naive summary that my 'sub-conscious guidance' led by my primary conception (the 'magnetic' field) was not as 'obvious' as it was with the other participant analyses where those summaries seemed to correspond very comfortably with the ultimate findings.

b.  If I had continued with the 'relationships' route I feel I would have been overly conceptualising and thus surmising, as well as diverting focus from the particular subject under scrutiny (specifically being a parent of a baby with a learning difficulty). Maggie mentions her ex-partner in the context of him 'being there' yet what she revealed about their companionship was insufficient, I feel, to interpret fairly. I was also conscious of being very judgmental about the relationship that Maggie had with her mother and I feel this would have been 'unstoppable' if I had elaborated upon this element of her experience (see also, notes below). Maggie's other sons also play a huge part in her life as she idolises them and whilst this was important in terms of her wanting to please them, I did not feel it necessary to explicate her relationship with them much further. Despite their adoration of Barney, it is not they to whom Maggie turns for approval, to set example or show understanding of her behaviours, it is her mother. As a consequence, whilst there was an abundance of supporting data regarding the older boys relating to Maggie's sense of her responsibility towards them and in the emotional rewards she feels from being their mother, I felt this was 'only' relevant in terms of her previous experience and sense of normality giving her a 'benchmark' in relation to her meanings of motherhood.

c.  There are many aspects in all the participants' accounts that could have found the 'spotlight' but did not; as a student researcher, creating a paper for specific purpose and where there is limited space, I feel I must be mindful of what can be included and thus how much data I (re)generate.

<u>My pre-judgemental attitude</u>:

These issues above bring to light the interaction of my pre-understandings, bias' and prejudices' within the research process as well as towards the research subject. A prime example came in analysing Maggie's data where I was extremely aware of being fascinated by the relationship she has with her mother. Her mother clearly tries to reassure her, but in my opinion, she seems to be saying all the wrong things. I will use this opportunity to reveal some of these 'disagreeable' issues to the reader in a bid to expose more of my 'horizon':

1.  Maggie's mother would have terminated the baby and this leaves Maggie believing she is a strong person for doing something 'even' her mother could not do. This may be a nice sentiment but for me, her mother gives the wrong underlying message. It perpetrates the notion that Maggie has made a mistake, that she has a baby 'nobody' would want (least of all her important mother) and moreover, it serves to undermine Barney by confirming his apparent lack of worth.

2.  Maggie is worried about his looks and her mother offers to pay for cosmetic surgery and corrective treatment. This is supporting Maggie in a sense, but again, I feel it is the wrong message. I would feel more comfortable if her mother had reassured Maggie that Barney looked fine and his finding alternative ways to communicate was a positive development. However, this thread then led me to question (as there is no evidence as far as I can tell) if surgery was her mother's idea in the first place...

3.  When Maggie became upset about attending the CDU group her mother advised her not to go, rather than help her to understand why going might be a good idea. For me, her mother's behaviour came across as compounding the 'problem'. By not helping Maggie to 'face her fears' she appeared to sanction Maggie being frightened, condone her discriminatory understandings and excuse and even approve of her self-centred behaviour. When Maggie explains this incident, she portrays her mother as being supportive, 'letting' her behave in a way that will satiate her desire to remove herself from Disability yet, I also see this as her mother taking the 'easy option' in not listening to her daughter 'whining' or; as her mother simply trying to stop the upset regardless of the consequences as it might be painful for her to hear Maggie being so distraught. This particular issue was difficult to interpret on the limited data I had and my own emotions were clearly getting in the way.

The 'issue' I had with Maggie's mother brought to mind broader concepts in preparation for thinking about the whole study data that had been generated. I could not help comparing Maggie's mother's behaviour to Hannah's mother who apparently behaves in a completely different way, seemingly telling Hannah to (for instance) 'get on with it!' Neither of the mothers offered a solution to their daughter's upset, in fact, they seem to have compounded their problems. I then went on to consider the male participants and relationships with fathers' fathers. Interestingly, grandfathers were least brought up of all the parental relationships and I wondered if this meant support is expected from grandmothers and specifically mothers' mothers? Given that there was no room in this study to explore these issues per se, I am recommending this to be an area of research that requires further investigation.

Whole page example

## <u>Emergent Themes – Chronological List</u>

(from Hannah data p.13)

ORGANISING THE DATA:
EMERGENT THEMES – Chronological – Hannah

OTHER impact (H13-14:50-1-7) – meeting someone who she thinks understands, her feelings, is a relief – doesn't matter that this person has bad news potentially, ignore that, she' s 'on our side', 'it was a big relief that somebody actually listened to us' (10-11)
FEELING (H14:10-11) – relief of *being heard*
OTHER impact (H14:12-15) – comparison to others who haven't had diagnosis, left hanging on to nothing, PW is better than that, comfort
DIAGNOSIS (H14:14) – can organise, get control if you have this
CONTROL (H14:15-16) – given a 'category' she can 'belong to something', she can know what to/how to deal with – importance of having a plan 'knowing'
OTHER projection of self (H14:16) – 'everybody likes to, (me: ?) in some ways belong to something then they c', then they can deal with it' she sees this is how others behave, *she* behaves
WOMAN (H14:17) – comparison, women are better at that (dealing with what's on your plate, what you know about – not the unknown) than men' ie *she* has been better at it than her husband
HUSBAND (H14:20) – he was insistant, had found out what it was, she would not accept from him, thought he was exaggerating, being over gloomy –she stayed positive, on the outside, convincing self
CONVINCING SELF (H14:22) – when husband/nurse gave diagnosis she stayed positive, on the outside, convincing self 'kidology' (23), *so convinced* went to get official diagnosis on her own
FEELINGS (H14:27) – relief or devastated? Confused, felt relief, what was said all along, confirmed *was* something wrong as suspected all along, but *terrible* news, shatters her 'convinced self' Bottled feelings of tears
CONTROL (H14:28-29) – controlled emotion, holding back tears, fighting to stay composed 'I think by the time I got out of there, I got me head round' quick, smart! Organise!
MOTHERING (H14:30-31) – 'not looking for ourselves anymore' *weren't before*, already had a daughter, twins, but the diagnosis meant their lives taken away, *massive* responsibility, bigger than anything before, mothering on a huge scale
GRAPHIC (H14:37-41) – 'absolute nightmare' awfulness of cases seen, found searching the internet for information 'eoughhh' –'it was hell for people'
REALISATION (H14:40) – meetings, had forgotton that part of the experience
CONTROL (H14:44-48) gaining control of her babies, learning practical things
MOTHERING (H14:44-48) – extraordinary activities of mothering, learning to tube feed, inject, having to be shown, unnatural...
CONTROL (H15:4- 11) – of emotions, 'holding back' not giving totally, reserving
MOTHERING (H15:5-6) – 'I know she's going to be with me a long time' sense of prolonged motherhood
FUTURE (15:7-8) – expectations of what children will be like, other girls 'like me', not daughter PW
MOTHERING (H15:5-7) – knowing her children important, loving them equally, wanting what's best for them, understanding they will (expecting them to be) independent 'they've got a life to live' (10)
MOTHERING (H15:12) – being practical, don't let emotion get in the way, harden up to solve problems that are bound to arise in the future
FUTURE (H15:13) – she knows problems are imminent with daughter
OTHERs perceptions (H15:14) – 'sounds terrible that' she knows she would feel that before having this daughter

# Creating Data Maps

(Some examples of workings)

**Creating 'Data maps' from emergent themes - all participant data:**
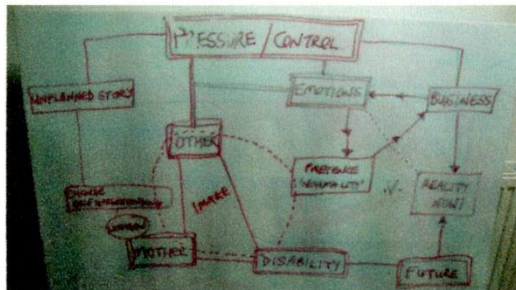


**From Hannah :**
*Left:* Development of data maps
 - working out how *all* her data links together

**From Maggie** (BELOW): Super ordinate themes - Data Map development

| 'Emotions of Mothering' | 'Being a Mother' | 'Physicality' |
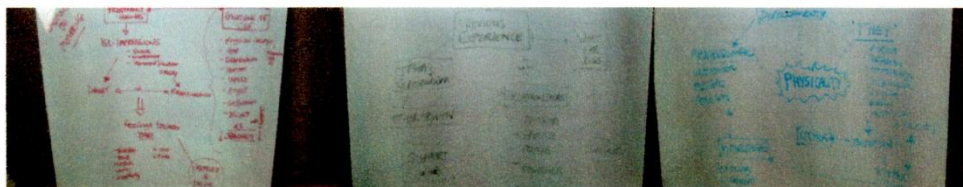


