'Challenging the Status Quo'

Mothers of Children with Disability and their

Relationships with Professionals:

Counselling Psychology and its Social Justice Agenda

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I am also hugely indebted to the eight women who so generously donated their valuable time in order that the story might be told. I hope I have served you well.

I would like to make a special dedication to my children, who light up my world and afford me the wonder of being a mother.

And of course to my Mum & Dad- thank you for everything.

DECLARATION

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ABSTRACT

Family practitioners are increasing likely to engage with mothers whose child has a disability (The Common Assessment Framework, Department of Education and Skills, 2006). This Portfolio aims to uncover the dynamics that shape such relationships and to throw light on what needs to be addressed in order to achieve best outcomes. The first section presents an overview which briefly describes each section and identifies the various threads which interlink through them. The second section, the research component, explores how mothers of children with complex disabilities experience their relationships with professionals supporting them. The study describes the strengths and difficulties within these relationships as being influenced at personal, systemic and social levels and explores the implications of these findings with regard to Counselling Psychology. The third section is the clinical component and describes professional engagement with the mother bereaved of her disabled son. This piece reflects on the use of Person Centred Counselling in supporting her to restructure her identity as she copes with her loss. The final section, the commentary piece, sets the research findings into a broader conceptualisation of social injustice, oppression and disempowerment and calls on British Counselling Psychology to renew its appreciation and involvement in social issues.

SECTION A

Introduction to the Portfolio

1   Overview of Section

The first section presents an exploratory piece of research focusing on the relationships between mothers of children with complex disability and the professionals engaged to support them. Secondly, a case study describes Person Centred Therapy with a mother unexpectedly bereaved of her disabled son. Finally, a critical literature review extends the findings of the research into a broader arena and explores social justice issues as a Counselling Psychology concern. It is hoped that this portfolio will increase awareness of the experience of mothers with disabled children, draw attention to the ways in which the world around them shapes and characterises such experiences at all levels and how Counselling Psychology can mediate understanding and improvements.

2   The Research

This section comprises of an original piece of qualitative research designed to explore how mothers of children with complex disability understand and experience their relationships with professionals. The study was undertaken in order to capture the mothers' point of view and involves semi-structured interviews with a homogenous sample of eight women. The data is analysed using Interpretative Phenomenological Analysis (IPA). Outcomes suggest a bi-linear view of the relationship is flawed and illuminates strong personal, systemic and social influences within the dynamic. The analysis also generates themes that exemplify such processes and reveals how the mothers' experience of such relationship proves transformational. A model generated from the findings is produced in the hope that this may be utilised to address philosophies and practices that contribute to the struggles many mothers have when dealing with professionals. The capability and opportunities for Counselling Psychology to be involved in the process of such change is also discussed as are the implications for future research.

3 Professional Practice

The aim of the client study is three-fold. Firstly, it is intended to spotlight my own experience of working as a professional with a mother of a child with disability. Secondly, it is hoped that by describing Jenny's struggle with a sense of fractured identity and purpose following the death of George, I can demonstrate something of the personal and contextual circumstance from which these women come to professional relationships. I also wanted this section to offer a contrast to the nature of many relationships described in the research section. For example it showcases the usefulness of the strong therapeutic alliance of Person Centred Therapy and considers the disempowerment of the professional, again as a foil to the personal, systemic and social understandings of expertise and authority unveiled in the previous section.

4 Critical Literature Review

The research generated a model that incorporates social discourses and systems that are played out in the interpersonal, serving to silence and constrain the mother in her efforts to achieve what she feels her child needs. The relationship is therefore depicted as being grounded in society and not immune to its influences. Many of the difficulties and struggles the mothers describe can be viewed as arising from social narratives on, for example, mothering and disability which contrast sharply with those on expertise and health capital. The critical literature review is based on the premise that the experiences of the mothers in the study maps onto that of many others who individually struggle against the disempowerment of excluding and marginalising social discourses. It outlines the consequences of injustice on well being and draws on models of social justice to explore how these might be remedied. A major part of the section is given over to how the philosophical underpinnings of counselling psychology lend themselves to both personally supporting those contending with injustice as well as addressing the presence of such injustices within society itself. The literature is used to highlight reasons why this has not happened to any great extent in the UK and how we might utilise the American experience in our endeavours to re-establish the links between the personal and the social in the practice and philosophies of Counselling Psychology.

5 Reflective Threads and Personal Experiences.

When the idea of the research first came to me thirty six years ago, I was an eighteen year old trainee teacher, incensed by the treatment of parents with children with disabilities- a sense of anger at what I now recognise to be social injustice. The notion of injustice runs throughout the portfolio, through the women's experiences of professional relationships, the loss of a much loved child which unravels a life built around his specific needs and through the challenge to Counselling Psychology to pick up the mantle and address social injustice as a major contaminant in mental health and emotional well being.

A further link is the desire not to accept the status quo that provides such injustice. The research suggests, for example, that he mothers are transformed in their ability to understand what it is their child needs, to manage their struggle to get it and to challenge when they sense unfair treatment or responses. They create new frontiers in crossing the boundaries from the personal to the social environment, blazing a path of change that will support their child and others like them. So also does Jenny come to understand life after George and, driven by the motivation to self actualise, she picks up the pieces in order to regenerate who and what she wants to be. Neither can Counselling Psychology be immune from the challenge. Instead, the literature review calls for our professional community to once again get a fire in its belly in order to fulfil the promise and mission it was built upon and really make a difference in the world. I hope the model and the sections within the portfolio itself will, in their dissemination, draw attention to the bigger picture and encourage readers to reflect and challenge where they see injustice particularly in relation to need and helping.

Themes of power and disempowerment also draw the sections together. My eighteen year old self felt shamed by the treatment I witnessed and read about and lamented both the parents and my own powerlessness in changing hearts and minds. Disappointingly, while I might have hoped that almost four decades would have resulted in change, the research clearly demonstrates how social discourses, personal attitudes and systemic practices all serve to bestow and withhold power in relation to the mother and professional. In contrast, the client study depicts the powerlessness of the expert

therapist and how this was demonstrated through empathy, genuineness and unconditional regard of the client's experience. The work shows how this built on the psychological connectedness of two people and strengthened their therapeutic alliance rather than unravelled it. Finally, the literature review demonstrates the allocation of power capital and its consequences in society. It suggests social justice work can generate the empowerment of communities and that Counselling Psychology could take the lead. However, more deeply, it also depicts how in America, the move to social justice work, is recognised as having the potential to create a two tier profession with those who promote social justice endowed with accolades of generosity of spirit that establish personal and professional power and reduce communities to the status of the helped. Back in Britain, the review suggests the emerging professional, social and economic power of Counselling Psychologists is something which, in essence, may effectively reduce their ability and motivation to build on the inclusive, socially based approach that is seen as the unique strengths of the discipline.

The portfolio is also about identity and how fractures in identity can become something of a catalyst in personal development and growth. My own mothering of a child with disabilities unveiled much more of the personal challenges and tensions such parenting generates and gave an understanding never before available to me as the professional. In the research piece, attention is drawn to how the mothers struggle with approaches that stem from models that undermine their mothering and represent their child as deficient and flawed. Again, the client study outlines Jenny's journey towards renewing her identity as a mother after George. Similarly, the literature review calls on Counselling Psychology to recharge itself and to rediscover the separate identity it fought so hard to establish against the tide of clinical and psychiatric understanding.

The portfolio also represents the development of my own identity as mother, researcher, family practitioner and Counselling Psychologist. While fulfilling a life time's ambition to get the voices of mothers of children with disability out there, in its development, I too, have learned much about myself and my work. It is a sobering thought that I may have come to the task thinking I knew more than most about the experiences of these mothers and yet, having had the time to truly listen, I come away with incredible new insights and meanings. Working with Jenny also taught me much about my role as a therapist and brought a new, dynamic understanding of the person centred approach I

prefer. Researching and writing the critical literature review has had an incredible impact. I have been refreshed with a rekindled passion for helping and afforded a deeper understanding and confidence of what being a Counselling Psychologist should mean in my life.

SECTION B

The Research Component

Mothers of children with complex disabilities and their relationships with the professionals who support them.

Supervised by Dr. Deborah Rafalin

ABSTRACT

This research is designed to illuminate the meaning mothers of children with disability attach to their experiences of professional relationships. While there is evidence relating to the elements that shape the dynamics and outcomes of such relationships, there is a dearth of information about how the women themselves experience and bring meaning to them. Semi-structured interviews gave voice to eight mothers who had a child whose complex disabilities resulted in professional involvement. The ensuing data was analysed using Interpretative Phenomenological Analysis (IPA) and gave way to four superordinate themes; Expertise and Empathy, Power and Disempowerment, Challenge and Conflict, Time and Transformation. A model was then generated to capture these findings. The evidence suggests the mothers view relationships with professionals as part of their motherwork and understand them against a backdrop of satisfying the needs of their child. The mothers' experience offers further evidence of the struggle against power capital imbalances generated by notions of expertise and need within helping relationships and systems, exposing a more complex dynamic than current models might suggest. Vital to these findings is the mothers' experience of challenging the status quo, with their narratives highlighting how they utilise and acquire strategies, skills and knowledge in order to balance their position and achieve their aims. The process of relating to professionals appears to be transformative in terms of their understanding of themselves, expertise and their motherwork. The implications of these findings are examined in terms of how they might inform and influence current practice and be utilised in ways which could support mothers involved in professional relationships. All of which will ultimately support the child also. It is proposed that Counselling Psychologists are particularly well placed to support the process of change and development. Further areas of research including that with fathers, children and the professionals themselves are also discussed with a view to broadening and deepening the understanding generated within this study.

CHAPTER 1

THE INTRODUCTION

1.1 OVERVIEW

This chapter introduces the study and explores areas of the literature pertinent to the question. These include theories of mothering and disability, research specific to the personal experiences of mothers of children with disabilities and what they do in their mothering practice. The chapter will also consider constructs around the professional relationship and the social and interpersonal elements that impact upon it. The review is followed by a summary of findings which lead to the rationale and aims of the present study.

1.2 PERSONAL STATEMENT

The restrictions inherent in the nature and extent of this volume disallows the breadth and depth of analysis deserving of the topics included and indeed, to those omitted. I recognise that other readers may have drawn different conclusions from the literature examined in the review, whilst still others may have considered alternative issues and studies to be more relevant than those I have chosen. Further, my own cultural background and understanding will mean I come to the study with a very specific view of mothering as experienced within the United Kingdom.

While I have aimed to explain my choices and interpretations throughout the chapter, it feels important nevertheless, to immediately 'set out my stall' in terms of the beliefs and values I hold in relation to the topics highlighted. This will allow the reader to be more aware of any pre-existing influences that may have shaped what was included, the interpretations and critiques presented and the conclusions drawn from them.

1.2.1 MOTHERING

Hays (1996) suggests 'we all know something about mothering .... or at least we think we know' (p.*ix*, italics original). And so it is with me. I have a mother, am a mother, have experience of others' mothering and now have academic learning about mothering. I therefore come to the review with distinct expectations, assumptions and meanings around motherhood.   For example, my real world experience and critical realist perspective mean I acknowledge all influences; biological, psychological, social, cultural and economic, upon the mothering experience (Bhasker & Danermark, 2006). I therefore agree with Smart (2002) who declares that motherhood presents itself as biological and that the emotional bond between mother and child is built upon such processes. This accommodates my belief in maternal instinct and knowing. However, I also acknowledge that our modern age means such biological events are not only experienced in private domesticity but are acted out in an influential global social stage (Miller, 2005).

I believe that although a female dominated activity, motherhood is shaped by the historical, economic, political and philosophical influences of a patriarchal society that disguises the power women could have in the world. As Rich (1976) declares "We do not think of the power stolen from us and the power withheld from us in the name of the institution of motherhood" (p275).   I also recognise women are socialised in anticipation of motherhood and the experience of formidable social pressure to conform and perform means mothers believe they are the 'critical players', and view dissent or exposure of difficulties as too socially 'risky' and to this end, will often hold a self regulating silence in their behaviour and thought (Miller, 2005, p64).

I also judge that although ascribed with particular language and imagery, mothering cannot be seen as a universal experience (Arendell, 2000; Kinser, 2010) and celebrate a growing understanding of how personality, race, class and culture intersect to contour the individual meaning given to the highly complicated and often contradictory dimensions of motherhood (Douglas & Michaels, 2005).

1.2.2 DISABILITY

Smart (2009) suggests that the model of disability adhered to by a practitioner will influence much of the work they do. It is important then to set out my stall in relation to my views on disability. I have worked with people with disabilities of various types for nearly 40 years. Times and attitudes, ways and means of helping have changed and my own understandings and practices have reflected that. However, from an initial B.Ed. in 'Retardation' to my current consultant's post leading Learning Disabilities Community Teams, I have had an acute sense that those with disabilities and the families supporting them suffer social injustice and oppression (My personal reflections on my motivations for the study at the end of the introduction offers further details of the origins of such beliefs).

I recognise the power that social discourses and models of disability wield over all levels of individual life experience and in the shaping of services, attitudes and opportunities (Williams, Copestake, Eversley & Stafford, 2008). I believe models that are entrenched solely in a bio/medical or social paradigm have failed to generate authentic narratives of the disabled person's experience nor have they produced a universal responsibility towards reducing their exclusion and disempowerment (Williams et al., 2008). I now look towards Social Justice (Morris, 2011) and Capability Models (Mitre, 2006) which reflect the nature of the differences between functional and potential disablement and highlight the impact of the intersectioning of personal, environmental and social factors in the lived experience of disabled people in our community (Thomas, 2004). Underpinning such models is the Alliance paradigm (Brett, 2002; Swain & French, 2000) which emphasises a communicative and problem solving approach. I actively promote such understandings as part of my personal and professional commitment to both Counselling Psychology and people with learning disabilities and have no doubt these beliefs will have influenced the nature of my research.

1.3   FOREWORD

It could be said that theories of motherhood and mothering have existed since the earliest of times and that throughout history those in diverse contexts such as religious,

philosophical, psychological and social arenas feel able to counsel and dictate (O'Reilly 2010). This space could not possibly allow adequate examination of the vast emerging literature. I have therefore chosen to consider maternity by contextualising the mothers' experiences through biological, social construct and feminist theories. These I believe give an overview of the journey to current understanding of motherhood, fit my critical realist perspective and allow sufficient breadth of thought for the reader. Other theories such as Role Attainment for example, (Mercer, 2004) are not discussed in depth as these tend to focus on how women achieve within the institution of motherhood and often represent a patriarchal narrative that reduces the agency of mothers and neglects their subjective experience (Green, 2004).

The review will also consider the particular nature of the participants' situation as mothers of children with complex disability and explore current conceptualisation of the nature of the mother-professional relationship. It is hoped that the examination of the literature will position this research and support extrapolations made of it.

1.4 THEORY OF MOTHERING AND MOTHERHOOD

While their philosophical and intellectual understandings might differ, theorists commonly agree that becoming a mother simultaneously leads to a redefinition of the woman's identity (Maushart, 2000). This identity is recognised within a disparate social group with economic, legal and cultural meanings and particular 'mother' roles, behaviours and attitudes (Kinser, 2010). Moreover, mothers in the modern world must deal with often competing social and cultural scripts (Douglas & Michaels, 2005). Thus according to O'Reilly (2010), we need to attend to *motherhood,* understood in terms of the social institution of maternity, to *mothering,* seen as the experience and practices mothers meet as they conform or resist such institutional narratives and finally, *identity,* which incorporates the personal, subjective sense of oneself as a mother. This section will briefly outline the core assumptions of three dominant models that pertain to the topic.

1.4.1 THE BIOLOGICAL MODEL

Those who view mothering through a biological lens assume that motherhood is an evolutionary imperative and that women are destined to be mothers and will only be truly fulfilled in having children (Miller, 2005).   Thus womanhood becomes inextricably linked to having children and the femininity of individuals weighed against it (Choi, Henshaw, Baker & Tree, 2005).   It follows logically that only females can mother (Doucet, 2006).   Further, from this perspective, mothering becomes a 'natural' pre-programmed activity; one that is designed to respond in harmony with the child's needs and equip the woman to provide through instinctive ways of knowing (Bowlby, 1973;   Blaffer-Hrdy, 2000; Winnicott, 1963).   Not being able to access this innate ability to nurture is seen as damaging for the child and often cited as the reason for psychological difficulties in adulthood (Weich, Patterson, Shaw & Stewart-Brown, 2009). Such assumptions underpin Psychoanalytical perceptions of mothering (Doane & Hodges, 1992; Stone, 2012).

The potential for harm means mothering is viewed in terms of quality and ability (Gerhardt, 2004; Krane & Davies, 2007).   A good mother demonstrates her natural skill and unconditional love; anything else is seen as failing (Goodwin & Huppatz, 2010). Thus ideologies based on the biological nature of maternity depict motherhood as an instinctive, gendered motivation to produce children and raise them into adulthood (Thornhill & Gangestad, 2009).

1.4.2 THE SOCIAL CONSTRUCTION MODEL

Although dissenting voices were raised in the early decades of the 20th century, it was not until mid way through that the biological, determinist models were more robustly challenged by those who attended more to the psycho-social elements of motherhood (Arendell, 2000).   Thus embedded within a much wider sociological and psychological exploration, questions were asked about how cultural ideologies, social structures, conventions and institutional values not only shaped and evaluated mothering but also influenced the position women in society (Hanisch, 1969) gendered behaviour and life choices (West & Zimmerman, 1987). Researchers have looked across societies and

noted culturally led variation in child rearing practices and family construction (Georgas, Berry, von de Vijver, Kagitcibasi & Poortinga, 2006).

This generates an alternative narrative suggesting mothering and motherhood are less about instinctive, biologically driven behaviours and more about the social construction of economically and politically motivated, engendered systems that allowed for the production and care of future citizens (Dinnerstein, 1977, p33 – 34; Kinser, 2010). New models moved away from the primacy of female responsibility towards a greater role for both co-carers and community (Rich, 1976). It is from this post modern, feminist constructionism that contemporary research, theory and debate around motherhood is generated (Arendell, 2000; Coontz, 1992).

1.4.3 THE FEMINIST MODEL

Feminist approaches have produced diverse and often conflicting views on motherhood (Kinser, 2010, p6), developing from dualistic theories of male domination (Dinnerstein, 1987) to understanding mothering as power (Rich, 1976), but at their collective core however is the premise that whilst biology affords women the ability to give birth to children it should not predetermine the role they play and the responsibilities they take in relation to them (Chase & Rogers, 2001). Feminism views the gendered nature of mothering and the social constructs that pertain to it as a means of oppressing women and controlling the influence they have in society (Badinter, 2013). Mothering is seen as hugely undervalued both because of the subordinate position generally held by women (Silva, 2002) and because of the commercial and productivity ethos of dominant capitalist systems within which it occurs (Mies, 1999).

Further, the social act of mothering is seen as perpetuating its own existence in the morality attached to 'good' or 'bad' mothering which serves to silence mothers who might depict a less than perfect experience (Goodwin & Huppatz, 2010). Arendell (2000, p1194) draws attention to how the power of such judgements also impact on feminist activism and research. Clews (2001) suggests we have finally arrived at the stage of maternal text whereby the woman speaks about her own experiences rather than have them spoken about by others. Those supporting such theories call for a complete

reappraisal of theory on mothering and motherhood; a new understanding based on the experiences of women themselves (Douglas & Michaels, 2005).

1.5   BEING A MOTHER

Ruddick (1995) believes mothering comprises of three responsibilities that ensure preservation, growth and social acceptability. Thus mothering is not seen as just satisfying the child's physical and emotional needs and developing their intellectual and emotional growth; it is seen as providing a bridge between them and society (Leyendecker, Lamb, Harwood & Schölmerich, 2013). This is viewed as a two way process whereupon the mother teaches appropriate morals and values and, through social networking and negotiating, generates a place in society for them (Hansen, 2005). All three aspects are seen to be practiced throughout childhood, although taking different forms at different stages of the child's life (Francis-Connolly, 2000).

Rich (1976) suggests the ''physical and psychic weight of responsibility on the woman with children is by far the heaviest of social burdens'' and that ''it is she, finally, who is held accountable for her children's health, the clothes they wear, their behaviour at school, their intelligence and general development'' (p29). It is, therefore, perhaps not surprising that mothering is often associated with poor psychological well-being (Rizzo, Schiffrin & Liss, 2013) and many dialectical tensions of empowerment and oppression (Badinter, 2013), of intense delight and ambivalence (Almond, 2011), of personal growth and isolation, and interpersonal and economic stress (Crittenden, 2010).

Mothering it would seem carries extensive, complex emotional content far beyond the performance of tasks. Further such content is dynamic and variable depending upon a myriad of personal, child and temporally related pleasures and frustrations such as ill health, paid employment, poor social and partner support or limited finances (Cassiman, 2011; Hayes, 2008; Nomaguchi & Brown, 2011) with depression levels in under resourced mothers estimated at twice those of mothers having sufficient resources (Goodman, 2007; Targosz et al., 2003). Mothering cannot therefore be constructed as a unitary experience for individual women nor one that is experienced similarly by all women. Instead, it carries multiple and often shifting meanings shaped within a

personal, social, political and economic framework (Bell, 2004). Mothering practices are therefore considered pluralistic and are reframed as mother work to accommodate their diversity (Taylor, 2011).

1.5.1 MOTHERHOOD

Contemporary theorists also consider public discourse around the social institution of motherhood and how that impacts on mothers' expectations and experiences of mothering. They suggest that the understanding of motherhood is neither universally shared nor even stable within cultures as both society and mothering contexts change and evolve (O'Reilly, 2010). Twenty first century women for example, are more likely to be single mothers, to work outside the home and to mother in reconstituted, blended families (Hadfield, Rudoe & Sanderson-Mann, 2007). Women are now more likely to be older when they have their first child, to have fewer children and to conceive through assisted reproduction techniques (Mamo, 2007).

While society's presumption and portrayal of motherhood may have adjusted somewhat to accept these demographic and communal changes, on the whole it continues to champion entrenched notions of the ideal middle-class nuclear family (Johnston & Swanson, 2003) and to depict the caring, accomplished mother of a healthy happy baby, albeit now as one with a successful career and a beautiful post baby body (Jordon, Capdevila & Johnson, 2005). Such constructions, as well as being unattainable for many women, also prove contradictory. For example, current political support for parenting programmes (Lindsay et al., 2011) that value quality time with children conflicts with the policy to deny benefits to 'stay-at-home' mothers (Lyons, 2013). The media too offers a fluid value base in, for example, simultaneously denigrating one single mother for having too many children (Simpson, 2013) while celebrating another with television stardom (Hayez, 2007). Such duplicitous messages can be seen as the interplay of biological, constructionist and feminist scripts with the social realities of race, class and culture in the social positioning of mothers and suggests that the understanding and expectations of mothers within one society may be as differentiated as it is between societies.

Notwithstanding their own conflicting ideological contributions (Nathanson, 2008), feminists argue that women continue to internalize particular social expectations of motherhood and depict mothering as a moral minefield of motherhood (Miller, 2005) that challenges the female sense of self and agency (Belenky, Clinchy, Goldberger & Tarule, 1997). They suggest the contextual personalization of modern mothers, who simultaneously inhabit conflicting identities of woman, worker and mother in diverse contexts and with varied demands (Hansen, 2005; Hochschild, 1997), serves to generate a disparate understanding of motherhood even amongst mothers themselves. This, they believe, provides the need for alternative narratives of mothering experience that challenge the ways of knowing that are currently privileged in society (Kinser, 2010).

One of those disparate narratives comes from the mothers of children with disabilities who sit at the interface of discourses and ideologies not only around mothering and motherhood, but disability and ableism also.

1.6 MOTHERS OF CHILDREN WITH DISABILITY

This section is designed to consider the literature in relation to the social understanding and personal experience of mothering a child with disability. It will begin by reviewing models of disability before considering a number of models used to conceptualise this particular mothering experience.

1.6.1 MODELS OF DISABILITY

Traditional conceptualisations of disability have evolved around a 'deficit model' (Barnes, Thomas, French & Swain, 2004, p80; Ryan & Runswick-Cole, 2008a; Smith, 2006) where any societal difficulties or limitations are seen as the consequence of the impairment which needs to be overcome or 'fixed' for the person to be integrated into the community (Barnes et al., 2004, p43).   Thus it has become simultaneously represented as the 'medical model' whereby cures and interventions are sought not only to alleviate distressing symptoms but to improve the person's social integration. Such tenets are considered to reduce people with disabilities to lesser citizens and generate judgments around their potential and worth (Read, 2000).

This has, to a great extent, been replaced by a social-political model which identifies that it is society's discriminatory practices and restrictive environments, external to the disabled person that reduce that their capability and impose barriers to their inclusion (Carson, 2009; Case, 2001). This was viewed as the further disablement of the person (The Union of the Physically Impaired Against Segregation & The Disability Alliance, 1975, pg 14). Thus the model re-casts disability as a societal concern, calling for individual and collective responsibility to reduce such obstacles, thus shifting the debate away from medically dominated agendas that place the problem upon the disabled individual (Chappell, Goodley & Lawthom, 2001).

Although widely supported and used to shape policy and practice, the social model has attracted criticism from those who suggest any changes in environment and opportunity continue to be underpinned by the medical model. They argue this means that despite equality and diversity now being integral to political and legislative systems, people with disabilities continue to experience difficulties and restrictions in society (Carson 2009). Further, protagonists propose that the removal of all physical and systemic obstacles is not enough for real inclusion and point towards a shared social conscience of pity, distain and fear (Shakespeare 1994). They submit that those with disability are still frequently viewed as less worthy, problematic and often burdensome to society and that changes in processes and environments are seen as concessions rather than entitlements. (Brett, 2002; Scullion, 2010).

Such minded campaigners aspire to an Alliance Model (Brett, 2002) underpinned by a Capability approach (Kuno, 2012). This model depicts the conceptualisation of disability as founded in any given society's historical, cultural and economic influences (Kuno, 2012). How disabled people experience their lives is therefore framed by the psychosocial mind set as played out at the intra-psychic, interpersonal, organisational and societal levels (Barnes et al, 2004). Proponents of the model seek to show that the negative perception of disability generate emotional and psychological barriers, meaning the equality and inclusion of people with disabilities cannot solely be achieved by measures such as adapting stairs or introducing employment laws (Brantlinger, 2001). They believe oppression and discrimination will not be remedied until the non disabled community views them as worthy of inclusion. Activists see the issue as a social justice concern and call for disability to be re cast as a cultural concern, in the

same way as gender and colour have been in recent decades (Brantlinger 2001). The argument then moves from the person being fixed, beyond society's responsibility to accommodate their difficulty towards discussions about valuing diversity and achieving equality and citizenship (Chappell, Goodley & Lawthom, 2001).

The Alliance Model purports that such discussions must focus on what people think about and feel toward, those with disabilities and the disabled person's actual experience of it. Thus the model has an added value in that it also offers greater voice to those with disability, allowing more authentic experiential narratives that identify ableist attitudes and processes (Goodley & Tregaskis, 2006). In utilising a capability approach that facilitates at both individual and systems level (Sen, 2010, pg231), the Alliance model allows for both differentiation of experience and support for those who have disabilities (Kuno 2012) **and** the promotion of learning and recognition among those who do not.

It is against a background of such perceptions, constructs and arguments that a woman welcomes a disabled child into the world.

1.6.2 MODELS OF MATERNAL RESPONSE TO A CHILD'S DISABILITY

The models of disability outlined above further influence and shape the constructs used to explain the experience of mothering a child with disabilities. Since such understandings will be utilised in the generation of research aims, questions, methods and processes, it feels important to briefly describe the major ensuing paradigms before reviewing the literature. The section will then focus on the literature generated through the stress and coping and growth paradigms as these offer contrasting perspectives.

1.6.2.1   GRIEF AND TRAUMA MODELS

It is perhaps not surprising, given the negative connotations attached to disability, that one of the most dominant narratives around the birth of a baby with disabilities is that of a tragic catastrophe (Rogers, 2007) involving pathological maternal response

(McKeever & Miller, 2004; Todd & Jones, 2003). The mother's situation is presented as a challenging and often destructive emotional journey through stages of shock, sadness, denial, adaptation and acceptance (Fitzpatrick & Dowling, 2007; Nelson, 2002; Roll-Pettersson, 2001). The model reflects much in the literature on grief and it is in this way that observations about mothers of children with disability are often made (Carpenter, 2000). Other researchers, including those who are mothers to children with disabilities themselves (Brett, 2002; Lawson, 2004; Ryan & Runswick-Cole, 2008b; Harnett, Tierney & Guerin, 2009) have suggested that those who deal with maternity and paediatrics tend to align to such views, evident in, for example, practitioner reluctance to disclose disability and the use of the 'tragic talk' when they do (Huang, Kellett & St John, 2010).

Others conceptualise mothers' response as dealing with a personal trauma. They utilise theories such as Janoff-Bulman (2002) who suggests we hold protective assumptions of a benevolent world, a meaningful life and that we ourselves are sufficiently worthy to experience only good things. Events that undermine these beliefs, such as giving birth unexpectedly to a baby with disabilities, attack the assumptive world, undermining our sense of self efficacy and stability causing trauma. Thus shock and difficulty in accepting a challenging situation, if managed appropriately, is viewed as a 'normal' protective response rather than a pathological reaction (Bruce & Schultz, 2002).

Many researchers applying grief, loss and trauma theory subscribe to social discourse and feminist arguments that hypothesize women are socialised into the view that motherhood will bring meaning and fulfilment to their lives and that raising a child is their claim to happiness (Graungaard & Skov, 2007). The loss of the idealised child undermines this, resulting in them being stripped of their hopes and dreams (Graungaard & Skov, 2007). Rogers (2007) and Gray (2002) further suggest women come to motherhood with internalised norms not only of what a good mother is (Goodwin & Huppatz, 2010) but with a social pressure to produce the perfect baby (Jordon et al., 2005). In not doing so she experiences a disrupted biography that generates a fractured intrapersonal and social identity as a mother and a woman (Huang et al., 2010). Douglas & Michaels (2005, p11 - 13) believe such views are increasingly reinforced by current interest in successful and celebrity mothers franchised by the media.

1.6.2.2   SOCIAL COST MODELS

The notion that the mother's experience is socially shaped is also part of models based on social cost. One suggestion is that a disabled baby fractures both personal and social understanding and acceptance of the woman's identity as a mother. For example, Social Identification Theory (Tajfel & Turner, 1979) postulates that members of society will group together according to the characteristics they value and share. Internalising the defining features of the group to which we attach and those to which we do not, contributes to our understanding of ourselves and generates our social identity (Tajfel & Turner, 1979). Women who give birth to disabled babies then, may not be easily categorised since, while they are mothers, their children do not fulfil normative expectations, for example in reaching developmental stages and their mothering practices, such as tube feeding, may appear quite foreign (Blum, 2007; Kirk & Glendinning, 2004).

Goffman (1963) suggests adverse reactions to the negatively evaluated difference overshadow all other characteristics resulting in the individual being stigmatised and seen as separate. Beyond being excluded from the mother 'in group' because their practices are different, having a baby with disabilities may also carry negative meanings for other mothers in that it represents things going wrong (Huang et al., 2010). Barnes (1996), for example, suggests that since society highly values health, beauty and independence, people with disabilities are stigmatised as the bearers of negatively valued traits. Faced with these traits, others often feel awkward, anxious or sad and may react in a variety of ways to compensate for their discomfort (Gray, 2002; Green, Davis, Karshmer, Marsh & Straight, 2005).

Green (2003), in applying Modified Labelling Theory (Link, Cullen, Struening, Shrout & Dohrenwend, 1989), argues that mothers recognise the social cost of disability through their own social learning that allows them to view the child as an 'outsider'. She shows that maternal perceptions that individuals with disabilities are devalued and discriminated correlated with their increased distress. Further, her research suggests mothers believe they, and the wider family, can also be stigmatised by the child's disability, supporting Goffman's edict that stigma also affects the experiences of those

appended to individuals in possession of the stigmatizing characteristic (see also Brett, 2002; Green et al., 2005).

1.6.2.3 RESOURCE MODELS

Resource models contend that the poor mental and physical well being attached to parenting a child with disabilities (Britner, Morog, Pianta & Marvin, 2003; Eisenhower, Baker & Blacher, 2005; Song & Singer, 2006) is not due to their sense of loss, trauma or social stigma but rather a heightened sense of an actual or perceived inability to cope (Bruce & Schultz, 2002). It is argued that while many women may lack confidence and suffer anxiety around their mothering (Craib, 1994; Douglas & Michaels, 2005), the experience of those having a child with disabilities may be even more pronounced as they recognise the map previously imagined for their parenting journey is now redundant before another, more appropriate one, becomes available (Rogers, 2007).

Resource models have often been built on a stress and coping paradigm which emphasises the burden of having a child with disabilities (Van Riper, 2007). Recently, however, there has been a move away from a focus of the difficulties toward generating theories as to why some families have better outcomes than others. This has given way to research that utilises transactional models (Quine & Pahl, 1991) to highlight the importance of various influences such as personal and support resources, the nature of the disability and the family context to capacity and resilience (McCubbin & Patterson, 1983). Such models challenge deterministic and predictive models and espouse more fluid, contextualised and socially embedded outcomes to mothering of a child with disability.

1. 6.2.4   GROWTH MODELS

Growth approaches build on the notion of loss, capacity and resilience and posit that the ability to generate meaning, control and order from adverse experience results in positive transformational, growth enhancing change (Tedeschi & Calhoun, 2004). It is proposed that negative events impact on self –perception, interpersonal relationships and philosophy of life, but in altering established values and beliefs and positively

reconstruing events, the individual resists damage and can draw strength and existential meaning from the experience (Morris, Shakespeare-Finch, Rieck, & Newbery, 2005; Oulton & Heyman, 2009). The application of such models allows research questions previously underpinned by the grief, cost and stress models to be replaced by those which recognise that despite emotional, social and resource challenges, most mothers become accomplished and loving carers of their disabled child (Skinner, Bailey, Correa & Rodriguez, 1999), that families are able to accommodate them successfully (Van Riper, 2007) and will be able to identify many benefits in having them (Bruce & Schultz, 2002; Ferguson, 2001).

1.6.3 RESEARCH PARADIGMS

Two particular areas of the literature will now be discussed in depth. This is designed to to provide an overview of the spectrum of thought around the topic of maternal response to the birth and mothering of a disabled child.

1.6.3.1 BURDEN, STRESS AND COPING

Studies show more stress and poorer emotional well being in parents of children with disabilities than in those parenting a typically developing child (Britner et al., 2003; Eisenhower et al., 2005; Song & Singer, 2006). Further, such evidence often supports the notion that motherhood carries more risks to well being risks than does being a father. For example, mothers are shown to experience greater stress (Rezendes & Scarpa, 2011), depression (Bailey, Golden, Roberts & Ford, 2007), pessimism (Little, 2002) and anxiety (Pelchat et al., 1999) than fathers within the same studies. Gray (2003) suggests this may be explained by a more direct impact on mothers, who feel they disproportionally provide care, relinquish employment and manage most of the medical and professional appointments, whilst fathers in his study were stressed by reduced personal time with their spouse, greater financial demands and fewer opportunities for socialising.

Other work would seem to indicate a correlation between the presentation of the child's disability and the nature and levels of stress experienced by the mother (Head &

Abbeduto, 2007). Dabrowska & Pisula (2010), for example, found that mothers of children diagnosed with autism had higher stress levels not only of mothers of typically developing children but also higher than those mothers of children with Down Syndrome. Spratt, Saylor & Macias (2007) and Hastings (2002) report maternal stress levels correlated with the presence of both behaviour and cognitive difficulties. However, not all studies concur, with Britner et al (2003) and Cavallo, Feldman, Swaine & Meshefedjian (2009), for example, finding no correlation between severity of the presentation of Cerebral Palsy and the mother's emotional well being.

Unsurprisingly perhaps, studies also mirror the gender differences in coping identified in the broader literature (Taylor, 2006), with mothers utilising more emotionally based coping strategies than fathers. Seeking support in their spouse (Van der Veek, Kraaij & Garnefski, 2009), family (Twoy, Connolly & Novak, 2007), through support groups (Hill & Rose, 2009; Solomon, Pistrang & Barker, 2001), and accessing framed educational and coaching approaches (Harnett et al., 2009; Todd et al., 2010) are shown to reduce stress and improve coping skills (Hastings & Beck, 2004). Somewhat against expectations, Macdonald, Fitzsimons and Walsh (2006) found mothers used problem solving strategies more than fathers, who in turn used more meaning making strategies. Long & Kahn (1993) suggest women are much more likely to use problem solving in a work environment than at home. It may be then that these mothers conceptualise their child rearing activities as more work-like than other mothers might. This interesting finding warrants further exploration within all coping contexts.

Longitudinal studies also offer some insight. Gray (1994, 2002) and Glidden and his colleagues (Glidden & Jobe, 2006; Glidden & Natcher, 2009) report on the same cohort of families at ten and six year intervals respectively, while Baxter, Cummins & Yiolitis (2000) assessed levels of stress and worry in three core groups of mothers of children in early, middle and final stages of schooling, with a follow up seven years later. Other researchers (Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008) have compared mothers of children at different age groups simultaneously. The intuitive hypothesis that time and experience lessens stress is challenged by an overall picture that suggests very few changes over time, with comparable measures of depression (Smith e al., 2008), worry (Baxter et al., 2000), and pessimism (Lyons, Leon, Roecker-Phelps &

Dunleavy, 2010) intimating that coping does not greatly improve as the child gets older.

There have been a number of suggestions about why this might be. Some obvious reasons may be caregiver fatigue, that responses to stress are fixed through life or that we all become more pessimistic, anxious and use more emotionally focussed strategies as we get older (Green, 2007). It may also be that studies focus on particularly stressful life stages that disguise improved coping (Smith et al., 2008). For example, while mothers of young disabled children may experience a growing sense of confidence and competence as they are introduced to support (Lindblad, Rasmussen & Sandman, 2005b), those with adolescent children may be worrying about loss of services (Glidden & Natcher, 2009; Seligman & Darling, 2009). Similarly, it may be that family resources such as grandparents and siblings become depleted as time passes (Smith et al., 2008).

Research underpinned by the stress and coping model is limited in its usefulness in illuminating mothering experience. For example, mixed parent groups neglect gender differences in social learning and expectations in relation to responsibility and role in parenting (Douglas & Michaels, 2005). Studies that measure mental health as an indication of experience do not always account for women being twice as likely as men to experience depressive symptoms (Kessler, Zhao, Blazer & Swartz, 1997), with motherhood itself implicated (World Health Organization, 2008). Indeed those studies indicating little difference would appear to be counterintuitive (Dukmak, 2009; Oelofsen & Richardson, 2006). Further, coping studies often lack the sophistication to identify gender differences in how loss and stress are construed (Gray, 2003), triggered (Taylor, 2006), declared (Mind, 2009), and managed (Pelchat, Lefebvre & Perreault, 2003).

The indicators of stress and burden, such as help seeking, are also questionable (Turnbull, Summers, Lee & Kyzar, 2007). For example, a recognisable, severe disability is likely to provide access to services immediately, while less obvious disability might generate help seeking behaviours representing positive problem solving and not a coping deficit (Levine, 2009). Moreover, studies have shown mothers who have more limited personal and economic resources seek help more often, implying the

need is related to their individual need rather than their child's disability (Cavallo et al., 2009). Neither can not seeking services be seen as an indicator that the mother is coping well. Lessenberry and Rehdfeldt (2004) suggest support is not always valued in terms of aiding coping while Reeve (2004) theorises the hierarchical nature of social acceptability of disability presentations may determine social support and moderate parental need of services even when stress levels are high.

Studies around short break or respite services have also shown that it is parental confidence in the service that determines use and not levels of stress (Hartley, Ojwang, Baguwemu, Ddamulira & Chavuta, 2005; Hill & Rose, 2009; Kenny & McGilloway, 2007). Other, more practically based difficulties, such as cost, transport and reluctance to take the child into the community may all impede uptake despite need (Making Space, 2011; Ryan, 2005a). Such studies must also be considered in the light of evidence which privileges engendered help seeking behaviours (Ptacek, Smith & Dodge, 1994). Thus mothers may communicate difficulties and seek support, not only because that is what women do (Taylor, 2006), but because such tasks are bestowed upon her as primary caregiver (McLaughlin, 2006), whilst fathers are often unintentionally excluded and silenced by the design and delivery of services (Fitzpatrick & Dowling, 2007).

Stress and coping studies are built on the belief that the mother will appraise and manage her situation in terms of threat (Quine & Pahl 1999). Such assumptions may result in questions which seek to measure the negative, and do little to illuminate alternative meanings such motherhood might have. Neither do they account for studies which show equitable measures of personal reward across groups of others of disabled and typically developing children (Dabrowska & Pisula, 2010). Further, they fail to portray how these mothers understand their mothering role and how their practices differ to those of other mothers. These omissions are highly relevant to the current research which seeks to unveil the nature of the mother's experience within a working relationship with professionals.

1.6.3.2 ADAPTATION AND GROWTH

Researchers using adaptation and growth theory offer an alternative view to the experience of mothering disabled children. In applying measures of life satisfaction (Seligman & Darling, 2009), sense of coherence (Al-Yagon & Cinamon, 2008) and personal goal disturbance (Van der Veek et al., 2009) rather than stress and burden, researchers argue that positive changes can come from what might have been construed as an adverse experience (Ferguson, 2001).

Such studies show that best outcomes occur when the mother shifts emphasis away from notions of loss and burden and is able to construct a positive worth in their motherwork (Tunali & Power, 2002). This is seen as a normative transformational process that mirrors that of many women who experience restricted life choices and additional responsibilities upon entering motherhood (Chase & Rogers, 2001). Further, and perhaps most importantly, the mothers did not simply accept such restrictions, they actively re-evaluated what they continued to have; for example, their spousal relationship (Cunningham & Davis, 1985). Van der Veek et al (2009) echoes that such re-evaluation is vital when he showed that those mothers who felt their life plans most disrupted by the child's disability experienced greatest stress, those who passively accepted their situation displayed depressive symptoms while mothers who positively redefined their situation showed greatest positive affect (see also Trute, Benzies, Worthington, Reddon & Moore, 2010).

Construing benefits in having a child with disabilities is quite contrary to the nature of the research described earlier, yet it emerges strongly as a theme within studies specifically looking for positive outcomes and successful coping (Bayat, 2007). A number of researchers have suggested how such positive reappraisal might be achieved. Cunningham & Davis (1985) use Kelly's Personal Construct theory, suggesting mothers move from original constructs about successful motherhood to new constructs built on the enhancements and challenges of the situation. Holding multiple perspectives also allows them to engage in a world that perhaps views them as different or wanting. Seligman & Darling's social negotiation model (2009) further emphasises social interactions in the re-evaluating process, suggesting that social definitions and meanings extensively shape the mother's response to her child and their situation (Goodley &

Tregaskis, 2006; Landsman, 2003). They believe knowledge, understanding, and affirming, reassuring experiences are more likely to bring new meanings whilst mothers who remain 'in the dark' or are given pessimistic messages may become trapped in negative appraisal.

Other studies identify building knowledge and skills (Fitzpatrick & Dowling, 2007; Tunali & Power, 1993), being optimistic about the future (Trute et al., 2010) and developing a positive task sharing dynamic within the household (McCubbin & Patterson, 1983) as contributing to mothers' positive outlook and well-being. Vermaes, Janssens, Mullaart, Vinck and Gerris (2008) also posit positive attitude as important to the experience, showing that while severity of physical dysfunctions was positively associated with parenting stress, positive affect was more important in determining parental adjustment and reward.

Trute et al (2010) suggest mothers begin to 'accentuate the positive and mitigate the negative' (p36) as they experience positive aspects of love, coping, understanding and skill. He and other researchers highlight how the mother's build a sense of self efficacy and resilience over time (Bayat, 2007; Grant & Ramcharan, 2001; Scorgie & Wilgosh, 2008); something which appears to conflict with the previously attested notion of little change in stress and burden over time. However, this and other studies suggest that it is quite possible for the situation to contain the same level of stress and yet hold a greater satisfaction in coping with it. Van Riper (2007) and other researchers view the positive reconstruction as neither linear nor stable (Altiere & Von Kluge, 2009; Trute et al., 2010), suggesting parents will have a myriad of feelings and positions over time and indeed at any one time. This is often presented as a parallel or dual process whereby opposing experiences co-exist (Van der Veek et al., 2009). Kenny & McGilloway (2007), for example, describe subjective and objective challenges that demand internal and external responses. This indicates there may be a number of parallel processes involved in appraising the situation so that, for instance, a mother may simultaneously feel positive about improvements in her child's speech and negative about their poor sleep. Trute et al., (2010) posit that while positive appraisal may be correlated to a more healthy adjustment, negative appraisal need not mean poor adaptation, since it may accurately reflect the situation and allow for appropriate and realistic reframing.

They suggest negative appraisal in itself is not a difficulty; it is when the ratio of positive and negative becomes unbalanced that coping begins to fail.

While further work around the duality of experience and multiplicity of perspectives in the mothers of children with disabilities would appear useful (Nachshen & Minnes, 2005), there are some concerns. For example, many of the same structural issues related to gender differentials, nature of the disability, personal, social and cultural context remain unaccounted for (Zoellner & Maercker, 2006). Similarly, there is little offered in terms of mediating factors within interpretative experiences and how these might be positively enhanced when mothers may feel implicated in their child's difficulties (Blum, 2007).

While a paradigm shift away from burden and loss is to be welcomed, there is the danger that growth models could mask the impact of having a disabled child resulting in poorer understanding and service provision. It could also be that research outcomes that identify positivity could be viewed as evidence that families are generally unrealistic, unaccepting and in denial (Green, 2007; Todd & Jones, 2003). Further, while the adaptation and growth literature identifies similarities with the experiences of mothers raising typically developing children, there is little said about any differences in the nature of the mother work that provides life satisfaction and growth (Pelchat et al., 2003). It is therefore useful to explore research that has sought to uncover such differences and parallels (Redmond & Richardson, 2003).

1.7   MOTHERWORK FOR CHILDREN WITH DISABILITIES

Edelson (2000) identifies that mothers of children with disabilities must become health experts, educators, advocates and negotiators. While, as previous discussion suggests, this may be the case in all motherwork, here it often means working in systems which offer conflicting understandings and demands (McKeever & Miller, 2004). Such mothers may operate most effectively within a disabling culture (Redmond & Richardson, 2003), for example, in engaging with support systems underpinned by a

medical model that demands diagnosis and labels, and conveys a compensatory ethos that re-enforces disability as negative and undesired (Reeve, 2004; Ryan & Runswick-Cole, 2008a). However, acquiescing to such philosophies may be the only way the mother can acquire currency that translates into services and treatment (Redmond & Richardson, 2003).

Whilst being useful in accessing support, the same activity can generate a view, both within the woman and society, of a disempowered mother, sustained and dependent on experts (Green et al., 2007; Monsen, 1999). However, extraction from the relationship may reduce effective support, and could result in mothers feeling judged uncooperative or unmotivated. Monsen (1999) suggests this is a particular form of social judgement that further oppresses these women and denies their strengths and successes.

Such engagement brings the mother into conflict with others who view diagnostic and other labels as pathologising the disabled person and maintaining an ableist agenda. Veck (2002), for example, defines mothers as co-oppressors with professionals in making life changing choices for the child who has often little voice (British Council of Disabled People, 2005; Reeve, 2004). Indeed, Middleton (1999) asserts that non disabled mothers are not appropriate carers for disabled children as their tendency toward normalisation reduces supportive challenge in a nondisabled world. So mothers of children with disability work within complex frames of negotiation, shifting both their presentation of their child and the interpretation of its disability depending on the circumstances and function of the interaction (Blum, 2007). This fits with the assertion such mothers must generate and maintain multiple constructs around themselves, their child and society (Cunningham & Davis, 1985; Ryan, 2005b).

It is perhaps because of this complexity that mothering children with disabilities is portrayed as distinctly different to other forms of motherwork (Shearn & Todd, 2000). For example, while other mothers might routinely meet expectations of care in feeding, clothing and keeping their children safe, these mothers may be required to include unusual medical or therapeutic practices such as tube feeding, administering injections, delivering physiotherapy and managing seizures. This 'transplanting' of medical knowledge and skills (Case, 2000), further alienates the mothers involved (Green et al., 2005) and is often resisted by mothers, both because of the fear they will get things

wrong (Brett, 2002; Leiter, 2004) and because it morphs their role into something other than mother (Oulton & Heyman, 2009).

Conversely, mothers' efforts to fulfil social expectations to develop her child intellectually and physically will often involve seeking out suitable practitioners and services (Shearn & Todd, 2000). Ryan & Runswick-Cole (2008a) highlight the irony that the mothers' development of unique skills and knowledge will often be overlooked or undermined by this continued dependence on others to augment mothering practices. Yet this too involves complex negotiations, with studies highlighting frustration when their 'maternal knowing' is ignored or negatively received as unrealistic or demanding and they are given the 'run around' as a consequence (Roger & Mandich, 2005; Ryan & Runswick-Cole, 2008a).

While most mothers are confident in their children finding their 'place' in society, and often actively work to increase their opportunities, the stigma and alienation afforded people with disability reduces the potential for a disabled child to be accepted as a fully integrated member of the community (Green, 2003; Scorgie & Wilgosh, 2008; Watson, 2008). Further, the mother will endeavour in a complicated, often contradictory, web of expectations and philosophies about the disabled child. For instance, stretching the child's skills or independence can, perhaps because of particular social narratives of pity and clemency for young children with disability, draw negative responses and criticism (Monsen, 1999).

Similarly, later residential choices may be impacted upon by polarised discourses that, for example, variously express desire for independence for the young person with notions of abandonment and rejection when this occurs (Home, 2002). In essence, their advocacy and networking for their social status involves being both bridge and buffer between the child and what they perceive may be a hostile, non-appreciative world, and includes managing their child's expectations (Read, 2000) as well as maintaining the advocacy role for much longer than would be the case for other mothers (Ryan & Runswick-Cole, 2008b).

Mothers appear to optimise acceptance and social status in a number of ways. They use positive narratives that promote the child's ability and positive characteristics while

minimising any difficult or challenging aspects of their disability (Tunali & Power, 1993). They may also try to reverse or disguise the child's difference. McKeever & Miller (2004, p1179) apply Bourdesian theory to suggest that this is not about deficit or normalisation but an attempt to raise the social capital available to children devalued in the world. There is evidence that such efforts may generate conflict (Todd & Jones, 2003), giving rise to difficulties with other members of the family and professionals (McKeever & Miller, 2004), general members of society (Gray, 2002) and indeed the child itself (Harrison and Freinberg, 2005).

Studies also suggest that mothers attempt to address societal barriers by engaging individuals (Todd & Jones, 2003) or becoming a crusader (Panitch, 2007), working to effect change at community, philosophical and legislative levels (Green, 2003; Ryan & Runswick-Cole, 2008b). Not all women will want to undertake such action and those that do can find it challenging of personal resources (Neufeld, Harrison, Stewart & Hughes, 2008). Green (2003) found that those mothers who felt most distressed about stigma had fewer contacts outside the home and restricted their child's engagement with non-disabled others. However, Read (2000) suggests that even in withdrawing, the mother is not passive, managing the child's expectations and developing resilience and coping strategies.

Ryan & Runswick-Cole (2008b) suggest that mothering activity which promotes their child's inclusion should be valued socially and economically, while other commentators suggest it may be interpreted by way of dominant discourses around women's emotionality and altruism or depicted as pathological (Read, 2000) or fanaticism (Panitch, 2007). Such arguments align the experience of mothers of children with disability with feminist thought on women and motherhood and how both are perceived and positioned within society. Increasingly, researchers have begun to reflect that, as with any mother, these women generate particular constructions of their motherwork in relation to their individual context and the needs of their child. The differences in mothering experience can then be viewed not as maladaptive, but as meaningful and reasoned mothering practices designed to optimise the outcomes for child and family. In this way, such activities may be located as appropriate motherwork rather than emotionally led responses indicative of difficulties accepting and adjusting to their child's disability (McKeever & Miller, 2004).

1.8 THE MOTHER – PROFESSIONAL RELATIONSHIP

This review suggests pluralistic and often conflicting theoretical and social conceptualisations of contemporary mothering and motherhood, and that mothers too have diverse and altering understandings, performing motherwork according to their particular needs, resources and within social and cultural confines. The previous section illustrated that mothers of children with disability were little different, providing for their child and seeking the same optimal social and welfare outcomes, albeit shaped by different precursors, challenges and reference points (Pelchat et al., 2003). It has been suggested, however, that one element – their involvement with professionals – can define their deviance as a group, attaching them to narratives of incompetence and failure rather than mothering diversity (Redmond & Richardson, 2003).

1.8.1 MODELS OF THE RELATIONSHIP

Five models are generally employed to illustrate the client-professional relationship. In the Expert Model, the professional will act as decision maker whilst the mother's role will be one of simply providing information (Brett, 2002). In the second, the Transplant Model, the mother takes responsibility to carry out activities relating to care on the instructions or advice of the professional (Case, 2000). Whilst she may be more actively involved, the practitioner or team remain in control (Ryan & Runswick-Cole, 2008b). Thus the Expert and Transplant models focus on the practitioner, marginalising and disempowering the mother in the helping process. Brandon (1976) warns that such power may influence professionals' behaviour towards those seeking help, in that they might see themselves as better people or unconsciously contrive to maintain their client's neediness in order to feel their own worth. He suggests that professionals should act in an 'unflaunting and unconscious way' in sharing their knowledge and skills (p14), with a focus on how knowledge and skills can be shared within a process of empowerment (Dodd, Saggers & Wildy, 2009; Gibson, 1999; Hodge & Runswick-Cole, 2008).

Three models offer more equity within the relationship. In the Consumer Model (Cunningham & Davis, 1985), the professional recognises the mother's expertise and

experience, and whilst their own knowledge is still valued, a process of exchange and negotiation ultimately leads to the mother taking responsibility for decision making. There is some criticism that this focuses responsibility on the mother who may not have knowledge of broader issues and choices. A fourth model, the Empowerment Model (Appleton & Minchom, 1991), reflects more recent thinking around the importance of a partnership approach. Here any concerns around liability are facilitated by the professional ensuring the mother has the resources, information and skills she requires in order to make the best informed decision and to fulfil any undertakings (Kirk, 2001). The greatest criticism of this model is that it depends on flexible, creative accessible services, when in reality most professionals will be limited in what they can offer.

Finally, the Negotiation Model (Dale, 1996) similarly offers parents an equal voice, however unlike previous models, the final decision is a shared one. Here the key is open and honest dialogue that addresses power, social context and the emotional and interpersonal content of the relationship itself. It is therefore a much deeper and more intimate process than those represented by the transactions in other models and comes closer to fulfilling the characteristics understood to be vital in true partnership, those of mutual co-operation, joint responsibility, reciprocal interactions and a shared goal (Fitzpatrick & Dowling, 2007). A criticism might be the need for effective interpersonal communication if the process is to be successful. Issues may arise when, for instance, skills or style are not a good fit perhaps because of personality, confidence or lack of motivation to engage.

It is likely that mothers will usefully experience relationships that extend across all five models. The Expert Model, for example, would be more appropriate than that of the Negotiation Model in the case of a medical emergency, while the reverse would be true in the case of engagements around sleeping or toileting. Research has shown that the model utilised may be impacted upon by the nature of the intervention and context of the relationship as well as the people involved. Ygge, Lindholm & Arnetz (2006), for example, found that parental contribution was encouraged at care giving level but not in decision making, the level where parents felt most empowered when included, illuminating perhaps the power and importance they held. They also found that support for parental involvement was related to practitioner working practices rather than their

professional standing or personal views suggesting that even with good intent, opportunity to consult parents may be reduced.

1.8.2 POWER IN THE RELATIONSHIP

That professionals are often endowed with privilege and power is well recognised within the literature (Kirk, 2001).   McKeever & Miller's (2004) application of Bourdieasian theory to explain maternal activity can be usefully extended to explore such dynamics as illuminated by the models above. For example, it suggests that the meanings we give and customs we adhere to in relation to particular roles and institutions stem from our habitus, a background perspective that depicts and predicts the patterns of how we behave, think and feel in the various contexts of our everyday life. Such knowledge comes from understandings of hierarchical social structures and conventions, characterized as 'rules of the game' that shape expectations of our own and others' position and behaviour in particular contexts or 'fields' (p1174).   The relationship is considered to be set in a social world (Murray, 2000) where mothers might expect professionals to have expert knowledge and skills, while professionals assume mothers will not; mothers might expect to listen and professionals to talk. There may be particular understandings of 'rules' where, in this instance, professionals might control location and duration while mothers comply with waiting times, treatment decisions and allocation of resources.

Bourdieu (Webb, Schirato & Danaher, 2002) also refers to various forms of capital that carry real or symbolic power and authority and further contour social and interpersonal interactions. Thus, professionals bring titles, knowledge and experience as cultural and symbolic capital (Baxter & Brumfitt, 2008), whilst not producing a healthy child and requiring help to mother might result in depleted social and symbolic capital for the woman (Green et al., 2005). Other background understandings such as experts have all the answers or that mothers of children with disabilities are over protective and emotional may also profoundly influence the nature of power in the relationship (McKeever & Miller, 2004), as can beliefs related to ethnicity, socioeconomics, gender and disability (Valle, 2011).   Organisational processes and structures often assign further power to such positions as they reduce access to specialists bequeathing control

of contact upon them (Aitkien, Mele & Barrett, 2004; Whitehead & Gosling, 2003). Even when the family are involved, they will not hold the power in relation to formulation, intervention, allocation of funds, recruitment of personnel and the nature of the service delivered (Runswick-Cole, 2007; Todd and Jones, 2003).

In a similar vein, mothers must contend with social constructs around womanhood and how women should behave in particular contexts and relationships (Panitch, 2007). They will recognise the capital of knowledge and skills in an area in which they have little experience and where current Government policy of professionalising support also serves to devalue maternal insight and experience (Valle, 2011; Whitehead & Gosling, 2003). The field work of Belenky et al (1997) offers some insight into how this might impact. They suggest women can take five perspectives of their view of reality, knowledge and truth and their ability to voice it. So the mother might hold a 'Silenced Perspective' in her belief that she does not know but the other does. She might voice 'Received Knowledge', that which she has been given without any ownership or processing of it. A third perspective, 'Subjective Knowledge', whereby the woman sees flaws in the views of others and a duality in truth, and in this authoritative failure begins to sense her own expertise and to be more comfortable in expressing her own judgements. The fourth perspective, 'Process and Procedural Knowledge', incorporates improved ways of asserting her views. The final perspective, 'Constructed Knowledge', allows integration of duplicity, with the ability to empathise with the others understanding at the same time as feeling a sense of duty to offer her own view.

Women are said to hold diverse perspectives in different aspects of their lives and to experience changes in perspective in relation to the same aspect over time and with changing situations. Belenky et al (1997) also draw attention to their belief that social expectations, conventions and positioning of women in terms of their gender, race and class, for example, all contrive to influence the nature of their knowing and their expression of it. The application of the theory would suggest that the mother's perspective of her knowing will highly influence her understanding of her place and role within the relationship. Those women who view the world through a silenced or received knowledge perspective are likely to sit contentedly in a relationship built on expert power whilst women who hold other perspectives might be very uncomfortable.

1.8.3 FACETS OF THE COLLABORATIVE PARTNERSHIP

The re-conceptualisation of the mother-professional relationship as a partnership brings with it the need to consider the interpersonal components that override power issues and facilitate joint endeavours (Smith et al., 2008). This section considers those aspects identified as influential and explores how they impact on the mother's experience.

1.8.3.1   PERSONAL QUALITIES

Researchers have hypothesized that the success of a helping relationship is as much about the personal attributes, beliefs and values of the helper as it is about the skills they bring (Neander & Skott, 2008). Brookes, Summers, Thornburg, Ispa and Lane (2006), for instance, argue that effective helping comes from the ability of the helper to be caring, committed and wise and to be authentic with the individual being supported. Ellerman (2001) suggests that a true helper starts with the problem as seen by the other and that help should not reduce autonomy, nor cause dependency and should be driven by the individual seeking support. Mezirow & Taylor (2009) suggest that the professional helper should work at objective, interpretative, reflective as well as the more commonly utilised decisive levels. Such propositions challenge the notion of professional power, supplanting it with cooperation, empathy and compassion.

1.8.3.2   COMMUNICATION

Good communication is commonly recognised as a component of successful partnership (Gallagher, Smith, Hardy & Wilkinson, 2012; McConkey, 2003). Mothers have identified clear, jargon free, open communications as the most helpful and report specialist terminology can leave them anxious and upset (Case, 2001; Pain, 1999). The timely and honest sharing of information seems particularly important (Stoner et al., 2005), especially around diagnosis (Watson, 2008; Wodehouse & McGill, 2009). Parents have also identified professional reluctance to discuss contentious or emotionally laden information (Dickinson, Smythe & Spence, 2006; Wright, 2006) but call for them to report tactfully and sensitively but without 'candy coating' (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004, p173). Perceived inaccessibility

or withholding of information would appear to leave the mother feeling both disempowered and anxious that there is something 'out there' that she should know (Blue-Banning et al, 2004; Tudball, Fisher, Sands & Dowse, 2002).

Mothers also report they can feel unheard (Maiter, Palmer & Manji, 2006; Roger & Mandich, 2005) or their concerns trivialised (Whitehead & Gosling, 2003; Wodehouse & McGill, 2009). The parents of children with motor disorders in the study by Ahern (2000)0 had, on average, to approach three professionals before receiving 'meaningful help' (p189) while those interviewed by Missiuna, Moll, Law, King & King (2006) described their experience as navigating 'mysteries and mazes' (p7). Mothers want professionals who value their contributions, with a number of studies correlating parents feeling listened to with increased service satisfaction (Neander & Skott, 2008; Samioti, Papanis & Giavrimis, 2011). Gibson (1999) suggests that this may mean more than the professional listening to the mother; it may involve actively encouraging her to reflect and offer her opinions. Since communication has both content and relational dimensions (Watson, Kieckhefer & Olshansky, 2006), effective interactions facilitate responsive traits such as empathy and honesty (Ygge et al., 2006), while poor communication may generate a conflictual cycle reducing the desire to communicate at all (Buelow, McNelis, Shore & Austin, 2006). This is very much in keeping with the relational models outlined previously and maps well onto the work of Belenky et al (1997).

1.8.3.3   CONNECTIVITY

A further facet of success, identified by both parents and professionals, is a positive personal connection (Betz, 2006; Blue-Banning et al., 2004). Whilst it is often difficult to find operational definitions with regards to what such connections involve, studies have revealed indicators such as respect, mutuality and trust to be integral to the experience (Jack, DiCenso & Lohfeld, 2005; Park & Turnbull, 2002; Ygge et al., 2006). Blue-Banning et al (2004, p179) noted that indicators of respect are often those thought to be 'common courtesy' such as being formally addressed, punctuality and attentiveness. Failure to recognise efforts or to accommodate diversity, have been highlighted as examples of disrespect (Todd & Jones, 2003). While being called 'Mum' or made to wait for a professional may be thought discourteous, exploration of mothers'

experience suggests that this kind of event alone may not capture the reverse of feeling respected. Instead, studies identify that mothers may not only feel themselves, their child and their circumstance disrespected, they feel actively judged in terms of their personal circumstance (Moore & Kordick, 2006; Partington, 2002) and ability to mother (Peckover, 2002). Jack et al. (2005) suggest this type of judgement leaves mothers fearful, wary and keen to seek out mutuality (Henson, 1997) within the relationship in order to counter authority and advocate for themselves as good mothers (Bryk & Schneider, 2003; Lord Nelson, Summers & Turnbull, 2004).

Whilst there is an apparent dearth of studies exploring professional views on the relationship, the literature does illuminate that connectivity may be hampered by practitioner boundaries. Although some theorists suggest that professionals keep a distance in order to secure power and authority (Tait, Beattie & Dejnega, 2002), others look to Professional Standards and Ethics Policies as maintaining relational asymmetry within helping relationships (Jack et al., 2005; McKenzie, Murray & Matheson, 1999). Pearson, Vaughan & Fitzgerald (2004) suggest practitioners can have a 'professional closeness' that involves an 'interpersonal intimacy' that is within boundaries but nevertheless is focussed on the connection between client and practitioner and in meeting client needs (p183).

1.8.3.4 TRUST

Studies have found that when trust is high in the relationship, collaboration and joint decision making between parent and professional increased, parental involvement in child outcomes improved, and service and system reforms were more readily achieved (Bryk & Schneider, 2003; Lake & Billingsley, 2000). Other studies found that low levels of trust resulted not only in fractured individual relationships (Oulton & Heyman, 2009), but also in poorer levels of service (Blue-Banning et al., 2004). Hoy & Tschannen-Moran (1999) suggest that trust in a relationship is achieved when the parties are willing to 'be vulnerable to another party based on the confidence that the other party is benevolent, reliable, competent, honest and open' (p189). This is perhaps illuminating in terms of the issues just discussed around power and mutuality.

Stoner & Angell (2006) explored maternal trust in professional relationships within school settings. They suggest characteristics of the mother, professional and the supporting system all serve to elevate or diminish perceived levels of trust. Their study identified the mother's personal disposition to offer trust more generally, their history of trust in professional relationships, and the meanings they give to their child's experience of the system were all implicated in the level of trust offered in the relationship. It was also intimated that measures of maternal trust oscillated with time and events, increasing with duration and success while incidents of fractured trust in practitioner or setting resulted in both heightened suspicion and caution to trust (Sloper, Greco, Beecham & Webb, 2006). Dunsmuir, Frederickson & Lang (2004) propose a cycle of reciprocity whereby increased trust between parent and professional facilitated greater trust across other relationships within the systems supporting them.

1.8.3.5 EXPERTISE

The literature bears testament to the way in which the relationship is influenced by mothers' experience of the perceived aptitude or ineptitude of the professional. For example, they appear to appreciate professionals able to exhibit knowledge about their child's condition (Kasahara & Turnbull, 2005) and those who know the child well enough to adapt plans to suit their needs (Samioti et al., 2011). Equally they report respect and approval of those who admit they do not know but are willing to improve their competence (Park & Turnbull, 2002; Shelden, Angell, Stoner & Roseland, 2010), and value professionals who keep abreast of current thinking and are willing to try new approaches (Lindblad, Rasmussen & Sandman, 2005a). Lack of confidence and overconfidence have been identified as barriers to accepting alternative viewpoints and inviting parental contribution (Hodge & Runswick-Cole, 2008; Whitehead & Gosling, 2003). Competence is not only viewed with regard to knowledge and skills however, it is also viewed in terms of interpersonal capability and outlook, with mothers finding cheerful, positive professionals who will 'go the extra mile' as being particularly helpful (Bryk & Schneider, 2003; Park & Turnbull, 2002).

1.8.3.6   ATTITUDE TO THE CHILD

Various studies have reported that parents feel their child is often looked upon in terms of deficit rather than a person (Hodge & Runswick-Cole, 2008; Lake & Billingsley, 2000; Park & Turnbull, 2002). Dickinson et al (2006) suggest this is a legacy of the medical model and suggest that those, particularly in health contexts, maintain a philosophy of healing and cure. The contrasting approach whereby the professional shows personal regard for the child is much valued by mothers (Nuutila & Salanterä, 2006). So too are those professionals who work to extend their child's ability (Kasahara & Turnbull, 2005) and build on the family's strengths (Applequist & Bailey, 2000; Bruder, 2000). Angell, Stoner and Shelden (2009) usefully differentiates between a professional's authentic caring, an unconditional desire to help the child and family, and aesthetic caring that is conditional and contingent on the child and family sharing the same priorities and adhering to the same rules as the professional and the system within which they work.

1.8.3.7   CONFLICT

Goodley and Tregaskis (2006) identify one hundred and twenty four professionals involved in the first year of one baby's life. It would be somewhat surprising if conflict never arose given such an expanse of connections, the nature of their objectives and the personality mixes likely to be involved. Indeed it would seem each of the relational models may generate conflict (Moore & Kordick, 2006). For example, Hodge & Runswick-Cole (2008) suggest that one cause of conflict is the continued use of the Expert and Transplant Models so that parents redress the balance by developing their own knowledge base and challenging authority (Stoner et al., 2005). Alternatively, and in order to reduce conflict, the parent may go against their own instinct and adhere to the professionals' point of view (Cavallo et al., 2009).

Hodge & Runswick-Cole (2008) suggest conflict may also arise out of the more collaborative models when parents are encouraged to have a view and a vision of what it is they want for their child, whilst the professional exists in a world that is economically and politically constrained. Parents appear to approach this conflict from a number of angles. For instance, they persist, returning again and again to the

professional and if they feel they are not receiving what they need from them they will go elsewhere (Missiuna et al., 2006; Whitehead & Gosling, 2003). An alternative is to compromise. Woodcock and Tregaskis (2006), for example, illustrate how parents in their study, whilst initially resisting labels, eventually agreed to go down that path as it was the only way to access specialised services.

The philosophies and culture of a service and team may mean that conflict is embedded in service delivery itself (Bruder, 2000; Dinnebeil, Hale & Rule, 1999). Generally family focused services, underpinned by parental involvement and choice, have been shown to be correlated to higher levels of service satisfaction (Applequist & Bailey, 2000). Conversely, issues such as limited resources which generate increased waiting times and reduced parental choice have the potential to impact negatively on the relationship (Whitehead & Gosling, 2003). Similarly, teams aligned to strength based approach that involve parents, for example, will present with very different philosophies and practices than would those clinically based practitioners working within the medical model (Brandon, 2005). Such findings might contest Hodge & Runswick-Cole's (2008) suggestion that parents challenge or compromise when in disagreement with professionals. Instead, it seems parents can be mindful of economic constraints and work with professionals in order to achieve best outcomes within them.

MacKenzie & Scully (2007) see such conflict in more global terms, suggesting that it arises from the fact that disabled and non disabled inhabit completely different life worlds, and construct the situation in completely different ways that generate different and competing epistemic positions. This is reflected in the mother/professional relationship since, as outlined previously, the mother assumes a disability perspective and habitus. Case (2001) provides an analysis of studies over time, highlighting reduced levels of reported conflict and posits this is a consequence of a broader application of the negotiation model, allowing parents to have greater voice which, in turn, allows professionals a better appreciation of the family situation.

1.9 AIMS & RATIONALE FOR THE CURRENT RESEARCH

This introduction has provided a review that places the current study in terms of the literature in respect of mothering, motherhood, disability and the professional relationship. It has illuminated the diversity in mothering and motherhood with direct references to those mothers raising children with disabilities. It has described the findings of the literature around the nature of their motherwork, and in particular the unique involvement with professionals. Reviewing the literature reveals that the interpersonal can be pivotal in the success of any helping intervention (Hoagwood, 2005), with the most fruitful based on equity, collaboration and a strong personal connection (Davis, Day & Bidmead, 2002). Yet, while this offers an insight into the aspects parents find useful and difficult in their dealings with professionals, the literature often fails to identify any particular gender differences, and appears to be limited in respect of how the relationship is actually experienced or understood by either party (Davies, 2005; Patterson, Jernell, Leonard & Titus, 2004).

The current study aims to help close the gap by investigating the parent/professional relationship with particular reference to the subjective experience of mothers of children with complex needs. It asks the question 'How do mothers of children with complex disabilities experience their relationships with the professionals involved in their care?' The intention is to use outcomes to support mothers and practitioners to get the best out of their encounters and to inform the discipline of counselling psychology in how it might help in the process. My personal reasons and drivers are described in a later section (2.3).

CHAPTER 2

METHODOLODY

2.1   RESEARCH DESIGN

This study employed a qualitative methodology using data gathered from semi structured interviews with a homogenous small sample. Data were examined using Interpretative Phenomenological Analysis (IPA).

2.2   RATIONALE FOR ADOPTING A QUALITATIVE RESEARCH PARADIGM

Qualitative research emerged from an anthropological and sociological desire to better understand the intricacies of human social living (Willig, 2001) and continues to be utilised to expose the diversity of individual life which traditional quantitative and deductive methodologies often fail to capture (Flick, 2002; Silverman, 2006). Underpinning the approach is a move away from controlled experiment and statistical analysis toward the researcher engaging with the uniqueness of human experience of everyday phenomena, not as an objective observer, but rather as implicated in the findings (Willig, 2001, p67).

The development of such approaches has not gone unchallenged with Denzin & Lincoln (2011) describing current qualitative research as the product of a variety of cross discipline 'wars' involving the epistemological and methodological struggles of positivism, constructionism, interpretivist, critical theory and evidence based models. They suggest that what has emerged is a myriad of qualitative approaches positioned across ontologies, epistemologies and methodologies. Qualitative approaches may therefore be thought of as a family of research activities, representing different ways of thinking and varied ways of exploring the richness of our human existence (Ashworth, 2003), designed to allow researchers to 'make sense of or interpret phenomena in terms of the meanings people bring to them' (Denzin & Lincoln, 2011, p3).

Qualitative methodology seemed appropriate for a number of reasons. For example, it was ontologically consistent with the aim to investigate subjective and intersubjective meaning of events and experiences. Further, the idiographic engagement suited the desire to have mothers tell their own story, to capture and examine individual nuance and similarities and differences across the group. It was also hoped that a qualitative approach would not only offer insight to the experience but would facilitate participant empowerment given potential power imbalances in the positioning of women and within the dynamics of client-professional engagement identified in the literature review.

The inductive nature of qualitative methodologies also sat well with the intention to make the study open and explorative without recourse to a pre-prescribed hypothesis or theoretical framework. It also allowed a broader lens with which to view the women's experience and meaning making which would offer a more comprehensive framework to support good and effective practice.

Whilst my interest was spawned many decades previously, the study itself is instituted as part of a Professional Doctorate in Counselling Psychology. This influenced the approach in a number of ways. For example, it seemed important that the principle of the Division of Counselling Psychology which draws upon and seeks to develop phenomenological models of practice and enquiry in addition to that of traditional scientific psychology should be reflected in the research piece (British Psychological Society, 2000). Further, a qualitative epistemological stance promoting the person as always in the throes of becoming, rather than a predictable, fixed entity, sits well with the values and ethos of Counselling Psychologists who further desire to 'engage with the subjectivity and intersubjectivity' and 'to know empathically and to respect first person accounts as valid in their own terms' (British Psychological Society, 2000, p1). The qualitative inclination towards the validity of individual experience proved intuitively appealing in that it correlated well with my professional person centred practice.

Finally, the reflexive and clinical abilities developed through training meant I felt well placed to engage participants in a sensitive and supportive manner. Extensive experience of sitting with strong or difficult feelings, and a skill base with which to

support their containment, meant I felt competent to effectively manage the pressures of the interpersonal processes and reflexivity demanded by the qualitative approach.

2.3 PERSONAL REFLEXIVITY

My journey to this research began with a little Pelican paperback, 'Parents and Mentally Handicapped Children' by Charles Hannam (1975). It was 1977 and I was a first year student teacher. The book was amongst many on the reading list but it had a power that no other held nor has assumed since. The book told the stories of seven parents who like the author had a child with Down Syndrome. Based on the analysis of interviews it gave voice to the parent's experience of anxiety and fear for their child and their life voyage navigating through the prejudice and ignorance of both their community and the professionals they met. A copy once again sits on my bookshelf, after many years of searching. It feels dated now with references to 'Mongol children' and 'mental handicap', but re-reading the parents' words only reignites the intense emotion the book generated at the time and reminds me of my determination that someday I would do something that would ease the journey. I hope this research will be another instalment towards fulfilling that promise.

I have spent my career working with families who have children with disabilities, initially as an educationalist and more recently as Clinical Lead for Learning Disability Psychological Services. Over the years I have recognised changes that have now brought us a professional culture that advocates for the disabled child, emphasises the importance of family context and embraces collaboration and respect between parents and professionals (Warner, 2006). This is a far cry from my early days when my professional induction involved visits to residential institutions where the intellectually disabled were cared for by professionals who believed permanent hospitalisation supported the parents in getting on with their life. Indeed my 'B.Ed Retardation' degree broke the mould in Northern Ireland as until then such children were considered 'educationally subnormal' and were not taught in school at all.

Whilst I might have predicted my working future, I could not know that one day, I too would be in the role of carer for a child with disabilities, bringing me into a wealth of

relationships with professionals, all diverse in their nature, quality and function. I discovered what the relationship was like from the other side, albeit as an informed and, quite probably, overassertive mother. I experienced the personal implications of negotiating systems and services and contending with professionals in order to advocate for my child. I learned that some relationships felt more effective and efficient, that I enjoyed some and dreaded others and that all impacted on me in one way or another.

While my initial curiosity around the nature of the parent professional relationships began when I was a young novice, in coming back to it as a seasoned mother and a practitioner nearing the end of my career, I recognised that I remained equally fascinated and perplexed. I queried how new social understandings proclaimed through legal, educational and care structures, had really influenced our thinking as subjective individuals and our practice as helping professionals. How did parents feel they and their child were perceived? Were parent/professional relationships any more collaborative?

I wanted to use this research to explore the mother/professional relationship in depth, but I wanted it to be shaped by the women's understanding and not just my own. I believe my open curiosity, my experience as mother and professional allowed an open approach and avoided, or at least balanced, any bias within the analysis.

2.4   OVERVIEW OF THE INTERPRETATIVE PHENOMENOLOGICAL APPROACH

Developed in the 1990s by Jonathan Smith, IPA has grown rapidly to become the tool of choice for many researchers in applied psychology and across other disciplines (Chapman & Smith, 2002; Smith, 2004; Smith, Flowers & Larkin, 2009). Grounded in psychology, it is concerned with 'the individual person's perception or account of an object or event' (Smith & Osborn, 2004, p53) and designed to allow the researcher to explore personal and social experience and the meanings accredited to be within the person and uniquely achieved through their particular engagement with their social world (Chapman & Smith, 2002). The individual is assumed to be able to access, reflect and communicate the nature of its meaning to another. In most cases, accounts

are gathered through interviews although other methods have also been utilised (Brocki & Wearden, 2006; Reid, Flowers & Larkin, 2005; Smith et al., 2009).

IPA acknowledges data will not reflect a true 'first person' version of the experience with the researcher equally interested in the social, affective, cognitive and temporal influences that may have shaped the participants meaning making (Larkin, Watts & Clifton, 2006, p104). Indeed, it is assumed that the engagement of participant and researcher may in itself generate new meaning and influence understanding. While, affording an empathetic acceptance of the individual's account as their reality, IPA researchers bring an investigative and actively interpretative approach to the data, seeking to reveal strands of related meanings as well as shaping influences that may not be readily apparent to, or directly articulated by, the participant. In a final level of examination, the researcher makes speculative theoretical connections to already established psychological theory (Smith, 2004). It is only when they feel they have illuminated all pieces of the jigsaw that researchers begin to assemble the final picture of their account of the individual's experience. Individual and cross case themes and their analysis are then recorded in narrative form, 'giving voice' to the participant's subjective experience and the researcher's understanding of it.

2.4.1 THEORETICAL AND PHILOSOPHICAL INFLUENCES UPON IPA

2.4.1.1 PHENOMENOLOGY

IPA's tenet that the subjective lived experience is unique to the individual draws on Phenomenology, a theoretical and methodological stance originating from Edmund Husserl (1859-1938). Husserl challenged the notion of objective reality and any lawful, predictive nature to human responses and asserted people may have completely different understandings and responses to the same object or event (Smith and Osborn, 2004). He proposed a natural propensity to reflect, albeit at different levels of awareness, and argued the case for 'intentionality', which moved the focus of experience away from the 'reality' of the object toward the subjective meanings given to it. Husserl was interested to know the 'essence' of an object before intentionality and

used reflection as a vehicle by which to 'transcend' consciousness and to illuminate things 'as they are', unadulterated by thought, IPA, in contrast, is more interested in what he aimed to preclude, the subjective experience.

In this respect, IPA is influenced by the work of Heidegger, who laid less emphasis on what constituted the core of the phenomenon and more on the transaction between individual, phenomenon and the world context in which they connected (Larkin et al., 2006, p106) and Merleau-Ponty (1962) who asserts that our mind, body and the world mutually 'commune' in a way that experience or 'knowledge' of any one phenomenon is inexhaustible according to personal and physical context and the relation between us and the phenomena at any particular time (Smith et al., 2009, p18). For Heidegger and Merleau-Ponty then, complete phenomenological reduction impossible since we exist as people in and of the world with lying not in the essence of the phenomenon or in our experience of it, but within the encounter itself. IPA reflects this ontological understanding in its assumption that we are embodied, intentional actors 'always-already immersed in a linguistic, relational, cultural and physical world' (Harper & Thompson, 2011, p102).

Heidegger and Merleau-Ponty's emphasis on transaction moves away from intentionality within the private inner world, towards intersubjectivity, whereby lived experiences, varied as they might be, are seen in terms of collective human understandings and thus commonly shared and shaped. IPA translates this as the researcher not only investigating and critiquing, rather than simply describing, the individual's self conscious exploration of private meanings but also in accepting that reflection and meaning making may be influenced by an intersubjective loop between researcher and participant.

It is worth noting that IPA has been challenged as not truly phenomenological since the actual experience of the phenomenon is reshaped in verbalising it. Further to inform their understanding of meaning making, researchers actively look to evidence 'what the particular respondent thinks or believes about the topic under discussion' generating another layer of description removed from the actual moment of occurrence (Chapman & Smith, 2002, p126). Larkin et al (2006) and Eatough and Smith (2008) suggest such arguments are grounded in the conceptualisation of cognition as a detached reflexive

process proposed by both early Cartesian Dualism and more recent cognitive models (Ashworth, 2003). They argue an alternative view, with cognition seen to be an interpretative, meaning making process in itself (Bruner, 1990). For them, thinking is not separate from phenomenological experience but an intrinsic part of it, in the same way Husserl sees acts of thought rather than perception per se, as representing intentional meaning.

2.4.1.2   HERMENEUTICS

Heidegger asserts that not only do we engage in a transactional way with phenomena, we always come to the engagement and meaning making 'from somewhere' in terms of pre structures established according to our personal history, social culture and present situation. Meaning is derived through a hermeneutic circle whereby the individual moves back and forth between old and new interpretations of a particular experience in an informative process that can reinforce established understanding or generate new or adaptive meanings. Heidegger and later, his student Gadamer (Smith et al., 2009) thus brought Phenomenology and Hermeneutics together, crafting a view of the person and their context inextricably meshed in a transactional and interpretative process whereby both were constituted and reconstituted by one another. IPA also asserts that individual experience is 'socially and historically contingent and contextually bounded' (Eatough & Smith, 2008, p180).

In the same vein, researchers also accept that interpretative processes mean they cannot ever have direct access to the participant's 'original' experience and sense making processes. Indeed, meaning may have already been shaped and reshaped in being intellectualised, coded linguistically, communicated and shared with others before the researcher.

IPA also reflects Hermeneutics in that the second and third order readings of the data go beyond describing the 'what' of the participant's experience toward creating an account of 'how' they might have come to their particular interpretation of the phenomenon, thus drawing ontological and epistemological positions together by way of a 'double hermeneutic' designed to utilise the researcher's conscious use of their own interpretative predilection, the 'understanding that interprets' (Eatough, Smith & Shaw,

2008, p1775). In the same vein, despite reflexivity and attention to the data, the resulting analysis is seen as only one of many possible interpretations (Brocki & Wearden, 2006; Larkin et al., 2006) both across researchers and amongst readers who may well construe the researcher's commentary in a way other than intended (Smith et al., 2009, p23).

Further, given the acceptance that there is no one concrete reality and that an individual's experience and interpretation of the same phenomenon may alter, the emergent understanding is seen as a temporally constrained 'glimpse' into the person's current, subjective 'mode-of-engagement' with some specific aspect of their world (Larkin et al., 2006, p109).

2.4.1.3   SOCIAL CONSTRUCTIONISM

The tenet that we are born into transaction with an already established physical and social world which impacts on how we interpret and define it, allies IPA to social constructionism, whose proponents advocate that our assumptions about the world do not reflect real structures but instead exist as a function of the historical, cultural and contextual influences of our time. They reason that individuals and groups, through social interaction, negotiate and maintain their particular 'constructions' and as a consequence assume a shared, objective reality to how things 'are'. This promotes a relativist ontology where multiple versions of reality can exist (Gergen, 2001). Language is seen as an exceptionally powerful medium in the process, viewed not only as a means of expressing constructs but also how they might be generated.

While IPA acknowledges the social constructionist view that 'our understandings are woven with the very fabric of our many and varied relationships with others' (Smith et al., 2009, p194), it also celebrates the individuality of meaning making not totally constrained by social discourse. IPA therefore subscribes more to a 'less strong' version of post structuralism which deems that while the individual may be subject to a pre shaped reality, they will have the ability to 'rework' that construction through experience, reflection and reinterpretation (p196). IPA is thus established as concurring with the social constructionist view of the interrelationship between knower and known whilst also being influenced by Mead's Symbolic Interaction (Elliot, 2010) and Kelly's

Personal Construct Theory (Kelly, 1992) that suggest that, as self reflecting individuals, we play a role in constantly interpreting and reshaping the meanings passed onto us through social interaction (p166).

The research process also captures social constructionism in that IPA assumes the researcher, participant and reader share meanings -a kind of 'insider' knowledge. Further, while striving to be inductive, ontological and epistemological limitations are recognised. For example, taking on the role and questions of researcher identifies that we think we already know something of the phenomenon and its nature. In this case, constructs around mothering, professionalism and disability might be shared or varied between participant and researcher. IPA attempts to account for these issues through personal and epistemological reflexivity, in line with Heidegger's view that our interpretative frame should be illuminated and explored rather than bracketed off (Smith et al., 2009). In disclosing and reflecting on any pre-constructions, the aim is to accurately reflect that which belongs to the participant and to highlight any possible interpretative bias.

2.4.1.4   IDIOGRAPHY

IPA researchers do not aim to make universal claims or to establish predictive laws relating to behaviour, instead they are concerned with 'the particular' (Larkin & Thompson, 2011, p102). This idiographic concern reveals itself in the methodology at two levels, in the desire to understand an individual's particular experience of a specific phenomenon and then in the researcher's detailed, intense attention to the rich, textured personal data gathered. Nevertheless, the interpretative and investigative elements of the process and the opportunity for cross case analysis, can sometimes allow the researcher to expose convergent and divergent themes that establish a more detailed account of the complexities of the 'in context' individual experience and to identify those meanings that may be shared by all of us.

Thus, while IPA studies tend to utilise small numbers of participants, selected because of their experience of the phenomenon in context, this does not impede findings being related to a broader experience of the phenomenon or to already established

psychological theory, since experience is seen as both individual and shared with the world.

2.4.1.5   EPISTEMOLOGICAL REFLEXIVITY

Qualitative approaches have an expectation of a methodological reflexivity that illuminates the research process and researcher experience (Willig, 2001) and in accordance reflexive segments have been included throughout this methodology chapter. In IPA research, reflexivity is also considered essential to ensure transparency and authenticity, given the assumption that despite best efforts to 'stand in the participant's shoes', the researcher will, nevertheless, look at the data through a lens created by his or her own personal, social and cultural meanings. The process of reflexivity can also facilitate IPA research in that it reduces parameters and generates an openness and curiosity that can enhance the quality and depth of the study (Maso, 2003). Given that counselling psychologists also privilege reflexivity as a way in which they remain alert to their personal influences on formulation and the client relationship, in this research reflexivity becomes important as a theoretical concept, a methodological tool and an ethical necessity.

Willig (2001, p.10) describes two types of research reflexivity. Epistemological reflexivity, she argues, allows the researcher to consider how their assumptions may impact on the nature of the research, methodological decisions and outcomes. She also suggests there should be a personal reflexivity, designed to uncover idiosyncratic influences that shape approach and interpretation and illuminate the personal impact of any new meanings generated through the process. While the paper includes other sections on methodological reflexivity that are additionally supported by reflexive narrative, it feels important to inform readers of my own particular theoretical and personal assumptions and motivations in order for them to contextualise the project.

I believe our social, cultural and historical worlds shape not only our external environment but also contour the nature of our subjective experience. I deduce the power of such external forces over my personal life roles and in my work to advocate and empower the lives of people with learning disabilities. I can look back over a relatively short period of five decades and see how technological, material and

institutional change has impacted on how we live, act and who we consider ourselves to be. I also acknowledge that individuals ascribe diverse meanings and responses to what appears to be the same event and that this may change over time and circumstance. Further, as a Chartered Counselling Psychologist, my practice is underpinned and motivated by the belief that people can alter how they think, adapt what they do and reinvent who they are. I can look back over the same five decades and celebrate those 'free' thinkers who individually changed the world.

My version of social constructionism then, is more akin to what Burr (2003) tagged as the 'micro' form as opposed to the 'macro' form which posits a relativist argument that sees no room for embodiment, subjectivity and the notion of self (Cromby & Standen, 1999). In allowing for subjective meaning making within a transactional social frame of influence I draw, as Smith does, on symbolic interactionism and uphold that individuals and their social worlds are constituted, not unambiguously constructed, by way of intersubjective, interpretative endeavours. In this research I align myself to critical realism, maintaining a central focus on the inner life world while remaining mindful of those social and physical forces and processes I believe to shape it.

Critical realism (Bhaskar 1989) asserts a middle ground between individual and social constructivism, arguing that while we may have access to creative subjectivity and choices in our 'ways of being', these will be limited by the nature of the world we live in and the ensuing social, psychological and physical consequences for us in taking that position. However, importantly with respect to this research, Critical Realism views the social world as inherently transformative, whereby particular contingencies facilitate processes that allow the emergence of alternative individual and social realities.

From this perspective, I consider the women's accounts as more than descriptions of what they and professionals 'do' within the relationship. Instead, in telling their stories, I judge them to be giving something of themselves, revealing their personal understanding, feelings, beliefs and values, so that the interview is, in itself, a social and linguistic act with transformative potential. In this study I want to spotlight the mothers' lived experience through the interpretation of the meanings carried in their words rather than exposing any function intended by them.

2.5   RATIONALE FOR THE USE OF INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

The philosophical arguments underpinning IPA sit well with my own theoretical position and desire to capture and interrogate the mothers' account at many different levels. However, several other options were considered when contemplating the most suitable qualitative approach to address the aims of the research.

2.5.1   GROUNDED THEORY METHODS

Grounded theory methods, arising from sociology and the ideas of theorists such as Glaser and Strauss (1967), have much in common with IPA.   Both offer an epistemological flexibility that is attractive across disciplines, are interested in individual experience and provide systematic ways of producing an interpretative thematic analysis of the collected data. However, grounded theory has a broader remit than the exploration of individual experience, since, although inductive, the researcher develops empirical links early in the process and uses the analysis to generate theoretical claims of explanation around the experience. It may have located and explained the women's experience of the relationship in terms of social-relational theory of disability or expertise or against a social learning backdrop for instance. While Grounded Theory can capture the social processes which account for the experience, IPA, perhaps because it has been developed as a psychological tool, is particularly able to engage with the nuance of individual experience, the focus of this study.

2.5.2   DISCOURSE ANALYSIS

The critical realist perspective brought to the study privileges language as a medium of influence so it seemed fitting to consider approaches that would attend to the linguistic elements that may drive and shape meaning making. Discourse analytic approaches grew as a challenge to the cognitivist assumption that language could provide a direct route to the individual's cognitive experience. They asserted language as a social act,

'orientated' depending on the context in which it was used and requiring contextual interpretation.

While IPA is interested in individual understanding of a phenomenon, Discourse Analysis focuses more sharply on how that meaning has been constructed through social engagement. It is more interested in the performative and functional aspects of the language used. What people are doing with their words, for example denying or persuading, is more important than the cognitive representations and schema behind them. Analysis therefore leans toward the understanding of the function of that act rather than the description of the experience. In this study for example, the mothers might have used language to highlight their own expertise to the researcher or to highlight the affective impact of particular relationships.