**From Jonathan** (BELOW): working with grouped themes

 - different coloured tags represent super-ordinate themes     - ideas notes - building the data map(s)
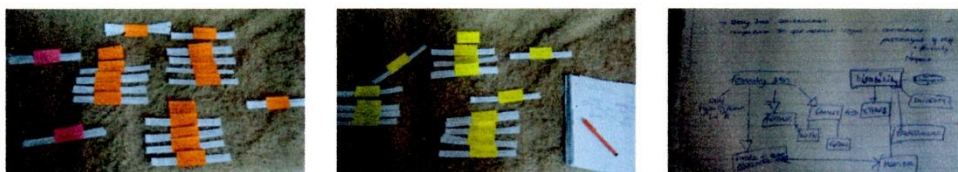


**From Colin** (BELOW):
- working with 'data strips' building  super-ordinate theme of 'other'
      - working with grouped emergent theme data for super-ordinate theme of 'life'
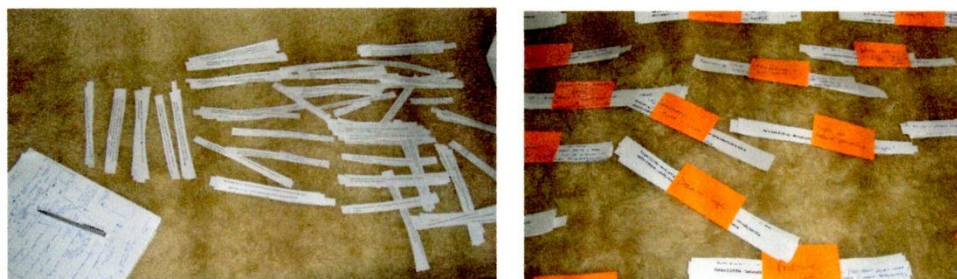
ANALYSIS

**Example 'Data Maps' and 'Data Tables'**

COLIN – Data Map: example super- ordinate theme 'life'

DATA ANALYSIS – Colin
ORGANISING THE DATA

DATA MAP 4 – 'LIFE' – *Being in the world*
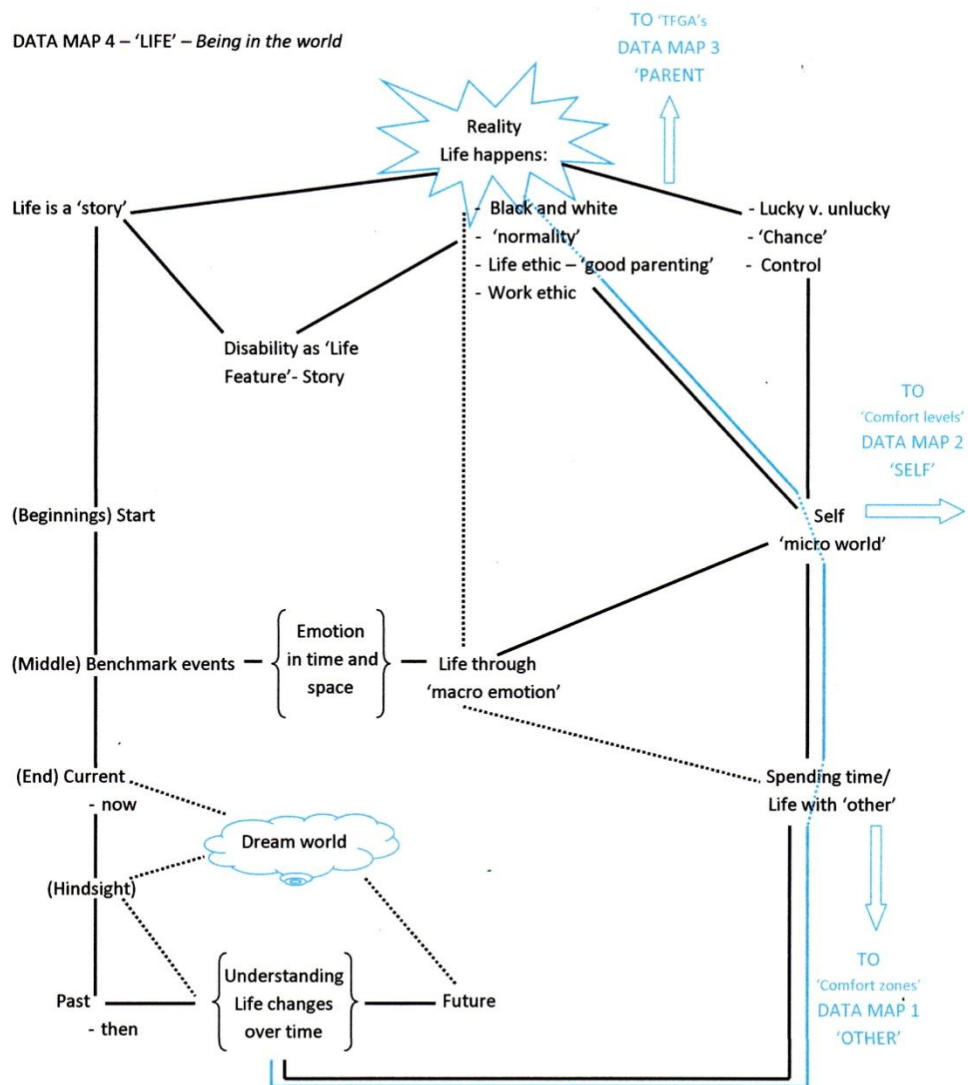


THOUGHT: STORIES FOR C. ARE A VEHICLE FOR HIM THROUGH WHICH HE CAN EXPRESS HIS EMOTIONS AND INTERNALISED FEELINGS? So many times, C starts a story and then has no detail or structure, sequence, place in time. He uses stories to support the saying of *how he felt* eg visit to a counsellor – can't remember when, or how long he went for, only the emotions running through him alongside that experience, not even the thoughts he was having at the time: I felt I had to draw those from him (C6:41) 'so they're still in hospital?' in order to make sense of and place those feelings

ANALYSIS

## Example 'Data Maps' and 'Data Tables'

COLIN – Data Table: example super-ordinate theme 'life'