2.5.3   FOUCAULDIAN DISCOURSE ANALYSIS (FDA)

While still concentrating on language and how it is used, FDA focuses on how language and other discursive practices are used to maintain historical and cultural power within a society. FDA considers the positioning of individuals and the dominance of particular institutions and structures as being constructed through discourse and explores the implications of this understanding and behaviour. This again sat well with the social constructionist influences on the research approach and might have drawn attention to the discourse resources around motherhood, expertise, helping or disability that locate the women to particular positions and impact on their relationship with professionals. Such data could then have been further explored by way of feminist and disability theory and research paradigms and in reference to broader societal issues such as power and control.

The present research was designed to unveil how the women make sense of their relationships with professionals, so whilst language was the medium of engagement, the research question required an analysis of what the mothers said rather than their motivations for saying it. This is not to dismiss the influences of context and the possible intra and interpersonal drivers that might shape the function of the language used within this particular topic and particular interviews. Indeed, such influences

would be considered as informative and would be held in mind during the interpretative analysis. Similarly, while the maintaining and legitimising influences of societal institutions and practices on the position of women and on the relationship under scrutiny will be important in the analysis, the primary focus of this study was the individual inner life world, making IPA the more appropriate tool.

2.6 VALIDITY

The growing number of qualitative research methods has been accompanied by debate on how best to ensure the validity and reliability of such projects. In the absence of any agreed guidelines, this study followed those suggestions offered by Yardley (2000) as applied by Smith et al (2009, p180 – 183). Yardley advocates the quality of qualitative research might be assessed through four broad principles; contextual sensitivity, commitment and rigour, transparency and coherence and impact and importance.

2.6.1 CONTEXTUAL SENSITIVITY

The in depth literature review contextualised the study in relation to what was already known about the topic and helped generate a research question that addressed the perceived gap. The idiographic nature of the research question, in that it sought to understand individual women's experiences, demonstrates a contextual sensitivity from the onset. The open ended nature of the interview facilitated a sensitivity to the women's own concerns rather than directing them towards something which interested the researcher alone. Sensitivity to possible emotional impact meant particular attention was paid to developing a rapport and providing debriefing along with a pre designed support pack (Appendix A). Contextual sensitivity was also embedded in the individual and collective analysis which facilitated breadth and depth of understanding. Further, the use of verbatim extracts allows the reader to contextualise interpretations in order to validate their founding or to generate other possible meanings.

2.6.2   COMMITMENT AND RIGOUR

The current research met with the demand for commitment in a number of ways. The project itself required considerable personal dedication and investment. I endeavoured to make participants feel committed to by ensuring they felt respected and listened to. The research was also framed by an ethical commitment to fair and safe procedures.

Rigour can be seen as a product of contextual sensitivity and commitment but is also apparent in the thoroughness of IPA studies. In this case, I meticulously transcribed and analysed the women's accounts and generated tables of interpretations evidenced with direct quotes from the interviews. Rigorous justification for the interpretation and development of themes and the efforts to prevent interpretations that were not embedded in the data were supported by the research supervisor. Maintaining both allied and contradictory themes ensured a thorough representation of the complexities within themes and allowed alternative understandings and meanings to emerge as the process continued.

2.6.3   TRANSPARENCY AND COHERENCE

Transparency is facilitated in this study through clear documentation at all stages of the process. Smith et al (2009, p186) suggests there should be a 'chain of evidence' that leads from initial idea through to the final paper. This research can be evidenced from the presentation given at interview to join the Doctor of Psychology Programme, to the proposal, question schedule, interview tapes and transcripts, analytical notes and tables, supervisory comments, draft chapters through to the final report. Careful descriptions of participant selection, the development of the interview schedule, procedures and analysis are supported by personal, epistemological and methodological reflexive accounts. There was also a degree of independent audit through the supervisor of the project who was periodically involved at the interpretive and drafting stages.

The coherence of the research is embedded first in the appropriate fit of the research question and the appropriate application of the methodology chosen to answer it. Deliberately choosing the most robust and pertinent emergent avenues to develop broader, over arching themes also offered a logical, consistent and coherent narrative of

the women's account. This was a challenging and arduous task which called for the apparent neglect of other, powerfully illuminating accounts of areas not applicable to the research question. The drafting and redrafting of the analysis and its reading by the research supervisor also contributed to the coherence of the final version.

2.6.4   IMPACT AND IMPORTANCE

The introduction and rationale for the study outline the gap in research and the relevance of the question in terms of service delivery, user support and professional training. The research also replicates to a great extent the work of Hannam (1975) which prompted its instigation and therefore offers reflection on the topic across thirty years. I am convinced the research has a large and diversified audience and am committed to disseminating the findings from it. However, while the issue has remained important to me throughout a life time, the measure of its relevance and the impact it has, can only be validated by the attitudes and actions it generates in its readers.

2.7   PROCEDURES

The following outlines the procedures of the research project. These will be further reviewed and critically assessed in the later discussion section (pgs. 164-168).

2.7.1 SAMPLING AND PARTICIPANTS

The ideographic nature of IPA and the detailed accounts it demands, tend to result in small size research projects involving homogenous samples. Thus purposive sampling was used in order to achieve a homogenous group of eight biological mothers of children with complex disability aged between four and ten years.

I chose to research mothers' experience only since, in many instances, previous work has not always specifically identified any particular nuances or disparate experience that may be related to gender and instead report on the parent experience per se (Lindblad, Rasmussen & Sandman 2005b; Bayat, 2007). This fails to account for or articulate clearly, the effects of both the gendered social, cultural and institutional aspects of

reproduction and parenting (Pelchat, Lefebvre & Perreault, 2003) and the gendered differences in interpersonal responses and meaning making (Taylor et al., 2000).

While fathers are no doubt underrepresented in the literature (Herbert & Carpenter, 1994), I nevertheless choose to include only mothers for a number of reasons. Having already invested much of my clinical and research career in representing fathers both in practice and research, I was keen to engage with mothers in the same way. Further, given that I was interested in the nature of the professional relationship, it seemed fitting that I spoke to mothers as both the literature (Davis, 2008) and anecdotal evidence from my clinical practice suggest that it is predominantly the mother who is directly involved with services.

Only biological mothers were included as the literature suggests those in assumed mothering roles to children with disabilities, will have quite different experiences in terms of their emotional responses (Partington, 2002), feelings of competence (Eanes & Fletcher, 2006), access to support (Spencer et al., 2005) and family context (Redmond & Richardson, 2003). So in keeping with IPA's request for homogeneity, it was decided that, while worthwhile in themselves, the impact of such differences in context and experience meant non biological mothers were not included in this study.

The age range for the children reflected the desire to account for particularly emotional or stressful stages for parents (Deater-Deckard, 2004). Thus a minimum age of four avoided the often challenging initial assessment processes, which for children with complex disabilities if usually completed by age three and also allowed mothers to have experienced the involvement of practitioners over a period of some length. Similarly, the upper age limit of ten was established to accommodate the changing nature and roles of parents and professionals as the child reaches adolescence (Morris, 1999; Todd & Jones, 2005) and in the belief that an older child would have a more personal interaction with the practitioner thus changing the focus of the relationship away from the parent.

No specific definition for complex disabilities exists and practitioners and agencies may use the term in different ways and to carry different meanings. This study maintained a working definition of complex disability as a 'mixture of physical and/or sensory disability with or without the presence of a learning difficulty' as outlined in the

National Service Framework's Complex Disabilities Exemplar and Standard 8 for Disabled Children and Young People and those with Complex Health Needs (Department of Skills and Education, 2004). Criteria disallowed children with acquired disabilities so as to focus on the stories of mothers whose children shared the same chronology and context in relation to professionals and services, thus preserving homogeneity.

The plan was to recruit eight to ten participants, a number low enough to facilitate manageable degree of in-depth analysis but also affording sufficient data to illuminate similar and contrasting experience and understanding (Reid et al., 2005; Smith & Osborn, 2004). Nineteen individuals identified themselves as interested over the period of three months. Seven potential participants were excluded because the age of their child fell outside the identified range or because their child's disability was singularly physical and did not fit the criteria for complex disability. A further four did not respond following the receipt of further information regarding the research process. The remaining eight respondents went on to be interviewed.

Demographic information gathered as a means to inform and contextualise the women's experience, is presented at the beginning of the next chapter. Further pen portraits designed to offer insight to their character and personal experience are included as Appendix B.

2.7.2   RECRUITMENT

Following ethical approval, a variety of agencies working with parents of children with disabilities were contacted and asked to disseminate information about the research. Those that agreed were sent the research flyer (Appendix C). As a result, posters for the research were forwarded to potential participants through support newsletters, e-magazines and e-mailing lists with circulation estimates of between 1,500 and 80,000 regulars. Posters were also further displayed in schools by mothers and practitioners who had become aware of the research via these initial contacts. Two additional support groups contacted the researcher to request further details and they also sent details of the research to those on their mailing lists.

A further flyer, (Appendix D) specifically requesting the involvement of mothers from the Black and Asian communities, was circulated through the same avenues when nine potential participants all from the white community had been identified. Two other agencies specifically involved in supporting families from the Black and Asian communities were contacted and agreed to have flyers on their reception desk and display them in family rooms. An electronic copy was forwarded along with twenty hard copies to save the group printing costs. No mother from these communities came forward. At the time it felt important that the process was inclusive, now, with a greater understanding of IPA, I realise this was methodologically inappropriate and feel the research was better served in being more homogeneous.

Potential participants making contact electronically were sent a detailed information sheet outlining the aims of the research and what would be expected of them if they agreed to continue (Appendix E) and were invited to get in touch with the researcher if they wished to participate or required further information. All those interested made contact by telephone and were given further information around inclusion criteria and the nature of the research. All those not meeting criteria were sent a follow-up email or letter which thanked them again for their interest in the project (Appendix F).

Those individuals meeting criteria and agreeing to take part were contacted in order to arrange a suitable time and place for interview. Those who failed to reply to the information sheet were sent a further one email reminder three weeks later. The lapse of time between first contact and interview varied according to mutual availability. A few days before the planned date, the researcher e-mailed the participant to confirm that the interview was still convenient. All interviews took place as arranged.

2.7.3   DATA COLLECTION

Initial ideas of gathering written data through the mothers' use of diaries in the belief that this would allow immediate sharing of experience and would situate meaning making with particular relationships were rejected as potentially too cumbersome and time consuming for the mothers to maintain over any length of time. Further, it was reasoned that the potential for rehearsal, review and editing were likely to result in the

loss of some of the spontaneous cognitive, linguistic and emotional richness that might be generated within oral dialogue. The approach was further disadvantaged in that it reduced the opportunity for impromptu prompts or probes and was devoid of non verbal cues that may have supported the interpretative process.

Thus, it was decided that data would be collected by way of semi structured interview; wherein pre-determined questions guide structure but where additional probing and prompting allow a responsive and reflexive approach to participant observations. Such spontaneity affords a synchronizicity that can support the relationship between researcher and participant and assist the unveiling of deeper subtexts and as such, was considered consistent with the philosophical underpinnings and theoretical constructs of both Counselling Psychology and IPA in privileging individual meaning making and interpretative processes.

2. 8   ETHICAL CONSIDERATIONS

It is essential that those involved in the research are protected from harm or exploitation. The following section deals with elements considered potentially detrimental and explores how they were addressed.

2.8.1   AVOIDING HARM

All interviews were held in the participant's home. Details of the visit were placed in a sealed envelope to protect anonymity and given to a colleague with the instructions these were to be used should there be no contact from the researcher within a particular time frame. Risk to personal emotional wellbeing (Bahn & Weatherill 2012) was managed through supervision although the option for therapy as a debrief was available.

While no risk to physical harm was anticipated, the literature around parenting of children with disabilities suggests high levels of stress and poor emotional well-being (Bourke-Taylor, Howie & Law, 2010) and it was therefore predicted that the interviews could prove upsetting for some participants. The concern was addressed in a number ways. For instance, a 'debriefing pack' that contained the contact details of established

support organisations and groups offering emotional and practical assistance was created (Appendix A). An electronic or hard copy was offered to every mother who made contact regarding the research and a further hard copy was brought to every interview and left if the mother felt it useful.

Further safeguards included the mothers being made aware they could stop at any time and attention being paid to any level of distress or discomfort displayed. Opportunity was also taken to discuss the interview and its impact at the end of the session. It was anticipated that given all participants were married there would be someone to call if required. It was also thought useful to contact participants again within 48 hours to thank them for their participation and to ask if they needed signposting for further support.

2.8.2   ETHICAL APPROVAL

Ethical approval was sought and granted from the City University in December 2006 (Appendix G). The research was carried out with due consideration and in accordance with the ethical and research guidelines of the British Psychological Society Code of Conduct, Ethical Principles and Guidelines (2005) and the Standards of Performance, Conduct and Ethics of the Health Professionals Council (2008).

2.8.3   INFORMED CONSENT

The information sheet (Appendix E) was used to review and discuss the purpose of the study at the beginning of each interview and was left with the participant as it contained the contact details of the researcher and the research supervisor. A consent form which explained the purpose of the study, the nature of their investment, the recording of the interview, confidentiality was also presented and discussed (Appendix H) as was their right to refuse to answer any question without penalty and to stop the interview and request any data destroyed. Two forms were signed with both the participant and the researcher each keeping a copy.

2.8.4 CONFIDENTIALITY

All participants had given consent for their interview to be recorded and transcribed. All identifying information in the transcripts was replaced by pseudonyms. Interviews were identified only by number. Each interview was downloaded twice onto CD in order to provide a backup, wiped from the recording device and retained in a locked cabinet in my home along with all identifying information such as signed consent forms and demographic information. These will be destroyed when the research has been fully assessed and completed.

2.9   THE INTERVIEW

The first part of the interview schedule (Appendix I) was given over to getting to know more about the participant and their situation. Questions about themselves and the family were designed not only to collect demographic information in order to situate the sample and to contextualise the women individually, but also to allow space to relax into the interview. The second stage questions were about the child specifically and were designed to allow the mother to provide a sense of the child that would support my understanding and give more personal meaning to later questions.

As the aim of IPA is to portray the understanding of the participant and not to test the researcher's hypothesis, initial items in the main section were deliberately open ended and framed as 'tell me about' requests. This allowed the participants to offer up their choice of experience, upon which, the next item directed them to an experience of a different quality. So although informed by the review, the questions were designed to capture the breadth and depth of the women's experience. The approach also avoided directing the participants down particular avenues as the use of language more explicit to the review, for example trust, power, conflict, may have done and instead allowed them to reflect on experiences over time and across a broad spectrum of relationships. Questions about beginnings and endings and about how participants thought the relationship should be were included as both areas had been identified as gaps in the literature. The final content and structure was decided after discussion with the research supervisor.

I formulated a minimum of probes as I reasoned they may appear artificial and preferred to go with in –the- moment queries and follow-ups which sit more comfortably with my practice and the IPA notion of the researcher and participant constructing meaning together within their encounter. Overall I believe the questions adequately addressed the research aims and were appropriate to the women as many of the items were addressed spontaneously through the interviews.

I was privileged that the women were very willing to share both their experiences and perceptions of them. I felt I made a connection with all of the mothers with the interviews flowing well and lasting between one and two hours. A number of participants did become tearful and were offered a break. None made use of the offer and preferred to continue. All interviews were audio-taped with a digital voice recorder. At the end of the interview participants were thanked, given time to talk about the experience and were offered a copy of the debrief pack. Each mother agreed to be contacted by email next day with all of them responding that the interview had been a positive experience.

2.9.1 TRANSCRIPTION

The recordings were reviewed on a number of occasions before transcription. This allowed a familiarity with the content and established a memory of the emotional content of the engagement, both of which allowed a sense of that particular participant's experience as related in their interview.

Interviews were then transcribed verbatim, line referenced and numbered sequentially as they took place. Non verbal material such as laughs, pauses and para-linguistic fillers such as 'um' and 'you know' were noted. All identifying material including the names and titles of people, places, agencies and institutions was removed and replaced with pseudonyms. Each transcript was then read alongside the appropriate voice record and necessary amendments were made.

2.9.2   ANALYTIC STRATEGY

The analysis was designed to illuminate how the mothers experienced their relationships with professionals by way of an interpretative engagement with their narrative. Smith et al (2009, p79) identify that there is no single way of progressing the analytical stages of IPA, instead they suggest it is characterised by common, psychologically focussed, processes and principles that move from the particular to the shared, and from the descriptive to the interpretative all the while remaining committed to giving voice to the participant's meaning making. Thus each transcript is afforded a detailed line by line scrutiny in order to illuminate 'experiential claims, concerns and understandings' (Smith et al., 2009, p79). Those noted are then reviewed for convergent and divergent themes or patterns, with attention also paid to peculiarities and tone, first within each case then across the group. The researcher then engages in a 'dialogue' with the results, aiming to move from descriptive to interpretative and to generate a narrative that remains close to the text but by the same token draws down on psychological understanding and theory. It is important to establishing a coherent, auditable pathway from curiosity to conclusion which in this case was achieved following guidelines in Smith et al (2009, chapter 5).

The first interview was reviewed in a free flowing exercise that identified even loose connections with the topic.   Comments thought relevant were highlighted and observations made in the left hand margin alongside them.   The transcript was then revisited in relation to the highlighted items and potential associations between them were identified and also noted. Phrases that captured the sense or quality of the initial notes or identified theory were generated and documented down the right hand margin, again against the pertinent utterance (Appendix J).

These ideas and relevant quotes were individually noted on separate postcards and those that appeared related were grouped together into clusters representing emergent themes. Headings for these greater themes were chosen to reflect the essence of the idea and matched the original vocabulary used by the participant wherever possible. Returning to the text and audio ensured meanings generated by the interpretative process remained connected to what the mother had actually said and that items of importance had not

been overlooked. Identified themes with their constituent quotes were organised onto a Interview One subtheme spread sheet (Appendix K). The same process was followed for the next and subsequent interviews, finally producing eight spread sheets of subthemes, their supporting data and corresponding themed bundles of quote cards.

Within the process, text that appeared to match previously identified themes was noted under already established headings. Novel or divergent ideas were given titles and previous interviews were reviewed to see if these had been missed before and if so were written on cards, added to the relevant bundle and noted on the subtheme spreadsheet for that participant. A final sifting of the spreadsheets allowed quotes that failed to fully fit their affiliated theme to be discarded, realigned or used to generate new themes. The research supervisor periodically reviewed the analysis and the themes identified.

All eight subtheme spread sheets were then printed off on different coloured paper and cut along individual theme lines. Identical, interrelated or opposing first order themes were piled together and a process of physical adjustment and readjustment was carried out until all clusters had been drawn together into new, best fit subtheme groups that now contained quotes that revealed the women's individual and shared interpretations of particular aspects of the relationship. The process was mirrored with the quote cards. Discarded initial emergent theme clusters were retained separately for later review. Broader headings that captured the focus of each subtheme were generated. New spreadsheets based on the subtheme, their initial cluster components and referenced raw data evidence were created (Appendix L). This final table and card bundles therefore contained evidenced, hierarchical themes that captured the women's understanding of their relationships with professionals.

Time was then spent readjusting the cards into coherent connected third order master themes. Increasing familiarity with the text meant supported an iterative, multi dimensional approach embracing alterations upon further reflections which resulted in new ideas, alternative headings and the realignment or removal of some first and second order subthemes. Initially six master themes were constructed and titled. These were to provide the structure for the analysis. This was later reduced to four when drafting of the write up of individual themes resulted in further interpretations that illuminated connections not seen previously, highlighted subthemes that were poorly evidenced or

did truly pertain to the women's relationship with professionals. The research supervisor again supported at this stage in reviewing drafts.

2.10 METHODOLOGICAL AND PROCEDURAL REFLEXIVITY

Whilst the most enjoyable part of the process was no doubt the opportunity to meet and listen to the participants' stories, I also experienced great difficulty in separating my lived roles as researcher and therapist at that stage. I had thought I might have to resist becoming another mother in the interview and was unprepared when, in actuality, I felt a powerful desire to take on the role of therapist. I feel this came from my clinical practice which is often devoted to building resilience and self worth in parents and which meant I wanted to engage in building alternative narratives with the women. I also struggled as a practitioner when I was reminded that some of the difficult situations the women spoke of might be the experience of our service users also.

I found that while I was moved by the spirit and commitment of all the mothers, I had connected with some more readily than others. I was also aware that some individuals appeared hardier and more assertive in their approach to the professionals. I was mindful of this experience especially at the analytical stages as I did not want to have voices quietened or enunciated depending on my emotional attachment to the speaker or because of how I felt they were being heard in their own context. I am happy that all the women and their concerns are equally represented in the final write up.

By far the most difficult and demanding aspect of the research was the analysis. It brought incredible demands on time, effort and emotion. My first efforts were shaped too heavily by diagnosis which I believe highlighted that I had not disengaged from the emotive content since, while only a part of the relationship, the topic seemed especially poignant for the women. It was only following further reflection and dialogue with my research supervisor that I came to understand that I was telling my story of the experience of my engagement with the mothers and not addressing the research question. Only then did I meet the data as the researcher and not advocate or therapist.

I experienced a protective, appreciative relationship with the data, as time went on, I could 'hear' the participants' words and quote text verbatim. The combination of this, my determination to stay close to the text and wanting to make sure that I repaid the women's time and trust by giving accurate account , meant that I was resistant to 'losing' any data. I felt unbelievable tensions in deciding which quotes to use and which to leave out. My first draft was twice the total word limit.

The research portion of the portfolio has been one of the most challenging tasks in all my years of professional practice. Many times the task felt overwhelming but the privileged responsibility of telling these women's stories and the vision of the front page of that little pelican paperback sustained and motivated me.

CHAPTER 3
THE ANALYSIS

3.1 CHAPTER OVERVIEW

This chapter presents the results of an Interpretative Phenomenological Analysis of the data arising from eight interviews with mothers who spoke about their relationships with the professionals involved in the care of their disabled child. The objective is to offer the reader a rich, in-depth account of the mothers' experiences within a coherent and connected prose. Initial emergent themes were compared, contrasted and eventually collated to gave form to four main super-ordinate themes; **Expertise and Empathy, Power and Disempowerment, Conflict and Challenge, Time and Transformation.** The themes and their constituent sub themes that make up the chapter are summarised in Table 1 (Appendix M).

3.2 OVERVIEW OF THE ANALYSIS

The content of the analysis is designed to offer an insight into the meaning professional relationships hold for participants. While they were at one level connected by their experiences and had been involved because they each met the particular inclusion criteria for the research, the women are also unique individuals with different characters, motivations and approaches. Thus, while Table 2 below offers the basic demographic information gathered at the time of interview, further pen portraits of each participant can be found in Appendix B. These contain information which will not be shared at publication but will, it is hoped, bring some life and further clarity to the analysis.

Table 2 Demographic Information and Pseudonyms

	Age	Ethnicity	Marital status	Child's age at interview	No. of siblings
Abbey	46	White British	Married	9	1
Barbara	41	White British	Married	6	1
Carole	42	White British	Married	10	2
Denise	37	White British	Married	9	3
Elaine	41	White British	Married	6	0
Fiona	46	White British	Married	9	1
Gwen	36	White British	Married	9	2
Hilary	46	White British	Married	10	2

The super-ordinate themes and their subthemes have arisen from close scrutiny of the interview data. Verbatim quotes are used throughout the chapter in order to maintain a direct link to the woman's voice. These further allow the reader some insight into the linguistic scaffolds used to construct the subthemes and permits them to consider the validity of the interpretation for themselves. Not all supporting quotes could be used due to space restrictions. Choices were made so that quotes considered most pertinent to the subject, that demonstrated both convergent and divergent thought, and allowed an equitable voice for each of the women were included. As a consequence, the analysis will not be supported by quantitative standardisation. Instead, because of the idiographic nature of IPA and the researcher's belief that one voice is as important in its isolation as eight might be in their unity, descriptive phrases such as *only, a few, many, most* and *all* have been used to indicate individual or shared experiences.

In some cases, it was thought desirable to clarify or extract non relevant content from what the mothers said in their noted responses. Thus, in the quotations, ellipses (...) specify where material has been omitted; while square brackets with content ([xxxx]) identify where clarifying material has been added by the researcher. Round brackets with italicised content explain where identifying material has been replaced (*names hospital*). The quotes have been made bold and italicised in order to highlight them above the text. The source of the quotation is indicated by the name of the participant followed by the line numbers of the text as it appears in the original transcripts.

The analysis used the mothers' words to generate themes that were collated into subthemes which were then drawn together into over arching, super-ordinate themes. Each theme stands alone and is interconnected with the others in its relevance to the mothers' experience. Thus, their presentation in no way reflects any greater significance of one over another, nor does the order suggest that any particular theme was more strongly represented or supported in the data. Essentially the order was devised to permit a fluid, coherent narrative which allows the reader to travel the women's journey of understanding.

The desire to present the analysis as the mothers' story also means that the chapter does not contain any references to, or discussions of, theory or literature that might be pertinent to the topic or theme being described. Rather, these will be drawn upon in the next discussion chapter. Then the themes will be interpreted further in order to identify links to the existing literature and to explore any novel or contradictory experiences and understandings.

3.3 MASTER THEME ONE
EXPERTISE and EMPATHY

I suppose it's quality not quantity. You need somebody who has experience and understands (Carole, 461-463)

3.3.1 OVERVIEW OF THEME

One might expect expertise to underpin the mothers' experience and meaning making with regard to professionals. Yet the analysis suggests that while know-how is highly appreciated, the women also value and gain support from other, more interpersonal and relational dynamics. For example, they not only talk about the helpfulness of professionals with a specialist knowledge or skill, they also appear to welcome relationships with those who have a sensitive, empathetic approach, who invest time and effort on their behalf and who view and relate positively to their child. Their comments reveal an often complex and intricate association between these elements and suggest it

may be this interplay, rather than the quality itself, that shapes their view of the professional and the relationship. Thus they   experience experts who generate difficulties because of their perceived negative attitude and successful relationships with other, less skilled practitioners, who appear to validate their professional worth through their efforts and positive approach. The title of the chapter, Expertise and Empathy, was chosen to express the women's experience of support in both these practical and relational terms.

3.3.2   SUBTHEME A – EXPERTISE

The notion of the professional in this study might be taken as synonymous with expertise and indeed, a number of the women, like Hilary and Denise, give testament to professionals who had the knowledge and skills to support them and their child effectively:

We used to go to him at (names hospital) once a month but again, that was like reliable and we felt committed to, and he was sort of like .... expertise on legs (Hilary, 563-567)

It was a good experience in the sense we were looked after, we had the best surgeon and we had great nurses, we didn't leave her at all but it was one of the better experiences (Denise, 312-315)

One might expect that the mother would be predominantly motivated by the benefits of such expertise and certainly, on some occasions, the women do appear to register the purpose of the relationship solely in terms of proficiency . Thus both Fiona and Barbara appear to gauge their involvement with a professional in line with their expertise:

I refuse to see the school nurse. I just say what is the point? ... is she a specialist in (names disability) and incontinence to do with that? Well no. She's a school nurse. Fine, we see enough people, Jordan does not need to see the school nurse (Fiona, 909-914)

I think because the health visitor was so useless really, I refused to see [her], I sort of said I just want to come and see the GP (Barbara, 273-275)

Here it seems the lack of expertise invalidated the association, indicating that the experience of and the value given to professional relationships may depend on levels of knowledge and skills. Yet, there are other examples of successful relationships where the mothers recognise that professional's limited know-how. Gwen, for example, refers to relationships that feel positive even though she believes she holds a higher level of relevant expertise than the practitioners involved:

I've got on quite well with Speech and Language therapists; although I almost hate them with a passion [laughter] Oh I shouldn't say that. But because my main thing is facilitated communication and there's only such a little bit learnt (Gwen, 629-632)

Denise offers examples which illustrate the complexity well, within one relationship the lack of expertise resulted in complete withdrawal while in another it appears to be viewed as inclusive and affirmative:

She was saying 'Do you think there is any difference at all? 'Blimey, if you don't know! You're the professional, I don't know' and I just said' No I don't think we'll be coming again really' (Denise, 1127-1131)

[She said] 'You just tell me, you phone me up and you tell me when you think she needs an operation' ... It was like, well, it's down to me. Somebody trusts what I feel about my daughter, so that was good! (Denise, 631-633, 642-644)

Analysing the quotes that recount good experiences, with expert or not, suggests the underlying experience was relational. Hilary, for example, *'felt committed to',* Denise was *'looked after'* and *'trusted'* while Gwen *'got on quite well'* with the speech and language therapists despite their perceived shortcomings. It seems in these cases that the lack of expertise was offset by the nature of the interpersonal relationship. It may therefore be that mothers remain in such relationships if they feel they can support the deficit or where other outcomes, such as personal connection or onward access redress the balance. Similarly, one wonders if more rewarding interpersonal dynamics may

have prevented the breakdown of relationships mentioned earlier. In any case it would seem expertise is not the determining factor in whether a relationship is considered useful or not.

If interpersonal dynamics influence the success of relationships with management of non- experts, then it seems fair to say that how the professional deals with their limitations will be of some significance. A number of the women express their belief that it is best for the practitioner to admit a lack of expertise, even though, as in Fiona's experience, they do not respond well to having their skills questioned:

That just goes down like a lead balloon ... If [she had] actually said `look I've read all this and I really don't understand it, I'm going to have to get advice` fine, lovely, admit what you don't know, we all have to do it. ... I haven't met a parent yet who says 'oh no, no! I want them always to tell me they know ... an admission of fallibility goes down well (Fiona, 435-438, 462-465)

Fiona's comments imply that she interpreted the practitioner's actions as a reluctance to admit she did not know. Her comment "*we all have to do it*" and the notion that professionals strive to be infallible suggests she believes professionals think they have to be seen as the expert. She sees this as unnecessary and reckons transparency might actually support the relationship. This notion contrasts with her refusal to see the nurse as quoted earlier. It might be that she was actually not measuring the worth of that relationship but was instead using expertise to manage the number of professionals she dealt as she does say "*we see enough people*" and perhaps had an already established relationship with another professional in the same field. Similarly, Barbara's withdrawal from the Health Visitor might have been prompted because she had the GP as an alternative. It could be that given different circumstances, both would have engaged with the less competent practitioner.

It could be suggested that professionals who want to present as expert or who disguise their limitations are motivated by a desire to instil confidence in the mother or to enhance the value of the relationship for her. Given their regard for expertise outlined previously, one might have expected the mothers to embrace such a notion. However, comments suggest they can be frustrated by any facade and may interpret it as a means

to uphold professional authority, therefore experiencing it as detrimental rather than facilitative to the relationship as Elaine explains:

[it's about] 'being open and honest, admitting your limitations ... You know, not hiding behind any uniform or professionalism (Elaine, 713-714)

It seems that while the women's understanding of their professional relationships incorporates expertise as a valued element it is not considered to be the sole determinant of success. Instead, they seem to appreciate the interpersonal connection and it is this that can often influence their experience. If this is the case then it would seem to have far reaching consequences on the nature of professional training, the qualities that are valued within notions of expertise and in how mother/ professional contact and context is construed since perhaps the personal rather than the professional becomes elevated within the relationship. It would also be vital to understand what it is about particular qualities that support the mothers. The following three subthemes further explore the mothers experience and meaning making around the interpersonal connection.

3.3.3   SUBTHEME B –EMPATHY

One of the relational aspects the women appear to value is the professional's ability to show empathy for their situation:

I didn't particularly want anyone to come up with any solutions although that would have been nice ... I didn't want sympathy, I wasn't, you know I don't do martyr, I can't be bothered with that, you know. I just wanted someone to listen and maybe empathise a bit (Elaine, 1741-1743, 1753-1755)

Elaine's comments again suggest that expertise is not the sum of what is sought from the relationship. Instead it seems that an understanding of her predicament supports her even when answers are not forthcoming. The women appear to have varied experiences of empathetic responses from professionals. Hilary and Denise both recall positive experiences of professionals who really understand what a difficult time they were having:

The fact that this was an amazing adjustment, a difficult adjustment, and not what we would have chosen for ourselves, ever, was acknowledged (Hilary, 503-506)

The paediatrician that we saw locally initially he was just lovely, he was very good at saying 'I totally understand how difficult this must be for you' just little things to let you know that he recognised what you were going through (Denise, 199-204)

In contrast, Carole describes a practitioner she feels was totally unable to show empathy:

The only words that I use to describe her is 'witch'...Oh, she was just the most awful person. She hadn't got any empathy. She hadn't got any understanding (Carole, 720-723)

The women also reflect on what it takes for the professional to be empathetic. Denise and Gwen seem to feel that it may help if the professional is a mother herself:

She said don't worry, I have a daughter the same age, I'll treat her like my own...she came from a perspective of somebody who really understood from a mother's point of view so that does help (Gwen, 977-978, 984-985)

Whether it helps I don't know because she's got 4 children...She seems a bit more in the real world. She can see more than just a medical picture she can see the bigger picture (Denise, 238-242)

However, Fiona seems irritated by professionals who think they understand her situation through their own mothering experiences:

[The] biggest mistake that a lot of professionals make...when they tell you about their children, my child was like that'...'Have they got (names Jordan's' disability)? I didn't know that...oh they haven't? Are they disabled then? No? SHUT UP THEN! (Fiona, 2111-2115)

Even though she recognises their attempt to connect with her through shared experiences, their lack of insight, and therefore the potential for a truly empathetic response, seems to only emphasise their differences:

I think they want to create a link but I'm afraid it doesn't...They try and make equivalencies, which I totally see why they are doing it, to make you feel that you're not on your own, but we are (Fiona, 2127-2129)

In the same vein, Gwen suggests that an empathetic approach is reliant on professionals having a greater awareness of the differences in the nature of mothering children with disabilities:

I think a lot of people go into jobs really with no awareness at all of disability or the problems or the emotions, everything around the disabled child and family... people going into jobs need to kind of get the full, the bigger picture (Gwen, 190-193, 205-206)

Again Gwen's comments highlight the intricacies of the relationship between the expert and interpersonal aspects of the relationship as it would seem she is suggesting that knowledge of disability, of the experience of mothering children with disability and the impact of a disabled child on the family would go some way to supporting real empathy within the situation.

3.3.4   SUBTHEME C -
THE PROFESSIONAL'S ATTITUDE AND APPROACH

The previous two sub themes suggest that while the mothers value expertise in the relationship this is not all they look for or appreciate. It seems on some occasions at least, the character of the person, their understanding of the situation and therefore the quality of the interpersonal relationship, is considered more important than any expertise the professional brings. Hilary makes this clear when she suggests that she sees benefit in a relationship with someone totally lacking in expertise but who,

nevertheless, works with a positive attitude and a genuine desire to help. In contrast, she feels she would not engage with someone pretending to be something they were not:

If I know they have good intent, I can cope with them being like really, really inept, ...once I found out that he really, really was, you know, positive actually and genuinely interested in the right result for us then I was fine with it (Hilary, 1224-1229)

I need to know that I'm dealing with a human being, warts and all and then I can cope with almost anything. But someone who's like disguising who they are, or holding back who they are, or pretending to be perfect, like well, why would I want to give you the time of day? (Hilary, 1559-1564)

Indeed, Denise goes further suggesting that even when expertise is afforded; the character of the professional is paramount:

They're all trained and qualified, great, but the person that they are can make or break something (Denise, 1158-1160)

The women told many stories of how their experience of the relationship was impacted upon by the professional's personal attitude and approach to them, their child and their disability. Barbara, for example, appears to see one successful relationship in these terms:

I have to say I think he's probably got it almost right, [he's] got quite a nice attitude, you know, he manages to sort of be pleasant and quite understanding (Barbara, 339-343)

Comments from Denise reinforce the notion that the personality and character of the professional is significant to the mother and certainly her remarks indicate a broad and experience:

At the very beginning [there] was the paediatrician that specialised in babies and he was brilliant. He was really lovely and supportive (Denise, 182-183)

[then you go to] the downright arrogant shit that just sits there (Denise, 569-570)

The interviews offer some insight into those personal qualities the women find helpful and those they find difficult. For example, Abbey appears to value attention and consideration, while Elaine appreciates determination and creativity:

No matter how long it took, if we were there till 5.30, he would go through that whole list of questions and he would deal with them with me and he was just so supportive (Abbey, 492-495)

I was just absolutely devastated but then the cardiac surgeon came in and he said 'I just want to try something more.' (Elaine, 274-276)

In these examples the professional's attitude and approach seems to offer the mothers a sense of investment. Abbey appreciates that the consultant invested time beyond his working hours while Elaine valued the surgeon trying something else that did in fact save Sarah's life.

The attitude and approach of the professional seems to be especially significant in particular circumstances. For instance, all of the mothers comment on how professionals pass on the results of assessment and diagnosis. Their remarks suggest that how they experienced each disclosure is impacted upon by the professional's manner and perspective. Elaine and Hilary note how well the professional delivering the news about their baby's disability had approached the situation and the life time impact it held:

I'll never forget his words because they were so positive compared to [what] other mums have had, because he said, he said 'you've got a beautiful daughter... he said, but I think she's got (names disability)'. (Elaine, 60-64)

For a long time I used how the consultant gave us the news about Darryl having (names disability) as my bench mark for delivering bad news well (Hilary, 1581-1584)

In contrast, Denise and Gwen feel the news of their child's disability was delivered in a very insensitive and thoughtless manner with little investment or understanding of the impact on the mother of hearing such news:

It felt like, oh a bit of paper. Here's Mr and Mrs. (surname). That's the results off you go, see you in six months. There was no kind of recognition of, I don't know what it was, maybe a recognition that these situations are quite emotionally difficult (Denise, 192-196)

She said `well er, yes erm, I've had a look at the report and she said yes, I'm afraid to say today (names mother), that you have been right all the time, she's got significant brain damage bla bla bla bla bla ...we'll put down this drug and ok well we'll see you in 2 weeks time' ` (Gwen, 306-309, 311-313)

Again one is reminded of the women's experience of a lack of empathy and the suggestion that many practitioners really do not understand the consequences of having a disabled child. Alternatively, it may be that the professionals do know and are keen to play the difficulties down. However, it seems that while the mothers value the professional ability to be both sensitive to and positive about their situation; this does not mean they wish things to be hidden or sanitised however. For example, Denise recollects how she apparently welcomed the brusque delivery of quite pessimistic judgments:

[The paediatrician said] 'There is no answer. There is no miracle. You can't go on a week and then it's all going to be better.' So she was really good. It just put a bit of reality in and helping us to see a bigger picture, which is what I've held onto (Denise, 250-253)

She was brilliant! A few years ago, she sat us down, she had the x-ray and said I'm not even going to give you the results because you don't want to know them (Denise, 628-631)

Denise may accept what appear to be quite insensitive and pessimistic approaches because the honesty was construed as helpful and protective and allowed the family to

reflect on the likely outcomes of various treatments. Any difficulties seem to have been diminished by the protective way in which the views were delivered. However, Denise's acceptance of the second professional's reluctance to share results seems surprising as she previously expresses annoyance about a similar experience:

Nobody talked to us [in the clinic] and we didn't get any results. We didn't get anything! (Denise, 187-188)

Perhaps in the clinic, Denise's anger was generated by feelings of exclusion and her desire to know the results was more about establishing herself as part of the process. Conversely, the consultant was reflectively engaging her and seemingly protecting her from distress. It is perhaps because she felt no disempowerment that she sat more comfortably with this decision not to share. It seems interpretation of the professional's intent is important in the women's understanding of their approach.

Some of the women recall very difficult relationships with practitioners whose approach they found hard to deal with. In some cases the relational difficulties appear to be quite open and blatant:

The consultant that we were sent to was such an outrageous man it was just awful, it was just quite shocking really (Denise, 646-648)

In others they would appear a little more subtle:

The principal doctor that we saw, he was quite nice and chatty but he was, there was always this sense of being a bit patronising (Barbara, 349-351)

These quotes suggest the mothers are sensitive to the professional's manner beyond what it is they are offering in terms of information and support. They appear to interpret this as a guide to how they professional perceives them as Hilary does when she recalls her experience of one particular relationship:

We were always right. We were always affirmed. It was always about building on success. It was always about us, you know. There was a reliability. There was the

punctuality. There was enthusiasm... there was the boundaries. There was like the optimism and you know there was actually trust in the relationship (Hilary, 517-522)

Hilary shows how impactful a difficult approach can be as she becomes tearful shortly after when her thoughts turn from this successful relationship towards others that did not work out so well:

[Researcher-You seem a bit upset Hilary?] Oh well it's because we're going to get to the contrasting experiences soon (Hilary, 510-511)

It is difficult to know whether her negative experiences were more common than those which were positive and this is why Hilary becomes overwhelmed. In any case, it is clearly seen that those negative experiences carry sufficient weight to erode the positivity she felt looking back on the good.

The women seem to make sense of difficult attitudes and approaches in a number of ways. Elaine suggests the professional's attitude and approach may be compromised by the systems and culture of the organisations within which they work:

I think everyone goes into careers in the medical profession with the right, you know, mindset. That's why they want to do it ultimately, but then you get embroiled in the politics of and the finances of and also you become a bit institutionalised and you get into this 'othering' scenario (Elaine, 896-901)

The sentiment that professionals can become "*institutionalised*" and somewhat removed from the client highlights the apparent struggle the women experience in making sense of what professionalism is. So, while Hilary celebrates a positive and collaborative relationship built on boundaried professional behaviour, Carole experiences it as a barrier which can negate any personal connection:

[Some professionals are] very stand offis ...and I know they have to be professional and you have to keep that, you have to sort of have that barrier almost but they're human, just be like a normal human being! (Carole, 393-397)

It may be that the kind of "*professional*" attitude Carole is speaking of relates less to principled practice and emotional resilience and more to assumed practitioner authority, which again suggests the professional's character and attitude is important even within what might be considered to be a professional approach. It is also interesting that the mothers do not appear to have considered an alternative interpretation that, rather than a face saving strategy, this type of detached approach is the professionals' way of dealing with feeling deskilled and powerless to help the family. This would suggest a far greater degree of humanity than Carol suggests and may be the meaning behind Denise's comment:

Maybe it's because they see so many they can't afford to be going down that road [emotional connection] probably, they have to remain very detached, I do understand that (Denise, 197-199)

3.3.5   SUBTHEME D
THE PROFESSIONAL'S RELATIONSHIP WITH THE CHILD

The interviews reveal that it is not only the relationship between mother and professional that influences the experience, it is also that between professional and child. Indeed, for Fiona, it seems how Jordan relates to the professional overrides her experience of them and will ultimately determine whether she engages or not:

Definitely if he didn't like them we would have a problem because I would side with him [even] if I really liked them (Fiona, 1933-34)

A number of other comments reinforce the notion of an association between how the child views the professional and how the mother views them. These suggest the mother's experience of the relationship may itself be positively and negatively influenced by the child's experience:

My most positive [relationship] has been with speech therapists ...[the] one at the school, I, erm, I'm just really pleased that Joshua really loves her and she's really patient and she seems to be doing really good work with him (Barbara, 514-517)
When you have a play specialist that goes to every child in the ward and gives them a book and gives them crayons and they completely ignore your child and you're sat with them (Gwen, 223-226)

Gwen's comment "*and you're sat with them*" would seem to suggest that the practitioner's attitude to Katie resulted in Gwen feeling ignored too. It is not difficult to see how a mother would be pleased and enthusiastic about a professional who engaged well with their child or be aggrieved and feel personal affront at them being ignored. Yet the women's experiences suggest that this is a common occurrence for them and that their children are not always given due consideration. A comment from Hilary captures the idea that the mothers feel the child is an integral part of the working relationship while professionals may not :

They don't see it as a triangle of relationships; them, the parents and the child (Hilary, 724-725)

On the surface it may seem that this experience is based on the lack of inclusive practices or understanding that a child can contribute. However, there is a sense of something more than this through the interviews with the mothers suggesting that some professionals actually do not see their child as a child but rather view them in terms of their disability. Denise's poignant words describe her delight when Emily received a warm, personal welcome from a consultant:

We went in and he walked over to Emily and he went straight to her face and said `Hello darling, I bet you're enjoying a nice morning off school` and oh my god! Somebody has actually recognised that she is a live human being ....he was just so lovely! (Denise, 829-835)

Gwen reasons that the disability becomes paramount because the professional sees the child from a very different perspective to the mother. She describes how distressing it is for her to think of her child being seen in this depersonalised way:

What I found the most painful and the hardest to deal with is when I've gone into see somebody [and I see her] ... giggling and laughing and smiling at me ... and then suddenly saw how her head flopped, dribbling and thinking that's what he sees, and that's all he sees (Gwen, 1518-1526)

The result of the professional's understanding may mean they overlook the nature of the mother/ child relationship. This would go some way to account for a professional's open negativity and disrespectful attitude towards the child in front of the mother:

He said `What? You're actually having another baby... Don't you think that's a bit irresponsible, you don't know if they're going to have the same problems as Emily`. I said 'Would that be so awful?' I don't know where it came from because I actually wanted to cry, `Would that be really awful to have another child like Emily, Is that how you see her, just as completely awful, dreadful?' And he didn't say anything else (Denise, 588-596)

I could just tell straight away that he was dismissive of Sarah. He wasn't talking to her and yet we'd just been to the audiology technician who was wonderful! ... I just didn't like his attitude at all and that was just his whole body language and everything. I don't know if it was because he was overworked or if he had a prejudice (Elaine, 757-760, 795-799)

It is difficult to imagine the pain a mother would experience in perceiving her child to be ridiculed, ignored or viewed only in terms of their disability. It would seem quite understandable that their interpersonal relationship with the professional concerned would be blighted by the experience. Elaine tries to make sense of the experience in terms of the professional's personal context and understanding while others, like Denise and Barbara follow Gwen's logic and understand in terms of professionals seeing the child through a solely academic or medical lens:

We get the whole batch of young professionals eager to do their job, but haven't got a bloody clue about how to treat people, they just say `oh that's a great case' type of thing (Denise, 566-569)

[The consultant was] quite academic about it all you know, about the information, quite happy, he seemed sort of excited ... couldn't even conceal the sort of academic glee in sort of explaining 'this is permanent damage' (Barbara, 384-386, 390-391)

Both mothers appear to see an intellectualised, skills based approach as reducing awareness of what the situation might mean for the family. It would seem as if in these instances the professional role may impede the role of helper, relating back to the assertion that the professional can become '*institutionalised*' or that their '*professionalism*' may create a barrier between them and in this case with the child. Again the suggestion is that the women seek a professional approach that draws on both the ability to empathise, connect and support the mother as well as academic or technical expertise. It would seem that the professional's attitude to the child is understood as a reflection of the kind of person they are and used as a barometer of their understanding and attitude to disability.

3.3.6 SUMMARY OF EXPERTISE AND EMPATHY

The first super-ordinate theme, **Expertise & Empathy**, reflects the mothers' understanding and experience of what they value in their relationships with professionals. It indicates that while the mothers welcome expertise and know-how, they also recognise and appreciate a positive, empathetic approach and a professional who relates well to their child. The women's stories suggest this is not always what they experience. The content of the theme also highlights the entanglement of the desire for a good interpersonal connection and the need for help in managing their child's complex disabilities. It suggests that the interplay of these experiences uniquely impacts on the women's experience of the relationship, the meaning they give to it and how they invest.

3.3.4 MASTER THEME TWO
POWER AND DISEMPOWERMENT

Maybe because they've spent so long training or whatever [they] have a bit of a jumped up image, you know, 'You're coming here asking me for something and I can say yes or no' (Carole, 1007-1011)

3.4.1 OVERVIEW OF THEME

This chapter is designed to reflect the women's experiences of professionals laying claim to power and their sense of limited control as a result. It evolves from mothers' beliefs that professionals assume authority and control over contact, information and communication within the relationship. It also addresses their understanding of how this claim to power is supported through perceived social expectations that the professional will take charge, and by way of particular props and system processes that serve to maintain such constructions.

The experience that professionals assert authority within the relationship is paralleled by the women's descriptions of their respective disempowerment. They identify that their lack of control and expected compliance reduces their opportunities to influence dialogue and outcomes within the relationship. They also recognise the restricted influence they have on who they work with, the nature of the contact and the longevity of the association. The mothers also identify that their lack of understanding of their child's disability, their inexperience of the support systems, and the emotional impact of the situation can further contribute to reducing their ability and motivation to address such power issues. Moreover, many of them recognise instances when practitioners themselves were similarly disempowered in the same way and how this further serves to disempower them in attaining what they feel they need for their child.

3.4.2   SUBTHEME A – POWER GIVENS

The interviews revealed the women's understanding that professionals expect to have authority and control simply because they were the professional;

[It was] very much you know `I'm God in my ivory tower and you'll do as I say and not question it` (Abbey, 710-711)

Even further, some of them experienced times when they felt the professional's position was so powerful that their contribution, even their presence was negated;

I was treated like an idiot ... Mum stands at the back whilst the professionals look into the cot (Fiona, 1333-1335)

While one can imagine how distressing being excluded from decision making around your child could be, it appears that this would be doubly difficult and frustrating for these women given that the previous theme illuminated their drive to gain knowledge and understanding from the expert.

The mothers appear to understand the situation in terms of a broad social acceptance that professionals are given power because they are better equipped with knowledge and skills:

I just think it's a natural thing ... they're trained, this is their job, they've told me so it must be right (Fiona, 2189-2191)

They're the professional, they're trained and they're qualified and I'm just a mum, that's how I feel (Denise, 798-799)

Both quotes suggest an acceptance that the training and knowledge afforded the professionals means they are the better placed to identify the difficulties and needs arising from their child's condition. However, one can see that while Fiona's comment

describes what she sees as a social norm without attaching herself to it, Denise seems to fully subscribe to the notion and as a result reduces her own standing to "*just*" a mum.

It is interesting to note Elaine's experience since she herself had a professional background that afforded her extensive skills and knowledge relating to Sarah's disabilities. One might expect that this would facilitate her inclusion in treatment and intervention decisions. This was not always her experience however as, although she made known her expertise, she still had to deal with those who saw themselves as in authority because of the position they held;

When I used to question them about [treatment Sarah was receiving in hospital] they'd say I am the nurse (Elaine, 389-390, her emphasis)

In as much as the experience of being disempowered and excluded may frustrate and upset a mother, it also appears to have a secondary effect in that it serves to undermine notions of their own authority . This may be so robust that it can mean they accept the situation, even when they feel uneasy, as Denise and Barbara recount:

I went along with it because, because it was like well you're the professionals, you know what you're talking about, I'll go along with it but I was worried (Denise, 334-337)

We should have put our foot down at the start ... but you do think 'oh the doctors know best' (Barbara, 445-447)

A number of the women identified that even in the instances where they did question the professional's judgement, those around them held fast to this belief that 'doctor knows best';

My husband was getting really cross then. He was like going, 'Gwen, they are doctors! They do know what they are talking about!' (Gwen, 260-262)

Of course, in such circumstances, one could understand the response as a desire to accept that nothing was wrong. However, Abbey highlights her experience that even given when the difficulty was recognised, the lack of answers was perceived to be her failure and not the professional's:

So constantly when we were coming home with no answers we were being questioned from relatives from within the family, by friends, by neighbours, by other people that we worked with, who said `well your obviously not seeing the right doctor` you know, `somebody who knows what it is`, or `you're not seeing the right person (Abbey, 404-410)

There was evidence of differences in how the women accept and adhere to such power givens. For example, Elaine and Fiona, while recognising the assertion of authority, appear to redress any imbalance by way of their own perceived aptitude:

I had some medical knowledge. I didn't feel disempowered (Elaine, 342-343)

I've done it before in a completely different life and so I'm not bothered ... I don't mind meeting a minister or you know, a bin man, it doesn't matter to me, I don't feel disempowered by authority (Fiona, 543-546)

Abbey, on the other hand, appears to dispute such power givens not as a consequence of her own standing but on the premise that a belief in the omniscience of medics is rather out of date:

[what] people older than our generation always believe in is that the doctor knows everything (Abbey, 403-404)

While these women exploit their understandings of professionals and themselves in order to provide some equity in the relationship, Denise, it seems, steadfastly adheres to the constructs passed onto her, despite her disquiet in how she is treated:

They're not going to listen, they're not going to want to know, I know that I'm a good girl and like, because mum's a nurse, she's always passed on consultants regards, doctors regards, you have to totally respect them (Denise, 788-792)

It is illuminating that so powerful is Denise's belief that she talks about being a "*good girl*" as if she were taking the role of a child while viewing the professional as the adult in the relationship. This could suggest that in contrast to Abbey, Fiona and Elaine, Denise believes she is subject to the professional's power, making her more open to accept the authority asserted by them.

The subtheme draws attention not only to the power capital of knowledge and skills within the relationship, but also to the women's understanding that such capital is often translated into controlling and condescending attitudes. This appears to generate a barrier to them both learning about their child's disability and being involved in their care. One might guess at how frustrating this must be, since not having a position of influence is likely to impact negatively on their contribution to choices and decisions made on behalf of their child. Perhaps even more striking is that those mothers such as Fiona, Abbey and Elaine who recognise and challenge the power imbalance still struggle to be heard and appreciated. It appears that despite their faith in their own assertiveness and personal authority, they fail to redress the power imbalance. This raises concerns for those mothers such as Denise and Barbara, who appear to give a greater credence to professional authority and who, as a consequence, feel they have no voice at all. Such difficulties, especially when the mother feels at odds with the professional's decision, are likely to provoke anxiety, challenge self esteem and reduce self confidence.

3.4.3 SUBTHEME B – MAINTAINING POWER GIVENS

3.4.3.1 POWER PROPS

Whether or not they accept professional authority, the women appear to interpret certain props and processes as designed to legitimise and maintain the elevated power position

of professionals. For instance, Elaine comments on her belief that professionals exploit the power inherent in the clinical costume:

I try to take the power off the white coat ... they do use that a bit (Elaine, 743)

She and Abbey seem to see titles in a similar way and appear indignant at the power and authority utilised through them:

(You should) not assume that because, you know, you're trained in the field that you know everything ... I hate the words ... specialist or expert (Elaine, 878-881)

Very sort of in the, you know, 'I'm the consultant, I know best' manner of things (Abbey, 720-721)

While those like Denise, who may accept the professional's authority, could be expected to regard such props as validation, Elaine however, is not so persuaded:

I don't have white coat syndrome at all (Elaine, 343)

It seems that Elaine in particular sees through the claim to power that such props give professionals. She appears not only to disregard their status markers but seems to resent the use practitioners make of them. This could be because she herself at one time wore professional garb. It may be that her familiarity with the costume and her knowledge of herself as person wearing it, allows her to see beyond the prop to the people, thus dissipating any power attached to them. .

3.4.3.2   POWER OVER ACCESS

Many of the women identify a struggle to access services and individuals they feel are needed to support their child. They appear to interpret such barriers as affording the professional control over contact, thus placing them in a place of disempowerment. This appears to be particularly aggravating for Abbey who uses a powerful metaphor to describe her experience:

All sitting around in their little ivory towers and all those ivory towers have shark infested pools underneath them (Abbey, 692-694)

Abbey's notion of 'shark invested waters' may represent a belief that professionals want to keep clients out of their world. This perhaps links back to earlier comments about the barriers 'professionalism' can create. In any case, it expresses clearly Abbey's understanding that professionals actively resist engaging with parents.

Denise recalls an actual experience of such barriers. Emily who had just been discharged from a baby unit, had taken turn for the worse. Denise wanted to speak to the consultant who had treated Emily there in order to seek his advice as he knew her best:

We tried to go back [to the baby unit] but they said no, you've been discharged **and** *you think,' Where do we go now? What the heck? Who are we supposed to see now?' (Denise, 440-443)*

Denise's words carry an urgency and desperation even though she is discussing an event that had occurred nearly eight years before. One can feel the sense of panic and powerlessness generated by not getting access to the professional and not knowing from where else she might seek help. It also feels significant that Denise seems to have assumed her and Emily's relationship with the consultant would continue whilst procedures appear to have disallowed it.

Barbara experienced a different kind of gate keeping at a more personal level. She had researched Joshua's condition on the internet and had found a particular intervention she thought might be useful. However, when she asked if she could forward it to the professional via email;

He was very much 'no I'm not having patients emailing', he didn't like patients emailing him; it does seem a little bit, you know, ridiculous really in this day and age (Barbara, 365-369)

She appears somewhat incredulous that "*in this day and age*" a consultant was not prepared to correspond with her. It may be that she is referring to a disinclination to

embrace new communication technologies but it appears more likely that it was his maintain a barrier to open communication that had amazed her.

Abbey's further comments would suggest that she too has experienced professionals similarly controlling the nature and quality of the engagement:

You've got your allocated slot of 8 minutes or whatever it is and you were very much dealt with and out the door (Abbey, 499-501)

Abbey's conceptualisation of a timed "*slot*" in which to engage before the next person comes along conjures up images of the habitual and mechanical routines of a factory production line. This notion of a perfunctory approach is also reflected elsewhere in hers and Denise's interviews:

You're just one of a number of cattle in the market that day to be dealt with and it's roll them in, roll them out (Abbey, 430-432)

We felt like a number really (Denise, 186)

The notion of an allotted slot of time with a practitioner, or barriers to personal contact with professionals is probably familiar to most and likely to be construed in practical terms. However, in this case, it seems the mothers take it very personally, perceiving the professionals to be rejecting them or perhaps not even seeing them as people at all. It could also be suggested that part of their upset is because in rejecting them, the professional also rejects their child, perhaps seen as a further extension of the negative appraisals discussed in subtheme 1.4.

In any case, the situation seems to jar heavily on the mothers who would seem desperate for information or advice or who want to share what they know and feel about treatments and interventions. This is all the more significant when one recognises that the mothers may believe this professional will have insight no one else has and that they might hold the answers. It is perhaps not surprising then, that they seem perplexed by a professional attitude that makes them invisible and reduces the opportunities to

communicate and collaborate while they seek exactly that in their mission to support their child.

3.4.3.3 POWER OVER INFORMATION

The women also appear to hold the belief that many professionals take ownership of information. They seem to interpret this as the professionals withholding information that might be of benefit to them and their child, in turn thwarting their desire to understand their child's needs and reducing how they can contribute to their care. Abbey and Hilary observe:

You can come away quite frustrated, disappointed and with unanswered questions which you've got to wait another 3 or 6 months to get answered (Abbey, 797-799)

He asked me too many questions about my views and wouldn't tell me any of his (Hilary, 1232-1233)

It is worth noting that Abbey was frustrated at not having a voice within the appointment while Hilary seems to feel she was given too much of a say. It seems there is a need for a balance of contributions from the professional and the mother. Further, both mothers appear to automatically assume the professional has knowledge to give. There is no indication that they might understand lack of sharing as a consequence of the professional simply not knowing. Instead, they seem to experience the non-communication as the professional taking ownership of information thereby maintaining control in the situation.

A complicating aspect is that the mothers do seem to experience an element of ambivalence around the access to information about their child's condition, for, whilst they voice a general desire to know, they also express experiences of apprehension and trepidation around the sharing of it:

We got scared a lot by the medical information ... Knowledge has just brought me fear and anxiety, trauma and has kind of stopped me actually getting on with my life (Barbara, 474, 480-482)

It seems important that Barbara refers to "*medical*" information since their experiences suggest that the degree to which information empowers them is not only in that it is offered but in how it is presented. Abbey and Fiona provide examples of 'professionalised' information that only served to generate more questions:

I honestly thought they hadn't told me half of Tommy's condition ... the letter had not been put in layman's terms, so that could have been very frightening for a lot of families (Abbey, 356-358, 360-362)

He used words that he understood, in a scenario that he understood that we didn't know anything about, what does that mean? (Fiona, 1236-1238)

In these instances the professional, in using language alien to the mothers has, intentionally or not, maintained a power imbalance even in the sharing.

Sometimes it seems like the professional does not have any understanding of what traumas and distress their words may cause. It would seem the power they hold can be measured quite differently between mother and professional. Gwen's description of being given information also suggests that, in the first instance at least, she experienced it as more emotionally debilitating than empowering, the effect of which is sometimes still felt ten years later:

I got up and I was just gob smacked ... and I walked out completely stunned ... I've told that story quite a few times and now I'm quite calm about it but sometimes I get upset (Gwen, 312-316)

A story from Barbara captures the further complexities of this different understanding and illuminates how the sharing of information relating to the child's disability requires care and consideration:

I think he almost forgot that I was the mother because I was asking questions about the brain scan he said 'oh actually I've got them on CD, we'll go and have a look at them on the computer if you like ... I just suddenly thought don't you realise I don't

want to look [laughing], I don't want to look at my sons brain dissected' (Barbara, 377-382)

Barbara appears to make sense of the situation by assuming her questioning had momentarily duped the professional into thinking she was a fellow practitioner, the implication being that he was not used to mothers asking questions and that he may not have shared the information had he remembered who she was. While her understanding of why he would not have shown them to a mother is not clear, it would appear she feels both came to the same information from diverse angles and distinct understandings of the power the results held. This would add further support to the notion that different perspectives can cause issues and tensions in the relationship.

Barbara's story again brings attention to the professional's ability to provide an empathetic approach to the mother. Knowing the pain and anxiety such pictures might cause Barbara could have influenced the professionals sharing. This suggests that in order to make such decisions the practitioner needs not only to have sufficient insight into the bigger picture of the experience of having a disabled child, they need to know that particular mother well enough to understand her needs. Further, it is likely that the mother will only trust the practitioner with such decisions when the relationship feels supportive.

This subtheme has dealt with the trials that power imbalances in professional relationships generate for mothers. It suggests that they perceive particular notions of what they should expect and how they should behave toward practitioners. It highlights professional control over access and information and explores the mothers' experience of both. It has been suggested that the power imbalance thwarts the mothers' attempts to understand and support their child's needs and that this causes them anxiety and upset. While it cannot be said if the professionals they meet actively exploit the props and systems that serve to maintain power, it can be assumed that addressing them will facilitate the mothers to be more actively involved. This will be discussed at greater length in the next chapter.

3.4.4 SUBTHEME C– BEING DISEMPOWERED

While Elaine and Fiona assert that they are not intimidated by professional power, Denise's attachment to notions of their authority and her experience of their challenges and attitude toward Emily, seem to generate an upsetting expectation of disempowerment:

I feel sick, I feel sick, because I feel like whatever I've thought, whatever I've tried to find out it won't matter at all, because actually they're going to make this judgement and tell me what they think (Denise, 785-788)

The quote suggests that Denise is not so much anxious about meeting the professional themselves but rather she feels sick at the thought that anything she has to say will not be listened to despite the fact it seems she has made an effort to find things out. Her expectation is that whatever she says, she will be over ruled. Such expectation of inequality and lack of influence may taint new alliances and may also diminish the mother's ability to contribute to the dialogue and decision making processes even if offered the opportunity.

While the women recognise the disempowerment that results from professional status and approach, they also allude to influences which suggest an inherent powerlessness generated by the situation itself. Some of these influences will now be discussed.

3.4.4.1   DISEMPOWERED BY OVERFLOWING EMOTIONS

The women often talk about the emotional and psychical consequences of realising their baby had a disability. Barbara recalls:

At one point I actually went to her [the GP] crying because I'd started fainting from the stress of it all (Barbara, 278-280)

It seems that such depleted personal resources and overflowing emotion may further disempower the mother as she resists exposure to any negative or challenging professional. Carole and Hilary explain:

I am relatively confident and don't have too much of a problem talking to professionals, but sometimes,... if it's all going wrong and you're thinking 'I'm not sure if I can deal with this today' (Carole, 1016-1020)

Sometimes if I'm just finding it [engaging with practitioners] just like too hurtful or too painful I just like avoid it really (Hilary, 701-702)

Other mothers describe their emotional vulnerability in meeting such challenges:

I just thought you bloody swine. How dare you! How dare you! How dare you! I did complain straight away, no, not straight away because I came back into the room and just burst into tears (Denise 4.596)

[In the second meeting] I was really strong ... [but in] the first meeting I just broke down in tears (Gwen, 465)

Gwen appears to see strength in not showing emotions, perhaps because of the sense of being in control and therefore stronger. Fiona also observes the vulnerability attached to over spilling of emotions but goes further by suggesting that professionals deliberately manipulate the situation to their own advantage:

We've come to terms with it, but some people haven't of course, some people can't, but that not coming to terms with specifics can be interpreted and is sometimes by, usually by professionals with 'Oh, I don't think they're dealing with it.' They can write everything off to 'Oh, parents haven't accepted it, they haven't accepted the child's limitations, they haven't come to terms.' (Fiona, 1544-1550)

It tends to be the mothers, routinely reduced to tears, oh wow what a buzz that is for some types of people, you know, because they're totally in control then... [crying] immediately puts you on the back foot with some people (Fiona, 2154-2160)

It feels quite shocking that Fiona would believe some professionals deliberately exploit a mother's emotional pain in order to control the situation and actually enjoy the result. Her understanding would seem to be embedded in the notions of power discussed earlier and would suggest that, if this is indeed the experience of mothers, professionals are more heavily invested in power givens than might be expected and that extracting power from them may prove more difficult than imagined.

3.4.4.2   DISEMPOWERED BY NEED

The relationship between a mother and a professional will, most often, be based on the mother's desire for support. A number of the women describe experiences of such need resulting in lack of choice and control within the relationship. Abbey, for example, seems to feel unable to extract herself from an as yet unfruitful nine year relationship with a genetic consultant:

We're still trying to chase a diagnosis ...it might have implications for our older son (Abbey, 925-927)

In contrast, Elaine describes thinking twice before entering into a professional relationship as she feared expressing her need might lead to devastating consequences:

I thought shit, I'm going to have to phone social services here because I need help ... I thought oh my God they're going to take her off me (Elaine, 526, 535)

While both women appear disempowered in their choices around their engagement, constructions around their need and the professionals view of it is quite different. Abbey seems to interpret the genetic consultant as a collaborator in the struggle to find the cause of Tommy's disability. In contrast, Elaine seems to see the professionals who could offer her help as potential aggressors. It is likely to be that the context of the situation, the interpretation of the need and the meaning given to the professional's role and jurisdiction influence and shape the mother's ability and willingness to engage. While Abbey was risking little in her desire to gain help in achieving a diagnosis, Elaine seems to think seeking help was somewhat perilous and to be avoided.

The women's comments also reveal a resignation that sometimes their need will mean they have no choice but to be in a relationship with someone they do not like:

[She] drove me just to distraction, but again it was like god, this is all I've got so I can't alienate it, so I just bit my lip (Fiona, 1821-22)

I've accepted whoever we've had because you know that that is the person in that job so you can't change that. So it might not be what you wanted but you've got to make the best of it (Carole, 808-811)

They also appear to lack power and choice around changes in personnel, something which causes Carole great anxiety:

When you lose somebody who's really good it can be quite frightening I suppose because you wonder am I going to get the same quality? (Carole, 787-790)

Carole's comments suggest a degree of dependence on the "*good*" practitioner in that she worries how she will manage with someone of less quality. Such dependence may disempower the mother further, something which does not sit well with Denise:

[I said] I'm not needy so back off, I'm quite able to do this myself. So, yet I wasn't, so, I don't know, I don't know, I don't know, actually I don't know (Denise, 1035-1037)

While it appears Denise has maintained her independence, this may have come with a cost as it meant the loss of a relationship that may have benefitted Emily; something perhaps reflected in her thoughtful and searching "*I don't know[s]*". Reflecting on Denise's thoughtfulness conjures up many of the potential dilemmas central to the theme. It seems she seeks to assert her mothering responsibilities herself yet because of the nature of Emily's disabilities she is unable to detach herself from professional help. This in itself causes her distress as she feels needy yet it is actually Emily with the need. There is a sense of a searching 'what might have been' in what she says as though she feels a certain amount of regret or even guilt that she chose to withdraw from this particular relationship when there was something on offer. One wonders how often

these mothers continue to be involved in professional relationships they would have ended had it only been about how they felt about it and the emotional consequences of pulling out because they feel unhappy with the dynamics.

3.4.4.3 PROFESSIONAL DISEMPOWERMENT

The mothers appear not only to encounter professionals who maintain power positions; they also meet those they consider to be disempowered too. Their reflections suggest this is understood in a number of ways. For example, some identify a perceived skill deficit as disempowering for the professional as Gwen and Denise describe:

[They were] Professionals who are absolutely terrified of dealing with somebody like Katie and adamant that they weren't going to be involved in her care (Gwen, 455-457)

We went to GP `Oh I can't touch you because your under, da,da,da`... The doctor wouldn't touch her so we went to minor injuries, 'Oh no, we can't really touch you because you're under a paediatrician, you're under this and you're under that so we don't really want to get involved'. Went to the school nurse, 'Oh lord, actually you'd better go and sit in the hospital and wait to be seen by a professional' (Denise, 341-350)

While on the face of it Denise's comment refers to professionals' lack of confidence in their skills, further analysis suggests that she is alluding to a power hierarchy across disciplines and contexts as she seems to make sense of the reluctance to get involved in terms of stepping on toes. Indeed, it may be revealing that she recalls the school nurse referring her onward to "*a professional*" in the hospital. It would seem then that Denise recognises professionals being disempowered by their own perceived status in relation to other practitioners.

There is also some recognition that the demands of the system within which they work may prove disempowering for professionals. Elaine suggests that being over worked means professionals may not be able to work with every family they feel needs support:

I just got an immediate feel here that all the services were overstretched and it was very much the person who shouts the loudest and that everything was crisis led (Elaine, 573-576)

Clearly, such situations not only deny families help at a time they need it; they also generate further obstacles for the mother as getting access to services becomes competitive and based on being tenacious and challenging rather than need. This may lead them into direct conflict with practitioners, with whom they might have previously enjoyed a fruitful relationship, and indeed with other families, something which can only add to an already demanding situation.

Even being in a successful relationship does not guarantee that the needs identified within it will be met. Instead it seems the mothers experience a hierarchical power system that limits some professionals' ability to get what they seek for the family. The mothers seem to appreciate that some professionals are less successful in securing resources because they lack influence in the power systems that control the help given:

We had someone who was really sweet but she wasn't strong enough [within the team] to support me (Carole, 800-801)

She spoke up on our behalf and was just ignored by the department (Fiona, 401)

In Carole and Fiona's examples it appears that having a collaborative relationship was not enough to achieve agreed outcomes. Ultimate power was actually outside the relationship and in the realms of the power hierarchies surrounding it. Thus, those who may have bridged a gap and taken on an advocacy role for them are also silenced, leaving the mother once again responsible for doing battle in order to source what it is her child needs.   Fiona recognises the injustice:

What's unfair is having to fight, fight to get him a decent wheel chair and fight to get him a decent statement, and fight to get this and fight to get him to go on the school trip and fight blah blah blah (Fiona, 265-269)

3.4.5 SUMMARY OF POWER AND DISEMPOWERMENT

This second super-ordinate theme is intended to capture the mothers' experience of power imbalances within their relationships with professionals. The theme outlines their understanding that professionals come to the relationship already garnished with a power and control bestowed by society and reinforced by systems that lie behind them. It also illuminates their belief that they can be further disempowered through lack of knowledge, their need of practitioner help, restricted choices and by their own emotionality. The theme highlights their understanding that professional power is often hierarchical in itself and effective relationships may be thwarted by the professional's lack of influence within the broader service systems.

3.5 MASTER THEME THREE
CHALLENGE AND CONFLICT

I'm sure you've heard before, you feel like it's a constant fight, a constant battle
(Carole, 179-181)

3.5.1 OVERVIEW OF THEME

The previous chapter suggests the women often interpret their power within the relationships to be limited by traditional social expectation, system procedures and processes, and factors relating to their own coping. It identified that they experience relationships where control is disproportionally in the hands of the professional. This chapter explores how the mothers manage their disempowerment and the sense of responsibility that drives them to remain in what often seems to be constant conflict. Here the women describe their use of a number of approaches in the delivery of challenge and management of disagreement; some more overt than others. They also recognise the cost and risks in challenging and comment on their experience of letting go of some potential disputes.

3.5.2 SUBTHEME A – CHALLENGING AUTHORITY

The notion that skills and knowledge generate the construct 'doctor knows best' and affords professionals a premiership in the relationship has already been outlined. However, many of the women identify that they do not always accept such a premise and instead also give weight to a parallel construct that sometimes 'mother knows better'. This is often explained by way of maternal instinct supporting their understanding of their child:

Ever since then it was like I was right and I've got to go by my instinct (Gwen, 351-352)

Again it's my instinct, you can't put anything into, that doesn't translate to medical professionals (Denise, 385-386)

[The GP] put him on antibiotics and I was starting to get, by this point he was getting worse ... my instinct was that something was more serious (Barbara, 217-218)

It seems that the women identify a special connection with their child that allows them to recognise when something is wrong and to decide what is best for them. Having said that, only Elaine clearly identifies her belief that simply being the mother gives her the right to challenge professional opinion:

I said to my husband er, he said' they're the doctors' and I said 'yeah and we're her fucking parents', I said 'and don't underestimate that' (Elaine, 339-341)

Challenge appears to permeate many of the mothers' relationships with professionals with all of them describing particular conflicts and a number agreeing with Carole's comment quoted at the beginning of the chapter, that conflict feels constant and inevitable:

I've certainly had one or two where every time we've seen them we know it's going to be a battle, we know it's going to be difficult and I can't understand why (Abbey, 730-732)

We struggled and struggled and fought and fought (Gwen, 1358)

While Abbey, and others, experienced power struggles with particular professionals, a number of women appear to view conflict as a systemic part of the wider provision of services, and indeed often seem to interpret their struggle to be with that broader, faceless system rather than the practitioner themselves:

So I'm on the phone to them trying to be civil ... and I say I know it's not you personally but you know, this system isn't working (Fiona, 1074-1077)

We were having a really bad time and I thought an authority was there to help you, that was my big wakeup call (Hilary, 1344-1345)

[I said] the PCT's going to feel my wrath because you're telling me a load of lies (Elaine, 1416-1417)

A belief that their conflict is with 'the system' beyond the professional has a number of implications. For example, as described previously the onus is on the professional to be honest about limitations within the relationship. Further, it again reinforces the idea that the professional will not always have ultimate power to make decisions relating to the child's needs or services available to them. This has the potential to undermine the successful outcomes for collaborative relationships both in the professional's ability to deliver and in the mother's assessment of the value attached to investing in a relationship with the disempowered professional. Conversely, it may result in a stronger alliance; one that is against the system and therefore strengthens the mother's confidence in the practitioner who advocates on their behalf:

[The practitioner] didn't mind having an opinion that was uncomfortable to the educational authority ... [He] would say what he, erm, thought the child needed ... I'm

surprised he wasn't sacked really, truthfully, because you weren't really allowed to do that (Hilary 8.579-583)

Even when they perceive the fault to be with the wider system, the mothers nevertheless appreciate that the relationship provides the interface between the two and will often suffer for it:

[It's a] system that is set up to enable but because it's so bloody bureaucratic and it's financially driven cause ultimately it's political, it actually disables and wears people out and it's the very system that's supposed to support but it's so disjointed and everything so you get angry parents (Elaine, 998-1003)

We were on the other side of the fence to her when we went to Special Educational Needs Tribunal ... you are explicitly in opposition to people (Hilary, 622-624)

As illustrated in the previous chapter, predictive conflict and disempowerment may mean mothers withdrawing or avoiding the situation. Even when they do engage, levels of anxiety and stress may be so high that they do not achieve what they might in less demanding circumstances. Further, challenges may result in the breakdown effective relationships as when Hilary found herself in conflict with the very person whose skills she was fighting to retain. There is the sense that issues within the broader system fall heavily on the interpersonal level of the liaison so much that systems designed to support the relationship often actually threaten it. It must be incredibly painful and disheartening to experience a good relationship only to have it spoiled by bureaucratic processes.

3.5.3 SUBTHEME B – WHY CHALLENGE?

It's because she's non-verbal, if she was able to cry out for herself and say something and then they would have, they would have taken more notice. But because (she can't) I had to stand up for her (Gwen, 1141-1144)

Gwen's comment offers some insight into why the women persist in doing 'battle', especially when one considers the negative aspects of conflict and the energy taken to pursue it. It seems she accepts a particular role generated by the nature of Katie's disability. This sense of responsibility to protect and advocate for her child is echoed by other mothers:

Where Sarah's concerned I'd defend her like a lioness you know, but only if it's justified, I won't just go out the way, you know, to rock the boat for no reason (Elaine, 392-395)

It was almost like my animal instincts coming out I turned from being a mother into that lioness and by God if anybody got in the way the claws came out, erm so there was that protective side of it (Abbey, 457-460)

It is interesting that both Elaine and Abbey use the metaphor of the lioness which one can visualize stalking around its young on the lookout for danger. While this would surely resonate with most mothers, further comments illustrate that the circumstances of mothers of children with disabilities may mean they must be even more diligent as they involve themselves in making decisions around treatments and therapies:

[It's] frightening, because I'm someone with the knowledge and also someone that's assertive enough challenge. Oh gosh do you know how many children have needlessly gone under the knife because of that sort of blasé attitude and that just enrages me (Elaine, 854-858)

If I hadn't been able to stand up for myself I could have popped some medicine in Emily's mouth right now and that would be it for 5 years, 5 years until they review it! Completely unnecessarily with all those side effects (Denise, 861-865)

Here it seems that the mothers do not always trust the planned intervention of professionals. Perhaps this is not difficult to understand given earlier discussions around how they believe some practitioners see only the condition. In these cases it is almost as if the mother protects the personage of the child against decisions made solely in respect of their disability. Whilst Elaine says it is frightening that professionals would work in

this way, one might also imagine how frightening it would be a mother taking responsibility for decisions that were in opposition to the recommendations of an expert.

3.5.4   SUBTHEME C – PLAYING THE GAME

The women's reflections on delivering challenge would suggest that they often interpret it as 'playing the game' with a number of mothers actually using that terminology. It seems they prefer to offset power imbalances and to facilitate the outcome they desire without resorting to overt challenge. Such a strategy suggests that not only do they understand the nature of power and its currency within the relationship, but are on occasions, able to both counter and compliment it to their advantage:

I just completely changed my perspective and thought, 'OK, I'm just going to play the game now and I'm not going to even try and understand where you're coming from (Denise, 286-289)

3.5.4.1   USING ESTABLISHED SKILLS

Some mothers bring specific skills that are particularly useful to supporting their challenges. Abbey, Elaine and Fiona, who all reproached the notion of expert power, also relate personal and social skills they believe allow them to challenge confidently:

I stopped the conversation to him at that stage and said to him that what he needed to understand was that he had a medical degree and I had a [identifies discipline] degree and whilst they weren't equivalent to each other I was actually quite intelligent (Abbey, 318-322)

I'm someone with the knowledge and also someone that's assertive enough to challenge (Elaine, 854-856)

I could do it because of who I was. I didn't mean that I was posh or rich or special I just mean that I had the assertiveness to do it (Fiona, 1336-1338)

It could be that an awareness of their own interpersonal capability allows these women not only the confidence to challenge, but also affords them an insight into how professionals might gain power by adopting those very same skills. It seems reasonable to suggest a mother not familiar with such techniques and strategies is more likely to be influenced and disempowered by their use, something Fiona and Abbey seem to be aware of:

Jordan's probably quite lucky in that he's got 2 reasonably articulate well educated parents who can stand up for him and that's just a fact, but you know, and there's a lot of children like him who have very little because their parents haven't got the resources, either personally or financially (Fiona, 234-239)

I think I had the confidence to do that though I'm not sure that all parents would have (Abbey, 324-325)

Mothers also identify how they use established skills from their work life in order to challenge:

I go into it with a very clear sort of idea of what I want out of that meeting, and I try to treat them, rightly or wrongly, like my business meetings (Abbey, 809-812)

A tribunal's confrontational which in some ways is far more familiar territory to many of us, I think we were just able to go and put our work hats on for that (Hilary, 712-714)

It is interesting that the women frame the need to use such skills as work related and do not appear to identify with them as communication skills used in an interpersonal engagement. This would suggest that they view the relationship more as a business or working association than a personal one, in the context of challenge at least. This notion is in contrast to their assertions that they do actually appreciate a personal approach. Again it would seem the mothers configure their motherwork around what it takes for them to get what they want for their child rather than what they personally might want to get out of the relationship.

3.5.4.2   ROLE PLAY

In contrast to exploiting their own skills as a foil to professional authority, the mothers also, on occasion, engage a strategy that plays to the idea that they are less capable than the professional:

I played the dizzy blonde sort of thing and then I said `if you just let me put my coat down and settle Sarah down', I said 'I'll be quite willing to answer all of your questions OK?' In other words you arrogant bugger don't talk to me through the back of your head (Elaine, 752-754)

Although she does not identify that the practitioner actually altered his manner, playing the part and using it to gain some control over the process seems to have allowed Elaine to feel she had challenged a discourteous and dismissive approach. Other mothers describe using similar non confrontational, self effacing strategies. For example, Denise manages to get a practitioner to review a decision by suggesting it was she that was at fault:

I said perhaps you just, just for me, for my satisfaction, I know I'm being stupid and I know I'm being paranoid, perhaps you could just, just have one more check I know you've read it, could you just read the file one more time, just check that the information, the results haven't just slipped in between 2 bits of paper that you haven't seen, could you just for me, just check. And she flicked and said `oh I've got some happy news after all` (Denise, 733-741)

Just as they play to the view they perceive the professionals to have of them in order to avoid open conflict, so too do the women exploit the view they feel professionals may have of themselves. For example, Hilary talks about trying to achieve outcomes by persuading the practitioner that the idea was theirs in the first place:

If you want your idea implemented, you know, make it so the other person thinks it's their own, it's not quite as manipulative as that, you know, but actually it is something about not making it look a big deal, there is something all the time about making this look as if it's possible (Hilary, 1015-1019)

It seems Hilary plays a game that taps into the professional's desire to present as knowing and in control, something previously discussed in respect to expertise and power. It seems she manages to have influence without direct conflict by ensuring the professional does not lose face. By playing the role of the person being influenced she actually generate the influence for herself. Interestingly, in this sort of role play, the mothers are giving away the power and expertise they could actually assert in the relationship in favour of keeping the interpersonal connection safe. Something professionals are loathe to do in the women's experience.

3.5.4.3   THE INFORMATION GAME

The women also embrace the capital they perceive information to hold and use it to restore power imbalances, arming themselves with information as Gwen and Denise observe:

[It's about] trying to have the right jargon and the right saying, and knowing the law etc, so people get put in their place before they even go onto hurting or saying hurtful things (Gwen, 479-482)

I need to be as prepared as I can possibly can be and stand up for what I think and feel, no matter what they say (Denise, 1161-1163)

However, it seems feeling prepared and informed may not be enough to secure a non-confrontational challenge, with Denise still expecting to have to "*stand up*" against entrenched attitudes and Hilary believing she needs "*courage*" to offer her opinion:

I feel like am I going to actually have the courage to actually stand up for what I think? (Denise, 795-797)

Actually part of it is about that, having the courage to bat your own opinion (Hilary, 934-935)

It seems the success of even an informed challenge will rest on the mother's confidence and audacity to deliver it. It is likely that many will know they ought to challenge and why but not have the skills to do it. How that must feel is difficult to imagine.

3.5.4.4   THE EMOTIONS GAME

As previously noted, the women can feel more vulnerable to the effects of professional authority when they are in an emotional state.   Sometimes they use strategies to dissipate the anxiety and level the playing field:

If I'm feeling a bit urrrr! or not totally happy or confident I just imagine they are sitting in the nude ... you know, at the end of the day they are only like me (Carole, 955-960)

At other times, they recognise the emotion but determine to control it in order to get the best outcome:

I was angry ... but ... I knew that I couldn't tell the truth in that meeting because it wouldn't, it wouldn't help me one little bit and it was almost like I was involved in playing in this game, being politically correct, and being non emotional, trying to be as professional and unparent like as possible (Gwen, 472-479)

Gwen seems to be doing more than just holding back emotions in order to reduce the potential for disempowerment or persuasion. Instead, it seems she is playing a game that involves not exhibiting the emotional responses she feels professionals expect of her as the mother. It seems for Gwen that emotional restraint raises her status to something other than mother and more equal to the professional.

While it appears managing the expression of emotion can be useful in the empowerment of the women, on occasion becoming emotional can also be used to their advantage, as Denise explains:

I had ... learnt on the way from friends, if you phone up, this is awful, if you phone up and you cry on the phone you get a phone call back within an hour, but if you phone

up and you're quite OK and you're calm and everything else then you don't get the phone call back, not treated as the kind of emergency, so I said to David I'm just going to do it and just pretend to cry ... so I phoned up and cried and literally she was on the phone in an hour and I thought she was away for a week (Denise, 275-285)

Being tearful proved a very powerful tool and Denise used it to great effect in managing to get access to a professional where she been unable to before. This would suggest that perhaps the professional in this case did not get the 'buzz' Fiona refers to and instead is moved enough to make time for Denise. The telling of the story reveals a certain sense of embarrassment at having resorted to such a tactic. It may be that Denise was uncomfortable being manipulative, but it seems more likely that a professional viewing her as a vulnerable mother did not sit easily. Indeed, it may be important that in her next sentences she offers the picture of a strong but still effective Denise:

[I thought] I'm not going to allow myself to get upset or emotional to you I'm just going to play the game and get what I want out of all these people instead (Denise, 290-293)

3.5.4.5 MARSHALLING SUPPORT

A number of mothers appear to interpret being on their own in conflict as disadvantageous:

I've really felt that I've needed extra support in the meetings where the message is going to be clearer from the both of us (Gwen, 447-449)

There's been a few meetings that I really wished we'd had witnesses, definitely take someone else with you (Fiona, 2078-2079)

However, just as being informed is not necessarily enough to mount a challenge, having support does not necessarily mean winning the battle. As Hilary found out, both sides have to be engaged:

I try and raise this and don't get listened to, I bring in the expert from the [names organisation], they don't want to listen to her. I organised to see the educational psychologist and tell her to come round to the house and get her to help them, but this isn't appropriate, by which time they'd left it too late really (Hilary, 819-824)

As might be expected, the mothers often look to their partners to attend and seem to experience a difference when they do:

When he [names husband] comes to the meeting it's much more charged and people sit up and take more notice ... they tend to take more notice of the Dad when he comes to a meeting than just the Mum (Gwen, 400-402, 407-409)

I'm not stupid! ... he never gets treated like that because he's a bloke, I don't know what it is, I don't know, I don't know. It's very different, that would be a good piece of research to see the difference in how the dads are treated (Denise, 575-608)

Denise and Gwen both recognise a difference when their husband attends a meeting but appear to understand it quite differently. Gwen believes the professionals simply pay more attention to the father than they would the mother. Denise's comments carry a sense of something a little different to being more willing to take on board the father's opinions. She declares that she is treated as though her ideas are stupid whilst that does not happen to her husband. In either case, neither interprets the different dynamics as a consequence of the husband's skills or personality. Instead, they seem to see him affecting a power shift because he is a man. Neither mother offers a reason for the difference in treatment; indeed Denise struggles to bring meaning to the situation as she speaks.

Despite the conviction that the father will possess a greater power, a number of women highlight not only their husband's reluctance to engage with the challenge but their expectation that the mother will:

[Names husband] just doesn't question authority, that's always me who gets to have to do that (Elaine, 397-399)

He kind of sticks his head, it's too much emotionally so [he says] I'm not going to go, so he leaves me completely (Denise, 688-690)

Husbands can't go, 'well I'm at work, how do you expect me to do all this, I'm earning the money', and then it comes as a big fight about that (Fiona, 2235-2237)

The subtheme draws attention to how mothers attempt to manage the power and influence imbalances they experience within the relationship. It appears they often disguise their challenges in order to avoid conflict and fallout. Further when they do challenge directly this often this appears to be on the strength of their experience outside of motherhood and not directly based on their power and authority as the child's mother.   While one might suggest their approach is designed to maintain the interpersonal connection, something previously highlighted as very important to them, their further comments suggest that they are perhaps more often trying to reduce the potential risks and dangers in openly challenging professionals and service systems, something the next subtheme explores.

3.5.5   SUBTHEME D– THE RISK IN CHALLENGING

Regardless of the way in which they manage it, the positive outcomes of challenging are often offset by some degree of risk to the relationship or a cost to themselves.

3.5.5.1   PERSONAL RISKS

One example of a perceived risk is that their actions may lead to them being labelled or stereotyped as Gwen observes:

As a parent you are labelled and once you start to fight for something it's almost like you've got a black mark over your file or your child's file. You are a problem parent and you are just seen as someone difficult in the end (Gwen, 501-504)

Fiona too reflects that being assertive can generate a particular reputation, in this case, that parents enjoy the battle, a view she rejects:

I have no problem at all to disagree sharply, but I don't actually like causing conflict. It's not actually something I enjoy doing and I think a lot of professionals get to the stage that they think the parents like us actually enjoy it. But nothing could be further from the truth, no not at all (Fiona, 875-880)

The belief that mothers dislike conflict is supported in the way many talk about such events, highlighting a negative impact on their self-esteem and emotional wellbeing:

I always thought oh my god I'm the trouble maker, you know, thought that I was a bit of a trouble maker and asking too many questions (Barbara, 442-444)

I came away thinking was that me? Did I not handle that properly? Do I get seen as an overprotective mother? (Gwen, 1136-1138)

I felt so stupid that I was questioning the midwives (Denise, 492)
I just experienced a lot of rejection and being told I was being unreasonable really (Hilary, 833)

There is also the understanding that other members of the family, particularly other children, have a price to pay:

The whole two weeks leading up to that [meeting] was so shitty for us as a family, [becomes upset] (Denise, 819-820)

If I can get this middle course ... most of the time being good enough then I can, actually, I can pay attention to my other children as well (Hilary, 242-245)

If I didn't have to fight for the things she really needs, that can give me more time with my children to be a normal family- to be a mother (Gwen, 1540-1542)

The comments generate a number of interpretations. For example, it is clear that Denise recognises that her anxiety had affected the rest of the family. It is difficult to know if she becomes upset in recalling the anxiety or if she was regretful of the way the

situation had impacted on them all. Gwen and Hilary's comments perhaps reveal the conflict around doing enough for their disabled child without denying their siblings. Hilary, it seems, struggles to get the right balance and identifies that she is willing to do a less good job if that means more time for her other children. Gwen seems to yearn time to be a "*normal*" family which insinuates that when she is 'fighting' on Katie's behalf she is not being a "*mother*". It seems she views her role within the relationship, with respect to challenge at least, as one that is not totally akin to mothering, reflecting again that she and others appear to view their contribution to the relationship in terms of something other than mother.