DATA ANALYSIS – Colin
ORGANISING THE DATA

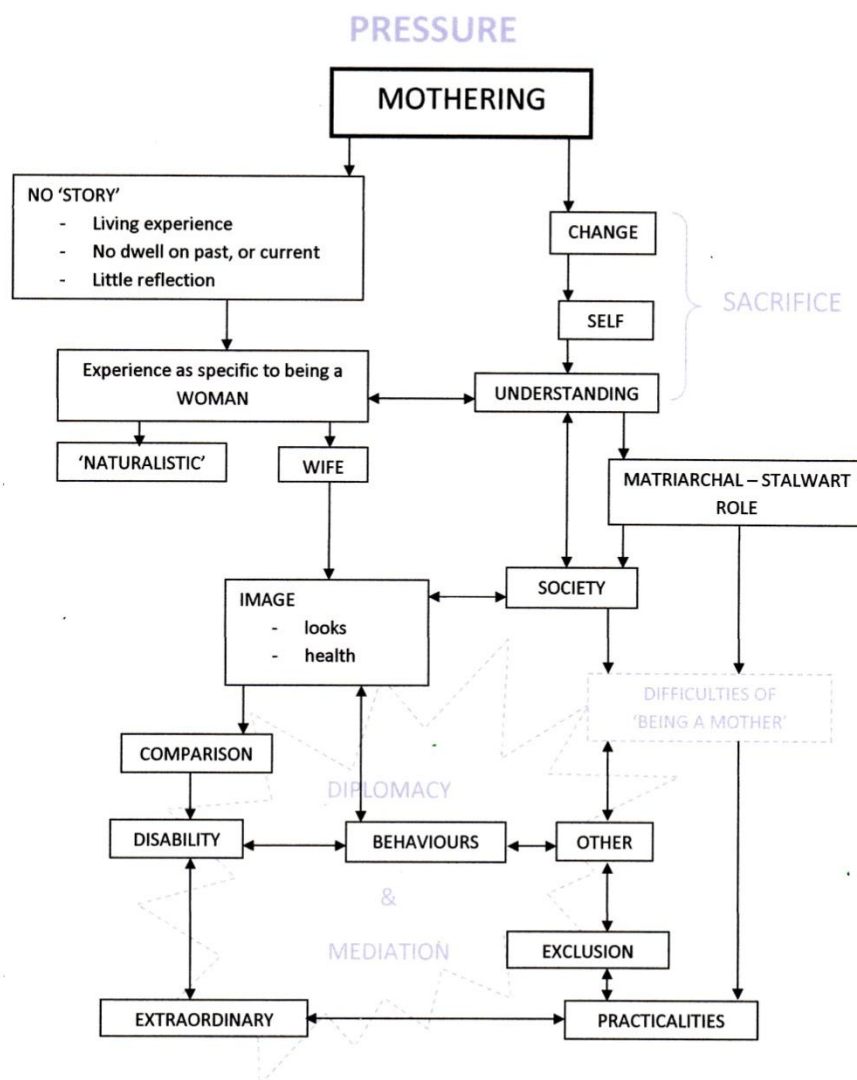| EMERGENT THEME: | KEY EXAMPLES: |
|---|---|
| Life happens | C7:39-24 C10:47 C17:13-17 all or nothing 'sink or swim' bad v good, black or white – pragmatic C12:9,11,13 no fuss communication, world uncomplicated, easier to deal with?C5:42 'I started to go downhill', ups and downs, also C9:24 C24:25-26 'dealt a shit blow' harsh reality, 'don't ever forget' its here to last C22:36 'I wouldn't have liked to go down a normal route now' life's a journey, a path, there is such a thing as 'normality' C16:45-50 life by numbers, factual/practicalities C17:1, C18:25-30, C10:33 'good parenting, there is a 'right way' life ethic C17:37-38 morals and manners C9:33 'muddle on' no focus, goal, direction C8:4 'getting to grips' a sense of life slipping away/through C19:25 life as a competition, from the word go (rogue sperm is a good fighter) Life is about TFGAs eg C22:1-2 life is about belonging to groups, coffee morning (or not) C21:1, C22:32 life runs in stages (of biological development) grow up, have kids is ordinary C23:49 'I don't believe in God' – what then – chance/luck/destiny C15:12-16 wants people to be 'honest' with him, he wants to *hear* the reality of his life, as if to confirm it, (keep it real desensitising) C8:45 life has different perspectives over time and space (meeting boy with CP, looking back now...) C13:34 grass is greener? (Other people nice lives) |
| Work ethic | C14:42 benefits = free money C10:29 housework mundane imagery 'if house is a shit tip' C10:37 'things have run like clockwork' routine C18:32 'amazingly lazy' = bad, to be avoided C9:1-2 boy with CP 'doesn't do anything' C22:42 'chasing the money' means to an end, never gonna get there |
| Lucky/unlucky<br>Chance<br>Control | Lucky circumstances: C9:35 can compare twins, C20:27 he can 'talk to anyone' C10:49 he's a 'people person' C24:25-26 'dealt a shit blow' no choice, this is what he's been given C12:28 people say he's lucky, he doesn't think so (he has damaged goods) C11:30 'dealt the shitty card' = unlucky C24:27 life's a game, dealt cards, play the game 'but it's how you play those cards in it?' life/the game can be controlled C21:29 can be 'caught out' in the game C12:49 feels 'cheated' of nice experience C22:42 'chasing the money' a catch up game, never be caught C16:47 probabilities chances of something happening C21:49 'that's the way it works out isn't it?' C15:2 'not a lot we can do about it' can't alter course C20:24 'I'm gonna deal with this' master of own destiny? C10:37 'things have run like clockwork' under control C8:4 'getting to grips' able to bring under control C12:32-33 'turn around', life can be steered |
| His immediate<br>world | C12:33 'doesn't happen to me C12:33 being at home *safe*, in control C12:34 routine from hospital helps him C13:34 bitterness, people have normal, nice lifestyle, his has gone C14:24 'I'm getting my life back now' couldn't recognise what his life was about, starting to see 'straight' C14:40 'I get out there', from his little world into the big one? C23:49 'I don't believe in God' family, bonding is his thing C16:32-33 his world is his family, in his environment C19:5-6 'thought me life had ended' his world had ended, what he knew (comfort zone/levels) felt gone |
| Life through<br>macro-emotion | C19:34 'through going what we've been through' a big thing, no ordinary experience of emotion (eg wishing child had died) C16:30-31 life is a huge struggle, strong, massive bursts of emotion, so angry 'you could shake 'em to death' C23:37 life on the edge, 'bottled' emotions are deep, they 'stick' with you (and can be revisited, see emotion time and space) C6:4 'this doesn't happ..' he was frightened by what was happening to him, the unknown, it was *unusual* behaviour (crying), he knew he needed help, the emotion was so *over powering*, he *couldn't control it* alone |
| Life is<br>storytelling | C6:2-3 reliving the moment C7:33 'anyway, back on the main thing' there is a storyline, stick to it also C2:38 'back onto it now'C21:41 wife will put 'a different spin on it' more than one version of this story C3:51 some bits of story not important, glosses over detail C11:7 'well here's one for you' life is a patchwork of stories, piece together, bring in experience to make sense of the story C3:49 'story jumping' to piece story together C5:43 'obviously, I can't remember it now, the exact thing with it, but I just remember thinking..' salient points build the picture C2:47 'I remember...' slow speaking to get it 'right'? C2:8 exact detail important '8 o'clock in the morning' reliving the exact moment C18:24 tells exact date, important (to him) detail |
| Disability view | Percieved notion of disability:C19:12 'were dirty' C22:32 C14:8-9 disability 'spoils' the life view of 'normality C22:47 disability = deserving, worthy cause, taxation to be spent on it ok C13:31 it is earth shattering, *that* bad C15:6 negative, developmental delay, C24:18 its a 'shit blow' blunt reality C16:49-50 'they become so objectionable' this is what disability is about, doesn't fit in to bigger picture |
| Start (beginnings) | C23:14 C14:36 C10:23 there is a beginning, several identifiable moments, why difficult to pinpoint at the beginning of interview (I asked where does it start for you? He stammers, hasn't got a clue) |
| Bench mark<br>events<br>(middle) | C11:25-30 blurred recollections brought to life through remembering key events C4:36 hospital transfer of babies, happened, no detail, event important impact, but not when V. C6:14 remembers detail but not 'bigger picture' C20:6-13 man in a woman's world made real by breastfeeding encounter C18:25-30 park, other's reactions made obvious C24:33-36 initiated into 'different' world 'you're in a unique club now' C18:24 exact date, child's development (being 'normal') so important to this story, his experience C12:18 C12:32 going home, a turning point, 'Sunday' detail, high impact, C6:46 seeing a counsellor& stopping work (C6:40) turning points C8:45 can feel how events/encounters have helped to change him/put life in perspective (meeting boy with CP) C9:42 current benchmark, reality of today (daughter eating dog biscuits) |
| Emotion in time<br>and *space* | C6:46 thinking specifically about a time and place, emotions he felt in the past, he replicates now (cries) C6:4 'this doesn't happ..' he is bewildered telling the story of being bewildered C6:32 'emotions ran high at the time' feelings were relevant to occasion: events and experience C13:5 'need time to grieve' belongs to time and place, those feelings can be recalled |
| Current Now<br>(end , 'arrival') | C23:9-10 realisation, happening now, 'why didn't he think of this before?' C14:27 'honest to God' convincing life *is* better now C8:7 hard to think about going back to work C9:34 'a lot of our problems' he *has* problems (not *had*) C9:42-45 window into life now, breakfast time C10:8-10 graphic illustration of life feels like now 'draggin' from dog food C15:30 'things are very positive now' C4:48-50 listing possible now', nothing to report getting back to 'how it was' doesn't *feel* like disaster C21:33 believes he now has transferable, real skills, positive outlook for future 'I'm enjoying things' C13:11 example of his day, going out and about (donkey) C21:19-22 this is what he knows, *now* today.meeting people |
| | Hindsight | C7:22 'didn't even think how serious it was at the time' C11:40-45 sees own parent's perspective now, couldn't at the time C4:6 C4:31-35 glossing over detail, unimportant because its ok now C4:48-50 listing possible impairment, easy with hindsight? C14:24 'its been a doodle' C11:23 laughs after saying he wanted to wallow in self pity C7:39 life changed thought for worse, but now realises for better C13:40 'this past 12 months' reflection/evaluation |
| | Dream world | C15:12-16 C24:25-26 harsh reality 'shit blow' thinks he would appreciate 'honesty' from others, keeps him off the dreams? C22:16 how he sees himself in 10yrs C2:4 'what happens if...' C5:34 regret 'I just wished it hadn't have happened C6:8 losing sense of reality 'whats happening here' C7:6-7 'wake up call' *was he asleep?* C8:41 'the truth of it is..' not pretending C9:19 'wouldn't swap' & C19:29 'would I change her?' (unprompted) & C22:40-43 confused life scenarios, convincing he's in the right choice – he plays with unachievable C11:50 emotional telling others, it makes it real, its happening C14:7 multiple realities 'no point pretending' C17:6 facts to back up, encourage 'dreams' / imagery of future C17:13-17 dreams of uncomplicated life C23:23-26 uncomplicated self (who he is now) C24:20 & 44-45 'if you could rewind', you would like to be' magic wand? |
| Future | Scary: C10:13 'we know she's gonna be harder to manage' going to get worse, not better & C11:33 'she's gonna struggle' 'they need you for the rest of your life' C10:19 challenges ahead C18:32 'they can become amazingly lazy...' C10:21 keep in touch with older PW parents C6:9-10 'can't do this, can't do that' futures, expectations, plans C14:1-15 schooling issues a head ache. Good: C15:31 immediate future good, doable (feels normal) C17:1, 4-6 using facts for the future 'the reality is....' vivid image daughter away is a comfort zone C17:6-8 comfort from facts (those he's cherry picked) a 'true' prophecy to cling on to for comfortC16:48-50 setting up for disappointment? *Will the info now be relevant in future?* Some future too difficult to think about – self! C22:16 driving a truck 10 yrs off, quickly changes subject |
| Past (then) | C7:22 'selfish pig' C13:19 'not as bad as I was' C15:6 'we're 100% positive now' weren't before C2:7 IVF difficult history, impact today ie parenting a privilege C12:47 nightmare past C19:6 a 'dirty' part of his life – the dark ages C23:8 'world blown apart' he had a comfy existence, earthquake C6:9 'me life's changed' it *was*, now its.... |
| Life changes over<br>time | SLOW: C8:431-42 'all in the same boat' over 12 months to realise C13:5 'need time to grieve' length of time/ is a healer C15:9-10 frustration, child development slow C12:42 'slowly come to terms with it' QUICK: C13:45 'changing so quickly' (now) FEELING CHANGE: C14:27 5 yrs nights, now can go to the pub, life seems at a faster pace, he's part of it C20:39-50 C7:39 'I knew my life had changed' C13:40 'this past 12 months' WATCHING: C16:23-24 improvement of daughter from 2 yrs ago C6:31 DS go ahead of PW C8:5 future time, 'off 2 years, another 12 months to go' |
| 'Life' time is<br>'Being there' | C13:12-20 others remind you of who you were/are C12:27 cloak of shared pretending through life, they say 'everything's alright', you know, they know, it's not. C13:23 network/back up C9:25 being with people (like minded) C12:37 relationships build over time, no matter how short C13:39-40 'not a wake up call' no, a reminder, shock has gone |

ANALYSIS

## Example 'Data Maps' and 'Data Tables'

HANNAH – Data Map: example super-ordinate theme 'mothering'

ORGANISING THE DATA – HANNAH
Data Map 1 - Mothering

DATA MAP 1 – MOTHERING

ANALYSIS

**Example 'Data Maps' and 'Data Tables'**

HANNAH – Data Table: example super-ordinate theme 'mothering'

*192.*

ORGANISING THE DATA – HANNAH
Data Map 1 - Mothering

| Emergent theme: | Key examples: |
|---|---|
| No 'Story' | Time scales: H2:27 'weeks and weeks' H3:8-9, H3:2-:23, H2:25, H2:37-38, H3:6-7, H3:38, H7:11-12, H7:44, H6:23 all blurred recollections, unknown lengths of time H4:26, H8:20 trying to formulate the 'story, what to tell H6:22 thoughts as feelings not the 'when', the what H6:24-25 2yrs how does she judge this, made up? H4:28 couldn't talk to counsellor, not a story, holding emotions |
| Realisation | H4:28 lived the experience, didn't dwell, H7:20 was fright 'I never really thought of it like that before' H8:36, H11:47, H25:7, H17:38 things happen that make her stop and think, that's it, that's why... H11:47 forgotten experience brought to mind, |
| Specific to being a *woman* | H4:3 'very hard coming from a woman', H6:5 I find that hard as a female' H14:17 comparison, H9:29 others upsetting as a woman, H18:36 kinship, womankind 'I think that's what a lot of women do' H18:36-39 making sense of 'other' mothering |
| 'Naturalistic' | H2:31 natural birth, H10:29-32 importance of being a mother H6:46 protecting H12:1-2 H24:38 activities with children H15:5-7 knowing children, equality what's best for them  H24:27 cruel to be kind 'nasty mummy'H19:6-9 connection to daughter – starves herself **Senses:** H1:45-48, gut feeling H2:40, H2:48, , H7:2 weird, sensations, H3:3 senses of doom, H6:9 H6:47projection on to daughter, as a female, H2:1-2, H2:40-41 H2:48-49'proof' H18:13-14 – heightened because I'm there? |
| 'wife' | **Team:** H2:40, H10:13, H16:33, H18:17-18, H3:44 'we', shared understandings, working together **Own:** H3:13, H3:18, H8:40 H9:29 having to get on, he didn't H7:41-42, H8:19detachment,H9:29, H15:20 not the same, not discussed H3:36 H20:30-32 no support, he disappears if there's trouble H14:20 he's gloomy Loyal: H4:15-16 hide emotion, H6:30-31 takes opposite stance to boost him, H7:24-25 act normally for his sake H4:30, H10:5 he is an individual, help him learn (as child) she is maternal, H6:47 respect |
| Change and Sacrifice | H4:46 learning H5:30-34 H6:42 expectations shallowness H5:30 change not female H10:27 can see progress H11:35 disability massive impact, would have been same otherwiseH15:14 sees how she's changed through 'eyes' of others H19:25 more change to come H15:20 different to hubby H5:32 different values deep v. shallow H11:40-47 sacrifice H12:49-50 parents are still in bubble, won't give 'it' up H19:38 the 'start' knuckle down, accept change |
| Self | H3:12, H3:14, H4:2, H4:14, H4:42, H7:34-35, H8:26-27, H10:48-50, H11:36, H12:18, H15:14, H19:39 H16:33 – other's projection on self as image 'sounds terrible' sounds really odd'H14:16 everybody likes to belong...' H18:41-44 if woman could have her time again – *would she*? H19:38 she focus on start, regret not starting earlier? H5:9-10 others wouldn't like to be in her shoes, *she* doesn't like being in her shoes, H5:9-10, H9:3-4 don't say it to anyone else – it has hurt *her*. H4:7, H5:30 H4:39 type of person, not just female H8:28 selfish? For what? H14:16 everybody wants to belong H18:41-44 if 'other' could start again – would *she*? H5:9-10 don't say that to anyone else & H9:3-4 |
| Understanding | H10:50 'I suppose I try and balance things..'  how she appears to others H15:40-42 trying to understand holding back H19 why she behaved in certain waysH18:36 how another woman would be, how *she* would beH16:45-50 projection of self seeing others 'you can't let yourself go like this' H5:32 others gloat, she was but is no longer, *that* person H19:6-9 extreme understanding H19:13 to understand, should have had the experience H9:10-15 compassion, feeling for other PW parents 'a little bit different' H21:3 what it *feels* like to have PWS |
| Matriarch | H6:46 family close, H14:20, positive for family, H22:43 'our little unit' H18:1-9 proud H23:5-6 PW child who did not get family support, example of why important H17:36 her children understand eachotherH5:31 sense of motherhood deepened, deep v shallow people H19:22-25 daughter has become an 'outsider' – strong bond in family so most upsetting – treating her differently yet: H6:11-15 overt focus from grandparents, unfairness to others  H7:24 deep breath to go back into family from business – its a big(ger) job! ....See also burden of responsibility.... |
| Society | H6.5 'I find that hard as a female' H7:33-35 guilt hospital H9:41-43 diplomacy, putting up with H12:19 being an older mum H13:30 mother/child behaviour, doesn't fit, painful H17:30 older daughter being 'mother'  H24:38, H25:9 other mothers |

ANALYSIS

**Example 'Data Maps' and 'Data Tables'**

JONATHAN – Data Map: example super-ordinate theme 'disability'