3.5.5.2   RISK IN THE PROFESSIONAL RESPONSE

One relationship at least seems to have been enhanced as a result of challenge:

I have to say once he was brought up short about it we had a fantastic relationship after that, we got on really well (Abbey, 344-346)

Other practitioners appear not so conciliatory and women across the group spoke of various types of blocking behaviours they encountered when trying to mount a challenge. Some were experienced as overt and direct assertions of authority:

[I tried] on a number of occasions to find out what his reasoning was for overruling another consultant in the hospital who felt that it was urgent and he refused to speak to me, so we ended up in a big complaint with the hospital (Abbey, 522-526)

[I asked him to] explain this to me, giving x, y and z of my son's needs. I just got an absolutely antagonising reply -because it is, it didn't say that, that was the jist, because it is and that's how it is (Fiona, 696-699)

While others are seen to be equally dismissive if somewhat more veiled:

I actually went saying look you know `Christ, he's wasting away`, and she said 'Oh don't be silly.' (Barbara, 281-283)

Finally the surgical senior reg kind of gave me a bit of a talking to, real patronising, `well [real name] ... you've come up here again and we really need to sort this out don't we? (Gwen, 292-295)

The comments carry a sense that the women feel they are being 'put in their place' by the professionals' non-engagement with their genuine concerns. In these cases the relationship could go on uninterrupted as the professional has blocked or dismissed the challenge; in other cases however the women interpret the professional response as negative and defensive and impactful on the relationship:

The other erm consequence [of challenging] is that they completely close ranks (Fiona, 661)

I decided that I would like to speak with the people who had been on duty and of course ... everyone went on the defensive (Elaine, 356-360)

That had been the first thing I'd said about the school. They were like, they were really offended and defensive (Gwen, 1176-1177)

Gwen's reflections lead her to consider that there may have been some sort of conspiring between professionals she had challenged and those she was due to meet:

I'm just thinking that what happened at [names hospital] might have been a repercussion of the professionals at the school getting in contact with the hospital first so they already had this preconception of me as a parent (Gwen, 1210-1212)

The expectation of negative fallout appears to sometimes caution the challenge with Gwen and Hilary relating circumstances where relationships were already difficult and where they understood making a challenge could result in further difficulties:

[I was] terrified to go to them and say you know, she's got another bruise, she's got this, and I'm really worried about that because I wanted to keep the relationship good (Gwen, 1364-1366)

I don't really know what got in the way of why we just didn't say that. I think because it was already a sort of, like, prickly relationship (Hilary, 673-675)

It may be that Gwen and Hilary were cautious not only because they were mindful of the risk to the relationship with the person, but also to the help they received as a consequence of it, as indeed appears to be the case:

I wrote it in the book and I said I was just really upset to come in and see bla, bla, bla, anyway that day she'd come back and they'd tied her nappies to the back of her wheelchair and sent her home with a message, bla, bla, if you're not happy we suggest you contact your LEA for immediate transfer to another school (Gwen, 1162-1167)

Cause when it finally blew up ... this teacher that isn't communicating and in the end I was talking to the deputy head and I was being told, you know, this might sound so silly, but I couldn't go on the school trip because my name was off the list (Hilary, 880-884)

Barbara also shows awareness of the nature of this 'double' risk as she recollects a time when a consultant suggested in front of Joshua that he 'wasn't normal':

I didn't say anything! I sort of er, again I thought why didn't I say something, but it's just really hard when you're in that situation because you always feel slightly you know, you're kind of reliant on them and it's very hard to turn around and go `actually I'd rather you didn't say that in front of my son`, but I should of, you know I should have done (Barbara, 436-440)

Although she questions why she did not confront the consultant, and seems now to regrets not speaking up, Barbara's comments suggest that at the time she was conscious of Joshua's dependence on the practitioner and experienced a concern that this need might not be met if her challenge caused affront. Her actions seem to have been more about preserving the support than they were about powerlessness.

The fear that conflict could result in some sort of penalty that impacts on the relationship or the support derived from it also seems to be in Elaine's mind having successfully challenged her local NHS trust:

I said I want a formal apology and I said I want to know that there won't be any comeback on this (Elaine, 1465-1466)

Whilst Elaine was anxious about riposte, Fiona recalls a situation when her challenge was met by what she perceived to be warning of a price to pay if she continued:

It was a threat, a veiled threat, if you take this higher, you will receive the consequences (Fiona, 682-683)

In this instance too, it appears that the mother's dependence on the service or professional has the potential to diminish challenge. However, whereas in Barbara's case, she herself made that connection, in this case it seems as though the professional is well aware of the dependence and using it to their advantage. The decision to challenge then attracts much more dire consequences than ill feeling between professional and mother.

The mothers make sense of professional responses to challenge in several ways. For example, Elaine suggests that the response is determined by the personality and commitment of the professional:

I think it came down to individual personalities and the nurses who didn't like it [being questioned] I don't know, it tended to be the ones who weren't as committed as others, shall we say, who, I don't know, were maybe a bit lazy? (Elaine, 401-405)

Fiona seems to interpret negative responses in different ways at different points in her interview, perhaps because she is considering the nature of particular conflicts. Early on she conjectures that negative reactions are due to the professionals' fear that their position may be eroded by knowledgeable parents:

I think it's the fact that you're even challenging their decision and it's that threat thing [pause] 'hmm, they [parents] know too much' (Fiona, 715-717)

Later, she seems to suggest that the professional is forced in a strongly defensive stance in order to exist in the inadequate system within which they are embedded:

The only way they can do their jobs when they know they don't have the resources is to be as hard faced as they possibly can (Fiona, 2170-2172)

In any case, it appears the mothers perceive the consequences of challenge to go much further than the personal interface and understand it may result in both overt and covert sanctions on them and their child. This adds another feature to their experience as they further negotiate risk within the web of factors, such as the interpersonal connection, level of expertise, the nature of their need, they must address in their choice and decision making with regard to the professional.

3.5.6   SUBTHEME E – LETTING GO

Mothers do sometimes give up the challenge. Whether because of the threat to support, potential relationship breakdown or personal cost, they weigh up the consequences and on occasion s decide to place less energy into the fight or to let it go completely:

I'm still sort of fighting the cause in my way but I'm not, you know, I'm not giving all of my life to it, I've realised that actually having fun is the main thing because life can turn, you know (Elaine, 1107-1110)

I haven't once complained to any of the doctors, I nearly did after the whole thing and I just got kind of well, just got to try, what's the point raking over more negativity you know, I just kind of wanted to look forward really and so, you know, I never really complained, you know, I suppose I've just avoided that (Barbara, 550-555)

I thought no, how is that going to benefit Sophie if I put in a complaint, so I didn't, I didn't bother in the end (Carole, 729-731)

However, letting go is not always easy, with Carole recalling different circumstances when she became embattled as the residue of previous disagreements impacted on her attitude and perpetuated conflict across old and new relationships:

Because you maybe had a battle with somebody else so you've already decided THIS is what I'm going to do, THIS is what I'm going to in my mind, my aim for the meeting is THIS and you won't accept anything else (Carole, 374-377)

Giving up is also difficult as the mothers seem to perceive experiencing challenge as part of their responsibility to do their utmost on their child's behalf:

there was bitchiness, sidelong glances and rolled up eyes and things like that going through and it was just so, it was so hard to do. It was so hard, I thought if my child could do speech, you know, speak for herself, but she can't, so I have to be there and talk for her (Gwen, 488-493)

Perhaps as a consequence, letting go can generate feelings of selfishness and guilt as Elaine and Denise explain:

I've let go of that and I've concentrated more on me, but it took a hell of a lot for me to do that because it felt like I was being so selfish (Elaine, 1086-1089)

I have felt guilty, looking back I have felt dreadfully dreadfully guilty, immensely guilty that I didn't stand up for Emily more (Denise, 974-976)

These comments draw back to Denise's unease at not wanting to engage with a practitioner because it made her feel needy. It seems that even when they feel the decision is best for them as individuals, the mothers find it difficult to extract themselves just in case they are losing something that might have helped. This conjures up an image of the women approaching the relationship holding at least three perspectives, the woman, the mother and the child. This contrasts sharply with notions of the single perspective professional described earlier and might explain the

complexities in how the women experience the relationships and ascribe meaning to them

3.5.7 SUMMARY OF CONFLICT AND CHALLENGE

The third theme examines the mothers' descriptions of the various ways in which they attempt to manage and challenge the power imbalances, and the struggle and conflict they perceive as the outcome. They talk about the pervasiveness of conflict and the system processes which generate and perpetuate it, what helps to redress the imbalance, asserting their own authority and playing the game in order to achieve what they desire. The theme also explores their thoughts on the impact and risks involved in engaging with such discord and why it is that they do it anyway. It highlights once again the complexities of the experience of the relationship in terms of being an individual, a woman and a mother of a disabled child within it.

3.6 MASTER THEME FOUR
TIME AND TRANSFORMATION

You could have asked these questions to me five years ago and I might have given completely different answers...I've moved on so much... I think I've adapted and I've changed (Gwen, 1468-1469)

3.6.1 OVERVIEW OF THEME

The final theme generated from the interviews is that of Time and Transformation. As all of the children were over six years old, the mothers had already spent some considerable time working with practitioners. The chapter draws attention to the mothers' thoughts on how the women see differences in their experience of professional relationships over time. The analysis suggests they gain a better appreciation of their children's needs and a greater understanding of the function of professionals and the systems that support them. This affords an increased confidence within the relationship.

The mothers also identify that they take on a number of tasks and roles that further enhance their contribution and control. Such considerations illuminate what appears to be a dynamic, transformative, interrelated experience of themselves as the mother of a child with complex disabilities and as an agent within the relationship itself.

It is worth noting that while varied in their experiences and understandings, most of the women spoke of the passage of time allowing a 'coming to terms' with having a child with disability. Whilst sitting outside the realms of the research question, such experience can be viewed as transformative in itself and, given previous analysis of emotionality and resilience within the dynamics of the relationship, it feels important as a backdrop to changes in the women's position and capacity in relation to professionals they meet. This was not thought to be directly pertinent to the question and therefore not included, but may be something that could be explored in further research.

3.6.2   SUBTHEME A – UNDERSTANDING OVER TIME

This subtheme captures the essence of how new and deeper understandings in particular areas can empower the mother. Analysis suggests the acquisition of knowledge and insight can grow the mother's self-assurance in her own authority and decision making. An improved awareness of systems and how they work also allows her more independence and choice in pursuing what she feels her child needs. Altogether this transforms the nature of the mother's role within the relationship and allows her a confidence in the outcome:

As he's got older, I've got more confident ... I think part of the difficulty was that I couldn't imagine how it was going to work (Hilary, 45-49)

3.6.2.1 UNDERSTANDING THE CHILD'S DISABILITY

Many of the mothers reflect back to their early understandings of the child and their disability:

We'd just got this bucket of symptoms that we all looked after and marshal together at certain points, but erm yes, quite inadequate and very very frustrated, and very very stressed, incredibly stressed (Abbey, 466-470)

[In the beginning] everything you say is negative about your own child and you're fed all that information anyway. Oh she is very severe, oh she is complex, oh she will need this and she will need that, so when you're dealt with by professionals it's not really healthy because you don't get encouraged to see the child through the child, it's all medical (Gwen, 107-112)

The idea that the mother might initially see her baby in medical terms may be relevant to the earlier suggestion that professionals sometimes see the disability rather than the child. It could be that the lack of opportunity to engage in any other way with the child means the practitioner continues to define them by their illness or disability, whereas the mother, in relating to them in different ways, develops an understanding of the child as much more than their disability:

I've gone through so many different emotions really. Erm, I think when you first realise that your child has got special needs it's grieving and loss and everything. And then they kind of, then he, you know, then he became older and a real personality so then it's just Joshua. It's just Joshua really and then to kind of enjoy him a lot (Barbara, 102-108)

I think I'm very lucky to have Katie because she's taught me a lot about stuff that I never knew before, and I feel like I have, I belong to a world that is so much more richer because of having a wider knowledge of the diversity of life (Gwen, 46-50)

As time allows the mother to get to know her child as an individual, so too does it facilitate further understanding of the child's disability. Gwen suggests that an improved understanding of Katie's needs affords her the confidence to exert her opinion within the professional relationship and to put her stamp on the decisions being made:

[Information means] you can have a choice of what to do rather than just be very passive and going' Well I've no choice. I just do this because I'm told to' (Gwen, 177-180)

The chapter on 'Power and Disempowerment' has already illuminated how the mothers inform themselves in order to level imbalances of power. It was also suggested that they need to have a certain degree of confidence in order to apply their knowledge authoritatively. Comments through Carole's interview provide some insight into how time might support the process, as she recalls her journey from naivety and powerlessness to a place of expertise and influence within the relationship:

[In the beginning] You're new at this you haven't got a clue. You just don't know where you're going, being pulled up different avenues. You really need someone to tell you, help you, be supportive (Carole, 640-643)

Once I've got a bit of understanding of where Sophie was going and I could do some digging and could find out a bit more I felt more in control so I could then go to people and pose questions to them (Carole, 1104-1107)

I'm more confident. At the end of the day if they're just doing their job and I'm just doing my job … I'm definitely more confident, more assertive and I generally know what I would like the outcome to be (Carole, 953-955)

The growth of their knowledge is well illustrated in the contrast between how the mothers remember their understanding of the disability:

You've got this child and you're feeding this child and you're changing this child and you know you're looking after this child but you actually don't know what you've got, so you do sometimes feel inadequate (Abbey, 449-453)

The women also spoke of their children's disabilities in an informed and insightful way (no references in order to maintain anonymity):

cerebral palsy, four limb spastic, has no speech but communicates well with an eye point tip and is fed totally by a gastrostomy

severe learning difficulties... microcaphily, which is a small head and therefore a small brain as well...cerebral palsy like movement difficulties and ...is visually impaired

epilepsy and (names particular syndrome)... no verbal communication... very severe learning difficulties... [poor] fine motor skills... Spatial awareness is not good... incontinent

It is interesting that here the mothers are able to share a language with the professional yet there is no suggestion that they are seeing the child from the medical or academic perspective spoken about previously. It seems instead that the mothers are now able to simultaneously hold a double perspective on the child; one as mother and the other as expert carer.

3.6.2.2 UNDERSTANDING THE PROFESSIONAL

The mothers' growing understanding and confidence over time is mirrored by the transformation in their understanding of experts and expertise. It seems in the early days many, like Abbey, expected professionals to have the answers:

I think in the early days whenever I met a new practitioner I was expecting them to be the person that solved the riddle and they never were (Abbey, 633-655)

In reality, it was often the case that professionals did not know or could not agree:

Nobody seemed obviously in the early [days] to be able to really, really help us... because nobody could sort of say ... well she's maybe got this or this and that for me was really difficult, that was the most frustrating thing (Carole, 681-690)

Some of the women appear to make sense of these limits in terms of the rarity and complexity of their child's disability:

He's unique, bless him, he's outfoxed them all! (Abbey, 415)

They don't have enough knowledge cause there's not that many unique children like Katie (Gwen, 235-236)

While others see the limitations as a failure on the part of the practitioner:

To be told 'Oh, he's not badly affected at all' and gradually as the years go on and you think well [he] bloody is, it's because you didn't know what you were looking for! (Fiona, 1353-1356)
Three times I was interviewed, for about two to three hours each time. They wrote it all down and sent me a report of what I said, it was like' but you're supposed to tell me what to do with my child!' (Barbara, 607-609)

As the mothers experience the limitations of practitioner knowledge so too do they discover the extent of their own. Indeed, it seems time allows for situations where the mother is proven correct despite professional scepticism:

I kept thinking this is, it feels like something is wrong and six months later, I think to shut me up, they said, 'Oh, let's give her an X-ray.' and she had (names condition) (Denise, 262-265)

She said `Well er, yes erm, I've had a look at the report' and she said 'Yes, I'm afraid to say ... that you have been right all the time, she's got significant brain damage' (Gwen, 306-309)

It seems that over time better understanding of the nature of professional expertise and their own successes in managing their child's needs can transform the mothers' expectations of the role and function played by the professional:

Because it's happened so many times I feel like actually you don't know what you're talking about I know more ...That's what gets me cross...the more you see them you

realise that it's all opinions and even though they're qualified to the same extent they all have their opinions... (Denise, 395-397, 849-851)

I expect them to have the knowledge they're trained in but how can they know what's specific to Sarah? So I try to dot the 'i's if you like (Elaine, 1669-1672)

Such experiences are likely to weaken the construct of 'doctor knows best' previously discussed as helping to maintain professional power within the relationship and, as a consequence, facilitates and supports the women's own authority within the relationship.

This subtheme has drawn attention to how the mother reconstructs much of her earlier thinking around her child's disability, the professional relationship and her place in it. Over time it would seem that such reconstructions are influential in how she behaves in relation to professionals and what she expects from the relationship. There appears to be a cyclical affect whereby the mothers extended experience grows her understanding and confidence which in turn cultivates further her desires for the relationship. Such desires may mean taking on particular roles and tasks designed to shape and drive the relationship. The following subtheme explores these further.

3.6.3   SUBTHEME B– ROLES AND TASKS

Time also appears to afford mothers the opportunity to understand and adapt to the nature of their mothering role and the additional responsibilities which come with it:

You have to deal with a far more than a mum of a non disabled child, but it's not recognised (Gwen, 166-167)

The women speak of various aspects of mothering a child with disability that not only grows their identity and understanding of what is expected, it further develop the woman's understanding of her position in relation to the professionals she encounters.

3.6.3.1 THE EXPERT CARER

Carole's comments in the previous section have been used to show how improved knowledge about the disability facilitates a different perspective of professionals and allows her to assert greater influence within the relationship. Other mothers make similar comments about how increased confidence in knowing what is best for their child improves their ability to influence interventions:

I think you become more confident about being the advocate for your child really and having the confidence to deal with it from their point of view (Abbey, 858-861)

I'm definitely more confident, more assertive and I generally know what I would like the outcome to be (Carole, 963-966)

This greater assurance may also be translated into a new understanding of the nature of their mothering. Elaine, for example, reflects on the early days of caring for Sarah:

So we've got to do this portage, we've got to do the just 10 minutes for physio, just 10 minutes of this, and you're so bloody knackered cause you've probably been up all night ... if you don't do it and then you feel real bloody guilty and then you feel as if you're under scrutiny, and so when they next come back and you haven't done it then you say that you have done it! (Elaine, 1148-1156)

Her comments suggest that she understood her mothering of Sarah to involve doing the kinds of things the professional wanted her to do. There is a sense of urgency and frustration about the situation with a pressure to perform and guilt if she did not succeed. She seems to have been very aware of the judgements of the professionals and indeed earlier in the interview had identified the fear of their disapproval:

Not only is it exhausting but frightening as well because...you want to be seen as this perfect parent so you bloody run yourself ragged (Elaine, 989-992)

Whilst it may be the case that any mother would want to be the "*perfect*" parent, Elaine seems to contend that being the mother of a child with disabilities results in added pressure as the involvement of professionals means continual and constant assessment:

[There is a] lack of privacy, er and the feeling that as a parent with a child with disabilities that you're constantly under scrutiny (Elaine, 1826-1827)

As her confidence and understanding in her ability and approach grows, Elaine's attitude to caring for Sarah and the importance she places on what professionals request appears to be transformed:

I did it for long enough, all the stimulating and everything and I thought its unquantifiable anyway really, so I thought I've let go of that ... and because of that I'm enjoying her so much more, and I think actually possibly doing more ... but in a fun way (Elaine, 1084-1090)

Elaine's comments suggest that she has grown to see that the role she plays is a dual one, in which she follows the advice of professionals in how best to develop Sarah's skills and abilities but not so far as to detract from her mothering position, which is less about teaching and more about fun. Again this seems to suggest that the mothers can take multiple perspectives of the child, their role and the position of the professional helper. Abbey's comment highlights the idea:

[It's] very interesting. It's not a role that I ever envisaged doing, being a carer as well as being a Mum (Abbey, 61-62)

Other mothers' comments also show how their increased understanding and experience transforms how they view the input of the professional:

I won't have his thyroid done every two years now. I'm confident that he hasn't got thyroid and it's a horrible test (Hilary, 1267-1268)

I don't feel the need to see those people and I don't think they're going to tell me anything I didn't know (Fiona, 930-931)

It is sometimes the case that the mother's increasing knowledge and experience means that she has a better understanding of the child than the professional trying to support her. Many of the women describe this as their experience including Hilary and Gwen:

She actually said 'well, I've not done this before. How do we do it?' and I said I've done it and ... we worked together (Hilary, 969-971)

We had an education psychologist who was really open and very honest with me and he right from the start and said I haven't dealt with children like Katie. So I'm going to be led by you. And that was encouraging (Gwen, 511-515)

It seems that these professionals accept the mother's expertise and are happy to work with them in a collaborative, facilitative way. This too can evolve over time:

I think also as well, over time, relationships with people change because we became more comfortable with each other and your confidence grows as well because you know your own child (Abbey, 851-854)

Hilary and Gwen seem to recognise their achievement and celebrate their greater awareness and independence in caring for their child:

Isn't it great that I'm in a position to be declining services that I don't think are needed, you know at least I'm not having to fight for them (Hilary, 1284-1286)

There's also the danger of actually becoming so dependent on your support that you go into anxiety stress levels because that support is going (Gwen, 730-733)

However, while both women recognise the accomplishment of being an expert carer, they appear to understand it in different ways. Hilary, it seems, interprets her increased capacity to cope as reduction in the potential for conflict. For Gwen, however, it appears to mean more about protecting herself from dependence, being able to manage without services that she may not have control over. Her comments suggest that she

feels mothers may actually become disempowered by their dependence on professionals and services.

3.6.3.2 PROJECT MANAGER

So it would seem that over time mothers begin to assert more influence on the nature and outcomes of their child's care. From this comes a broader understanding and expectation of what it is they want and will accept from services and practitioners. A number of them comment on their evolution into this role and identify how it has changed their approach and attitude to professionals:

I didn't know what was going on at all really and now I would never have let that go by that long but at the time I didn't really know what was happening (Barbara, 266-268)

I think I would have been much smarter about something like that now (Hilary, 746-747)

Did they listen to me? But I couldn't say that, you don't say that... [upset]...I would so say it now, oh God yeah (Denise, 357-359)

Whilst these observations portray a sense of passivity in earlier times, the comments imply an approach that is much more directive and assertive now; something that Denise is aware of:

I've never been this bolshie. I think that's what changed (Denise, 722-724)

This new ownership and assertiveness reveals itself in a role something akin to a project manager, where it seems the mother sees it as her function to direct and hold the professional to account as Fiona and Carole describe:

I have to chase this all up, every single little thing and chase it again and chase it again (Fiona, 740-741)

It's time consuming, I would say. Just trying, you know to you've sort of dotted all the Is and crossed all the Ts, everything's in, everything's in place (Carole, 189-191)

The quotes above imply that the mothers feel support that is not always delivered efficiently or effectively, meaning they need to monitor its delivery; something Hilary also refers to:

[It's] what you'd call over engineering... You just have to become skilled in spotting if something is going well and spotting when it isn't and when adjustments are needed. (Hilary, 1127, 1168-1170)

The women's comments reveal the constancy of the endeavour and, indeed, during their interviews, three of the mothers recalled something that had to be done, another interview was disrupted by an unexpected telephone call from a practitioner and another had to be paused when a new wheel chair arrived a day early. This experience demonstrated in real time the effort described in the women's comments.

Sometimes it appears that the project management of support becomes so much the concern of the mother it seems she, rather than the professional, takes responsibility:

I've structured the whole plans so that all her personal care and all the stuff that's involved where there could be a risk is in just that hour in the morning and I've asked for home care who are responsible for her in the home to go in and do that. So I'm not expecting the staff to do anything but help and teach her and support her in class (Gwen, 1438-1443)

I always tend to source Sophie's one to one support because I'm quite particular and she, you know, I have to have somebody who can cope with her and is willing to look after her (Carole, 213-216)

There seems therefore to be a further level of project management whereby the mothers not only make sure the professionals are completing the tasks they are supposed to but also where they direct decision making and stamp their authority upon it. In Gwen and Carole's comments on influencing choice, it seems they were not happy for the

professional to take the control. It is interesting that in both situations the support required was more of a personal nature in terms of carers and intimate care; it is perhaps in these areas that the roles of mother and expert carer interface.

It might be predicted that the nature of project management would bring the mothers into the kind of argumentative situation described in the Conflict and Challenge chapter, as the role could generate the potential for increased confrontation within the relationship. Yet it would appear that the woman's more direct engagement and time spent with the practitioner may in actuality allow her to adapt her approach for best results:

I suppose [I'm] just feeling a bit better about working out where to place your effort, you know. It didn't change anything that last time when we went ballistic and wrote to the head (Hilary, 1105-1109)

I might only see them once or twice a year [but] I've got a better understanding of how they might feel from past experience or I've got a better idea of how to ask for what I'm looking for in the way that I might receive it (Carole, 988-993)

Indeed some of the mothers identify that taking more control has allowed them to understand the relationship as a partnership leading to a more understanding and cooperative approach:

Although I'm more confident and assertive I have become a bit more rounded and a bit more open to other suggestions (Carole, 968-970)

As Darryl's got older we've been less fussed about loads of things and more fussed about, you know, actually the quality of the relationship (Hilary, 916-918)

The implication from previous themes was that some professionals do not take kindly to the mother wanting influence on decision making and that her assertion of control may result in conflict, breakdown of relationship and ultimately the withdrawal of services. It feels important then to point out that these mothers seem to believe a greater sense of influence and control has actually reduced their need to challenge and conflict even

when they may have reason. It may be that anxiety and stress is reduced when the women feel empowered as they recognise their own their knowledge and ability or that their improved understanding allows them to target their efforts were they are most needed. In any case, their experience suggests offering mothers an informed, power sharing relationship will not, necessarily, lead to increased disagreement or conflict.

3.6.3.3   THE EDUCATOR

The mothers also appear to see themselves in the role of educator, disseminating their knowledge and understanding to others. This can involve them advising professionals in respect of their child's condition or needs:

I seem to have to educate the school the whole time (Hilary, 100)

Maybe because they've actually seen some of the stuff that I do [facilitated communication]. Maybe I've been able to teach them something (Gwen, 644-646)

There's a lot of pointers from us ... there is no way Jordan would be where he is now without us (Fiona, 69-71)

Their educating role can also involve them in supporting other parents to collaborate with professionals and vice versa:

Sometimes some of the parents are sounding off. I try to give them an insight, not justify why things are the way they are, but to try to get them to understand the processes and how they could maybe work around that in order to get what they need (Elaine, 1876-1880)

[I got involved] with local things going on that were more multi agency and you would deliberately [have] parents and carers sat at a table with people from different agencies ... so they would be forced to talk (Abbey, 869-873)

Again it seems that knowledge and understanding does not result in elevated levels of disagreement and conflict. Indeed it would seem the more assured mother strives to

facilitate collaborative working and to share her more rounded view of the nature and context of the relationships. This often draws her into roles and tasks beyond the relationships she experiences.

3.6.3.4   ADVOCATE AND ACTIVIST

It is perhaps notable that three of the eight participants are currently employed in the field of disability, whilst two others, although unwaged, are intently and actively involved in particular support and campaigning groups developed to help children with the same condition as their own.   There is a sense that for some of the women, their own experience both enables and requires them to take up more general activist roles on behalf of the new community in which they find themselves. For Elaine the task is a global one:

It's far more than disability rights. It's about people power. It's not just around disability. It's about er, valuing people and valuing differences and celebrating difference and embracing it (Elaine, 1861-1865)

While for Gwen and Hilary it is about paving the way for the parents who come in their wake:

I'm changing and I'm not just changing for her. I'm changing for other people and I think where we struggle I have to remember that parents before us struggled even worse. So the least I can do is make it a little bit easier for the parents after us (Gwen, 1505-1509)

I'm ...pretty confident that we are going to be the first family with a child with [names disability] going to mainstream secondary school...which is sending ...excitement around [names town] at the moment. We're there being up front the whole time, you know, the pioneer if you like (Hilary, 193-203)

While both appear celebratory and confident it seems that, much like the more interpersonal experiences noted in the Challenge and Conflict chapter, such endeavours

are not without cost, with both women wondering if they have lost something of themselves in the process:

[It's] really important for me to do something for myself so that my children don't see me as an advocator or fighter or somebody for Katie because that's all I get seen as now, Katie's mum (Gwen, 1543-1546)

I wondered you know, whether I should ...be doing something in Special Needs and someone said to me 'Actually, maybe your job is to still be Hilary and to do what Hilary would like to do.' (Hilary, 229-232)

It seems as though the additional roles and tasks acquired over time affords a recognition that supporting their disabled child can be all consuming and may mean they become identified solely in that way. These quotes and Elaine's thoughts on the pressures of being an expert carer, suggest the women see and seek a separation between themselves as a person and mother and their persona as advocate for their child. Striking a balance is likely to be yet another struggle for the women since doing what they *'would like to do',* it will depend on their ability to tally their confidence in the professional and system and their own growing expertise with the previously discussed emotional consequences they experience in withdrawing.

There is a something of a parallel between this ability to prioritise their needs over what they feel they can do for the child and their experience of withdrawing from professional relationships they feel are not valuable since, it could be suggested, in just being Gwen, Hilary or Elaine they must extract themselves from their own professional persona. This expands on the earlier revelation that some of the mothers on occasion, feel they must not allow their parent identity to influence or corrupt their behaviour and that on other occasions they perceive their challenging to be underpinned by their own professional past.

3.6.4 SUMMARY OF TIME AND TRANSFORMATION

The final super-ordinate spotlights the mothers' thoughts on how time has impacted on the nature of their experiences of professional relationships. The analysis suggests they develop a growing confidence built upon a greater understanding of their child's needs, the professional role and what they need to do to get the best support they can. The theme highlights how this underpins a personal transformation that not only allows the mothers to re-position themselves within professional relationships but also facilitates them to take on roles that further enhance their contribution to the relationship and the child's care. The suggestion is made that as the mother becomes more knowledgeable and active on behalf of her child and others like them, she may struggle to retain her own identity as something other than advocate.

3.7 SUMMARY OF THE ANALYSIS

In summary then, the analysis has sought to present four major themes drawn from the interview data. These were labelled Expertise and Empathy, Power and Disempowerment, Challenge and Conflict and Time and Transformation, and contained a range of subordinate themes intended to build an interpretative account of the participants' experience of their relationships with professionals.

Theme one, Expertise and Empathy, explored the interplay of skills and personal characteristics in how the women experienced professional relationships. It showed that they meet practitioners with a wide mix of abilities and know-how. It also illuminated their experience of professionals whose personalities enhanced the relationship and others whose approach felt disrespectful and upsetting. The overall sense was that the women's experience of the relationship was often determined by the interpersonal than the skill and expertise of the professional. The section also suggests that professionals are not understanding of the mother's situation or often come to the relationship through an academic or discipline lense. This was thought to underpin the professionals lack of sensitivity toward the mother and their limited engagement with the child which also impacts on how the mothers view each relationship.

Theme Two, Power and Disempowerment, evolved from the women's descriptions of the power imbalances they perceived within the relationship. It considered the means through which these were maintained and how individual women experienced and responded to such dynamics in very different ways. The chapter also included the mothers' understanding of their lack of influence, choice and control within the relationship and how they believed some professionals experienced similar limitations meaning they are further silenced.

The third theme, Challenge and Conflict, examined the ways in which the mothers disputed and addressed power imbalances and illuminated their experience of conflict as constant and pervasive across their relationships with professionals. The theme outlines how the mothers feel they must play a game in order to disguise their challenges and not cause difficulties with the professional. The women's construal of the cost of such approaches was also considered. The theme gave rise to the suggestion that the mother sees from many perspectives when she engages with professionals while the professional may only hold their professional view.

The final theme, Time and Transformation, was designed to illustrate how time altered the mothers understanding of, and her position within, the relationship. It engaged with the interface whereupon the more experienced, knowledgeable and confident mother meets with the professional who is now familiar to her. Efforts were made to illustrate that the mother grows beyond the relationship, developing her identity as a mother of a disabled child, taking on tasks and responsibilities that, while outside of the association, nevertheless impact upon their function in it. The theme also draws attention to how such a process may detract from the mothers other roles and identities and the potential for further struggles in trying to maintain these as separate from what they do in relation to professionals.

The themes and their content will be now discussed further, both in relation to the mothers experience and also in terms of broader psychological theory and literature.

CHAPTER 4

DISCUSSION

4.1   INTRODUCTION

This research project explores how eight mothers of children with complex disabilities experience the relationships with professionals involved in their care. It is anticipated that insight into the meanings they attach to their lived experiences will illuminate the dynamics of particular helping scenarios and the factors that impact upon them. It is hoped this will help Counselling Psychologists to build on positive aspects and help address negative overtures cited previously (Davis, Day & Bidmead, 2002; Hoagwood, 2005). Thus, the investigation aims not only to close a gap in the existing literature (Panitch, 2007; Patterson, Jernell, Leonard & Titus, 2004), but also, in its application, to develop theory and practice in the field of disability, mothering and Counselling Psychology.

Previously, the analysis drew the researcher into a close scrutiny and exploration of the individual lifeworld of the participants. Four main themes arose to account for the meaning they give to their experiences of the relationships under question. Each theme is evidenced, explored and commented upon in the Analysis section. Now, however, the discussion will draw outward to provide a final commentary and to critically review the research project itself.

Completing the study has left me with the overall sense that, while the mothers experience some effective and satisfying associations, their stories, in the main, offer a prevailing impression of struggle at many levels. They struggle with the interpersonal content, to negotiate understanding and to influence the people and systems around them. This, sadly, mirrors Hannam's (1975) work, which first generated my interest some thirty years ago. However, the study is novel in that it highlights a transformational growth process arising from the experience whereby mothers resist the status quo, reconceptualise the relationship and develop their role within it.

Any critique will itself evolve from a personal perspective and understanding (Toomela, 2011) that generates my own distinct assumptions of the data, the relevance of the findings, and my perceptions of the function and role of Counselling Psychology. All of this will result in a discussion section that is as personal to me as are my area of interest, choice of question, preference for IPA, and interpretation of what was said in the interviews. The epitome of such influence may be seen in that, as a Counselling Psychologist, I endeavour to recognise and address the relationship between social context, subjective experience and the emotional wellbeing of my clients. This, my previous declaration of a perspective shaped by critical realism, and a research tool grounded in the social embeddedness of individual meaning making, will mean my understanding of the women's experience will be framed by considerations of social influence and positioning.

Although I have endeavoured to remain open and mindful to other possibilities, I am aware of the power attached to such persuasions and my commitment to them, and recognise that the reader might have chosen to draw on many other aspects of the data and may hold completely different views on the research outcomes. That this might generate debate is all the more exciting.

MOTHER & CHILD

SOCIETY

SOCIETY

THEME 4

TIME & TRANSFORMATION
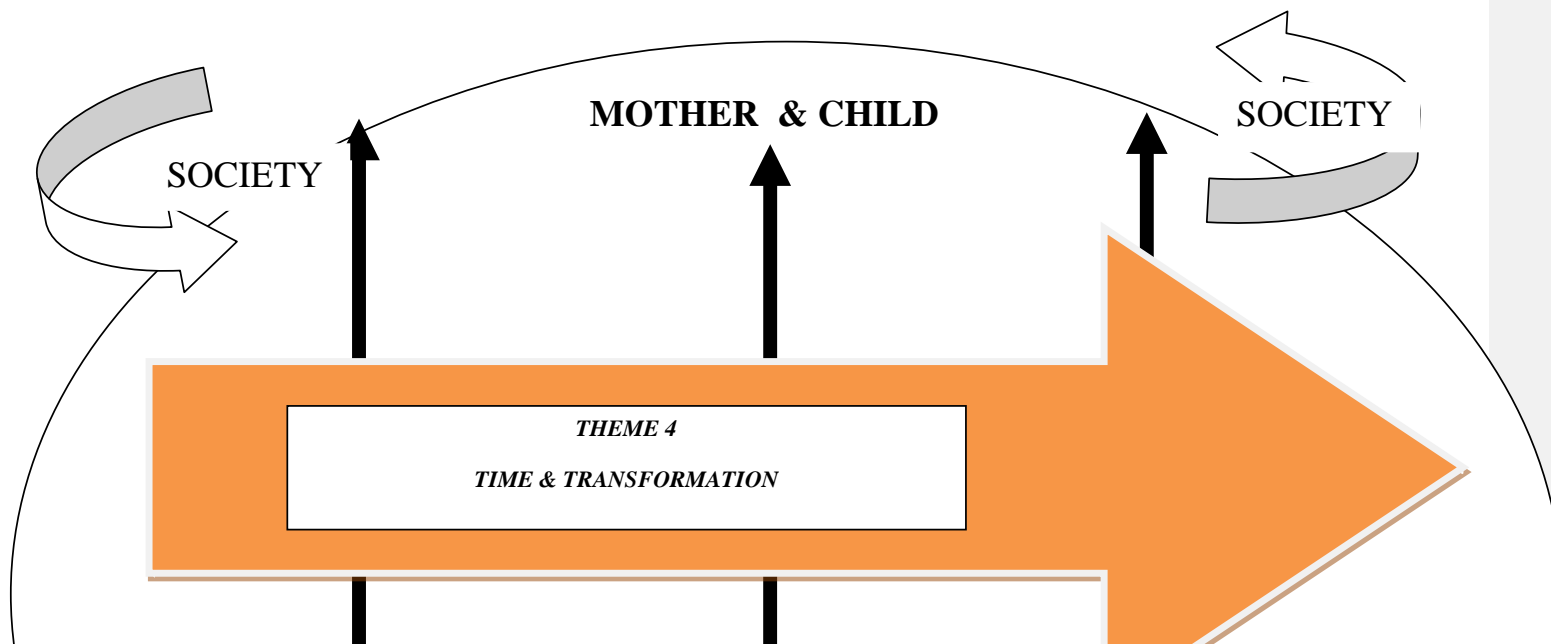
4.1.1 OVERVIEW OF RESEARCH FINDINGS

Figure 1 represents the outcome of my research. Perhaps one of the most fundamental findings is that participants articulated how they considered their relationships to also include their child and noted their experience was often influenced by how the child was involved. They also spoke of seeing themselves as a representative or spokesperson for the child, acting on their behalf, advocating, challenging and working to protect their wellbeing. They also highlighted how they felt they were engaging with a system rather than the practitioner. Some identified their belief that system processes, the ethos and culture of the organisation, and any financial or resource constraints, served to shape professional attitudes, interventions and the relationship itself.

Three of the four themes which arose from the analysis can be seen at the professional/ system end of the model. They sit here because it appears the mothers believe the professional has greater control over the dynamic. However, the two way arrows moderate this to the extent that mothers do have some influence on how they manage the impact on them and what they want for their child. The fourth theme, Time and Transformation, is set separately as the research suggests time delivers a more global, contouring influence across individuals, the relationship and the experience of the elements within the other themes.

While Time may have a broad influence, the study's focus prioritises its effect on the mother and suggests it can allow functional, developmental transformational growth. The arrows purposely point to a Transformation process rather than a target position or way of being within the relationship. This is because the mothers articulate their experience of professional relationships as a journey of discovery over time and not one that has a final destination. This is illuminated in that, although the children in the study were aged just six to ten years, the relationships had already been influenced by their child's altering needs, the duration of the association and their own varied emotional well being and personal context.

Comment [B1]: This was inventions but changed it to interventions?

Comment [JD2]:

Further, each association will involve unique individuals with different personal ingredients and outside influences, generating distinct experiences across the range of relationships. There will therefore be no constant relational frame or way to be. Indeed, given the shifting nature of our mood, needs and personal circumstance, alongside organisational and situational change, it is unlikely that the experience of any relationship will remain wholly predictable through its life time.

The model also depicts that the relationship does not exist in isolation of the world around it. Thus the women discuss how societal understandings influenced their early expectations of professionals, and how dominant discourses about expertise, for example, shape their perception of their position in comparison. They also articulate their belief that society influences how professionals view them, their child and how the relationship should be. But the data suggests that this process is not a uni-directional one and that part of the mother's transformational experience is that she challenges such understandings and disputing societal 'rules', such as how and where disabled children should be taught. Just as the relationship is not immune from the impact or injustices of society, neither do these mothers always allow its influences to go unchallenged.

In summary then, the research indicates that mothers view their relationships with professionals as more than bi-party, and experience them in terms of expertise and empathy, power and disempowerment, and challenge and conflict. Such experiences are mediated by the influences of time and the transforming effect it has on the mothers' understanding, skills and approach. It also suggests that society dictates much in terms of the nature of the dynamics within the relationship, and the mother's position and status in relation to it. Challenging such edicts is often part of the mother's role.

4.1.2 OVERVIEW OF THE DISCUSSION

The discussion section is designed to put some theoretical meat on the bones of the model. In the first instance, I will reflect on the methodology used in the study and on my experience of it. This section will also consider issues of transferability and

validity. Secondly, the findings will be discussed in light of the previous studies and theories highlighted in the introduction. This will allow me to locate my findings and illuminate how this study contributes to current thought. While the discussion of an IPA study will often address each of the generated themes in turn, this has proved difficult in the current research given the intersectionality of the ideas and concepts depicted in the model. In this case then, I will adopt a narrative style which will generate points of discussion that apply across the various findings. Thus, the ebb and flow of the interaction between aspects of the research will be maintained and not hidden by the structure of the prose. Some points will be reinforced by linking them back to quotes and discussion within the analysis. These will be referenced using the theme- subtheme combination within which they are cited e.g. (2.3.1).

The final section of the discussion will consider the implications of the findings upon professional practice, recommendations for further research and the relevance of the study to the discipline and practice of Counselling Psychology.

4.2 THE RESEARCH

This section will consider the research process itself. It will begin with a discussion on the validity of qualitative methodologies and on IPA in particular. This will then be extended with personal reflections on the overall experience of the investigative process. Finally, issues of transferability, validity and any limitations of the study will be explored with a view to support the reader's understanding of how the research effectively contributes to the literature.

4.2.1 REFLECTIONS ON THE METHODOLOGY

Qualitative methodologies are often criticised for a lack of hypothesis, limited numbers of participants and insufficient accounts of validity (Hagger & Chatzisarantis, 2011; McLeod, 2011). This could be seen as something akin to the researcher making a lone journey into the data, fuelled by their own philosophies and agendas and creating a personally favoured route underpinned by intuitive,

idiosyncratic preferences. Such understandings give rise to accusations of potential researcher bias and questionable reliability, replication and generalisation (Toomela, 2011; Willig, 2008).

It is perhaps for these reasons that qualitative research appears to be perceived as less valuable than that underpinned by quantitative methods (Carrera-Fernández, Guàrdia-Olmos & Peró-Cebollero, 2011; Hickson, 2011). The undermining of the 'interpretative, experiential, situational and personalistic' (Stake, 2010, p14) is particularly difficult for Counselling Psychologists, as such concerns best match their epistemological stance (McLeod, 2011). The impact of such notions on the research decisions and pursuits of practitioners are well documented (Henton, 2012; Kasket & Gil-Rodriguez, 2011).

Those who support qualitative methods argue that qualitative studies generate novel questions, provide alternative perspectives and offer a different way of treating phenomenon and, as such, contribute to all areas and levels of research (Stake, 2010). They challenge that no research can ever be value free, that quantitative researchers also make intuitive judgements and that every researcher meets their study with personal and philosophical bias (Carrera-Fernández et al., 2011; Hickson, 2011). It is also suggested that the benefit and strength of qualitative research actually lies in its often maligned interest in the 'science of the particular' and its emphasis on personal experience and meaning making (Stake, 2010, p13). Carrera-Fernández et al (2011) suggest that it is the quality of the tool that matters and that some methods in both camps are open to criticisms around validity and reliability.

Stake (2010) also celebrates the ability of qualitative approaches to generate and accommodate multiple perspectives, and to be comfortable in raising more questions than they answer as a positive and valuable way of extending knowledge. In this instance, a quantitative approach would not have delivered the depth of information required, however it was important to choose a qualitative tool that was both theoretically credible (Morrow, 2005) and 'fit for purpose' (Cassell & Symon, 2011, p638). I would argue that the philosophical underpinnings and procedure of IPA fulfils this criterion, that it is a well-established, documented method that sits

particularly well with the values and principles of Counselling Psychology and its practice. Thus the knowledge gained becomes relevant not only to the academic field but to the work we do with clients. Not only is the destination known, the vehicle is road worthy and the route options clearly marked.

4.2.2 PERSONAL REFLECTIONS ON THE PROCESS

The sort of tension outlined above had a personal bearing whilst I was completing the research. For thirty years I had planned research based on interviews in order to mirror Hannam's (1975) work. IPA had been chosen after much deliberation. Yet the positivist, boulder influences of my initial psychology training still holds me to ransom it would seem, and in the first draft of my introduction I found myself attempting epistemological suicide by criticising studies for not having pre-test measures, sufficient numbers and control groups. Old habits die hard and doubt, uncertainty and misgiving around subjectivity, accuracy and proof were constant.

At the analysis stage, I worried some kind of romanticised notions of motherhood or negative view of professional support would prejudice my analysis and reporting. I struggled to allow myself to make interpretative decisions and to generate intuitive links, to leave out 'evidence' and accept that descriptive research was as valid as that which sought predictive or causal information. Perhaps more disconcerting and less easily dispelled were my concerns about how seriously the research outcomes might be taken in the light of criticisms of qualitative research. The mothers had bestowed me with the guardianship of their history, their thoughts and feelings, wanting me not only to tell their story but to make sure it were heard. How cruel would it be if their efforts were sabotaged by the methodological decisions I had made?

I reasoned that a qualitative approach was a way of applying my Counselling Psychology principles and philosophies into research, and to undermine their usefulness was to challenge my profession to the core. I had sought an intimate account of the personal life world, to offer open questions that allowed participants to reflect upon and explore their experience. I was reassured in hearing the woman's

words coming from the page. I was gifted with a deep, rich narrative that reflected a broad spectrum of experiences. I had the kind of data I wanted.

On good days I told myself that the best fit experience of IPA meant I should be as confident a researcher as I am a practitioner, that my rounded experience of being both a family professional and mother to a child with disabilities provided hermeneutic balance and allowed openness to the women's breadth of experience. On good days, I believed the project allowed me a bridge between my scientist and reflexive practitioner roles.

4.2.3 TRANSFERABILITY AND LIMITATIONS

While I hope the research will draw attention to the nature of mothers' experience and initiate discussion and debate around the findings and implications for practice, I aim to report only on the group of women interviewed and in the knowledge that in the time taken to write up, the meanings they held might already have shifted. Indeed the interview itself may have facilitated reflections that generated alternative views. Qualitative researchers acknowledge that even beyond the influences of the questions asked, given a different interviewer at a different time, the mothers might have expressed alternative points of view or focussed on other events and experiences (McLeod, 2011). Further, this study captures but a moment in the inner lives of the women and does not assume that the meanings they give to their experience of relationships on this occasion are in any way static or fixed.

As described previously in the methodology section, IPA studies seek to explore the experiences of small, homogenous groups. In this case the findings of the study are based on purposive sample of eight mothers who have children with complex disabilities who also shared much in terms of ethnicity, age, social background and education. Such factors must be considered in transferring the results of the study since, for example, there was no representative of mothers from minority groups who, evidence would suggest, have an altogether different relationship with services than do those from the white population (Simon, 2006).

The mothers self-nominated and may have done so because they had had particularly difficult experiences of professional relationships. Further, their communicative confidence and abilities shown in the interview, along with their descriptions of drive, assertiveness and tenacity within the relationship, revealed particular interpersonal strengths. Such a dynamic would be in contrast to mothers who, for one reason or another, do not have such skills or characteristics at their disposal. For example, mothers who may not be as intellectually able or whose personal approach does not lend to challenging the status quo, may have a completely different understanding and experience to the mothers in this particular study. Nevertheless, IPA's deep exploration and analysis unveils the intricacies of a particular group's meaning making around a shared experience, allowing a representation of the individual's experience and interpretation of the similarities and differences occurring across the group.