ORGANISING THE DATA - JONATHAN
DATA MAP 1 – 'DISABILITY'
**DATA MAP 1**
'DISABILITY'
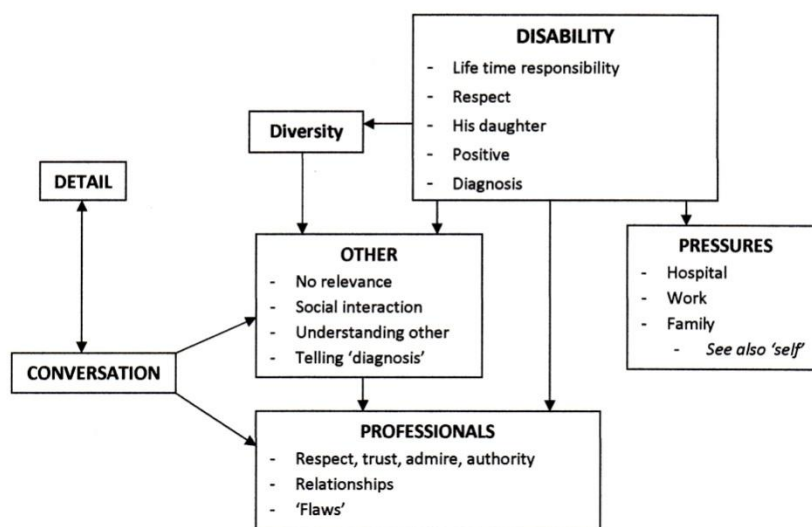


**Notes to Map 1:**

**Detail** – **Corrections:** wants to get it right, for correctness, 'truth' **Terminology**: respect, self portrayal, again, 'to get it right' **Feelings**: how he felt at time brings him to remember another 'story' – he slows up when he *thinks* as he speaks – again, 'to get it right'
**Conversation** – his way of telling the story – through his interactions with others – what was said – detail

**Disability** – he has *positive* things to say about disability, he knows the Issues, but it's *not an* issue eg it is a lifetime, but not a burden, an added responsibility, that's *all*. – His daughter *is*, so *can't be a bad thing*: **respect** for Disability and diversity
    **Diversity** – everybody is different – difference between disabled as well as non disabled... can't use others as a 'benchmark'
    **Diagnosis** – had understanding of disability from school (poor terminology here) – had to work it out for himself, and tell wife – not bothered though! Respect for professionals, telling people not easy – he found his own way
**Professionals** – **Trust, admiration & respect**, will not knock – if he has something bad to say, he builds up with the good first – can see *flaws* tho' – appreciates *relationships, G.P.* confidante.
**Other** – *social interaction* important, *older* people respect, *understanding* of others – but they hold *no relevance* (see also refs for compassion?).

**Pressures** – pulled between work and home, home and hospital, hospital and work – overload – *family* wins

ANALYSIS

## Example 'Data Maps' and 'Data Tables'

JONATHAN – Data Table: example super-ordinate theme 'disability'

ORGANISING THE DATA - JONATHAN
DATA MAP 1 – 'DISABILITY'

| Themes | Key examples: |
|---|---|
| Detail | *Respect*: J12:24-30 J15:5-18 Terminology, J13:28 telling gran, J14:46-47, J14:20-21 Feeling: J5:17-18, J12:23, J10:4,(J3:11, J2:5, J6:34-37 'blank'), J14:49– J15:3 "when… we… aren't around…"J6:7 "slap bang" J14:2-7 Confidence, 'hiya', *Correctness 'Truth', he was there*: J4:4-7, J7:30 J8:1-5, J8:41-44, J9:1-5, J9:13-14, J9:9-21, J9:21-22, J11:17, J13:6 "not an iss'", J14:45 *AND* in 'story', carefully telling others 'the news' see self: J5:25-28, J12:20-24 not bothered people's reactions |
| Conversation | J10:42-47 internet forums, J13:40-47 if there was a cure, J10:12-20 nurses, J2:21 midwife, J14:10-12, J6:46-48 GP, J6:34-37 girl breakdown trigger, J4:7-12 wife asking questions, J3:42 to aid story, its what happened J3:15 midwife, had he understood? J8:5-7 neonatal feeding J5:9-12 lady and pram – a cure, an example of look not bothered |
| DISABILITY | J10:35 *lifetime* – not a burden, J15:5-18 radio programme, J13:35 sees past, LD, J1:32-33 no tests, J2:31- not life or death, J10:35 internet for info no good, 'crazy', J5:8-12 no cure J10:43-46 not phased, + & -, J7:37-38 muscle tone & J14:46- 49–15:1-2 *responsibility* understand 'issues' of DS J13:28 & J5:25 *not* bad news J14:14-21 disability not the shock, *expectations* then lowered, ok J5:9-12 lady conversation – not bothered re cure J3:29-33, getting to know *her* J5:35-38 told others baby *ill first*, then DS, J6:28-29 *work was* the issue, not DS, Harriet *Respect*: J14:31-50 future job, house, independent, J12:44-47 was struggle, not upset gran J13:29 has moved on J12:36 wife difficulty understanding, need time J8:19-25 careful how he describes baby J2:47 &J14:9-10 *'a'* & *'the'* DS – from school terminology not important tho', he does respect J8:25-27 not machines, real babies *Not a bad thing*: J6:29-31&J13:40-47 no cure daughter *is* DS & VV, J3:29-30 looking for the DS, J5:41-42 DS forever, his daughter *Positives*: J14:45 " jobs" J9:26-31 take advantage of being special J5:30-40 J12:11 an 'extra' J4:38-39 new path in life J14:21 "you just think, God Harriet, you can achieve" J14:8 difference is good  Diagnosis: J2:41 guess, J4:11 telling wife J1:35 "whatever happens, we'll take it on the chin when it happens" prepared for unexpectedness, but no tests |
| Diversity | J10:42 & 46 extremes J8:25-27 babies not machines, need ind. Attention J8:17 same rules for all J15:5-8 impairment can't agree J13:35 uncle not relevant – all different, J14:8 daughters are like "chalk and cheese" good! See 'others' also |
| Other | *No relevance*: J14:31-34 adult DS with parents J10:40 - 11:1-2 other's stories J5:28 others reactions to DS not important (diagnosis) *Importance social interaction*: J8:39 older relatives in hospital, can interact J6:34-37 breakdown, girl trigger, J9:4-6 to cafe not home J14:1, J11:25-29: going to groups  - meet people J2:2 interest be amongst *Understanding*: J3:3 Dr didn't have time to weigh him up and decide what kind of person he is – wrong, J5:35-38 baby ill first, then DS J12:20-24 he knows people, bad people react badly that's their problem J5:8-12 older lady asks about cure – that's ok, she's older J8:25-27 *compassion*, babies, not machines  J8:47-48 can see what like for parents staying longer than 2 weeks *Diagnosis*: J5:2-3 no time to think, just said it easy J4:47-50 told parents straight away |
| Professionals | *Relationships*: J11:14-15 group input J13:15 midwife understood – too medical? J11:6-11 manner important J2:2-6 he understands midwife – (she's sorry he missed it) J11:3-4 info from profs & hospital "well looked after" J3:13 "got on well with her" midwife J18:19-25 midwives cuddling baby G.P. J14:11-12 confidante  J6:46-49 'no questions' being understood J6:24 time off extended  *Respect*: J3:34 nurses take baby to neonatal, *have to trust*, but he *is calm*, he *does* trust J1:48, J2:17 trust, he's outside waiting J2:35 admiration, builds Dr before 'knocking down' J2:15 authority, he waits, doesn't ask J14:24-29 authority baby drinking milk – they understand too J9:26-31 advice wedding, permission also J4:27 respect job, telling parents etc. *Flaws*: J4:1-3 didn't do pre natal,no good (but he did learn something last time! J2:31 left guessing J4:11 no one to tell wife diagnosis, ok, he understands J9:4-6 NHS food, facilities rubbish, doesn't like to say tho' J8:5-14 advice re 'food theory' he sees the flaws, but won't knock J7:14- NHS funding, knows this stopped daughter going for earlier scan, ok that's life J8:29:32 4 hr routine no good, need sleep, but ok, settled after 1 night |
| Pressures & *see also* 'Self' | *Hospital/baby*: J10:5-10 poorly baby, *back* in hospital, J9:13-14 to and from  H8:39 can't interact, lying in cot J8:29:32 4 hr routine no good, need sleep! J7:14 waiting for heart scan news, on day of discharge told would be later *Work*: J12:4-5 "silly hours" J11:19 flexibility, can be at home J6:6-9 work 'hectic', worse at Christmas J6:22 torture to go back to work J7:8-10 work/family a "boiling pot" *work gives way to family* J11:18 day off for family J12:6-7 pressure from home to 'provide' J6:18 brought baby home – back to work resentful J12:13-14 wife *needs* him for support "I wasn't there for her"(14) J6:12 "cheated" of time with baby, 3 days paternity leave, rest holiday, all in hospital – not quality time, couldn't afford anymore J6:28-29 *work* was the issue |