Thus this study provides a useful insight into how these women, in their particular context, experience their relationships with professionals. It is recognised that this is not the only way such relationships will be experienced and that further research will be required to expand on the findings.

4.3   THE SOCIAL CONTEXT OF THE RELATIONSHIP

The literature review reveals how the client-professional relationship is understood to exist within a social context (Murray 2000) and therefore influenced by how society views and positions its players. It suggests that authority is bestowed upon the expert (Kirk 2001) while the mother of a disabled child comes to the relationships with reduced power and social capital (McKeever & Miller 2004). The major models utilised to depict the relationship are based on variations of how power is managed (Case 200). This section discusses the participants' experience of such power dynamics and the meanings they give to them.

4.3.1 POWER AND PRACTICE

The notions of socially prescribed professional power and authority outlined in the introduction section (Hodge & Runswick-Cole, 2008) would seem to be prevalent through the women's stories. Although the difficulties implicated in the Expert and Transplant models are well documented (Kirk, 2001), the current study would suggest that some professionals do continue to adhere to such approaches. The mothers believe, for instance, that those professionals assume governance over decision making and that they take ownership of information and communication between the two, such as when Denise felt excluded from Emily's diagnostic assessments (1.2) or Abbey's anger at eight minute appointments (2.2.2). The women's comments support the challenges already existent in the literature (Brett, 2002), and expose the interpersonal processes such models produce, identifying their respective sense of powerlessness, experiences of feeling silenced or marginalised, and having their anxieties trivialised or not addressed as they feel they should be.

4.3.2 POWER, PRACTICE AND THE LOSS OF THE PERSONAL

Perhaps more significant however is the insight the research provides into why such dynamics feel so uncomfortable and unhelpful. The mothers' comments suggest, for example, that expertise can be more of a barrier than an attribute, with experts being deemed pompous and aloof and understood to be keeping an emotional distance. Indeed a number of women reflect on the absence of 'the person' in such alliances, and like Carole (1.2), seem to understand professionalism as the loss of 'humanity'. The introduction offered some insight into how training, the interpretation of professional boundaries, or organisational protocols, promote the expert model by inhibiting the kind of personal contributions that would elude to empathy (Jack, DiCenso & Lohfeld, 2005; McKenzie, Murray & Matheson, 1999). It may be that adhering to professional and organisational standards results in a somewhat more business-like approach than suits the mother's needs at the time.

Further, in the main, the mothers experience such authoritarian, distanced relationships in respect to those experts within hospitals. This again draws attention to

systemic influence and may be why Elaine suggests professionals are good people but their personal qualities are often lost within institutionalised health care (1.2). The women also acknowledge overwork generates barriers (2.3.3). Recent catastrophic events in Staffordshire have highlighted the validity and importance of such understandings, with the demands of understaffing, financial constraints and stretched resources resulting in working practices that minimised the humanity of both practitioner and patient (Francis, 2013).

4.3.3 POWER, PRACTICE AND PROTECTION

A few of the mothers appear to understand the businesslike and distanced approach as an attempt to protect the professional from being overwhelmed by the emotion and trauma experienced by patients and their families. Denise, for example, suggests professionals would be drained if they offered empathy and understanding to all those they saw (1.2). Further observations about professionals isolating themselves, being irritable and impatient, and desensitized to the situation could be mapped onto the literature around the cause and symptoms of professional burnout (2.2.2).

An alternative view, again implicating social context, might be generated from Barnes, Thomas, French and Swain's (2004) suggestion that the medical model is underpinned by desire to cure, and causes difficulties when medics face non curable conditions. It may be that the personal and professional identity of medical staff is challenged by the children's very severe and, in some cases, life limiting disabilities. Managing such threats may account for participant's descriptions of practitioners' reluctance to label acute conditions, to admit a lack of knowledge and their maintaining an academic stance (1.1).

The presence of such negativity may mean the professional wants to protect the mother and therefore resists communicating difficult news (Dickinson, Smythe & Spence, 2006; Wright, 2008). Yet, even though mothers identify a desire for sensitivity and compassion (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004, p173), this is not mentioned as a possible scenario in this study (1.3). Perhaps this is because the women, in contrast, appear able to acknowledge and accept the

severity of the disability and desire information that will help them understand and manage it, as when Sophie's late diagnosis empowered Carole to inform herself further (4.1.1).

4.3.4 THE MOTHER'S UNDERSTANDING OF POWER, PRACTICE AND THE PERSONAL

There is some evidence that the group understand these difficult relationships in terms similar to the Bordieusian theory outlined in the introduction. For example, Fiona (2.1) suggests a social expectation that the professional will take charge while the mother is compliant and accepting, while Carole (2.0) believes professional arrogance is the result of having been invested with training. Abbey's metaphor of shark infested moats surrounding ivory towers (2.2.2) conjures up notions of the professional protecting their expert status and expecting the women to 'stick to the rules' in respect of their authority. The mothers also see the professionals understanding of the child in terms of reduced capital in that they are often seen as flawed. This is evident in the poignant alternative descriptions Gwen (1.4) offers as she and the professional look at Katie.

The mothers also observe that some professionals dislike to admit their lack of expertise or that they got something wrong (1.1). Again, they appear to see this as maintaining capital in the professional role. Such resistance is construed negatively and again appears to provoke resentment in the women (1.2). It is perhaps worthy of note that in the absence of their own expertise, the mothers cite their maternal instinct as the competence that underpins their belief (3.1); something that cannot be readily compared to levels of academic training or professional know-how but which identifies their own specific capital value.

4.3.5 SUMMARY OF THE SOCIAL CONTEXT

This section outlines the mothers understanding of professional power, suggesting they experienced expert power as a barrier within the relationships. The women

appear to perceive professional power as exhibited in a functional approach that creates emotional distance while assuming control. They bring meaning in terms of practitioners being overworked, desensitized or protecting themselves from the negativity thy see in the disability.

4.4   THE PERSONAL CONTEXT OF THE RELATIONSHIP

The introduction also explored the literature around the interpersonal dynamics within the parent/ professional relationship. It suggests that mothers seek out and value particular qualities within the alliance. These included good communication, trust, connectivity and respect for the child. This section will discuss what the mothers in this study experience and understand the interpersonal dynamics of these relationships.

4.4.1 THE EXPERT

The mothers tell of successful collaborative relationships with expert professionals where the women feel that their views are listened to, accepted and acted upon. In contrast to the application of power, these practioners appear able to share knowledge and skills and credit the mother's insight and understanding. Bourdieu (1984) suggests that an individual will be socialized in how to behave in their particular domain and how to protect the various forms of capital pertaining to it. However, they continue to have the 'opportunity for agency' whereby, in a dynamic dialogue of internal and external worlds, their own personal disposition or social experiences influence their expectations of the part they play. So approachable experts like the one supporting Denise (1.2) are able to maintain a sense of mastery which acknowledges their limited ability to cure and remains uncontested by the mother's contributions.

4.4.2 THE NON EXPERT

If social constructions around expertise were upheld, non experts would be reduced in value to the mother and one might expect such relationships to prove dissatisfactory. However, the women note very positive experiences with professionals who had little expertise. It may be that while her sense of competence and power is displaced by imposed authority, a mother is better positioned and more readily offered an influence within a relationship with a novice practitioner. This supports the notion that the meaning or quality of the mother's experience is not based solely upon the extent of skills and knowledge proffered by the professional, but is arbitrated instead by the quality of the person they are, as Denise and Carole observe (1.1). So, while some professionals might possess valuable expertise, this can be seen as a barrier when it means the mother's ability to contribute is denied, or when it is accompanied by what is perceived to be a negative or non-accepting attitude. A good interpersonal connection can, on occasion, similarly arbitrate any lack of expertise producing a quality experience regardless (1.1).

4.4.3 CREATING A PERSONAL CONNECTION

There is some evidence that the women in this study also recognise that their ability to mother and care for their child is under scrutiny and that they make some effort, in the early days at least, to demonstrate their proficiency (Peckover, 2002). Such challenges can leave the mother feeling unsure and apprehensive, with Elaine identifying her fear that perceived incompetence might result in the loss of her child (2.3.1). Perhaps one of the most notable outcomes in this respect is the participants' experience of being trusted within collaborative relationships. Although the literature explores the mother's need to feel trust in the professional (Bryk & Schneider, 2003; Lake & Billingsley, 2000), there appears to be a gap in relation to how trust being placed in her contributes to the strength and purpose of the alliance.

 In this study, the mothers' struggle to be trusted was evident throughout the data, with Abbey, Barbara & Gwen all expressing frustration at not being taken seriously (2.1,

3.1). Similarly, Elaine and Denise identify times when their opinions about what was best for their child were met with distrust and undermined (2.1, 4.2.2). On the other hand, being trusted appears to influence both the mother and the relationship in a very positive way, such as when Denise conveys a sense of confidence when a consultant sought her views of Emily's needs (1.1)

A further factor in establishing connectivity is the professional's understanding and acceptance of the child. Again, there is the suggestion that a good relationship between child and practitioner outweighs the desire for expertise, shown when Fiona suggests that she would accept a less expert professional if Jordan liked them (1.4). While it might be expected that professionals dealing with disabled children would hold accepting, empathetic views about them (1.4), this study suggests that this is not always the mother's experience. Instead the mothers report the view that some practitioners see the child only in terms of their disability or condition (1.4). It may be that some professionals' attitudes are shaped by the lack of corrective opportunity and the social negatives of the disability.

Holding such perceptions may account for the sometimes insensitive and hostile attitudes the mothers reported, such as when Joshua was described as 'not normal' (3.4.2) and when Denise was challenged about having another child lest they have Emily's difficulties (1.4).   There is some evidence that the mothers may initially hold a similar perspective. Over time, however, it seems they can sit comfortably with both perspectives, at once ably describing the child's condition and relating the endearing sides of their personality (4.1.1). It seems getting to know their child as a person contests the singularity of the medical description. The mothers work to resist such constructions both within and beyond the relationship (4.1), supporting their understanding by separating their motherwork as carer and mum, as Abbey does (4.2.1)

4.4.4 THE MOTHER'S UNDERSTANDING OF THE INTERPERSONAL AND CONNECTIVITY

Taylor (2006) suggests that women exhibit a 'tend and befriend' rather than fight or flight response to stress, seeking out support and personal connectivity to help manage their discomfort. The literature review highlighted the increased stress and emotional demands experienced by mothers of disabled children (Britner, Morog, Pianta & Marvin, 2003; Eisenhower, Baker & Blacher, 2005; Song & Singer, 2006). This was demonstrated not only by their stories (2.3.2) but by the number of women who cried during their interview (3.4.1, 1.2). In this case, an empathetic, responsive non-expert would provide comfort and reassurance and thus support the mother's needs, while those who would abstain themselves might actually increase anxiety.

However, this research suggests something more in that participants appear resistant to seeing the desire for collaboration as indicative of an emotional need. In fact, Denise describes removing herself because she felt she was being viewed as needy (2.3.1). Instead, it appears they understand a facilitative, personal connection as less to do with having a mentor or friend and more to do with establishing lines of communication that allows for an open dialogue that grows mutual trust and confidence (1.1, 4.2.2). Relationships where the mother does not feel connected can result in her ignoring recommendations or disengaging altogether. Although Hilary and Carole do describe avoiding on occasions (2.3.2), in the main these participants remain to challenge as they feel it is the only way to achieve what is best for their child (3.5).

The interviews illuminate the difficulties such processes cause for the mothers. They may, like Denise for example, feel unsure that their withdrawal was the best idea even though she felt uncomfortable in the relationship (2.3.2) or like Gwen, feel they need to remain in relationships even though they mistrust and dislike the professionals involved (3.3.3). The analysis suggests that the mothers' investment in or extraction from relationships is not emotionally driven but the result of balancing a myriad of factors in their decision making.

4.4.5 SUMMARY OF THE PERSONAL CONTEXT

This section discussed the interpersonal aspects of the women's experience. It highlights their appreciation of good personal connections and how on occasion, not being an expert can facilitate that. It also reveals how the mothers value being trusted and have particular regard for professionals who engage with their child. The section challenges previous suggestion that the mother seeks connectivity because of an emotional need. Instead it is proposed that the mothers seek the interpersonal connection because it offers the qualities that facilitate her to gain what she needs for her child.

4.5   THE PERSONAL MEETS THE SOCIAL

The previous sections have dealt with the impact of social constructions upon the relationship and how these affect power, positioning, practice and the interpersonal. We now turn to consider more deeply how the mothers manage these social influences amidst their desire for a quality connection with the professional and their wish to influence the understanding and decision making around their child.

4.5.1 REBALANCING THE SOCIAL IN THE CONTEXT OF THE PERSONAL

The mothers describe how approaches based on power and expertise often incites their anger and frustration as Elaine describes (3.1). There is a sense that the women feel 'put in their place' by such attitudes as Fiona experienced when she was excluded from discussions about Jordan's condition (2.1). It would be expected that this would impact on the mother's contribution, as not only must she assert confidence in her own personal opinions against those of the expert, she must 'bend' social rules and expectations to do it. This is illuminated when Hilary and Denise both speak of needing courage to offer their opinion (3.3.3).

Foucault (1980) posits that the empowerment of some will mean the disempowerment of others, leaving them vulnerable to control and manipulation. In this relationship, the professional comes because they work in a particular field and have specific knowledge and experience; mothers, in the main, are there by accident (Nuutila & Salanterä, 2006). This may leave the mother exposed to being viewed as amateurish, needy or dependent whilst the professional is seen as the problem solver. Further, some of the women identify their vulnerability to reprisal if they challenge or question the professional. Hilary, for instance, describes how she believes she was refused a place on a school trip because of a challenge she made (3.4.2). Such experiences raise issues of morality and ethics within 'helping' approaches that generate such power imbalances (Panitch, 2007, p21).

Defying perceived expertise is not an easy task since, as Focault (1980) suggests, we are often challenging that which society shares as absolute truth, not only across its present members but across the generations. Such processes can be identified as particularly valid in the case of Denise, who acknowledges her own mother's influence on her perceptions of medics and how she should behave in relation to them (2.1). Challenge might prove particularly difficult in the case of medics as they are afforded particular authority since they often make the difference between life and death (Dickson, Hargie & Morrow 2003 pg 27). To challenge or ignore one's belief in such authority may incur significant risk and consequence.

4.5.2 CHALLENGING THE STATUS QUO

If the relationships under scrutiny were solely about expertise, then it is likely the mothers would abandon novice personnel. If they were just about being emotionally supported, there would be an expectation that they would withdraw from associations with those who upset or offend them, even if they were experts. Instead, it seems each relationship takes meaning in terms of how it positively impacts on the child's well-being and opportunities (2.3.1), with the mother developing new and sophisticated ways of managing and redressing inherent difficulties where it seems worthwhile (3.3.2). This is seen in Gwen's determination not to show emotion in order to be

taken seriously (3.3.4) and Hilary's notion of drip feeding ideas in order to disguise that they came from her (3.3.2).

Perhaps the crux of the study is that, driven by the need for the best care, these participants do not accept the status quo and are transformed in the process of challenging it. Over time it would seem they too develop 'opportunity for agency'. They begin to challenge the social and personal expectations. For example, Denise and Gwen describe re-evaluating their own understandings as they discover experts do not have all the answers, nor do they have experience of 'the bigger picture' as they do (4.1.2). There are also many illustrations of the women developing different techniques to counter perceived professional hostility (3.3.2). However, embracing their personal expertise and the validity of their understandings brings its own challenges as it places the mother in opposition to established social constructs and the resulting codes of behaviour, often supported by administrative protocols (3.4.1, 3.4.2). This is evidenced by the frustration the women feel with systems and processes beyond the relationship but nevertheless central to it (2.2.2). Such barriers reinforce their experience of expert power at a personal level by restricting access, communication and collaboration.

4.5.3 FINDING VOICE AND BEING HEARD

The mothers' stories about challenging the status quo supports Belenky, Clinchy, Goldberger and Tarule's (1997) theory as they illuminate how their perspective on their own knowledge or position impedes or liberates them. Many speak of times when, not only were they not listened to, but they could not actually say what they wanted to say, as when Gwen was given Katie's diagnosis (2.2.3) or when Carole fails to complain about their treatment (3.5). Yet, at other times the same mothers are able to voice opinions because they are confident in what they know or are facilitated to share it, as when Gwen worked with the Educational Psychologist (4.2.1) and Carole asserted her right to choose Sophie's carer (4.4.2).

The themes 'Conflict and Challenge', and 'Time and Transformation', illuminate something of the process that underpins the mother finding her voice. For example, a

number of the participants identify a time, like Abbey, when they realise they could transfer communication skills acquired in different contexts (3.3.1). They also learn that information helps them feel confident (3.3.3). Perhaps new insight comes from the way the mothers disclose 'playing' the expert at their own game, making use of how they believe they are perceived in order to have their say (3.3).

In this instance, Elaine's experience is rather different to the others in that she asserts the validity of her knowing from very early in Sarah's life (2.1) and declares that she is not overwhelmed by professional status (2.2). Elaine's stronger voice may come from previous training specifically relating to Sarah's condition or from a professional experience that tempered her social learning of medical infallibility long before. Yet, conversely, Elaine is the only woman to claim authority just by being a mother (3.1). This might suggest that there is an integration of the power of her knowledge across her professional and mothering roles, resulting in an identity that captures the strengths of both (Ruddick, 2005).

There is also something about character and personality in the mix, with Fiona generally presenting as a 'no-nonsense' person who has previously been involved in social movements and who believes she would have voice whoever she engaged with (2.1). It seems important that Barbara, who had effectively withdrawn from many professional relationships because of the stress and upset she had experienced (3.5), was also mother of the youngest child by some three years, suggesting that perhaps time spent is important in building resilience and confidence to engage. However, Barbara had recently had another baby which may have meant her withdrawal was more a consequence of limited personal resources and capacity than self protection (Neufeld, Harrison, Stewart & Hughes, 2008). Research that followed a mother's experience in real time would allow the exploration of such a proposition.

4.5.4 ESTABLISHING POWER

The mothers also illuminate what Belenky et al (1997) label 'constructed knowledge' whereby, over time, growing experience of caring for their child alongside a backdrop of professional shortcoming, allows them to perceive their knowledge as legitimate,

relevant and important (4.2). Further, increased understanding of how to manipulate access to systems and services (4.3) affords 'process and procedural' knowledge that generates the confidence to bring novel and personal understandings to the relationship (4.2). Time and Transformation suggests the mother uses her voice to assert change (4.2.1), challenge social discourses (4.2.3, 4.2.4), enhance power capital (4.2.1) and alter the currency of the transaction away from need and towards action (1.3).

This seems to further liberate her understanding of the contribution she can make to the relationship and, while this itself brings risks (3.4), these appear to be outweighed by the motivation to influence her child's care (3.2). Transformation comes not only in terms of their personal development or interpersonal effect, but also in terms of the mothers' understanding of their role and position. It seems that in order to gain such power capital, the woman may have to reconstruct herself as something other than mother. Their mothering, in this context, becomes almost professionalised as they resist emotion (3.3.4), utilise specialist language (4.1.1), establish networks (4.2.4), prepare their arguments (3.3.3) and try to meet the professionals as equals (4.1.2).

Nelson (2002, p521) describes the task of establishing this more powerful position as a learning curve to a new kind of mothering, while McKeever and Miller (2004) suggest such assertiveness can result in mothers being 'pathologized as over-protective, difficult, unrealistic, or in denial of the extent and impact of their children's disabilities' (p1177). The mothers in this study reflected on similar tensions, identifying that in becoming 'professional' they regrettably lose something of their motherhood (3.4) and yet are further labelled (3.4.2). It is as if, like some professionals described earlier, they too lose something personal in acquiring power in the relationship.

4.5.5 POWER, PRACTICE AND THE LOSS OF THE PERSONAL – MOTHERS

So while the mothers' transformation might be viewed as personal growth and development, the relational contexts in which it is generated are often challenging if

not altogether contentious and adversarial. This might suggest that transformation is not something the mothers seek but instead comes as a consequence of their motherwork. However, any unravelling of the nature of the dynamics that accompany this transformation feels complex, contradictory and messy. Such intricacies can be illuminated in how influences of gender ebb and flow within the relationship. For example, the study shows that while the women all articulate disdain for the social constructions of mothers at some point in their interview (3.1, 2.1), only Denise and Gwen make any comment on the weight the father's voice carries in comparison to theirs (3.3.5). Indeed, at the same time, many reflect on exploiting recognised taken-for-granted female characteristics by crying (3.3.4), acting the 'dizzy blonde' (3.3.2) and identifying themselves as emotional and pathological (3.3.2), should that be to their advantage.

In addition, their transformation appears to involve ways of relating that are, as Gwen declares, 'as un-parent-like as possible' (3.3.4), which could also be construed as a masculinisation of their role. This can be seen in the way they identify how they become rational and business like (3.3.4), driven by information (4.1.1) and seeking to be solution focussed (4.2.2); behaviours and 'no nonsense' qualities more often attributed to the male population. Paradoxically, the mothers identify male partners disengaging because they cannot cope with the pressure of meetings or decision making (3.3.5).

Further gender complexities are highlighted by the way the mothers do not appear to view the qualities traditionally attributed to women as valued within the relationship (3.2.3). Rather, it would seem the nurturing, intuitive characteristics often bestowed on motherhood (Maushart, 2000) serve to make them feel vulnerable and weak (2.3.1) while skills, strategies and attitudes taken from the work place prove more efficient and helpful in their advocacy (4.1.1). Such observations fit current feminist theory highlighting the engendered nature of esteemed occupations and the masculine ethos prevalent in the type of large organisations and systems providing the services and support these mothers' desire (Holvino, 2013). Further, it also suggests that the characteristics of a 'good mother', often already under scrutiny in respect of mothers of children with disabilities (Bryk & Schneider, 2003; Lord Nelson, Summers &

Turnbull, 2004), are not always compatible with the qualities and approach required to achieve effective motherwork in these relationships. Thus in abandoning particular 'feminine' characteristics in order to better advocate for her child, the woman actually lends herself to being viewed as a 'bad mother'.

4.5.6 CHALLENGING SOCIAL CONSTRUCTS BEYOND THE RELATIONSHIP

While these particular efforts can be seen to be a challenge of social constructs at micro interpersonal level, the study also reveals how some of the mothers acquire a broader political literacy (Edelson, 2000) and attempt to deconstruct dominant social discourses further afield. Thus Elaine and Abbey have taken up paid employment in the field of disability, where they see their experience as mothers contributing something more to the post than someone else might (4.2.4). They and other mothers have become mentors and activists within the community, sharing their experiences in the hope of educating and supporting other parents and professionals (4.2.3). In doing so, they follow in the footsteps of many mothers of children with disability who have historically broken taboos and challenged normative expectations of mothering by taking their private experience into the social domain (Buck, 1992; Read, 2000; Panitch, 2007) and, like those who have gone before them, these mothers appear to see their efforts as less about politics and more about fairness and justice (4.2.4) for disabled children.

4.5.7 SUMMARY OF THE PERSONAL MEETS THE SOCIAL

This section has explored how the mothers manage the impact of power and authority imbalances within the relationship. It is suggested that they challenge the position of professionals and enhance their own by changing their approach, demeanour and outlook within the alliance. Further, they also take their message into society in the hope of changing attitudes and developing fairer systems. They find their voice in utilising the various strategies outlined in the analysis (5.4 -5.5). This generates a

persona that, while effective within their relationships with professionals, causes some of the mothers to worry that they lose something of themselves in the process.

4. 6   CONCLUSION

Participants appear to experience the relationship as a struggle of authority and influence, something which has been previously noted in the literature (McKeever & Miller, 2004). This study strengthens earlier research by illuminating such struggles across the dynamics of expertise-empathy, power-disempowerment and challenge-conflict. It further implicates the influence of social norms around status, disability and motherhood in their formation. The depth of the probing and analysis unveils something about the women's processing and meaning that disputes previous literature interpreting the mother's emotional and behavioural responses as stress and anxiety driven (Van Riper, 2007), or caused by a reluctance to accept the reality of the disability (Green, 2007; Todd & Jones, 2003). This is not to say the women are never emotionally overwhelmed by concerns for their child's future – they often are (2.3.2) – however, this cannot be the only frame within which their behaviours are interpreted. Instead, the women's attitudes and activities can be seen as sophisticated and goal driven responses to the practitioner/ system, based on a social capital model, executed on behalf of the child and designed to get the best possible outcome for them.

4.7   IMPLICATIONS FOR PRACTICE

The intersectioning of the potential five –way dynamic shown in the model would seem to be pivotal with the mother's experience of the relationship determined by a combination of the influences of society, the professional, the system, the child and how she herself feels – often unique in that one point in time and certainly changing through the child's life (4.1).   Thus, perhaps a financially constrained system producing new criteria that the professional must apply, denies the child support which causes the mother, depending on how experienced or strong she feels, to challenge or resentfully accept, both of which may fracture what had been a

satisfactory relationship. The question for practitioners is how we manage such processes at the interface between them – that is our relationship with the mother.

The interpretation of the research findings has leant heavily on a Bordieusian social capital model. It suggests that much of the mothers' experience of professional relationships is grounded in the power and system differentials arising from social capital and in their attempts to resist it. This being the case it would seem that efforts to improve their experience should be targeted at reducing the divisive nature of such dynamics. A number of suggestions for ways to do this emerge from the mothers' comments.

4.7.1 BEING OPEN

One example identified on a number of occasions is the mothers' desire for honesty (1.1). They believe practitioners hide the truth, while they feel they can cope with it, and identify avoiding it as wearisome and problematic (1.2). They believe they would have more realistic expectations and conflict would be reduced if they knew nothing was being disguised, hidden or withheld (2.2.3). The relationship then may benefit from practitioners being able to acknowledge the severity and permanency of a condition, admit their lack of understanding and willingly disclose system constraints and fractures. Honesty that reveals limitations may cause the mother initial anxiety, but voicing challenges and worries could be seen as a natural part of the process to assimilate the new information. If this is the case, the mothers' experience of professionals responding negatively to criticism (3.4.2) raises some concerns about the consequences of them being transparent. Professional understanding of the stress response and ways to deal with conflict may go some way to reducing these kind of interpersonal difficulties.

A further related revelation was the notion that the mother becomes something other than mother because displaying 'parent like' qualities leaves them undervalued and vulnerable. Previously, the discussion illuminated how the person of the mother may be lost in the process. It seems fair to say a mother pretending to be unaffected is unlikely to generate robust, lasting lines of communication. Perhaps it is important

that practitioners understand that while anger and apprehension are natural emotional responses to stressful events, they do not represent incapacity or helplessness and, further, could be the result of difficulties dealing with the demands of professional support itself.

It would seem that open and honest dialogue is best facilitated in a relationship where the mother is seen as a co partner and where her expertise, albeit a maternal instinct as some suggest, (3.1) is recognised and valued. This is not to say that the professional should forget that the mother is a mother first and will have the emotional bond, caring and concern for her child that they, as a professional, will not feel. So the 'expert' will be required to give the relevant information in a sensitive and facilitative manner and to explain when information is not shared more fully (1.2).

4.7.2 INTERPERSONAL CONNECTIVITY

One way to ensure the professional gets sharing right is a solid personal connection between the two. This is not always easy in times of reduced staffing and waiting list pressures. However, the mothers challenge against professionals in 'ivory towers' (2.2.2) suggests they seek greater connectivity. The key worker role (Limberick, 2004) allows the mother to be connected to someone who may not be the decision maker but who knows the family and local services, thus acting as a bridge between the family and professionals who are somewhat removed from them.

A strong thread through the mothers' experience of connectivity was the professionals' attitude to the child (1.4). Accepting the relationship concerns the mother **and** the child, and acknowledging and openly valuing a much loved child, will show genuine connection and reduce the temptation to view the situation through a depersonalised academic lens (1.4).

4.7.3 ACCEPTING THE MOTHER'S ROLE

Being aware of the function of the mother's role and negotiations as purposeful and built on her maternal expertise could reduce potential power struggles within

challenge process. Professionals could direct mothers to the various schemes such as Patient and Advice Liaison Service (PALS), Service User Involvement Schemes and Patient Forums designed to allow voice to those in receipt of services. Some of the mothers in the study already engage with professionals outside the context of the relationship (4.2.4). Encouraging practitioners to get involved with support groups and networks may prove useful in reducing personal barriers, illuminating misrepresentations and providing useful information and shared resources.

A further way in which practitioners could reinforce the mother's role is to pursue stakeholder led research (Goodman, 2004). This would help draw mothers and professionals into a more ubiquitous relationship, where shared goals and barriers were exemplified and addressed. Larger systems-level change could be driven by the evidence from such collaborations.

4.7.4 THE SYSTEM

Although Fiona asserts that particular professionals get pleasure from the distress their power and control creates (2.3.2), it seems unlikely that many would enjoy hearing that mothers feel sick before they meet and like chastised children, cattle or a number when they do (2.1, 2.2.2). However, the routine customs and approaches that generate such upset, for example, not being seen by the same practitioner, the time limited appointment or a hierarchy that delays the sharing of information, may be difficult for the practitioner to change on their own. Further, professionals' may become immune to how their practice is often fashioned and constrained by their involvement in particular systems. Yet, in order to realise change, practitioners must hear and relate mothers' feelings to those with responsibility. The model produced in this research might prove useful in such a process.

4.7.4.1 CLIENT CENTRED PROCESSES

The mothers' difficulty with access to practitioners, their information and their services are most often understood as representing professional power and the mothers' respective disempowerment (2.2.3). This is perceived as a lack of empathy

or concern (1.3), generates conflict (3.1) and results in the mothers using stealth practices they do not sit comfortably with (3.3.4). It would seem easier access might significantly improve the relationship. Innovations such as single point of access, key workers, book and choose appointment schemes, open consultation time and use of modern technology and social media could all be utilised to improve practitioner availability. Information sharing could be improved by replacing the routine copying of medicalised or academic correspondence with more user friendly versions, suitably prepared information and signposting in leaflets or websites. Practitioner assisted support networks and educational groups could build lines of communication and family self sufficiency.

Comment [B3]: Not sure if this needs rephrasing slightly?

4.7.4.2   TRAINING

Perhaps one of the greatest issues for these participants is the lack of understanding and empathy shown by practitioners. Improvements may come from, for example, a broader training for medically based disciplines; one that harnesses the alliance and capability models (Brett, 2002; Mitre, 2006). The introduction highlighted the social expectations that medics cure (Kirk, 2001), and many of the women recognised practitioner discomfort with their child (1.4). A professional grounding that asserts helping is not always equated to repair would go some way to alleviate the pressure on practitioners and their difficulties dealing with those whose condition they cannot remedy. It would be hoped that this kind of meaning making would generate greater positivity and empathy within the relationship; something the mothers identify as missing on many occasions.

A further concern is that the mothers believed professionals did not understand the social and personal implications of having a disabled child. It could be that some degree of real life experience, perhaps in community placement, and teaching of models such as McCubbin and Patterson (1983), would highlight the complexities of positive as well as negative connotations of the situation.

4.7.4.3   SUPPORT SYSTEMS

The discussion has explored the women's understanding that professionals protect themselves by developing an emotional distance from them and their child (1.2). While changes in training mentioned above should help eradicate such threat, the 'system' surrounding practitioners needs to provide supervision that offers somewhere to explore feelings as well as managerial issues. In service, professional development could also enhance personal stress management, coping skills and build resilience.

It also seems that systems can cause the professional difficulties which permeate and corrupt the relationship (2.3.3). In a way similar to how mothers experience collaborative relationships, the system could reduce potential flash points by supplanting performance indicators, such as caseloads and contacts, with processes that offer shared case management, accommodate practitioner judgment and provide clear commissioning guideline. Practitioners who are supported and empowered may reduce conflict and express a greater degree of empathy as they will be required to protect themselves and the system less often.

4.7.4.4   SOCIETY

The analysis, model and discussion illuminate dominant discourses on disability, mothering and expertise as having a major impact in the shaping of the women's experience. To a great extent then, the women's struggle is against a powerful socially constructed narrative and can be viewed in terms of a social injustice. The difficulties in contesting such social constructs and challenging power givens have already been discussed, however, the study shows that mothers do dispute such understandings in ways with much in common with the social justice approach (Morris, 2011).

Any sea change will necessitate the recognition of power imbalances at all levels and the offloading of socially bestowed attributes and authority. The mothers' approach and activities could provide a working model for practitioners keen to fashion changes to the experiences illuminated in this research. For example, professionals involved in

Comment [B4]: I know what you mean (linked to the phrase to do with changing tides, right??), but not sure it sounds right

facilitative relationships with mothers would be charged to disseminate their good practice and inclusive philosophy. They could contribute to the multi-disciplinary process, volunteering as lead professional in case management and engaging in the training and development of others. Taking their approach away from the realms of the relationship and into support networks, the media and being published would broaden the scope of influence. It might also be useful to engage with commissioners in order to advocate for changes in the nature of service delivery and to be involved with the scoping and review exercises of the relevant government department in order to highlight issues and influence change.

4.8 SUGGESTIONS FOR FUTURE RESEARCH

Given the discussion above and that the experiences of this group are often extremely challenging, it now seems even more important that research be designed to capture the story of mothers with less voice or knowing, or whose treatment in society can be particularly oppressive or marginalising. Providing the same depth of analysis to diverse groups of mothers with children with disabilities, and indeed to those involved with professionals for other reasons, would allow a much fuller picture of the complexities of such relationships.

Perhaps one of the most obvious next steps would be to replicate the study with fathers of children with disability. Some participants suggested their husbands approached the situation differently, were not so involved and that being male made a difference in some relational contexts. Further work would not only contribute to understanding the nature of the parent- professional relationship, it would develop the dearth of literature that explores men's experiences of being fathers of children with disabilities (Carpenter, 2000) and could extend observations of the influence of gender, gender stereotypes and engendered discourse discussed earlier.

It would also be useful to explore mother/ professional relationships in terms of function. The review of literature highlighted that the context for assessment and disclosure often shaped and influenced the relationship (Watson, 2008). As a consequence, a question on diagnosis was included in the interview schedule. In

hindsight, I feel this might have been better left out as the majority of the women had not had a good experience, and this may have led them to think of other negative incidents and relationships. In a similar vein, other items related more to the women's experience of being a mother of a child with disabilities than to her experience of professionals. The questions were obviously relevant to the participants and led to a quantity of illuminative data, which was not directly related to the professional relationships and could not be used in the study. What can be done with this material will be considered following submission of the current research for appraisal, but it would suggest an area mothers do want to talk about.

The research question itself was wide ranging in that it asked about 'relationships with professionals' rather than focussing on particular service sections. However, as has been noted previously, there was a sense that the women believed context and discipline were implicated in the nature of their experience. Their descriptions of systems supporting the professional also revealed a particular divide between health and social care as opposed to education. However, the resulting data was not strong enough to offer a separate theme and any specific exploration would have drawn the women into areas that were not the focus of the study. It would be useful to narrow the focus in future research by asking questions about relationships with particular types of practitioner, social workers, paediatric health consultants and teachers for instance.

There was also some evidence that the mothers varied in their experience and views on how the physical context within which contact took place impacted on the interaction. Again it may be useful to relate the question to context, for example asking how mothers experienced relationships with professionals who offered home visits, hospital outpatients or school based consultations, in order to explore how these may influence mothers' experience. Some of the mothers also reflected on the differences in their experiences of novice and established practitioners. This suggests there is scope for research comparing these groups either at one point in time or as a longitudinal study of a group as they progress in their career.

The study also revealed how the mothers sometimes experienced their child as being ignored or neglected as party to the relationship. They appreciated those who acknowledged and included them. This research was not designed to elicit the child's views, although the schedule offered time and probes to allow the mother to talk about them, and there were occasions when some of the mothers contemplated or supposed how the child experienced the particular situation they were describing. Given the evidence that the mothers expect the relationship to include the child, then future research should offer children a voice. A creative and reciprocal dialogue would not only give insight to their experience but may also provide a template for their greater inclusion within professional relationships.

The study produced a major theme 'Time and Transformation' that hinged on the participants' recognition that over time, they experienced a cyclical influence of experience, changes in their attitudes, roles and understanding. The limitations of a single interview are particularly pertinent here. It would seem vital that future research investigates such transformational experiences and their consequences for the personal lives and mothering tasks of women in similar situations. Research where mothers specifically discussed how they changed in relation to professionals over time could be instigated, but it may be more profitable to generate longitudinal studies focussing on the nature and development of specific relationships, or following mothers through an extended period in which they were dealing with professionals.

4.9   THE RELEVANCE TO COUNSELLING PSYCHOLOGY

Many of those who already support families with a disabled child will do so by way of practical and behavioural interventions as well as providing therapeutic support to individuals or to the family as a whole. This study informs this kind of personal level involvement in that it offers a rich description of the mothers' encounters with professionals and provides some understanding of any negative experiences they may have. Further, it draws attention to the potential hazards in maintaining an 'expert'

persona, thus reinforcing Counselling Psychology's attention to power in the relationship.

The study has also shown the usefulness of interpersonal skills within the relationship. Counselling psychologists could be involved in providing training that might alleviate the tensions identified. For example, they could produce personal development courses for mothers that would concentrate on skills that would improve their ability to assert themselves, to negotiate effectively and to build communicative pathways. Similarly, Counselling Psychologists could also contribute to the identified needs in training and development of interpersonal skills in professionals. There is an opportunity for Counselling Psychologists not only to advocate for change in terms of the unhelpful attitudes and approaches the mothers have identified, but also to deliver the sort of reflective and experiential training that could promote alternative constructs of role and service delivery.

The study therefore provides practitioners with an opportunity to 'give psychology away' in order to empower and liberate both mother and professional (Miller, 1969). However, given that our discipline's understanding of the importance of social context is reinforced by the research, our work cannot be limited to the individual and interpersonal levels and we must instead endeavour to create effective change at a social level if we are to generate real change in the experience of such relationships. Counselling Psychologists could readily harness the mothers' intuitive understanding of their experiences and introduce them to theoretical ways of understanding social experiences around disability, expertise, mothering and helping and how these influence their experiences within their relationships with professionals. We could also enlighten and educate around the particular challenges being a woman brings within the relationship. Further research would also help, but additionally we could support mother/ professional led research and community action in the hope that gaining further insights, and drawing attention to the difficulties more widely, would also facilitate change.

There is work to be done and Counselling Psychology would appear to be well placed to support it. Is it our business? I would argue yes, it most certainly is. Counselling

Psychology is tasked to support those who experience unjust treatment into empowerment. We have a mission to attend and address social injustices as we see them. This research has identified that mothers of children with disability experience stigma, discrimination, exclusion and unjust practices even within their relationships with professionals. Counselling Psychology can influence the process, at personal, relational and social levels. It is likely that the message will not be readily received in some quarters and that Counselling Psychologists involved may be seen to be challenging both their professional colleagues and the way things are done. This simply positions us as the mothers are positioned within the relationships. However, we have the training, skills and knowledge to make a difference. We can and we should.

REFERENCES

Ahern, K. (2000). "Something is Wrong with My Child": A Phenomenological Account of a Search for a Diagnosis. *Early Education and Development, 11*(2), 187 – 201.

Aitkien, M. E., Mele, N. N. & Barrett, K. W. (2004). Recovery of injured children: parent perspectives on family needs. *Archives Of Physical Medicine & Rehabilitation*, *85*(4), 567 – 573.

Almond, B. (2011). *The Monster Within: The Hidden Side of Motherhood.* Berkeley, CA: University of California Press.

Altiere, M.J. & Von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability, 34*(2), 142 – 152.

Al-Yagon, M. & Cinamon, R.G. (2008). Work-family relations among mothers of children with learning disorders. *European Journal of Special Needs Education, 23*(2), 91 – 107.

Angell, M.E., Stoner, J.B. & Shelden, D.L. (2009). Trust in Education Professionals: Perspectives of Mothers of Children With Disabilities. *Remedial and Special Education, 30*(3), 160 – 176.

Applequist, K.L. & Bailey, D.B. (2000). Navajo caregivers' perceptions of early intervention services. *Journal of Early Intervention, 23*(1), 47 – 61.

Appleton, P.L. & Minchom, P.E. (1991). Models of parent partnership and child development centres. *Child: Care, Health and Development, 17*(1), 27 – 38.

Arendell, T. (2000). Conceiving and Investigating Motherhood: The Decade's Scholarship. *Journal of Marriage and Family, 62*(4), 1192 – 1207.

Ashworth, P. (2003). An approach to phenomenological psychology: The contingencies of the lifeworld. *Journal of Phenomenological Psychology 34*(2), 145-156.

Badinter, E. (2013). *The Conflict: How Modern Motherhood Undermines the Status of Women.* California, USA: Griffin Publishing.

Bailey, D.B., Golden, R.N., Roberts, J. & Ford, A. (2007). Maternal Depression and Developmental Disability: Research Critique. *Mental Retardation and developmental Disabilities Research Reviews, 13,* 321 – 329.

Baldwin, S. & Carlisle, J. (1999). Living with disability: the experiences of parents and children. In G. Allan (Ed), *The Sociology of the Family.* Oxford, UK: Blackwell.

Barnes, C. (1996). Theories of disability and the origins of the oppression of disabled people in western society. In L. Barton (Ed.), *Disability and society: Emerging issues and insights.* New York, NY: Longman Publishing.

Barnes, C., Thomas, C., French, S. & Swain, S. (Eds). (2004). *Disabling Barriers, Enabling Environments.* London, UK: Sage.

Baxter, C., Cummins, R.A. & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability*, *25*(2), 105 – 118.

Baxter, S., & Brumfitt, S. (2008). Professional differences in interprofessional working. *Journal Of Interprofessional Care*, *22*(3), 239-251.

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*(9), 702 – 714.

Belenky, M.F., Clinchy, B.M., Goldberger, N.R. & Tarule, J.M. (1997). *Women's Ways of Knowing: The Development of Self, Voice and Mind 10th Anniversary Edition*. New York, NY: Basic Books.

Bell, S.E. (2004). Intensive Performances of Mothering: a Sociological Perspective. *Qualitative Research, 4*(1), 45 – 75.

Betz, C.L. (2006). Parent-Professional Partnerships: Bridging the Disparate Worlds of Children, Families, and Professionals. *Journal of Pediatric Nursing, 21*(5), 333 – 336.

Bhaskar, R. (1989) *Reclaiming Reality: A Critical Introduction to Contemporary Philosophy*. London: Verso.

Bhasker, R. & Danermark, B. (2006). Meta-theory, Interdisciplinarity and Disability Research: A Critical Realist Perspective. *Scandinavian Journal of Disability Research, 8*(4), 278 – 297.

Blaffer-Hrdy, S. (2000). *Mother Nature: Maternal Instincts and How They Shape the Human Species*. New York, NY: Ballentine Books.

Blue-Banning, M., Summers, J.A., Frankland, H.C., Nelson, L.L. & Beegle, G. (2004). Dimensions of Family and Professional Partnerships: Constructive Guidelines for Collaboration. *Exceptional Children, 70*(2), 167 – 184.

Blum, L.M. (2007). Mother-Blame in the Prozac Nation: Raising Kids with Invisible Disabilities. *Gender and Society, 21*(2), 202 – 226.

Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste.* Cambridge, UK: Harvard University Press.

Bourke-Taylor, H., Howie, L. & Law, M. (2010). Impact of caring for a school-aged child with a disability: understanding mothers' perspectives. *Australian Occupational Therapy Journal, 57*(2), 127 – 36.

Bowlby, J. (1973). *Attachment and Loss, Volume 11: Separation, anxiety and anger.* London, UK: Hogarth Press.

Brandon, D. (1976). *Zen in the Art of Helping.* London, UK: Routledge.

Brandon, T. (2005). Empowerment, policy levels and service forums. *Journal Of Intellectual Disabilities*, *9*(4), 321 – 331.

Brantlinger, E. (2001). Poverty, Class, and Disability: A Historical, Social, and Political Perspective. *Focus On Exceptional Children*, *33*(7), 1 – 19.

Brett, J. (2002). The experience of disability from the perspective of parents of children with profound impairment: is it time for an alternative model of disability? *Disability and Society, 17*(7), 825 – 843.

British Council of Disabled People. (2005). British Council of Disabled People's response to the Education and Skills Select Committee on Children with SEN. Retrieved from http://www.publications.parliament.uk/pa/cm200506/cmselect/cmeduski/uc478-vii/uc11402.htm.

British Psychological Society (2005). *Code of conduct, ethical principles and guidelines.* Leicester, UK: British Psychological Society.

British Psychological Society. (2000). *Division of counselling psychology professional practice guidelines.* Leicester, UK: British Psychological Society.

Britner, P.A., Morog, M.C., Pianta, R.C. & Marvin, R.S. (2003). Stress and Coping: A Comparison of Self-Report Measures of Functioning in Families of Young Children with Cerebral Palsy. *Journal of Child and Family Studies, 12*(3), 335 – 348.

Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87 – 108.

Brookes, S. J., Summers, J., Thornburg, K. R., Ispa, J. M. & Lane, V. J. (2006). Building successful home visitor–mother relationships and reaching program goals in two Early Head Start programs: A qualitative look at contributing factors. *Early Childhood Research Quarterly*, *21*(1), 25 – 45.

Bruce, E. & Schultz, C. (2002). Non-finite loss and challenges to communication between parents and professionals. *British Journal of Special Education, 29*(1), 9 – 13.

Bruder, M.B. (2000). Family-Centred Early Intervention: Clarifying Our Values for the New Millennium. *Topics in Early Childhood Special Education, 20*(2), 105 – 115.

Bruner, J. (1990). *Acts of Meaning.* Cambridge, MA: Harvard University Press.

Bryk, A.S. & Schneider, B. (2003). Trust in schools: A core resource for school reform. *Educational Leadership, 60*(6), 40 – 44.

Buck, P.S. (1992). *The Child Who Never Grew*. Bethesda, MD: Woodbine House.

Buelow, J.M., McNelis, A., Shore, C.P. & Austin, J.K. (2006). Stressors of parents of children with epilepsy and intellectual disability. *Journal of Neuroscience Nursing, 38*(3), 147 – 154.