ANALYSIS

**Example 'Data Maps' and 'Data Tables'**

MAGGIE – Data Map: example super-ordinate theme 'physicality'

ORGANISING THE DATA
DATA MAP – PHYSICALITY – MAGGIE
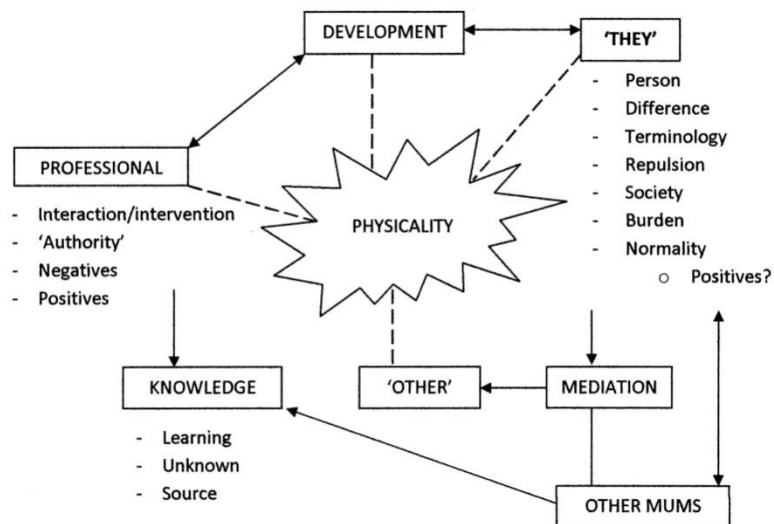


**NOTES:**

**Physicality:** Looks matter! Attractiveness & 'normality' – signs of abnormality - alien

**They:** *Person* – she sees 'the Down's Syndrome' before her baby

   *Difference*/alien - she sees People with Down's syndrome *as aliens*

   *Terminology* – disrespectful

   *Repulsed* – her reactions to older children and adults is shock, horror, feeling sick

   *Society* – her view of people with Down's syndrome in the public eye

   *Burden* – of ugliness, having to deal with DS

   *Wanting 'Normality'* – desperate to see child 'as normal', she does, but can't see other people with DS as normal

   *Positives* – can see beauty in 3yr old, breastfeeding, love

   *Miscellaneous* – Distance helps – USA little girl, not an issue, also friendship helps, ok with friend's older boy?

**Development:** slow development cause of anxiety – he needs to be normal – not alien

**Professionals:** *Interaction/intervention* – necessary when having a baby – more so when difficulties – more difference *'Authority'* – gatekeepers, pressure

*Negatives* – Inappropriateness midwife, diagnosis, manner, exposure

*Positives* – Advice, manner, coffee am

**Knowledge:** *Unknown* - No knowledge beforehand, never met, no understanding

*Learning* – within first 24hrs had gained much – scary knowledge, alien – later learning as development continues

*Source* – Other mums, professionals, baby, US contact

**Other mums:** For information & 'company', but also present 'otherness'

**Other:** To feel *normal*, feel accepted, for company, to 'belong' – but *Comparison* reminder of not being and being misunderstood

**Mediation:** blamed, wants to fit in so will lie to others, show off baby, get reaction – mediation with professionals, 'fight' to get what she wants.

ANALYSIS

**Example 'Data Maps' and 'Data Tables'**

MAGGIE – Data Table: example super-ordinate theme 'physicality'

ORGANISING THE DATA
DATA MAP – PHYSICALITY – MAGGIE
APRIL 2011

| Theme: | Key examples: |
|---|---|
| **Physicality** | M3:18 M3:24 M6:49 M7:31-32 looking at baby's hands (& feet)M3:27-28 flat face M3:37 'short' _features_, hands, fingers etc M3:38-39 emphasis on 'short' _not attractive_ M3:48 features – apart from 'the obvious' M4:3-8 'palmer crease' M8:35 ears drove her 'insane' M8:48-50 skin M11:49 12:1-2 hand – the proof –will I notice (I don't) – then shows me his 'funny ear' _Health_: M14:22-24 hearing ok, 'he's just as normal, as a normal baby' – but she knows he's prone to illness - other kids have asthma – its normal (29) _Looks_: M4:17-18 glad of a boy M7:38-39 dr says he looks like father M12:1-2 LOOKS shows me his 'funny ear' had put cellotape on it – make him look ok M13:8 Looks 'beautiful' little girl M13:10-11 she carries, lies – _image_ 'normal' she wants to fit in (13) M13:14-16 looks important – help her to pretend M16:11-14 eye and hearing tests etc, checking for _defect_ M18:45-47 '_a, I don't want my kid to be like that but don't forget, 'e was still only a little baby 'e still looked cute, they didn't look cute to me, just didn't'_ M19:18-22 'gorgeous white leather pram' showy M22:38-40 mentally slower, but physically normal M26:46-47 mum, DS girl in Sainsburys – '_dead pretty' – for reassurance_ M29:10 worried about baby not being able to speak properly – will go for _surgery_ if necessary M15:38 - 41 beautiful looking baby – its normal to want a good looking baby and he was |
| **'They'** | _DS before person:_ M3:16 DS before sex M16:43 '_cos you don't want it really, but I adore him, I'd die without him'_ DS separate from Baby M22:2-3 3 adults - shock, 'freaked out' panic, 'couldn't do it' expectations – could only see negative, what _can't do_ M27: 13-17 she remembers 'one' in Asda M27:47 in argue with friend '_would you want it? Would you want Barney? Would you want a Down syndrome? Description/difference/alien:_ M2:41 'they' are strong M4:2 'the' ave the palmer crease M7:34 'the DS, they have a thick line...' M7:43 'short stubby legs' making fun of dad – looks like he has DS M8:36 'they 'ave low ears M12:25 he is alien, DSA club for _other_, M12:41-43 '_are you telling me that baby dun't look like a Down syndrome, 'cos he's the spittin' image of a Down syndrome baby' not that I'd ever seen one, but I'd, I just knew'_ M17:5-6 M25:23-26 slow against _normal_ babies M18:42-43 '_well I had to go, I had to get it in to me 'ed, this gonna be me life from now on, I've gotta mix with them, I've got to'_ – burden, alien....'didn't look cute' (47) M21:41-43 '_a Down syndrome bloke walked past me..... an' a went (nudges her elbow out) an 'e went, 'stop it! Ah know' (shocked tone) and then another one! And then another!_ And there was 3 of them, grown up...' – looking all over for 'them' as would a ghost, or alien, disbelief, more proof M22:15-17 saw 'two more' at aunty's caravan – horrified – _"cos they're not normal are they? 'cos they're not normal an' a still can't see 'im as being normal,_ to me, 'e's normal... but a'm gonna have to face that when a come to it...' M22:23-26 'well, if I'm in Asda, _I wouldn't go to a Down syndrome, ever, would never 'ave gone over_ to 'em an' asked 'em...... M26:36-37 '_I can't do it, I don't want 'im to be like that'_ M27:19-20 knows there's '_different strengths'_ and '_different problems'_ M11:49 12:1-2 his hand _the proof_ his 'funny ear' _Terminology:_ M5:45-46 down syndromes M6:30 'down syndromes' M9:34 Down syndrome_s_ M10:23 Down syndrome_s_ M12:41 _a_ Down syndrome _Repulsed:_ M18:35-36 'oh my God, Oh my God' M18:42-43 forcing herself to 'join in' 'well I had to go...'didn't look cute' (47) M26:6-7 horrified at 4 yr old girl cross-eyed M26:30-32 '... ooooauugh, oh my God, my baby's gonna be a freak' M27:47 in argue with friend 'would you want it? Would you want Barney? Would you want a Down syndrome? _Society:_ M10:23 Down syndromes - name calling M29:10 '_I never knew, I never spoke to a Down syndrome...'_ M11:21-22 'I've never even met a Down syndrome, never even spoke to one' (24) M12:25 'DSA' social club M22:23-26 'well, if I'm in Asda, - Social placement M23:45 'what ma doin' 'ere, it was 'orrible' – coffee am, wrong side of fence M24:4-5 on her own, no relationship , gets down anyway – without having DS baby too –how will she find someone with DS baby? M27: 13-17 shouts at friend, panic, what about him being older – won't have xyz – then she remembers 'one' in Asda _Burden:_ M12:50 'all on me' M11:28 'I'll never, never be rid of 'im' M18:42-43 herself to 'join in' _I've gotta mix with them,_ M25:40 _bouts of being down_, like the caravan and then seeing this cross eyed little girl in clinic _Positives:_ M13:8 _but_ can see beauty in DS 3yr old M14:31 breast feeding good, not sore! M15:8-12 love – John is there - acceptance M19:41-43 easy baby _Wanting 'normality':_ M13 (tape cut 1) still wants to point out DS to others, hoping for 'no?!' reaction – but rarely gets it M14:22-24 hearing ok, '_he's just as normal, as a normal baby'_ – but she knows he's prone to illness '_the' get all this cold..'_ M22:15-17 horrified – _"cos they're not normal are they?_ 'cos they're not normal an' a still can't see 'im as being normal, _to me, 'e's normal..._ but a'm gonna have to face that when a come to it...' M25:49- 26:2 _signing – not normal_ doesn't want him to sign M26:36-37 'I can't do it, I don't want 'im to be like that' 4 yr old girl M26:43-47 I've seen this Down syndrome in Sainsburys' - boyfriend on phone and a friends who was 'normal ' M26:48 27:2 behaviours - she is told, can see 'they' are 'normal' – but it doesn't really help – other people tell other stories as if normal behaviour – _but its not normal_ –'a normal person wouldn't do that!' is she going mad!? M16:4-5 denial – 'I just saw 'im as normal' M24:17 can see she was in denial – she was treating him as' normal' _Miscellaneous:_ M23:4-6 _USA_ neighbour daughter, little older – _distance helps?_ & Friendship – Lindsay's 11 yr old son |
| **Development** | M4: 48 'major' diff bet sis in law's M5: 6-9 can't bear other baby takes over, he's older... M13:9 other child not walking until age 3 – horror M14:11 7 mths sitting up – important milestone – bouncy pram, did it in a week (15-16) M17:22-24 'put it to the back of yer mind' school etc M19:30 7 months, harder for her to be in denial if everyone knows M23:33-34 what all coffee morning babies were doing M25:18-20 is so slow – everyday its worse M24:21 '_I didn't even know the' walked later'_ at the time, didn't want help, couldn't see why |