Burr, V. (2003). *Social Constructionism (2ⁿᵈ Ed).* Sussex, UK: Routledge.

Canadian Scholars' Press. 31- 43.

Carpenter, B. (2000). Sustaining the family: Meeting the needs of families of children with disabilities. *British Journal of Special Education, 27*(3), 135 – 44.

Carrera-Fernández, M.., Guàrdia-Olmos, J. & Peró-Cebollero, M. (2011). Qualitative research in psychology: misunderstandings about textual analysis. Quality and Quantity, 47(3), 1589 – 1603.

Carson, G. (2009). *The Social Model of Disability.* Retrieved from http://www.ukdpc.net/site/ images/library/Social%20Model%20of%20Disability2.pdf.

Case, S. (2000). Refocusing on the parent: what are the social issues of concern for parents of disabled children? *Disability and Society, 15*(2), 271 – 292.

Case, S. (2001). Learning to Partner, Disabling Conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities. *Disability and Society, 16*(6), 837 – 854.

Cassell, C. & Symon, G. (2011). Assessing 'good' qualitative research in the work psychology field: A narrative analysis. *Journal of Occupational and Organizational Psychology, 84*(4), 633 – 650.

Cassiman, S.A. (2011). Mothering, Disability, and Poverty: Straddling Borders, Shifting Boundaries and Everyday Resistance. In C. Lewiecki-Wilson & J. Cellio (Eds), *Disability and Mothering: Liminal Spaces of Embodied Knowledge.* Syracuse, NY: Syracuse University Press.

Cavallo, S., Feldman, D., Swaine, B. & Meshefedjian, G. (2009). Is parental coping associated with the level of function in children with physical disabilities?. *Child: Care, Health & Development*, *35*(1), 33 – 40.

Chapman, E. & Smith, J. (2002). Interpretative phenomenological analysis and the new genetics. *Journal of Health Psychology, 7*(2), 125 – 130.

Chappell, A., Goodley, D. & Lawthom, R. (2001). Making connections: the relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities, 29*(2), 45 – 50.

Chase, S.E. & Rogers, M.F. (2001). *Mothers and Children: Feminist Analyses and Personal Narratives.* Piscataway, NJ: Rutgers University Press.

Choi, P., Henshaw, C., Baker, S. & Tree, J. (2005). Supermum, superwife, supereverything: performing femininity in the transition to motherhood. *Journal of Reproductive and Infant Psychology, 23*(2), 167 – 180.

Clews, B. (2001, October). *'Towards a Maternal Discourse'.* Paper presented at the 5th Annual International Conference of the Association for Research on Mothers, Toronto, Canada.

Coontz, S. (1992). *The Way We Never Were: American Families and the Nostalgia Trip.* New York, NY: Basic Books.

Craib, I. (1994). *The Importance of Disappointment.* London, UK: Routledge.

Crittenden, A. (2010). *The Price of Motherhood: Why the Most Important Job in the World is Still the Least Valued.* New York, NY: Picador USA.

Cromby, J. & Standen, P. (1999). Taking ourselves seriously. In D. Nightingale & J. Cromby (Eds), (1999), *Social Constructionist Psychology: A Critical Analysis of Theory and Practice* (p141 – 56). Buckingham, UK: Open University Press.

Cunningham, C.C. & Davis, H. (1985). *Working with Parents: frameworks for collaboration.* Buckingham, UK: Open University Press.

Dabrowska, A. & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266 – 280.

Dale, N. (1996). *Working with Families of Children with Special Needs: partnership and practice.* London, UK: Routledge.

Davies, J. (2005). *First Impressions – Emotional and practical support for families of a young child with a learning disability.* London, UK: The Mental Health Foundation.

Davis, H., Day, C. & Bidmead, C. (2002). *Working in Partnership with Parents: The Parent Advisor Model.* London, UK: The Psychological Corporation.

Davis, N.O. (2008). *Working alliance and maternal psychological functioning: Mothers raising toddlers with autism* (Dissertation, University of Massachusetts, Boston). Retrieved from ProQuest Information & Learning. (AAI 3299096).

Deater-Deckard, K. (2004). *Parenting Stress.* Yale, CT: Yale University Press.

Denzin, N.K. & Lincoln, Y.S. (Eds). (2011). *The SAGE Handbook of Qualitative Research*. London, UK: SAGE.

Department of Skills and Education. (2004). *National Service Framework for Children, Young People and Maternity Services: Standard 8: Disabled children and young people and those with complex health needs.* Retrieved from webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/ Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/ DH_4094479.

Dickinson, A.R., Smythe, E. & Spence, D. (2006). Within the web: the family-practitioner relationship in the context of chronic childhood illness. *Journal of Child Health Care, 10*(4), 309 – 325.

Dinnebeil, L.A., Hale, L. & Rule, S. (1999). Early Intervention Program Practices That Support Collaboration. *Topics in Early Childhood Special Education, 19*(4), 225 – 235.

Dinnerstein, D. (1987). *The Rocking of the Cradle and the Ruling of the World.* London, UK: Women's Press.

Doane, J. & Hodges, D. (1992). *From Klein to Kristeva: Psychoanalytic Feminism and the Search for*

Dodd, J., Saggers, S. &Wildy, H. (2009). Constructing the 'ideal' family for family-centred practice: challenges for delivery. *Disability and Society, 24*(2), 173 – 186.

Doucet, A. (2006). *Do Men Mother? Fathering, Care and Domestic Responsibilities.* Toronto, Canada: University of Toronto Press.

Douglas, S J. & Michaels, M. (2005). *The Mommy Myth: The idealization of Motherhood and How It Has Undermined All Women*. New York, NY: Free Press.

Dukmak, S. (2009). Parent adaptation to and parenting satisfaction with children with intellectual disability in the United Arab Emirates. *Journal of Intellectual and Developmental Disability, 34*(4), 324 – 328.

Dunsmuir, S., Frederickson, N. & Lang, J. (2004). Building home-school trust. *Educational and Child Psychology, 21*(4), 110 – 128.

Eanes, A.Y. & Fletcher, A.C. (2006). Factors Associated with perceived parenting competence among special needs adoptive mothers. *Family in Society, 87*(2), 249 – 61.

Eatough, V., Smith, J.A. & Shaw, R. (2008). Women, Anger and Aggression: An Interpretative Phenomenological Analysis. *Journal of Interpersonal Violence, 23*(12), 1767 – 99.

Edelson, M. (2000). *My Journey with Jake: A Memoir of Parenting and Disability.* Ontario, Canada: Between the Lines.

Eisenhower, A.S., Baker, B.L. & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems and maternal well-being. *Journal of Intellectual Disability Research, 49*(9), 657 – 671.

Ellerman, D. (2001). *Helping People Help Themselves: Towards a Theory of Autonomy-Compatible Help*. Retrieved from http://www.ellerman.org/Davids-Stuff/Dev-Theory/HPHT-precis.pdf.

Elliot, A. (2010). *The Routledge Companion to Social Theory.* Oxfordshire, UK: Routledge.

Ferguson, P.M. (2001). Mapping the family: disability studies and the exploration of parental response to disability. In G.L. Albrecht, K.D. Seelman & M. Bury (eds), *Handbook of disability studies*. California, USA: Sage Publications.

Fitzpatrick, A. & Dowling, M. (2007). Supporting parents caring for a child with a learning disability. *Nursing Standard, 22*(14 – 16), 35 – 39.

Flick, U. (2002). *An Introduction to Qualitative Research* (2nd Ed.). London, UK: Sage.

Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings 1972 - 1977*. New York, NY: Pantheon Books.

Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive summary*. London, UK: TSO.

Francis-Connolly, E. (2000). Toward an understanding of mothering: A comparison of two motherhood stages. *American Journal of Occupational Therapy, 54,* 281 – 289.

Gallagher, M., Smith, M., Hardy, M. & Wilkinson, H. (2012). Children and Families' Involvement in Social Work Decision Making. *Children and Society, 26*(1), 74 – 85.

Georgas, J., Berry, J.W., von de Vijver, F.J.R., Kagitcibasi, C. & Poortinga, Y.H. (2006). *Families Across Cultures: A 30-Nation Psychological Study*. Cambridge, UK: Cambridge University Press.

Gergen, K.J. (2001). Construction in Contention. *Theory and Psychology, 11*(3), 419 – 433.

Gerhardt, S. (2004). *Why Love Matters: How Affection Shapes a Baby's Brain.* London, UK: Routledge.

Gibson, C.H. (1999). Facilitating critical reflection in mothers of chronically ill children. *Journal of Clinical Nursing, 8*, 305 – 312.

Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New Jersey, USA: Transaction Publishers.

Glidden, L.M. & Jobe, B.M. (2006). The longitudinal course of depression in adoptive and birth mothers of children with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 139 – 142.

Glidden, L.M.& Natcher, A.L. (2009). Coping strategy use, personality and adjustment of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research, 53*(12), 998 – 1013.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* New York, NY: Simon & Schuster.

Goodley, D. & Tregaskis, C. (2006). Storying Disability and Impairment: Retrospective Accounts of Disabled Family Life. *Qualitative Health Research, 16*(5), 630 – 646.

Goodman, S.H. (2007). Depression in Mothers. *Annual Review of Clinical Psychology, 3*, 107 – 135.

Goodwin, S. & Huppatz, K. (Eds). (2010). *The Good Mother: Contemporary Motherhoods in Australia.* Sydney, Australia: SUP.

Grant, G. & Ramcharan, P. (2001). Views and Experiences of People with Intellectual Disabilities and Their Families. (2) The Family Perspective. *Journal of Applied Research in Intellectual Disabilities, 14,* 364 – 380.

Graungaard, A.H. & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development, 33*(3), 296 – 307.

Gray, D.E. (1994). Coping with autism: stresses and strategies. *Sociology of Health and Illness, 16,* 275 – 300.

Gray, D.E. (2002). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3), 215 – 222.

Gray, D.E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science and Medicine, 56*(3), 631 – 642.

Green, F. (2004). Feminist Mothers: Successfully Negotiating the Tensions Between Motherhood as 'Institution' and 'Experience. ' *Mother Outlaws: Theories and Practices $Empowered Mothering.* Ed. A. O'Reilly. Toronto:

Green, S., Davis, C., Karshmer, E., Marsh, P. & Straight, B. (2005). Living Stigma: The Impact of Labeling. Stereotyping, Separation, Status Loss and Discrimination in the Lives of Individuals with Disabilities and Their Families. *Sociological Inquiry, 75*(2), 197 – 215.

Green, S.E. (2003). 'What Do You Mean 'What's Wrong With Her?'': Stigma and the Lives of Families of Children with Disabilities. *Social Science and Medicine, 57*(8), 1361 – 1374.

Green, S.E. (2007). 'We're tired, not sad': Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64*(1), 150 – 163.

Hadfield, L., Rudoe, N. & Sanderson-Mann, J. (2007). Motherhood, choice and the British media: a time to reflect. *Gender and Education, 19*(2), 255 – 263.

Hagger, M.S. & Chatzisarantis, N.L.D. (2011). Never the twain shall meet? Quantitative psychological researchers' perspectives on qualitative research. *Qualitative Research in Sport, Exercise and Health, 3*(3), 266 – 277.

Hanisch, C. (1969). The Personal is Political. Retrieved from http://www.carolhanisch.org/ CHwritings/PIP.html.

Hannam, C. (1975). *Parents and Mentally Handicapped Children.* Middlesex, UK: Penguin Books Ltd.

Hansen, K.V. (2005). *Not-So-Nuclear Families: Class, Gender and Networks of Care.* Piscataway, NJ: Rutgers University Press.

Harnett, A., Tierney, E. & Guerin, S. (2009). Convention of hope – communicating positive, realistic messages to families at the time of a child's diagnosis with disabilities. *British Journal of Learning Disabilities, 37*(4), 257 – 264.

Harper, D, & Thompson, A.R. (2011). *Qualitative Research Methods in Mental Health and Psychotherapy.* Oxford, UK: Wiley-Blackwell.

Harrison, D., & Freinberg. T. (2005). Autistic Liberation Front fights the 'oppressors searching for a cure. Retrieved from http://www.telegraph.co.uk/education/3348641/Autistic-Liberation-Front-fights-the-oppressors-searching-for-a-cure.html.

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M. & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development, 31*(2), 167 – 180.

Hastings, R.P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability, 27*(3), 149 – 160.

Hastings, R.P. & Beck, A. (2004). Practitioner Review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*(8), 1338 – 1349.

Hayes, M.O. (2008). The lived experience of mothering after prison: the preliminary study. *Journal of Forensic Nursing, 4*(2), 61 – 67. doi: 10.1111/j.1939-3938.2008.00011.x.

Hayez, B. (Executive producer). (2007). *Jon & Kate Plus 8* [Television series]. USA: Discovery Health Channel.

Hays, S. (1996). *The Cultural Contradictions of Motherhood.* Yale, CT: Yale University Press.

Head, L.S. & Abbeduto, L. (2007). Recognizing the Role of Parents in Developmental Outcomes: A Systems Approach to Evaluating the Child with Developmental Disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 293 – 301.

Health Professions Council (2008). *Standards of conduct, performance and ethics.* Retrieved from hpc-uk.org/assets/documents/100002367FINALcopyofSCPEJuly2008.pdf.

Henson, R. (1997). Analysis of the concept of mutuality. *Image: Journal of Nursing Scholarship*, *29*(1), 77 – 81.

Henton, I. (2012). Practice-based research and counselling psychology: A critical review and proposal. *Counselling Psychology Review, 27*(3), 11 – 28.

Herbert, E. & Carpenter, B. (1994). Fathers – the secondary partners: Professional perceptions and fathers' reflections. *Children and Society, 8*(1), 31 – 41.

Hickson, M. (2011). Counting to one: The qualitative researcher's 'magic'. *Journal of Occupational and Organizational Psychology, 84*(4), 651 – 655.

Hill, C. & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 53*(12), 969 – 980.

Hoagwood, K.E. (2005). Family-based services in children's mental health: a research review and synthesis. *Journal of Child Psychology and Psychiatry, 46*(7), 690 – 713.

Hochschild, A. (1997). *The Time Bind: When Work Becomes Home and Home Becomes Work.* New York, NY: Metropolitan Books.

Hodge, N. & Runswick-Cole, K. (2008). Problematising parent-professional partnerships in education. *Disability and Society, 23*(6), 637 – 647.

Home, A. (2002). Challenging Hidden Oppression: Mothers Caring for Children with Disabilities. *Critical Social Work, 3*(1).

Hoy, W.K. & Tschannen-Moran, M. (1999). Five faces of trust: An empirical confirmation in urban elementary schools. *Journal of School Leadership, 9*, 184 – 208.

Huang, Y.P., Kellett, U. & St John, W. (2010). Cerebral palsy: experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing, 66*(6), 1213 – 1221.

Jack, S.M., DiCenso, A. & Lohfeld, L. (2005). A theory of maternal engagement with public health nurses and family visitors. *Journal of Advanced Nursing, 49*(2), 182 – 190.

Janoff-Bulman, R. (2002). *Shattered Assumptions*. New York, NY: The Free Press.

Johnston, D. & Swanson, D. (2003). Invisible mothers: a content analysis of motherhood ideologies and myths in magazines. *Sex Roles, 49*(1/2), 21 – 34.

Jordon, K., Capdevila, R. & Johnson, S. (2005). Baby or beauty: a Q study into post pregnancy body image. *Journal of Reproductive and Infant Psychology, 23*(1), 19 – 31.

Kasahara, M. & Turnbull, A.P. (2005). Meaning of Family-Professional Partnerships: Japanese Mothers' Perspectives. *Exceptional Children, 71*(3), 249 – 265.

Kasket, E. & Gil-Rodriguez, E. (2011). The identity crisis in trainee counselling psychology research. *Counselling Psychology Review, 26*(4), 20 – 30.

Kelly, G. (1992). *The Psychology of Personal Constructs, Volume 2.* London, UK: Routledge.

Kenny, K. & McGilloway, S. (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. *British Journal of Learning Disabilities, 35*, 221 – 228.

Kessler, R.C., Zhao, S., Blazer, D.G. & Swartz, M. (1997). Prevalence, correlates and course of minor depression and major depression in the national comorbidity survey. *Journal of Affective Disorders, 45*(1-2), 19 – 30.

Kinser, A.E. (2010). *Motherhood and Feminism: Seal Studies.* Berkeley, CA: Seal Press.

Kirk, S. (2001). Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of Advanced Nursing, 34*(5), 593 – 602.

Kirk, S. (2001). Negotiating lay and professional roles in the care of children with complex health care needs. *Journal of Advanced Nursing, 34*(5), 593 – 602.

Kirk, S. & Glendinning, C. (2004). Developing services to support parents caring for a technology-dependent child at home. *Child: Care, Health and Development, 30*(3), 209 – 218.

Krane, J. & Davies, L. (2007). Mothering under difficult and unusual circumstances: challenges to working with battered women. *Affilia: Journal of Women and Social Work, 22*(1), 23 – 38.

Kuno, K. (2012). *Doing disability equality training: a handbook for trainers.* Retrieved from http://detforum.com/wp-content/uploads/2009/03/DET-No-6-Doing-DET-Chapter-1.pdf.

Lake, J.F. & Billingsley, B.S. (2000). An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education, 21*(4), 240 – 251.

Landsman, G. (2003). Emplotting children's lives: Developmental delay vs. disability. *Social Science and Medicine, 56*, 1947 – 1960.

Larkin, M. & Thompson, A.R. (2001). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper & A. Thompson, *Qualitative Research methods in Mental Health and Psychotherapy*. Oxford, UK: Wiley-Blackwell.

Larkin, M., Watts, S. & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*, 102 – 120.

Lawson, J. (2004). Disclosing Childhood Impairment and the Consequences for Parent/Professional Relationships. *Practice, 16*(4), 273 – 81.

Leiter, V. (2004). Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. *Social Science and Medicine, 54*(4), 837 – 849.

Lessenberry, B.M. & Rehdfeldt, R.A. (2004). Evaluating stress levels of parents of children with disabilities. *Exceptional Children, 70*(2), 231 – 244.

Levine, K.A. (2009). Against All Odds: Resilience in Single Mothers of Children with Disabilities. *Social Work in Health Care, 48*(4), 402 – 419.

Leyendecker, B., Lamb, M.E., Harwood, R.L. & Schölmerich, A. (2013). Mothers' socialisation goals and evaluations of desirable and undesirable everyday situations in two diverse cultural groups. *International Journal of Behavioural Development, 26*(3), 248 – 258.

Lindblad B.M., Rasmussen B.H. & Sandman, P.O. (2005a). Being in tune with oneself, children, and parents: meanings of being a supporter to families with children who disabilities as narrated by parent-selected professionals. *Journal Of Pediatric Nursing*, *20*(3), 214 – 223.

Lindblad, B.M., Rasmussen, B.H. & Sandman, P.O. (2005b). Being Invigorated in Parenthood: Parents' Experiences of Being Supported by Professionals When Having a Disabled Child. *Journal of Pediatric Nursing, 20*(4), 288 – 297.

Lindsay, G., Strand, S., Cullen, M.A., Cullen, S., Band, S., Davis, H. … & Evans, R. (2011). *Parenting Early Intervention Programme Evaluation.* London, UK: Department for Education.

Link, B., Cullen, F., Struening, E., Shrout, P. & Dohrenwend, B. (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review, 54*(3), 400 – 423.

Little, L. (2002). Differences in Stress and Coping for Mothers and Fathers of Children with Asperger's Syndrome and Non-Verbal Learning Disorders. *Pediatric Nursing, 28*(6), 565 – 570.

Long, B.C. & Kahn, S.E. (Eds). (1993). *Women, Work and Coping: A Multi-disciplinary Approach to Workplace Stress.* Montreal, Canada: McGill-Queen's University Press.

Lord Nelson, L.G., Summers, J.A. & Turnbull, A.P. (2004). Boundaries in Family Professional Relationships: Implications for Special Education. *Remedial and Special Education, 25*(3), 153 – 165.

Lyons, A., Leon, S., Roecker-Phelps, C. & Dunleavy, A. (2010). The Impact of Child Symptom Severity on Stress Among Parents of Children with ASD: The Moderating Role of Coping Styles. *Journal of Child and Family Studies, 19*(4), 516 – 524.

Lyons, J. (2013, August 5). George Osborne accused of punishing stay-at-home mums by denying them tax breaks that working mothers will get. *The Mirror.* Retrieved from http://www.mirror. co.uk/

MacDonald, E., Fitzsimons, E. & Walsh, P.N. (2006). Use of respite care and coping strategies among Irish families of children with intellectual disabilities. *British Journal of Learning Disabilities, 35*, 62 – 68.

MacKenzie, C. & Scully, J.L. (2007). Moral Imagination, Disability and Embodiment. *Journal of Applied Philosophy, 24*(4), 335 – 351.

Maiter, S., Palmer, S. & Manji, S. (2006). Strengthening Social Worker – Client Relationships in Child Protective Services: Addressing Power Imbalances and 'Ruptured' Relationships. *Qualitative Social Work, 5*(2), 167 – 186.

Making Space. (2011). *Carers Respite: A Research Project in Cheshire East.* Retrieved from

http:// www .makingspace.co.uk/userfiles/Respite%20for%20Carers%20(1)(1).pdf.

Mamo, L. (2007). *Queering Reproduction: Achieving Pregnancy in the Age of Technoscience.* North Carolina, USA: Duke University Press.

Maso, I. (2003). Necessary subjectivity: Exploiting researchers' motives, passions and prejudices in pursuit of answering 'true' questions. In L. Finley and B. Gough (Eds), *Reflexivity: A practical guide for researchers in health and social sciences* (pp39 – 51). Oxford, UK: Blackwell Publishing Company.

Maushart, S. (2000). *The Mask of Motherhood: How Becoming a Mother Changes Our Lives and Why We Never Talk About It.* New York, NY: Penguin Books.

McConkey, R. (2003). Information Needs of Parents about Learning Disabilities. *Journal of Learning Disabilities, 7*(3), 211 – 219.

McCubbin, H.I. & Patterson, J.M. (1983). The family stress process: The Double ABCX Model of family adjustment and adaptation. In H.I. McCubbin, M.Sussman & J.M. Patterson (Eds), *Social stress and the family: Advances and developments in family stress theory and research.* New York, NY: Haworth.

McKeever, P. & Miller, K.L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science and Medicine, 59*(6), 1177 – 1191.

McKenzie, K., Murray, G.C. & Matheson, E. (1999). An examination of the importance of aspects of services to people with a learning disability. *British Journal of Learning Disabilities, 27*(1), 25 – 29.

McLaughlin, J. (2006). Conceptualising Intensive Caring Activities: the Changing Lives of Families with Young Disabled Children. *Sociological Research Online, 11*(1).

McLeod, J. (2011). *Qualitative Research in Counselling and Psychotherapy.* London, UK: Sage Publications Ltd.

Mercer, R. (2004). Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship, 36*(3), 228-232.

Merleau-Ponty, M. (1962). *The phenomenology of perception.* London, UK: Routledge.

Mezirow, J. & Taylor, E.W. (2009). *Transformative Learning in Practice: Insights from Community, Workplace, and Higher Education.* Chichester, UK: John Wiley and Sons Ltd.

Middleton, L. (1999). *Disabled children: Challenging social exclusion.* Oxford, UK: Blackwell.

Mies, M. (1999). *Patriarchy and Accumulation on a World Scale: Women in the International Division of Labour.* London, UK: Zed Books Ltd.

Miller, G.A. (1969). Psychology as a means of promoting human welfare. *American Psychologist, 24*(12), 1063 – 1075.

Miller, T. (2005). *Making Sense of Motherhood: A Narrative Approach.* Cambridge, UK: Cambridge University Press.

Mind. (2009). *Men & Mental health: Get it off your chest.* Retrieved from http://www. mind.org.uk /assets/0000/0186/men_and_mental_health_report.pdf.

Missiuna, C., Moll, S., Law, M., King, S. & King, G. (2006). Mysteries and mazes: Parents' experiences of children with developmental coordination disorder.

Mitre, S. (2006). The Capability Approach and Disability. *Journal of Disability Policy Studies, 16*(4), 236 – 247.

Monsen, R.B. (1999). Mothers' experiences of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing, 14*(3), 157 – 163.

Moore, J.B. & Kordick, M.F. (2006). Sources of Conflict Between Families and Health Care Professionals. *Journal of Pediatric Oncology Nursing, 23*(2), 82 – 91.

Morris, B.A., Shakespeare-Finch, J., Rieck, M. & Newbery, J. (2005). Multidimensional nature of posttraumatic growth in an Australian population. *Journal of Traumatic Stress, 18*(5), 575 – 585.

Morris, J. (1999). *Hurtling Into a Void: Transition to Adulthood for Young Disabled People with 'Complex Health and Support Needs'.* Brighton, UK: Anova Books.

Morris, J. (2011). *Rethinking disability policy.* York, UK: Joseph Rowntree Foundation.

Morrow, S.L. (2005). Quality and Trustworthiness in Qualitative Research in Counselling Psychology. *Journal of Counselling Psychology, 52*(2), 250 – 260.

Murray, P. (2000). Disabled children, parents and professionals: partnership on whose terms? *Disability and Society. 15*(4), 683 – 698.

Nachshen, J.S. & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research, 49*(12), 889 – 904.

Nathanson, J. (2008). Maternal Activism: How Feminist Is It? In A. O'Reilly, *Feminist Mothering.* Albany, NY: State University of New York Press.

Neander, K. & Skott, C. (2008). Bridging the Gap – the Co-creation of a Therapeutic Process: Reflections by Parents and professionals on their Shared Experiences of Early Childhood Interventions. *Qualitative Social Work, 7*(3), 289 – 309.

Nelson, A.M. (2002). A Metasynthesis: Mothering Other-than-Normal Children. *Qualitative Health Research, 12*(4), 515 – 530.

Neufeld, A., Harrison, M.J., Stewart, M. & Hughes, K. (2008). Advocacy of Women Family Caregivers: response to Nonsupportive Interactions With Professionals. *Qualitative Health Research, 18*(3), 301 – 310.

Nomaguchi, K.M. & Brown, S.L. (2011). Parental Strains and Rewards Among Mothers: The Role of Education. *Journal of Marriage and Family, 73*(3), 621 – 636.

Nuutila L. & Salanterä, S. (2006). Children with a long-term illness: parents' experiences of care. *Journal Of Pediatric Nursing*, *21*(2), 153 – 160.

O'Reilly, A. (2010). *Twenty-First Century Motherhood: Experience, Identity, Policy, Agency.* New York, NY: Columbia University Press.

Oelofsen, N. & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability, 31*(1), 1 – 12.

Oulton, K. & Heyman, B. (2009). Devoted protection: How parents of children with severe learning disabilities manage risks. *Health, Risk and Society, 11*(4), 303 – 319.

Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: the function of information. *Child: Care, Health and Development, 24*(4), 299 – 312.

Panitch, M. (2007). *Disability, Mothers and Organization: Accidental Activists.* London, UK: Routledge.

Park, J. & Turnbull, A.P. (2002). Quality Indicators of Professionals Who Work with Children with Problem Behaviour. *Journal of Positive Behaviour Interventions, 4*(2), 118 – 122.

Partington, K.J. (2002). Maternal responses to the diagnosis of learning disabilities in children: a qualitative study using a focus group approach. *Journal of Learning Disabilities, 6*(2), 163 – 173.

Patterson, J.M., Jernell, J., Leonard, B.J. & Titus, J.C. (2004). Caring for fragile children at home: the parent-professional relationship. *Journal of Paediatric Nursing, 9*(2), 98 – 106.

Patterson, J.M., Jernell, J., Leonard, B.J. & Titus, J.C. (2004). Caring for fragile children at home: the parent-professional relationship. *Journal of Paediatric Nursing, 9*(2), 98 – 106.

Pearson, A., Vaughan, B. & Fitzgerald, M. (2004). *Nursing Models for Practice.* London, UK: Elsevier Health Sciences.

Peckover, S. (2002). Supporting and policing mothers: an analysis of the disciplinary practices of health visiting. *Journal of Advanced Nursing, 38*(4), 369 – 377.

Pelchat, D., Lefebvre, H. & Perreault,M. (2003). Differences and similarities between mothers and fathers of parenting a child with a disability. *Journal of Child Health Care, 7*(4), 231 – 247.

Pelchat, D., Ricard, N., Bouchard, J.M., Perreault, M., Saucier, J.F., Berthiaume, M. & Bisson, J. (1999). Adaptation of Parents in Relation to their Six-month-old Infant's Type of Disability. *Child: Care, Health and Development, 25*(4), 377 – 397.

Ptacek, J. T., Smith, R. E., & Dodge, K. L. (1994). Gender differences in coping with stress: When stressor and appraisals do not differ. *Personality and Social Psychology Bulletin*, *20*(4), 421 – 430.

Quine, L. & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transactional model of coping. *Journal of Community and Applied Social Psychology, 1*(1), 57 – 70.

Read, J. (2000). *Disability, the family, and society: Listening to mothers.* Buckingham, UK: Open University Press.

Redmond, B. & Richardson, V. (2003). Just Getting on with it: Exploring the Service Needs of Mothers Who Care for Young Children with Severe/Profound and Life-Threatening Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities, 16,* 205 – 218.

Reeve, D. (2004). Psycho-Emotional Dimensions of Disability and the Social Model. In C. Barnes & G. Mercer (Eds), *Implementing the Social Model of Disability: Theory and Research*. Leeds, UK: The Disability Press.

Reid, K., Flowers, P. & Larkin, M. (2005). Exploring Lived Experience. *The Psychologist, 18*(1), 20 – 23

Rezendes, D.L. & Scarpa, A. (2011). Associations between Parental Anxiety/Depression and Child Behavior Problems Related to Autism Spectrum Disorders: The Roles of Parenting Stress and Parenting Self-Efficacy. *Autism Research and Treatment,* 1 – 10.

Rich, A. (1976). *Of Woman Born: Motherhood as Experience and Institution.* London, UK: W.W. Norton & Company.

Rizzo, K.M., Schiffrin, H.H. & Liss, M. (2013). Insight into the Parenthood Paradox: Mental Health Outcomes of Intensive Mothering. *Journal of Child and Family Studies, 22*(5), 614 – 620.

Roger, S. & Mandich, A. (2005). Getting the run around – accessing services for children with developmental co-ordination disorder. *Child: Care, Health and Development, 31*, 449 – 457.

Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education, 34*(3), 136 – 43.

Roll-Pettersson, L. (2001). Parents talk about how it feels to have a child with a cognitive disability. *European Journal of Special Needs Education, 16*(1), 1 – 14.

Ruddick, S. (1995). *Maternal Thinking: Toward a Politics of Peace* (2nd Ed). Boston, MA: Beacon.

Runswick-Cole, K. (2007). 'The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT). *Disability and Society, 22*(3), 315 – 328.

Ryan, S. (2005a). 'Busy Behaviour' in the 'Land of the Golden M': Going Out with Learning Disabled Children in Public Places. *Journal of Applied Research in Intellectual Disabilities, 18*, 65 – 74.

Ryan, S. (2005b). 'People don't do odd, do they?' Mothers making sense of the reactions of others towards their learning disabled children in public places. *Children's Geographies*, *3*(3), 291 – 305.

Ryan, S. & Runswick-Cole, K. (2008a). Repositioning mothers: mothers, disabled children and disability studies. *Disability and Society, 23*(3), 199 – 210.

Ryan, S. & Runswick-Cole, K. (2008b). From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum. *Journal of Applied Research in Intellectual Disabilities, 22*, 43 – 53.

Samioti, A., Papanis, E. & Giavrimis, P. (2011). Literature Review on the Needs of Families and Carers of People with Learning Disabilities. *International Journal of Business, Humanities and Technology, 1*(1), 45 – 53.

Scorgie, K. &Wilgosh, L. (2008). Reflections on an Uncommon Journey: A Follow-Up Study of Life Management of Six Mothers of Children with Diverse Disabilities. *International Journal of Special Education, 23*(1), 103 – 114.

Scullion, P.A. (2010). Models of disability: their influence in nursing and potential role in challenging discrimination. *Journal of Advanced Learning, 66*(3), 697 – 707. doi: 10.1111/j.1365-2648.2009.05211.x.

Seligman, M. & Darling, R.B. (2009). *Ordinary Families, Special Children: a systems approach to childhood disability (3rd Ed.).* New York, NY: Guilford Press.

Sen, A. (2010). *The idea of Justice.* London, UK; Penquin.

Shakespeare, T. (1994). Cultural representation of disabled people: Dustbins for disavowal? *Disability and Society, 9*(3), 283 – 99.

Shearn, J. (1998). Still at home: participation in paid employment of mothers of children with learning disabilities. *British Journal of Learning Disabilities, 26*(3), 100 – 104.

Shearn, J. & Todd, S. (2000). Maternal employment and family responsibilities: the perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13*, 109 – 131.

Shelden, D.L., Angell, M.E., Stoner, J.B. & Roseland, B.D. (2010). School Principals' Influence on Trust: Perspectives of Mothers of Children with Disabilities. *The Journal of Educational Research, 103*, 159 – 170.

Silva, E.B. (Ed). (2002). *Good Enough Mothering? Feminist Perspectives on Lone Motherhood.* London, UK: Routledge.

Silverman, D. (2006). *Interpreting qualitative data: Methods for analysing talk, text and interaction (3rd Ed).* London, UK: Sage.

Simon, J. (2006). *Diversity Matters: Good practice in services for disabled children and their families from black and other minority ethnic communities.* London, UK: Council for Disabled Children.

Simpson, L. (2013, April 17). Evicted again: Nadya 'Octomom' Suleman leaves home 'smelling like urine' after 'failing to make first rent payment of $2,590'. *The Daily Mail.* Retrieved from http:// www.dailymail.co.uk.

Skinner, D., Bailey, D.B., Correa, V. & Rodriguez, P. (1999). Narrating Self and Disability: Latino Mothers' Construction of Identities vis-à-vis Their Child with Special Needs. *Exceptional Children, 65*(4), 481 – 495.

Sloper, P., Greco, V., Beecham, J. & Webb, R. (2006). Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families. *Child: Care, Health & Development, 32*(2), 147 – 157.

Smart, C. (2002). Deconstructing motherhood. In E.B. Silva (Ed), *Good Enough Mothering? Feminist Perspectives on Lone Motherhood.* London, UK: Routledge.

Smart, J.F. (2009). The Power of Models of Disability. *The Journal of Rehabilitation, 75*(2), 3 – 11.

Smith, E.J. (2006). The Strength-Based Counselling Model. *The Counselling Psychologist, 34*(1), 13 – 79.

Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology,* 1, 39-54.

Smith, J.A. & Osborn, M. (2004). Interpretative Phenomenological Analysis. In Smith, J.A. (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods*. London, UK: Sage.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method, Research.* London, UK: Sage.

Smith, L.E., Seltzer, M.M., Tager-Flusberg, H., Greenberg, J.S. & Carter, A.S. (2008). A Comparative Analysis of Well-Being and Coping among Mothers of

Toddlers and Mothers of Adolescents with ASD. *Journal of Autism and Developmental Disorders, 38*(5), 876 – 889.

Solomon, M., Pistrang, N. & Barker, C. (2001). The Benefits of Mutual Support Groups for Parents of Children With Disabilities. *American Journal of Community Psychology, 29*(1), 113 – 132.

Song, L. & Singer, M. (2006). Life stress, social support, coping and depressive symptoms: a comparison between the general population and family caregivers. *International Journal of Social Welfare, 15*(2), 172 – 180.

Spencer, N., Devereux, E., Wallace, A., Sundrum, R., Shenoy, M., Bacchus, C. & Logan, S. (2005). Disabling conditions and registration for child abuse and neglect: A population based study. *Pediatrics, 116*(3), 609 – 613.

Spratt, E.G., Saylor, C.F. & Macias, M.M. (2007). Assessing parenting stress in multiple samples of children with special needs (CSN). *Families, Systems and Health, 25*(4), 435 – 449.

Stake, R.E. (2010). *Qualitative Research: Studying How Things Work.* New York, NY: Guilford Publications.

Stone, A. (2012). Feminism, Psychoanalysis, and Maternal Subjectivity. NY: Routledge.

Stoner, J.B. & Angell, M.E. (2006). Parent Perspectives on Role Engagement: An Investigation of Parents of Children With ASD and Their Self-Reported Roles With Education Professionals. *Focus on Autism and Other Developmental Disabilities, 21*(3), 177 – 189.

Stoner, J.B., Bock, S.J., Thompson, J.R., Angell, M.E., Heyl, B.S. & Crowley, E.P. (2005). Welcome to Our World: Parent Perceptions of Interactions Between Parents of Young Children With ASD and Education Professionals. *Focus on Autism and Other Developmental Disabilities, 20*(1), 39 – 51.

Swain, J. & French, S. (2000). Towards an Affirmation Model of Disability. *Disability and Society, 15*(4), 569 – 582.

Tait, T., Beattie, A. & Dejnega, S. (2002). Service co-ordination: A successful model for the delivery of multi-professional services to children with complex needs. *Nursing Times Research, 7*(1), 19 – 32.

Tajfel, H. & Turner, J.C. (1979). An Integrative Theory of Intergroup Conflict. In W.G. Austin & S. Worchel, *The Social Psychology of Intergroup Relations*. California, USA: Brooks/Cole Publishing.

Targosz, S., Bebbington, P., Lewis G., Brugha, T., Jenkins, R., Farrell, M. & Meltzer, H. (2003). Lone mothers, social exclusion and depression. *Psychological Medicine, 33*(4), 715 – 722.

Taylor, S.E. (2006). Tend and Befriend: Biobehavioral Bases of Affiliation Under Stress. *Current Directions in Psychological Science, 15*(6), 273 – 277.

Taylor, S.E., Klein, L.C., Lewis, B.P., Gruenewald, T.L., Gurung, R.A.R. & Updegraff, J.A. (2000). Behavioural responses in females: tend and befriend not fight or flight. *Psychological Review, 107*(3), 411 – 429.

Taylor, T. (2011). Re-examining Cultural Contradictions: Mothering Ideology and the Intersections of Class, Gender, and Race. *Sociology Compass, 5*(10), 898 – 907.

Tedeschi, R.G. & Calhoun, L.G. (2004). Posttraumatic growth: Conceptual foundations and empirical evidence. *Psychological Inquiry, 15,* 1 – 18.

the 'Good Enough' Mother. Ann Arbor, USA. University of Michigan Press.

The Union of the Physically Impaired Against Segregation & The Disability Alliance. (1975). *Fundamental Principles of Disability.* Retrieved from http://www.leeds.ac.uk/disability-studies/ archiveuk/UPIAS/fundamental%20principles.pdf.

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability and Society, 19*(6), 569 – 583.

Thornhill, R. & Gangestad, S.W. (2009). *The Evolutionary Biology of Human Female Sexuality.* New York, NY: Oxford University Press.

Todd, S. & Jones, S. (2003). Mum's the word!: maternal accounts of dealings with the professional world. *Journal of Applied Research in Intellectual Disabilities, 16*, 229 – 244.

Todd, S. & Jones, S. (2005). Looking at the future and seeing the past: the challenge of the middle years of parenting a child with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(6), 389 – 404.

Todd, S., Bromley, J., Ioannou, K, Harrison, J., Mellor, C., Taylor, E. & Crabtree, E. (2010). Using Group-Based Parent Training Interventions with Parents of Children with Disabilities: A Description of Process, Content and Outcomes in Clinical Practice. *Child and Adolescent Mental Health, 15*(3), 171 – 175.

Toomela, A. (2011). Travel Into a Fairy Land: A Critique of Modern Qualitative and Mixed Methods Psychologies. *Integrative Psychological and Behavioural Science, 45*(1), 21 – 47.

Trute, B., Benzies, K.M., Worthington, C., Reddon, J.R. & Moore, M. (2010). Accentuate the positive to mitigate the negative: Mother psychological coping resources and family adjustment in childhood disability. *Journal of Intellectual and Developmental Disability, 35*(1), 36 – 43.

Tudball, J., Fisher, K., Sands, T. & Dowse, L. (2002). *Supporting Families Who Have a Child With a Disability.* Sydney, Australia: Social Policy Research Publications.

Tunali, B. & Power, T.G. (1993). Creating Satisfaction: A Psychological Perspective on Stress and Coping in Families of Handicapped Children. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 34*(6), 945 – 957.

Tunali, B. & Power, T.G. (2002). Coping by Redefinition: Cognitive Appraisals in Mothers of Children With Autism and Children Without Autism. *Journal of Autism and Developmental Disorders, 32*(1), 25 – 34.

Turnbull, A.P., Summers, J.A., Lee, S. & Kyzar, K. (2007). Conceptualization and Measurement of Family Outcomes Associated with Families of Individuals with Intellectual Disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 346 – 356.

Twoy, R., Connolly, P.M. & Novak, J.M. (2007). Coping strategies used by parents of older children with autism. *Journal of the American Academy of Nurse Practitioners, 19*(5), 251 – 260.

Valle, J.W. (2011). Down the Rabbit Hole: A Commentary About Research on Parents and Special Education. *Learning Disability Quarterly, 34*(3), 183 – 190.

Van der Veek, S.M.C., Kraaij, V. & Garnefski, N. (2009). Down or up? Explaining positive and negative emotions in parents of children with Down's syndrome: Goals, cognitive coping, and resources. *Journal of Intellectual and Developmental Disability, 34*(3), 216 – 229.

Van Riper, M. (2007). Families of children with Down syndrome: responding to "a change in plans" with resilience. *Journal Of Pediatric Nursing, 22*(2), 116 – 128.

Veck, W. (2002). Completing the story: Connecting relational and psychological processes of exclusion. *Disability and Society, 17*(5), 529 – 540.

Vermaes, I.P.R., Janssens, J.M.A.M., Mullaart, R.A., Vinck, A. & Gerris, J.R.M. (2008). Parents' personality and parenting stress in families of children with spina bifida. *Child: Care, Health and Development, 34*(5), 665 – 674.

Warner, H. (2006). *Meeting the Needs of Children with Disabilities: Families and Professionals Facing the Challenge Together.* Oxfordshire, UK*:* Routledge.

Watson, K.C., Kieckhefer, G.M. & Olshansky, E. (2006). Striving for Therapeutic Relationships: Parent-Provider Communication in the Developmental Treatment Setting. *Qualitative Health Research, 16*(5), 647 – 663.

Watson, S.L. (2008). 'Something you have to do' – Why do parents of children with developmental disabilities seek a differential diagnosis? *Developmental Disabilities Bulletin, 36*(1 & 2), 168 – 198.

Webb, J., Schirato, T. & Danaher, G. (2002). *Understanding Bourdieu.* London, UK: Sage.

Weich, S., Patterson, J., Shaw, R. & Stewart-Brown, S. (2009). Family relationships in childhood and common psychiatric disorders in later life: systematic review of prospective studies. *British Journal of Psychiatry, 194*(5), 392 – 398.

West, C. & Zimmerman, D.H. (1987). Doing Gender. *Gender and Society, 1*(2), 125 – 151.

Whitehead, L.C. & Gosling, V. (2003). Parent's perceptions of interactions with health professionals in the pathway to gaining a diagnosis of tuberous sclerosis (TS) and beyond. *Research in Developmental Disabilities, 24*(2), 109 – 119.

Williams, B., Copestake, P., Eversley, J. & Stafford, B. (2008). *Experiences and Expectations of Disabled People: A Research Report for the Office for Disability Issues.* London, UK: Office for Disability Issues.

Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Maidenhead, UK: OUP.

Winnicott, D.W. (1991). *The Child, The Family and The Outside World.* London, UK: Penguin Books.

Wodehouse, G. & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: what stops it being helpful? *Journal of Intellectual Disability Research, 53*(7), 644 – 653.

Woodcock, J. & Tregaskis, C. (2006). Understanding Structural and Communication Barriers to Ordinary Family Life for Families with Disabled Children: A Combined Social Work and Social Model of Disability Analysis. *The British Journal of Social Work, 38*(1), 55 – 71.

World Health Organization. (2008). *Improving Maternal Mental Health.* Geneva, Switzerland: World Health Organization.

Wright, J.A. (2008). Prenatal and Postnatal Diagnosis of Infant Disability: Breaking the News to Mothers. *The Journal of Perinatal Education, 17*(3), 27 – 32.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*(2), 215 – 228.

Ygge, B.M., Lindholm, C. &Arnetz, J. (2006). Hospital staff perceptions of parental involvement in paediatric hospital care. *Journal of Advanced Nursing, 53*(5), 534 – 42.

Zoellner, T. & Maercker, A. (2006). Posttraumatic growth in clinical psychology: A critical review and introduction of a two component model. *Clinical Psychology Review, 26*(5), 626 – 653.

APPENDICES

Appendix A- Debrief Pack

Getting

Help and Advice

Some Useful Contacts

CARERS' SUPPORT

Care Co-Ordination Networks UK

Tower House, Fishergate, York   YO10 4UA

01904 567303   www.ccnuk.org.uk

"A networking organisation promoting and supporting key working for disabled children and their families in England, Northern Ireland, Scotland and Wales."

Carers UK

20-25 Glasshouse Yard, London EC1A 4JT

0808 808 7777 www.carersuk.org

"Carers UK is the voice of carers."

Contact a Family

209-211 City Road, London EC1V 1JN

0808 808 3555 www.cafamily.org.uk

"A charity providing advice, information and support to the parents of all disabled children - no matter

what their health condition."

Crossroads

10 Regent Place, Rugby, Warwickshire CV21 2PN

0845 4500350   www.crossroads.org.uk

"Caring for Carers"

Disabled Parents' Network

Unit F9, 89-93 Fonthill Road, London N4 3JH

0870 2410450 www.disabledparentsnetwork.org.uk

"A national network of disabled people who are parents or who hope to become parents"

Face to Face /Scope

PO Box 554, Worcester, WR4 0WL

0844 800 9189 www.facetofacenetwork.org.uk

"Parents supporting parents of disabled children"

Family Holiday Association

The Grants Officer, !6 Mortimer Street, London W1T 3JL

020 74363304   www.fhaonline.org.uk

"Working to promote family life for those parents and children who experience disadvantage

OAASIS

Brock House, Grigg Lane, Brockenhurst, Hampshire SO32 7RE

09068 633201   www.oaasis.co.uk

"Oasis offers information service for parents and professionals who care for a child who has (or is thought to have) special needs."