## 'Post'-ANALYSIS

## **All emergent themes total list: 'score sheet'**

## Page 1

Themes belong to participant as highlighted in red

| OTHER | | COLIN | HANNAH | JONATHAN | MAGGIE |
|---|---|---|---|---|---|
| Forced to belong | | 00000 | 000 | | 00000 |
| Excluded | | 00000 | 00000 | | |
| Other - Lack shared understanding | | 00000 | 00000 | | 00000 |
| Other - Shared understanding | | 00000 | | 000 | 00 |
| Being same as | | 00000 | | 00000 | 00000 |
| Being different | | 00000 | 00000 | 00000 | 00000 |
| Identifying with other - 'type' | | 00000 | | 0000 | 00 |
| Who am I? - social position | | 00000 | 000 | | 0000 |
| Self portrayal - eg brave face | | 00000 | 00000 | | 000 |
| Other - Making comparisons | | 00000 | 00000 | 000 | 00000 |
| Other - impact of | | 00000 | 00000 | 00000 | 00000 |
| DISABILITY | | 00000 | 00000 | 00000 | 00000 |
| under spotlight' | | 00000 | | | 00000 |
| Bonding/closeness | | 00000 | | 00000 | 00000 |
| Distance | | 00000 | 00000 | | |
| Boundaries/settlement | | 00000 | | | |
| Comfort zones | | 00000 | 00000 | 00000 | 00000 |
| SELF | Relationship/proximity other | 00000 | 00000 | 00000 | 00000 |
| | Spouse | 00000 | 000 | 00000 | 000 |
| | we' | 00000 | 000 | 00000 | |
| | I' | 00000 | 00000 | 000 | 00000 |
| | Self portrayal | 00000 | 00000 | 00000 | 00000 |
| | Developing self | 00000 | 00000 | 00 | 0000 |
| | Feelings/emotions | 00000 | 00000 | 00 | 00000 |
| | reassurances | 00000 | 00000 | 00 | 00000 |
| | Loss of control | 00000 | 0 | 0000 | 000 |
| | Support | 00000 | 0 | 000 | 00000 |
| | Control | 00000 | 00000 | 0000 | 0000 |
| | Autonomy | 00000 | 00000 | 0000 | 00 |
| | Maleness'/female | 00000 | 00000 | 00000 | 00 |
| PARENT | Family | 00000 | 0000 | 00000 | 00000 |
| | TFGAs | 00000 | 00000 | 00000 | 00000 |
| | good parenting' | 00000 | 00000 | 00000 | 00000 |
| | job role | 00000 | 0000 | 00000 | 00000 |
| | hard work | 00000 | 00000 | 00 | 00 |
| | Information gathering | 00000 | 0000 | 00 | 0000 |
| | skill set | 00000 | 000 | 0 | 0 |
| LIFE | Life as 'story' | 00000 | | | |
| | Brench mark events | 00000 | 00000 | 00000 | 00000 |
| | Current | 00000 | 0000 | 00000 | 00000 |
| | Dream world | 00000 | 00 | | 0000 |
| | Hindsight | 00000 | 0 | | |
| | Past | 00000 | | | 000 |
| | Spending time with | 00000 | 0000 | 00000 | 0000 |
| | Normality | 00000 | 00000 | 00000 | 00000 |
| | Future | 00000 | 00000 | 000 | 00000 |

# APPENDIX 10

## 'Post'-ANALYSIS

### All emergent themes total list: 'score sheet'

Pages 2, 3 & 4

Themes belong to participant as highlighted in red

| MOTHERING | COLIN | HANNAH | JONATHAN | MAGGIE |
|---|---|---|---|---|
| Living experience | | 00000 | | |
| No reflection | | 00000 | | |
| Specific to being female | | 00000 | | 000 |
| Naturalistic | | 00000 | | |
| Wife | | 00000 | | |
| Image - looks & health | | 00000 | | 00000 |
| Comparison | 00000 | 00000 | 000 | 0000 |
| DISABILITY | 00000 | 00000 | 00000 | 00000 |
| Extraordinary | 00000 | 00000 | 00 | 00000 |
| Behaviours | 00000 | 00000 | 000 | 00000 |
| Change | 00000 | 00000 | 000 | 000 |
| Self | 00000 | 00000 | 00 | 00 |
| Understanding | 000 | 00000 | 00000 | |
| Matriarchal | | 00000 | | 0000 |
| Society | 00000 | 00000 | 00000 | 00000 |
| Other | 00000 | 00000 | 00 | 00000 |
| Exclusion | 00000 | 00000 | | |
| Practicalities | 000 | 00000 | 0000 | |
| Diplomacy & mediation | 000 | 00000 | 0 | 0 |
| Sacrifice | 000 | 00000 | | 000 |
| **EMOTION** | | | | |
| Control | 00000 | 00000 | 00000 | 00000 |
| No control | 00000 | 00000 | 00000 | |
| Physicality of emotion | 00000 | 00000 | 0 | 00000 |
| Pretence/normality | 00000 | 00000 | 0 | 00000 |
| Business - work as focus | 00000 | 00000 | 00000 | |
| Reality | 00000 | 00000 | 0 | 00000 |
| Other- impact | 00000 | 00000 | 00000 | 00000 |
| Emotional triggers | | 00000 | | 00000 |
| Future - fright | 000 | 00000 | 0 | 00000 |
| **Pressure** | 000 | 00000 | 00000 | 000 |

| DISABILITY | COLIN | HANNAH | JONATHAN | MAGGIE |
|---|---|---|---|---|
| Responsibility | 00000 | 00000 | 00000 | 00000 |
| Diagnosis | 0000 | 0000 | 00000 | 00000 |
| Diversity | 000 | | 00000 | |
| Pressures | 00000 | 00000 | 00000 | 00000 |
| Other | 00000 | 00000 | 00000 | 00000 |
| Professionals | 00000 | 00000 | 00000 | 00000 |
| | | | | |
| Detail | 00000 | | 00000 | 00000 |
| Conversation | 000 | 000 | 00000 | 00000 |
| | | | | |
| **FAMILY MAN** | | | | |
| Love, bonding | 00000 | 0000 | 00000 | 00000 |
| Family life | 00000 | 00000 | 00000 | 00000 |
| Spouse | 00000 | 000 | 00000 | 00 |
| Gran (significant other relationship) | | | 00000 | 00000 |
| Self | 00000 | 00000 | 00000 | 00000 |
| Father | 00000 | | 00000 | |
| Expectations | 00000 | 00000 | 00000 | 00000 |
| Involvement | 00000 | 00 | 00000 | 000 |
| TFGAs | 00000 | 00000 | 00000 | 00000 |
| Future -indifference | | | 00000 | |

| BEING A MOTHER | COLIN | HANNAH | JONATHAN | MAGGIE |
|---|---|---|---|---|
| Previous experience | 00 | 00000 | 00 | 00000 |
| TFGAs & Expectations | 00000 | 00000 | 00000 | 00000 |
| Other opinion | 0 | 00000 | 0 | 00000 |
| Support (or not) | 00000 | 00000 | 00000 | 00000 |
| Relationships | 00 | 00 | 00000 | 00000 |
| Other children | 00000 | 00000 | 00000 | 00000 |
| What she does | 00000 | 00000 | 00000 | 00000 |
| Single | | | | 00000 |
| **EMOTIONAL MOTHERING** | | | | |
| Pregnancy & instinct | | 00000 | | 00000 |
| First impressions | 00000 | 00000 | | 00000 |
| Doubt | 00000 | 00000 | 00 | 00000 |
| Reassurances | 00000 | 00000 | 00000 | 00000 |
| Emotions: | 00000 | 00000 | 00000 | 00000 |
| physicality | 00000 | 00000 | | 00000 |
| bluntness | 00000 | | | 00000 |
| Jealousy | | | | 00000 |
| Feelings towards baby: | | | | |
| *Guilt* | 00000 | 00000 | 0000 | 00000 |
| *Selfish* | | 00000 | | 00000 |
| *Burden* | 00000 | 00000 | | 00000 |
| *Worry* | 00000 | 00000 | | 00000 |
| *Uncertainty* | 00000 | 00000 | 00000 | 00000 |
| *Love* | 00000 | 00000 | 00000 | 00000 |
| *Pride* | | | 00000 | 00000 |
| Pretence | | 00000 | | 00000 |
| Denial | | | | 00000 |
| | | | | |
| **PHYSICALITY** | | 00000 | | 00000 |
| Development | 00000 | 00000 | 00000 | 00000 |
| Professionals | 00 | 00 | 00000 | 00000 |
| Knowledge | 000 | 00000 | 00 | 00000 |
| Unknown | 000 | 0000 | 00000 | 00000 |
| They' - incl. *'abnormality'* etc | 00000 | 00000 | | 00000 |
| Mediation | 000 | 00000 | | 00000 |
| Other | 00000 | 00000 | 0 | 00000 |
| Other mothers | 00000 | 0 | 000 | 00000 |

'Post'- ANALYSIS

## **All Participant Themes 'League Table' Development**

Colour coding added re: 'popularity' of theme ie black = most popular, red = least

**Analysis - Comparison Data 2**
**Development: Counting 'stars'!**

| 5* x 4 participants | 15* - 19 * | 10* - 14* | 6*-9* | 5* (single person) |
|---|---|---|---|---|
| *From Colin:* | No shared understanding | | | |
| Being different | Same as | Forced to belong | Hindsight (6 - 2p) | Boundaries |
| Impact of other | Comparing | Excluded | Past (8 - 2p) | Life a story |
| Disability | Bonding | Shared understanding | | |
| Comfort zones | Spouse | Identifying with 'type' | | |
| Relationships | I' | Self portrayal | | |
| Self portrayal | Developing self | Spotlight | | |
| Family | Feelings | Distance | | |
| TFGAs | Reassurances | we' | | |
| Good parenting | Control | Loss control | | |
| job role' | Autonomy | Support | | |
| Bench mark events | Job role | Hard work | | |
| Normality | Info gathering | Skill set | | |
| | Current | Dream world | | |
| | Spending time | Social position - who am I? | | |
| | Future | | | |
| | Maleness/female | | | |
| *From Hannah:* | | | | |
| Disability | Comparison | self | | living experience |
| Society | Extraordinary | Exclusion | specific to female | no reflection |
| Emotional control | Behaviours | Practicalities | | Naturalistic |
| Emotions: no control | Change | Diplomacy/mediation | | Wife |
| Impact of other | Understanding | Sacrifice | Matriarchal (9 - 2p) | |
| | Other | Emotional triggers | | |
| | Physicality of emot | Future fright | | |
| | Pretence/normality | | | |
| | Business/work | | | |
| | Reality | | | |
| | Pressure | Image, looks, health | | |
| *From Jonathan :* | | | | |
| Responsibility | Diagnosis | Significant other (gran) | | Future indifference |
| Pressures | Detail | Father | Diversity (8- 2p) | |
| Professionals | Conversation | | | |
| Family life | Love/bonding | | | |
| Self | Spouse | | | |
| Expectations | Involvement | | | |
| TFGAs | | | | |
| Other | | | | |
| *From Maggie :* | | | | |
| TFGAs & Expectations | Doubt | Previous experience | | Jealousy |
| Support (or not) | Physicality | Other opinion | | Denial |
| Other children | Guilt | Relationships | | Single |
| What she does | Burden | Pregnancy & instinct | | |
| Reassurances | Worry | Bluntness | | |
| Emotions | Unknown/knowled | Selfish | | |
| Uncertainty | They' | Pride | | |
| Love | Other | Pretence | | |
| Development | 1st impressions | Professionals | | |
| | other mums | Mediation | | |

## 'Post' - ANALYSIS

## <u>All Participant Themes 'League Table'</u>

ORGANISING THE DATA: 'COMPARISON ANALYSIS' in preparation for possible discussion topics

| Emotions | Normality | Disability | Relationships & 'Other' | Self | Good Parenting | Telling of experience | Pressures |
|---|---|---|---|---|---|---|---|
| Control | Expectations | Being different | Family | Portrayal | Job role | Benchmarks | Comfort zones |
| No control | TFGAs | Development | Impact of Other | 'I' | Responsibility | Conversation | Support (or not) |
| Love | Pretence | Professionals | Society | Developing self | Family life | Detail | Business/work |
| Uncertainty | Current | Behaviours | Comparing | 'who am I?' | Other children | Story | Reassurance |
| Physicality | Future / Fears / Indifference | Same as | Spouse / 'we' | Sacrifice | What s/he does | Living experience | Control Autonomy |
| Doubt | Change | 'They' | Lack of Understanding | Image | Bonding | No reflection | Control loss |
| Guilt | Reality | Physicality/looks/health | Understanding | | Spending time | | Forced to belong |
| Worry | Dreamworld | | Other parents | Bluntness | Info gathering | | Spotlight |
| Burden | | Diversity | Other opinion | Boundaries | Extraordinary | | |
| Feelings | | Denial | Excluded | | Involvement | | |
| Unknown | Previous experience | | Identifying with 'type' | Male/Female | 1st impressions | | |
| Triggers | Hindsight | | Distance | 'Mother' | Hard work | | |
| Fright | No reflection | | Diplomacy | 'Father' | Skill set | | |
| Selfish | | | Mediation | | Practicalities | | |
| Jealousy | | | Significant other (ie gran, mum) | Pregnancy & instinct | Pride | | |
| | | | | Matriarchal | | | |
| Denial | | | | Naturalistic | | | |
| (n.b. + list of many more, eg happy, upset etc) | | | | Wife | | | |
| | | | | Denial | | | |

- Each participant's key themes from their analysis were typed into a list; 4 lists were thus produced.
- Each participant experience was then 'graded' against each theme appearing on all 4 lists.
- A score of 1 to 5 stars was given against a theme depending upon relevance to their own 'case'; as such, an individual scored 5* against all the themes on their own list.
- These tables were then used to sort the data according to 'scores' which resulted in the 'league table' above graded by colour. *Please see key*

**KEY:** Where colours represent a 'sliding scale of interest' and thus, 'particularity' to themes

**Black Bold** = theme encompassing others, becoming 'title'

Black (incl. Black bold) = 20* (particular to all 4 participants)

Blue = 15* - 19* (particular to 3 or more participants) **Bold** = new header under same theme

Green = 10* - 14* (particular to 2 or more participants)

Orange = 6* -9* (particular to 2 participants)

Red = 5* (particular to single participant) *italic = placed under more than one column*