Parentline Plus

520 Highgate Studios, 53-79 Highgate Road, London NW5 1TL

0808 800 2222   www.parentlineplus.org.uk

"Providing accessible, responsive and flexible high quality parent to parent services"

Sibs

Meadowfield, Oxenhope, West Yorks BD22 9JD

01535 645453   www.sibs.org.uk

"Sibs is for people who grow up with a brother or sister with special needs, disability, chronic illness."

Working Families

1-3 Berry Street, London EC1V 0AA

020 7253 7243 www.workingfamilies.org.uk

"A unique service to parents of disabled children who work or wish to work"

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GENERAL

4 Children (formerly Kids Clubs Network)

5 Greenwich View Place, London E14 9NN

020 7512 2112 www.4children.org.uk

"Provides information, advice training and development help for parents, schools and employers"

BILD (British Institute of Learning Disabilities)

Campion House, Green Street, Kidderminster, Worcestershire DY10 1JL

01562 723 010 www.bild.org.uk

"Committed to improving the quality of life for people with a learning disability."

Childline

Studd Street, London N1 0QW

0800 1111 www.childline.org.uk

"ChildLine is the free helpline for children and young people in the UK"

Council for Disabled Children

National Childrens Bureau, 8 Wakely Street, London EC1V 7QE

020 7843 6000 www.ncb.org.uk

"Provides information on children and disability issues"

Children in Scotland

Princes House, 5 Shandwick Place, Edinburgh EH2 4RG

0131 228 8484 www.childreninscotland.org.uk

Children in Wales

25 Windsor Place, Cardiff CF10 3BZ

029 20342434 www.childreninwales.org.uk

Children in Northern Ireland

Unit 9, Montgomery Road, Belfast BT6 9HL

028 90709418 www.ci-ni.org.uk

"The national agencies for voluntary, statutory and professional organisations and individuals

working with children and their families"

Foundation for People with Learning Disabilities

Sea Containers House,   20 Upper Ground, London SE1 9QB

020 7803 1100 www.learningdisabilities.org.uk

"Promotes the rights, quality of life and opportunities of people with learning disabilities and their families"

KIDS

6 Aztec Row, Berners Road,London N1 0PW

020 7359 3635 www.kids-online.org.uk

"Working for disabled children, young people and their families"

Mencap

123 Golden Lane, London EC1Y 0RT

020 7454 0454   www.mencap.org.uk

"*Working with people with a learning disability, their families and carers."*

National Children's Bureau (NCB)

8 Wakley Street, London, EC1V 7QE

020 7843 6000   www.ncb.org.uk

"Putting children and young people first"

RADAR

12 City Forum,   250 City Road, London EC1V 8AF

020 7250 3222 www.radar.org.uk

*_"Informs, advises and campaigns on disability issues"_

Rathbone Society

Rathbone Head Office,   Churchgate House, 56 Oxford Street, Manchester M1 6EU

0800 731 5321   www.rathboneuk.org

"Giving young people who are experiencing significant disadvantage the right opportunity to learn and to achieve"

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<u>SPECIFIC</u>

ADDIS

PO Box 340, Edgeware, Middx HA8 9HL

020 8906 9068   www.addiss.co.uk

"Provides people-friendly information and resources about Attention Deficit Hyperactivity

Disorder to anyone who needs assistance - parents, sufferers, teachers or health professionals"

ADHD UK Alliance

209-211 City Road, London EC14 1JN

020 7608 8760 www.adhdalliance.org.uk/

"Working to raise awareness, influence policy and improve services''

AFASIC

2nd Floor, 50-52 Great Sutton Street, London EC1V 0DJ

020 7490 9410 www.afasic.org.uk

"Unlocking Speech and Language"

After Adoption

Canterbury House, 12-14 Chapel Street, Manchester M3 7NH

0161 839 4932 www.afteradoption.org.uk

"Helping everyone affected by adoption"

Children's Brain Injury Trust

Unit 1, The Great Barn, Baynards Green, Nr. Bicester, Oxfordshire OX27 7SG

01869 341075 www.cbituk.org.uk

"Supports anyone in the UK affected bychildhood acquired brain injury"

Challenging Behaviour Foundation

32 Tydall Lane, Gillingham, *ME8 6HX*

01634 838739 www.thecbf.org.uk

"To provide information and support to parents and professionals caring for individuals with severe

learning disabiities and challenging behaviour"

Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park, Teddington, TW11 9PS

0845 230 0372 www.downs-syndrome.org.uk

"For all enquiries including referral to local support groups, information, fundraising &

membership"

Dyspraxia Foundation
8 West Alley, Hitchin, Herts SG5 1EG

01462 455016 / Helpline 01462 454986

www.dyspraxiafoundation.org.uk

"A resource for parents, for teenagers and adults who have the condition, and for professionals

who help all of them."

Foundation for the study of Sudden Infant Death Syndrome

Artillery House, **11-19 Artillery Row,** London SW1P 1RT

020 7777 8001 helpline 020 7233 2090

www.fsid.org.uk

"Aiming to promote unexpected deaths in infancy and promote infant health"

Hyperactive Children's Support Group
71 Whyke Lane, Chichester, West Sussex PO19 2LD

01243 539966 www.hacsg.org.uk

"Britains leading proponent of the dietary approach to ADHD"

ICAN
4 Dyer's Buildings, London EC1N 2QP

0845 2254071 www.ican.org.uk

"ICAN is the charity that helps children communicate"

National Association of Wheelchair Children
6 Woodman Parade, North Woolwich, London E16 2LL

08701210050 www.wheelchairchildren.org.uk

"Helping children with wheelchairs become independently mobile"

National Autistic Society

393 City Road, London EC1V 1NG

0845 070 4004   www.nas.org.uk

"Exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs"

National Blind Children's Society

Bradbury House, Market Sytreet, Highbridge, Somerset TA9 3BW

01278 764 764 www.nbcs.org.uk

"To enable blind and partially sighted children and young people to achieve their educational and recreational goals"

National Deaf Children's Society

15 Dufferin Street, London, EC1Y 8UR

Helpline 0808 800 8880 (Voice and Text)

www.ndcs.org.uk

" Solely dedicated to providing support, information and advice for deaf children, young people, their families and professionals working with them"

National Society for Epilepsy

Chesham Lane, Chalfront St. Peter, Buckinghamshire SL9 0RJ

01494 601 400   www.epilepsynse.org.uk

"Providing care for people with epiilepsy through medical, residential and rehabilitation services"

Royal National Institute for Deaf People (RNID)

19-23 Featherstone Street, London, EC1Y 8SL

0808 808 0123 (Textphone) www.rnid.org.uk

"We help to make life better by campaigning offering services and training and by supportiing research"

Royal National Institute of the Blind(RNIB)

105 Judd Street, London, WC1H 9NE

0845 766 9999 www.rnib.org.uk

"Offering information, support and advice to people with sight problems"

Scope National Office (England/Wales)

6 Market Road, London N7 9 PW

0808 800 3333 www.scope.org.uk

"The disability organisation in England and Wales whose focus is people with cerebral palsy."

SENSE

11-13 Clifton Terrace, Finsbury Park, London N4 3SR

020 7272 7774 www.sense.org.uk

" The UK's largest organisation for children and adults who are deafblind or have associated disabilities"

Twin and Multiple Births Association (TAMBA)

2 The Willows, Gardner Road, Guildford, Surrey, GU1 4PG

0870 770 3305   www.tamba.org.uk

"Providing information and mutual support networks for families of twins, triplets and more"

Unique

PO Box 2189, Caterham, Surrey CR3 5GN

01883 330766 www.rarechromo.org/html/home.asp

To inform, support and alleviate the isolation of anyone affected by a rare chromosome disorder and

to raise public awareness."

Winston's Wish

The Clara Burgess Centre, Bayshill Road, Cheltenham, Gloucester GL 50 3AW

www.winstonswish.org.uk

"Help for grieving children and their families"

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EDUCATION

Advisory Centre for Education (ACE)

1c Aberdeen Studios, 22 Highbury Grove, London N5 2DQ

0808 800 5793 / 020 7704 9822 www.ace-ed.org.uk

"Ace offers free advice on aspects of state education."

Independent Panel for Special Education Advise (IPSEA)

6 Carlow Mews, Woodbridge, Suffolk IP2 1EA

Eng/Wales 0800 0184 016

N.Ireland 02890 705654

Scotland 0131 454 0096

www.ipsea.org.uk/

"Defending children"s right to special education provision"

National Association for Special Educational Needs

4/5 Amber Business Village, Amington, Tamworth, Staffordshire B77 4RP

01827 311500

www.nasen.org.uk

"Aims to promote the education, training, advancement and development of all those with special

educational needs"

National Parent Partnership Network (NPPN)

Council for Disabled Children,

 8 Wakely Street, London EC1V

0207 843 6058   www.parentpartnership.org.uk

"Supports all parent partnership services across England."

Network 81

1-7 Woodfield Terrace, Stanstead, Essex CM23 8AJ

0870 770 3306 / 0870 770 3262 www.network81.co.uk

"Gives information, guidance, help and advice on the Education Act and other procedures

concerned with special educational provision and training"

Parents for Inclusion

Unit 2, 70 South Lambeth Road , London SW8 1RL

020 7735 7735 /0800 652 3145 www.parentsforinclusion.org

"*Promotes the rights of children with special needs or disabilitiess to attend their local mainstream school"*

Pre-school Learning Alliance

The Fitzpatrick Building, 188 York Way, London N7 9AD

020 7697 2500 www.pre-school.org.uk

"Dedicated to supporting the work of community pre-schools"

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<u>EARLY *YEARS*</u>

Home Start UK

2 Salisbury Road, Leicester, LE1 7QR

0800 068 63 68 www.home-start.org.uk

"*Support for parents who are struggling to cope.*"

National Portage Association

PO Box 3075, Yeovil, BA 21 3FB

01935 471641 www.portage.org.uk

"Portage is a home-visiting educational service for pre-school children with additional support needs

and their families."

Sure Start

Department for Education and Skills and Department for Work and Pensions

Level 2, Caxton House, Tothill Street, London SW1H 9NA

0870 000 2288 www.surestart.gov.uk

"Sure Start is the government programme to deliver the best start in life for every child."

Early Support Programme (England only)

19 - 23 Featherstone Street , London, EC1Y 8SL

020 7296 8238   www.espp.org.uk

"The central government mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families"

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WELL-BEING

Association of Children's Hospices

King's House, 14 Orchard Street, Bristol BS1 5 EH

0117 9055082 www.childhospice.org.uk

"The national voice for children's hospice"

Change

Units19/20, Unity Business Centre, 26 Round Hay Road, Leeds LS7 1AB

0113 2340202 www.changepeople@btconnect.com

"A national organisation run by disabled people"

Kidscape

2 Grosvenor Gardens, London WS1W 0DH

020 7730 3300   www.kidscape.org.uk

"Publications and advice. Bullying counsellor available Monday and Wednesday"

Relate
Pageant House, 2 Jury Street, Warwick, Warwickshire CV34 4EW

01926 403340 www.relate.org.uk

Support for relationship difficulties

United Kingdom Psychiatric Pharmacy Group
College of Mental Health Pharmacists, 62, Park Hill, Moseley, Birmingham B13 18DT

Fax 0121 4343270 www.ukppg.org.uk

" A helpline run by pharmacists to answer questons on psychiatric drugs"

Young Minds

48-50 St John Street, London EC1M 4DG

020 7336 8445 www.youngminds.org.uk

"A parents' information service for an adult with concerns about the mental health of a child or young person."

Finding Accredited Practitioners

British Association for Counselling and Psychotherapy

BACP House, 15 St John"s Business Park, Lutterworth Leics. LE17 4HB

0870 443 5252   www.counselling.org

British Psychological Society

St Andrews House, 48 Princess Road East, Leicester LE1 7DR

0116 254 9568   www.bps.org.uk

United Kingdom Council for Psychotherapy (UKCP)

2nd Floor, Edward House, 21 Wakley Street, London EC1V 7LT

0870 167 2131   www.psychoterapy.org.uk

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LEISURE

Action for Leisure

PO box 9, West Molesey, KT8 1WT

020 8783 0163 www .trans-active.org.uk

"Provides information on play, leisure and recreation for children, young people and adults with disabilities"

Abilitynet

PO Box 94, Warwick, Warwickshire CV34 4WS

01926 312847 www.abilitynet.co.uk

"Offers adfice and information, training and suppliers of computers and software for children with special needs"

Kidsactive

6 Aztec Row, Berners Road, London N1 0PW

020 7359 3635 www.kidsactive.org.uk

"Offers a national information service with advice and resources on all aspects of play"

Letterbox Library

71-73 Allen Road, London, N16 8RY

020 7503 4801 www.letterboxlibrary.com

"Celebrating equality and diversity in children's books"

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FINANCE & LEGAL

Disability Information Advice Line (DIAL)

DIAL UK, Doncaster,

01302 310123 www.dialuk.info

"Provides advice and information including help and advice on obtaining benefits and allowances"

Disability Alliance (finance)

Universal House, 88-94 Wentworth Street, London E1 7SA

020 7247 8776 www.disabilityalliance.org

"For disabled people, their families, carers and professional advisers. Offers benefit entitlement advice, information, campaign work, research and training"

Disability Benefit Enquiry Line

0800 882200

Disability Living Allowance Advice Line
08457 123456

"Provide information on DLA and the best way of accessing application forms"

Citizen's Advice Bureau

Myddelton House, 115-123 Pentonville Road, London N1 9LZ

020 7833 2181 www.citizensadvice.org.uk

"The Citizen's Advice Bureau helps people resolve their legal, money and other problems by

providing free information and advice"

Disability Law Service

39-45 Cavell Street, London E1 2BP

020 7791 9800 www.dls.org.uk/

"*Solicitors, advisors and trained volunteers who offer free, confidential legal advice and*

representation to people with disabilities"

Disability Rights Commission

DRC Helpline, Freepost MID02164, Warwickshire, CV37 9BR,

08457 622 633   www.drc.gov.uk

"One key goal:A society where all disabled people can participate fully as equal citizens".

The Childrens Legal Centre

University of Essex, Wivenhoe Park, Colchester, Essex CO4 3SQ

01206 872466 www.childrenslegalcentre.com

"The Children"s Legal Centre is a unique, independent national charity concerned with law and
policy affecting children and young people."

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APPENDIX C FLYER

Can You Help?

Are you the mother of a child with complex disabilities aged between 4 & 10 years old?

I am carrying out a study that explores the relationship between mothers of children with complex needs and the professionals involved in their care.

Would you be willing to tell me about your experience of such relationships?

If you would or if you would like further information, please contact me, Joy Davis, on
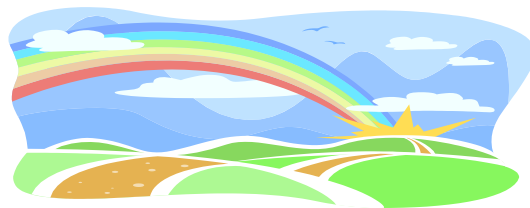
██████████

or at

███████████████████████████

This research is being conducted as part of a Practitioner Doctorate in Counselling Psychology from City University, London. Further information can also be sought from the supervisor of the project, Dr. Deborah Rafalin (███████████████)

Can You Help?

Are you a Black or Asian mother of a child with complex disability aged between 4 -10 years?

I am carrying out a study that explores the relationship between mothers of children with complex needs and the professionals involved in their care.

I have not yet been able to speak with mothers from the Black or Asian Communities.

Would you like your story to be told too?

If you would or if you would like further information, please contact me, Joy Davis, on

██████████

or at

████████████████████

This research is being conducted as part of a Practitioner Doctorate in Counselling Psychology from City University, London. Further information can also be sought from the supervisor of the project, Dr. Deborah Rafalin (████████*)*

APPENDIX E   INFORMATION SHEET

How do mothers experience the practitioners supporting their child with complex disability?

Dear parent,

I am currently studying for a Practitioner Doctorate in Counselling Psychology at City University, London. My research is designed to explore the experience of mothers of children with complex disability. I am particularly interested in what mothers think of their relationships with the professionals who help support their child. I would like to know how they feel about the people rather than the service they provide. I hope you can help.

If you are the biological mother of a child who has complex disabilities I would like to talk with you. We would meet in a face-to-face interview that will last approximately an hour and a half. In the interview, you will be invited to share your experiences and asked about your relationships with the professionals you have dealt with. The interview will be tape recorded and transcribed. Everything you say will be treated confidentially. All identifying data will be removed and a pseudonym will replace your real name.

The tape recording of your experiences will then be analysed to identify feelings and opinions you have. I believe knowing these feelings will help professionals to understand what it is like from a mother's point of view and will help them in their practice.

My work is supervised by Dr. Deborah Rafalin (███████) from The Counselling Psychology Programme at City University, London and supported by Hilton Davis, Professor of Child Health Psychology at The Centre for Parent and Child Support, Guy's Hospital, London. I abide by the ethical codes governing research laid down by the British Psychological Society and City University.

If you think you would like to help with the research or would like more information, please feel free to contact me, or Dr. Rafalin, to discuss it further.

Joy Davis C.Psych. B.Ed. M.Sc.

☎ ████████
🖱 ███████████

APPENDIX F

Thank you

Dear x

Thank you so very much for expressing an interest in my research. You told me that your x is x years old and therefore outside the age criterion which was established to avoid the early diagnostic process and the transitional post primary experience.

I have been overwhelmed with the response to my poster and would find it impossible to offer quality time to everyone who has contacted me. So, having discussed the issue with the project supervisor I feel I need to apply the criteria in all cases. I am truly aware that no one's experience is less valid than any others and that most of us will have a unique element to our story. So, I have found it a real challenge not to engage everyone but, I hope maintaining the parameters of recruitment will mean a robust and comparative piece of research that can be effectively evaluated by professionals.

I appreciate that raising a child with complex needs can be an incredibly difficult and isolating experience and that it can be helpful just to be able to talk to someone about it. I have compiled a pack of names and numbers of useful and supportive contacts which I can e-mail to you if you feel it worthwhile. I will also send you a summary of the findings of the completed research if that would be of interest.

Again, thank you so much for your kind offer of help and may I wish you and x all the very best for the future.

Yours sincerely

Joy

APPENDIX G   ETHICAL APPROVAL

Ethics Release Form for Psychology Research Projects

All students planning to undertake any research activity in the Department of Psychology are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department of Psychology does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2004) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Students are not permitted to begin their research work until approval has been received and this form has been signed by 2 members of Department of Psychology staff.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc   M.Phil   M.Sc   Ph.D   D.Psych   X   n/a

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project
How do mothers experience their relationships with the practitioners supporting their child with complex disability?
----

2. Name of student researcher (please include contact address and telephone number)
Jeanette Joy Davis, 7 Jourdain Park, Heathcote, Warwick, CV34 6FJ   07713638017
----

3. Name of research supervisor
Dr. Deborah Rafalin
----

4. Is a research proposal appended to this ethics release form?   Yes

5. Does the research involve the use of human subjects/participants?   **Yes**

If yes, a. Approximately how many are planned to be involved? 10--------------

   b. How will you recruit them? **I will advertise through support networks and voluntary agencies providing support for such families** --

   c. What are your recruitment criteria? **Participants will be biological mothers of children with complex disability**--
   (Please append your recruitment material/advertisement/flyer)

   d. Will the research involve the participation of minors (under 16 years of age) or those unable to give informed consent?

                                                                         No

   e. If yes, will signed parental/carer consent be obtained?   Yes   No

1

6. What will be required of each subject/participant (e.g. time commitment, task/activity). If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).

Each participant will be interviewed for approximately 90 minutes --------------

7. Is there any risk of physical or psychological harm to the subjects/participants?

No

If yes, a. Please detail the possible harm? ------

   b. How can this be justified? ------

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

9. Will any person's treatment/care be in any way compromised if they choose not to participate in the research?

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes

(Please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers)

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings)?

Transcript notes and audio tape recordings--------------

12. What provision will there be for the safe-keeping of these records? **All data will be kept in a locked fireproof filing cabinet**

13. What will happen to the records at the end of the project? **The data will continue to be kept secured for a period of six years to allow for peer researcher scrutiny**

14. How will you protect the anonymity of the subjects/participants? **All identifying details will be removed and tapes will be catalogued under a pseudonym**

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

A debrief pack containing contact details of support and advice groups will be made available

2

(Please append any de-brief information sheets or resource lists detailing possible support options)

If you have circled an item in bold print, please provide further explanation here:

Participants will be adult females

Signature of student researcher ⸻ ~~JoyDavis~~ ⸻ Date ⸻ 15/11/06

Section B: To be completed by the research supervisor

Please mark the appropriate box below:

Ethical approval granted ✓

Refer to the Department of Psychology Research Committee

Refer to the University Senate Research Committee

Signature ⸻ Date ⸻ 6/12/6

Section C: To be completed by the 2ⁿᵈ Department of Psychology staff member *(Please read this ethics release form fully and pay particular attention to any answers on the form where bold items have been circled and any relevant appendices.)*

I agree with the decision of the research supervisor as indicated above

Signature ⸻ Date ⸻

3

APPENDIX H CONFIDENTIALITY & CONSENT

How do mothers experience the professionals who support the care of their child with complex disability?

This research is investigating how mothers feel about their relationships with professionals involved with their child with disability. Please read and consider the information contained on this page. Feel free to ask for further information or to have any of the points clarified. Signing this form shows we have discussed the research and how it will be structured. It does not commit you to remaining involved if at any point during the study you decide to withdraw.

I understand and agree that

- I will be interviewed by Joy Davis for approximately an hour and a half.
- I will be given the opportunity to describe how I feel about my relationships with the professionals who have supported my child with disabilities.
- The interview will be audio taped and transcribed verbatim.
- Confidentiality will be strictly maintained and all identifying information will be removed.
- Tapes and transcripts will be stored securely.
- I can withdraw from the study at any time.
- I have had the opportunity to ask any questions of Joy Davis.

Participant

Name _____

Signature_____

Date_____

I undertake, on behalf of all those involved in this project, to ensure that the audiotape made within this interview and the transcription of its contents, will be used for the purposes of research only. Such material will be treated with professional confidentiality and the anonymity of the above interviewee will be protected at all times.

Researcher

Name_____

Signature_____

Date_____

APPENDIX I - INTERVIEW SHEDULE

Revisit the aims of the research and outline procedure.

Explain confidentiality practice and obtain signed consent to audio tape the interview.

Emphasise participant autonomy and freedom to withdraw.

Address any questions or issues raised.

Verify understanding.

BACKGROUND INFORMATION

To begin, I'd like to find out something about you and your family. This will help me to understand your experience and will allow me to show that I have talked to mothers who come from different backgrounds and situations. The information I will gather will be treated with the same confidentiality as the rest of the interview and will never be used to identify you.

DEMOGRAPHIC INFORMATION   INTERVIEWEE   _____

1. In which region do you live? _____

2. Do you live in a----- Rural-----Urban------City locality?

3. How old are you? _____

4. What is your highest educational qualification?

 None   GCSE/O levels/CSE   A levels   Diploma   Degree Post Graduate

5. Are you working outside the home at present? Yes----- No

6. If so how many hours do you work?_____

 7.What is your occupation?_____

8. If not when was the last time you worked outside the home?_____

9. Are you----- single---married------living with a partner?

10. Is that the child's biological father?   Yes--- No

11. If not , how often does your child have contact with his/her father?

12. How many children do you have?_____

13. How old are they? _____

INFORMATION ABOUT YOUR CHILD WITH DISABILITIES

I would like to know a little more about XXXXX

How old is s/he?_____

What is the nature of his/her difficulties?

Do you have a diagnosis?_____

Tell me a little about his/her likes and dislikes?

What about his/her personality?

What is it like to be xxxx's mum?

Before we go on to consider professional groups I'd like to know more about other kinds of support available to you.

What kind of help do you get at the moment?

Family- groups-community-professionals

I'd like to move on to consider your relationships with professionals who are involved in xxxxx's care.

What qualities make for a helpful mother-professional relationship in your opinion?

What do you think are the barriers to a helpful mother-professional relationship?

EARLY PROFESSIONAL RELATIONSHIPS

I would like to know a little about your relationships with professionals in the very early days.

1When did you first began to realise xxxx had difficulties?

2Tell me about the time when you first sought help? What kind of help did you get?

3 What were you looking for in your relationships with professionals at that time?

4What do you remember about your experiences of professionals at that early stage?

5How did these experiences make you feel?   (as a mother)

6Can you tell me about a particularly helpful/unhelpful relationship back then?

7 What might have made for better relationships at that time?

OVER THE YEARS

I would like to talk a little more about your relationships with the professional involved in xxxx's care up to now.

8 Tell me about the types of professionals who have been involved over the years.

9 Have you seen everyone you were referred to or who has offered you a service? If not how do you decide who to engage with?

10What has caused you stay or withdraw from a service?

11 What does it feel like to meet a new /end with a known practitioner? Have those feelings changed over the years?

12 Have you ever experienced a situation when you appreciated the professional role but wished you could have a different individual delivering the service? Tell me about that.

13 Can you tell me about a type of professional you wish you had and don't?

14 Can you describe specific relationships that have been particularly helpful/unhelpful?

15 Tell me how you generally feel about the relationships you have had with professionals over the years.

I would like to know what it feels like to work with professionals now?

16 Who is currently involved with xxxxxx?

17. How do you think the nature of your relationships with professionals now differs from those in the early years?

18. What has influenced that?

19 How would you describe your most/least positive relationship with a current practitioner?

20 Can you tell me about an experience or situation that you feel has helped you in your relating to professionals?

21 Have you ever been offered therapy, counselling or interpersonal skills training?

22 If so did you take it up and how did it impact on your relationships with professionals?

23 If not do you think it might be helpful?

24 I'm very aware that I'm a professional interviewing you about your relationship with other professionals- how has that felt for you?

25 Is there anything else you would like to add?

Thank you very much for your help. As I have previously explained all identifying information will be deleted from the transcript of the interview. The tapes and transcripts will be held securely and only viewed in relation to my research. I can provide you with a summary of the findings of my work when it is complete.

How do mothers experience their relationships with the professionals supporting their child with complex disabilities?

Handwritten left margin: not all parents really tolerate. Can relate?

334   Yeah, I think you certainly do get that. I think that what we've

Handwritten: What does she think she has that helps.

335   tended to find over the years whilst we've been dealing with

Handwritten left margin: What is do that mean they don't need to...

336   consultants is that the new breed of consultants that are

Handwritten left margin: her confidence knowledge / status!

337   coming through now, the younger consultants, are very

338   much more switched on to explaining things in the right

Handwritten: to needs of... or whether they know that we don't?

Handwritten left margin: change in professionals over generations?

339   language and bringing it down to a level of which parents will

Handwritten left margin: understanding is that what she feels

340   understand and very much more seen to empathise with

Handwritten left margin: making a diff between carer & mother? true carers!

341   parents situations as carers, as they really are true carers

342   and are not just parents of the children. Where I've tended to

Handwritten: Is it about time in job?

Handwritten left margin: parents # emphasising that as if believed?
understanding of mothers role — is that — just?

Handwritten: Do B's change over time?

343   have had problems in the past has been with older

Handwritten right margin: younger P's has better — empathy. they get parents role. ↓ But also be able to cross language empathy a bridge for understanding.

why are they better

parents of child disability more than just parents - (true carers.

bigger picture not just medical approach

Does empat = a different way / approach

344   consultants and I think there is a divide there in training most

345   definitely, erm so we've had this one particular that did and I

346   have to say once he was brought up short about it we had a

347   fantastic relationship after that, we got on really well. so

348   whether I'd just caught him on a bad day I don't know, but

349   certainly, when you talk about language we had a letter,

350   Tommy would have been about 2 years old, and we had a 3

351   page letter which was a copy of a letter sent from our

352   neurological consultant to our paediatric consultant

353   explaining the examination he'd done on Tommy and

R'ship
mean the
s-impacted
my r'ship
n one of them.

354   looking at all the case notes and decided where they needed

Being Dis Emp.
by Dr Knwldg
of language –
not condition

355   to go from there with the case and who we needed to be

356   referred to and there was ==so much medical language== in it

Actively
seeking
understndig

diad
nguge causes

_2√_   357   because it was a letter between two consultants that I

letter raises
cons Qu's 358   honestly thought they hadn't told me half of Tommys

What could
have been
understood was
wrapped up in
scary technical
language

didn't know
of they knew

Disempowered ?

359   condition, so I had to go and get a ==medical dictionary== and

arming myself
to be re-sure _decisly Pf._
  speak

360   look at it all and once I'd done that there was nothing in that

s quell my fear

Relief

understanding
is reassuring

361   letter that hadn't been discussed with me first, but the letter

, need to find
out offnd 362   had not been put in ==layman's== terms, so that could have been

this etc. _it's sh?_

But not all
Parents could do
that ?

363   very frightening for a lot of families, that is really difficult but

Better reasured
than othr families

364   they wanted to keep us informed by sending us a copy of the

[margin note, left: mistake / "...letter" / "+ REALLY!"]

[margin note, right: Power capital of having the language]

365   letter, but it needed a covering letter almost to go with it

366   (laughter) breaking it down into English. Yes, ~~so language~~

[margin note, left: unsure / my back]

[margin note, right: Using humour looking back]

367   can be a barrier. Erm, and ~~I've worked with quite a few sort~~

[margin note, left: ...the... / amused in the / situation]

[margin note, right: involved with disability gps]

368   of consultants on various committees and they still even get

369   stopped by their own peers to explain things, so it isn't just a

[margin note, left: it only exists to a barrier – ...]

[margin note, right: language a barrier between Pfs & poor & Pfs & profs]

370   barrier between parents and carers and consultants or

[margin note, left: ...by... / ...word?]

371   professionals at any level, it's a barrier, a multi agency

[margin note, right: other professionals disempowered by M Kings language? how can Pfs help this]

372   barrier, even (a barrier between peers) and their own

[margin note, left: they know... / ...they know... / ...were... / ...?]

Shared frustrations?

APPENDIX K INTERVIEW 1 SUBTHEME SPREADSHEET

287	Being talked down to	315-322	I always remember the one situation though when I had a consultant I'd say talking down to me, a neurological consultant at one point that we went to see, very much sort of talking down to me as a parent and I stopped the conversation to him at that stage and said to him that what he needed to understand was that he had a medical degree and I had a (names) degree and whilst they weren't equivalent to each other I was actually quite intelligent
288	Taking control of conversation	318-319	
289	Challenging	318-319	
290	Brokering equality	320-322	
291	Drawing from skills in another life arena	320-322	
292	Challenge improved relationship	346-347	Once he was brought up short about it we had a fantastic relationship after that
293	Identity and self belief shape my approach	324-325	I think I had the confidence to do that though I'm not sure that all parents would have
294	Deserving to be told		
295	Information is power		
296			
297	Younger Profs have better understanding & Empathy-they get the parent role	336-142	The new breed of consultants that are coming through now, the younger consultants, are very much more switched on to explaining things in the right language and bringing it down to a level of which the parents will understand and very much more seem to empathise with parents' situations
298	Younger profs better able to adapt language		
299	Switched on to what they know/parents don't know		
300	Empathy as a bridge to understanding	340-341	(young profs) seem to empathise with parents' situations as carers, true carers, and are not just parents
301	Parents + true carers		
302	Bigger picture – new training		

APPENDIX L   CHALLENGE & CONFLICT MASTER THEME

Challenge & Conflict A	ABBEY	BARBARA	CAROLE	DENISE
MOTHER KNOWS BETTER		217 by this point he was getting worse and ..., my instinct was that something was more serious	437 I think there is probably on both sides a bit of learning that could happen, and I'm obviously going to say that the professionals need to learn more than I do because as a parent I do believe that I know what's best for my child	950 At the end of the day I have to trust my instinct Emily

358 Again it's my instinct, you can't put anything into, that doesn't translate to medical professionals. |
| **CONSTANT AND EXPECTED** | 730 I've certainly had one or two where every time we've seen them we know it's going to be a battle, we know it's going to be difficult and I can't understand why | | 180 as I'm sure you've heard before, you feel like it's a constant fight, a constant battle | 826 You think 'Oh! God. Here we go again you don't even know anything about us, we're going to have to start the whole story over again and now someone else is going to shout at us' |

| INTRINSIC IN THE SYSTEM/RELATIONSHIP | | | 459 some of the therapy services I think would benefit from having more folk there, money permitting

379 (I would like) the professional as well to, again, not come in with right this is the only service we can offer, this is all we are going to give you.

222 you've got to try to speak to the Council again to find out and they don't know who's paying for the transport, you know, that, that's the sort of thing. And I can't say that's the scenario for everything but its ongoing, | 679 she (practitioner) did warn me, she did say 'look, they're going to want to push drugs onto her, but you're just going to have to stand up for yourself and be strong', so I did. |

			69 having to wait for an appointment for the 3 or 4 months and that to me is a real barrier because I change my opinion and my perception, so by the time I get there I'm just all fired up	
PROTECTING	457 It was almost like my animal instincts coming out I turned from being a mother into that lioness and by God if anybody got in the way the claws came out, erm so there was that protective side of it		421 Time is understanding and learning for your child if something is held up.	861 If I hadn't been able to stand up for my self I could have popped some medicine in Emily's mouth right now and that would be it for 5 years , 5 years until they review it! Completely unnecessarily with all those side effects

BECAUSE H/SHE CAN'T AND I CAN	315 I always remember the one situation though when I had a consultant I'd say talking down to me			1197 You think right, now you start to see that she's not just a little piece of paper.. this is who we are actually
	316 I stopped the conversation to him at that stage and said to him that what he needed to understand was that he had a medical degree and I had a (names) degree and whilst they weren't equivalent to each other I was actually quite intelligent			

SUPPORT	281 (parents) need to be supported to make a complaint	431 I'm glad someone else can be, you know, can think how I'm thinking. Surely, you know, it doesn't have to just be believing every single word that these doctors say	714 it was a real battle, a no go, but she (Health Visitor) was really behind me and helped me	1037 The best advice I had was never go and see somebody by yourself
				806 You're leaving me to go back and face that and you know that if he starts going on at me about drugs I'll probably come out with a prescription
		570 I did write to them (parent support group) to ask them how I would go about complaining if I needed to and they wrote me quite a long letter about it, I think they are very good	541 I have to say the genetics clinician we still see was great, she did get it (brought) forward for us.	570 If I'm not with x I think that's the difference ... he never gets treated like that (stupid) because he's a bloke, I don't know what it is, I don't know, I don't know. It's very different, that would be a good piece of research to see the difference in how the dads are treated.

| | | | | 811 …without you there I won't be, I don't know if I can stand up to him If it was a woman I might be able to but it's a bloke andI'm not sure I could.

671 I went to see the community paediatrician first... .. I want to know what you think so that I can go armed when I see this consultant

687 He kind of sticks his head, it's too much emotionally so (he says)I'm not going to go, so he leaves me completely, |
|---|---|---|---|---|

EMOTIONALLY CHARGED				727 I was going to put in a complaint against her, against this woman because I was so incensed	586 I don't know where it came from because I actually wanted to cry.
					596 I just thought you bloody swine, How dare you! How dare you! How dare you! I did complain straight away, no, not straight away because I came back into the room and just burst into tears
				161from my part to remain open minded and not get angry	
				1015 I am relatively confident and don't have too much of a problem talking to professionals, but sometimes, maybe if we're, if it's all going wrong and you're thinking I'm not sure if I can deal with this today	496 We were about to be discharged again, I don't know whether I would have had the courage to do anything else and then God help me...

				810 I felt sick and worked up and so did (husband) and rowing together about it all for a 50 minute meeting that's just awful
				175 R- OK, do you want to tell me a little bit about that experience? You look a little bit upset, do you want to leave it? D-No, no, no I don't want to leave it, I've been thinking about it all week the different kind of professionals that have been involved really.

COST	462 at the same time feeling very inadequate cause you didn't actually really know what you were fighting against (disability)		939 getting through the receptionists is a big issue. I'm having tears down there and all sorts cause- 'oh no, you can't do this, you can't do that' and I don't want to tell 'why do you have to see the doctor?'	449 I felt so stupid that I was questioning the midwives
				795 I feel like am I going to actually have the courage to actually stand up for what I think,
	47 (older brother) has been fairly self sufficient right from Tommy being born because (brother) was seven then, er so that's been quite useful from our point of view as a family because its meant that when we've been having troublesome times with Tommy, (older brother) has been able to get on and do things on his own			687 I hate to deal with it
				807 The whole two weeks leading up to that (a meeting with a professional whose treatment plan she disagreed with) was so shitty for us as a family, (becomes upset)

PREVIOUS SKILLS	814 I've got a list of questions I will write them down and I will take them with me and I'll start that list sometimes for weeks before 809 I go into it with a very clear sort of idea of what I want out of that meeting, and I try to treat them, rightly or wrongly, like business meetings			
LEVELS OF CHALLENGE	223 from my point of view I think it's no holds barred if you can't have an honest relationship they can't help you get the best out of their service 460 I really do mean fighting for his rights and for our rights as a family to try to unravel it all.	445 I wasn't aggressive enough, we should have put our foot down right at the start and say we want these results, please,	641 I started to say that this just isn't acceptable	1161 I need to be as prepared as I can possibly can be and stand up for what I think and feel, no matter what they said

RISK		436 You're kind of reliant on them and it's very hard to turn around and go 'actually I'd rather you didn't say that in front of my son' 442 I always thought oh my god I'm the trouble maker, you know, thought that I was a bit of a trouble maker and asking too many questions.	426 Patience isn't my strong point so I expect everything to happen in a day and I get on the phone to 3 or 4 people and sometimes you need to do that but sometimes I will look back and I will think why didn't I just give that another day and I might have got a better result	

OPTING OUT /LETTING GO		552 What's the point of raking over more negativity, you know, I just kind of wanted to look forward really 441 I regret with all those doctors that I was privy to that I wasn't more assertive... (husband) thought I was being a bit aggressive and I said 'No I wasn't aggressive enough, We should have put our foot down right at the start and say we want these results, please!' 554 I never really complained, you know, I suppose I've just avoided that	374 Because you maybe had a battle with somebody else so you've already decided THIS is what I'm going to do, THIS is what I'm going to in my mind, my aim for the meeting is THIS and you won't accept anything else. 72 I thought no, how is that going to benefit Sophie if I put in a complaint so I didn't, I didn't bother in the end	356 (He said) She needs surgery today, do you know what, this started 2 months ago, did they listen to me? But I couldn't say that, you don't say that, but at least somebody is listening to me now. (very upset) 974 I have felt guilty, looking back I have felt dreadfully dreadfully guilty, immensely guilty that I didn't stand up for Emily more.

PROFESSIONAL RESPONSE	344 I have to say once he was brought up short about it we had a fantastic relationship after that, we got on really well 522 (I tried) on a number of occasions to try to find out what his reasoning was for overruling another consultant in the hospital who felt that it was urgent and he refused to speak to me, so we ended up in a big complaint with the hospital Abbey	351 there was always this sense of being a bit patronising, there was also a feeling of blocking questions, not quite liking questions and things like you know, 281 I actually went saying look you know `Christ, he's wasting away`, and she said 'Oh don't be silly.'	541 I have to say the genetics clinician we still see was great, she did get it (brought) forward for us	750 (I said) I'm telling you now I'm leaving to go home and I will be faxing a complaint to the consultant about you. She just went `Right, Ok, well I think we're in agreement, she doesn't need any drugs and you've got the results`! 1158 they're all trained and qualified, great, but the person that they are can make or break something .

GENDER		567 I think the female ones sometimes get it a little better		811 If it was a woman I might be able to (challenge) but it's a bloke and I'm not sure I could.
FOR OTHERS	961 a lot of it is about skilling up parents to give them the confidence and the tools to deal with it.			864 Completely unnecessarily with all those side effects, and .. the next parent that goes into her that might be their fate
WHAT IT COULD BE LIKE	712 life would be much easier rather than having arguments 277 explain to parents the restrictions on your organisation whether that's financial or whether its members of staff (they) will understand and they will work with you around			

APPENDIX M - Table 1 Summary of presented themes and their section reference

SUPER-ORDINATE THEME	SUBORDINATE THEME	SUBTHEME
1 Expertise &Empathy		
	1.1 Expertise	
	1.2 Empathy	
	1.3 Professional's attitude & Approach	
	1.4 Professional's Relationship with the child	
2 Power & Disempowerment		
	2.1 Power Givens	
	2.2 Maintaining Power	2.2.1 Power Props
		2.2.2 Power over Access
		2.2.3 Power over information
	2.3 Being Disempowered	2.3.1 Disempowered by Need
		2.3.2 Disempowered by Overflowing Emotions
		2.3.3 Professional Disempowerment

SUPER-ORDINATE THEME	SUBORDINATE THEME	SUBTHEME
3 Challenge & Conflict		
	3.1 Challenging Authority	
	3.2 Why Challenge?	
	3.3 Playing the game	3.3.1 Using Established Skills
		3.3.2 Role Play
		3.3.3 The Information Game
		3.3.4 The Emotions Game
		3.3.5 Marshalling Support
	3.4 The Risk in Challenging	3.4.1 Personal risks
		3.4.2 Risk in the Professional Response
	3.5 Letting Go	
4 Time &Transformation		
	4.1 Understanding over Time	4.1.1 Understanding the Child's Disability
		4.1.2 Understanding the Professional
	4.2 Roles and Tasks	4.2.1 The Expert Carer
		4.2.2 The Project Manager
		4.2.3 The Educator
		4.2.4 The Advocate

SECTION C

Advanced Professional Practice

'What am I without him?'

Using Person Centred Therapy to support a bereaved mother.

PART A   INTRODUCTION AND START OF THERAPY

1.1   INTRODUCTION AND RATIONALE FOR THE CHOICE OF CLIENT

I submit my work with Jenny because I believe it draws together various themes running through the portfolio.   For example, I feel her story connects with my empirical piece and unveils an evocative, experiential backdrop to the research question.   I also wanted to present work using a Person Centred Approach (PCA) as I feel it has very specific things to say about personal and structural power; a major theme running throughout the portfolio.   Further, the strong representation I have made for British Counselling Psychology to again practice and celebrate its humanistic and phenomenological roots make it fitting, perhaps even obligatory, that I reflect on client work grounded in the same.

1.2   SUMMARY OF THEORETICAL ORIENTATION

The Person Centred Approach (Rogers, 1980) assumes a natural motivation and propensity in humans to self-actualise.   Distress is viewed as the result of circumstances or experiences so challenging for the individual that they undermine the integrity of their self concept, creating an incongruence which halts the actualisation process (Wilkins, 2010).   Individuals may become behaviourally, emotionally and psychologically compromised as they attempt to make sense of the conflict and redress the balance in ways that are not always helpful   (Rogers, 1959, p228 – 229). The aim of person-centred therapy is to co-create a growth enhancing, healing relationship within which the client can develop an understanding of their processing difficulties thus reducing incongruence (Sanders, 2006b).   The alliance is further underpinned by trust and respect for the client's subjective experience and their innate ability to overcome their struggle.

Although the classical view in Person Centred Therapy (PCT) suggests subjective experiencing is something generated in private and within the person (Rogers, 1959), many contemporary practitioners, myself included, suggest experiences have an

intersubjective socio- cultural element, in that our meaning making is infused and shaped by language, ideas and the interpersonal context of our lives (Barrett-Lennard, 2005; Mearns & Cooper, 2005). Distress is seen as being rooted in these relationships, with difficulties in resolution being hinged on personal, social, political and environmental powerlessness to affect change (Proctor, 2002, p3). Thus, PCT strongly disputes the medical model that views such difficulties to be biological or intrinsic to the person (Sanders, 2006a, p33) and, in keeping, practitioners are called upon to work holistically, taking account of the client's external world as well as their inner experiencing.

While no interaction can be devoid of power influences, particularly within the helping relationship (Haugh, 2012; Wilkins, 2010, p17), the person-centred counsellor intends not to exert authority 'over' or present as the expert on the person's experience (Cain, 2002, p366 - 368; Grant, 2002, p371 - 372). Indeed, given the assumptions about the loci of the difficulties, it is thought counter-therapeutic for the therapist to be seen to know what is best for the client as this maintains their disempowerment and lack of control (Wilkins, 2010, p17). So, while therapists are required to bring a strong, reassuring 'sense of personal power' (Natiello, 2001, p11) this is consciously not used to influence. This does not mean therapists do not probe or challenge but rather they do it from the 'moral position' that the client knows best (Wilkins, 2006). This results in empathy, congruence and unconditional positive regard for the client's subjective experience. As the client recognises and addresses acceptance of their own meaning making, incongruence is reduced and self worth, motivation and confidence to address that which is perceived to be causing the difficulties is supported.

1.3 THE REFERRAL, CONTEXT OF THE WORK AND PRESENTING DIFFICULTY

Personal and process details are changed to protect anonymity.

Jenny phoned to self refer into my community practice. She explained that she was finding it very hard to make sense of her world after the sudden death of her son, who had complex disabilities, some seven months before. She described feeling lonely, aimless and empty and felt she was 'only existing', getting by because she had

immersed herself in fund raising projects. She felt she needed a place to reflect, a place that would allow her to revisit what had happened and to begin to think of rebuilding her life without him. We arranged to meet two weeks later at her home where she believed she would feel most comfortable.

1.4 INITIAL ASSESSMENT

There continues to be some controversy around the place of assessment within the PCA (Simms, 2011). My view is that assessment need not be akin to diagnosis and is important in PCT as it facilitates the recognition of any immediate barriers to therapeutic process or alliance (Wilkins, 2010, p101 - 103). The relationship between the client and therapist is pivotal and therefore demands an assessment of the suitability of the match. Further, given the core assumption that psychological growth is dependent on the client experiencing both their incongruence and the acceptance of the therapist, initial assessment must also involve clinical opinion about the client's current level of processing.

1.4.1 ASSESSMENT OF READINESS AND THERAPIST SUITABILITY

Jenny's self-referral and the conviction with which she requested support evidenced that she had reached a stage of processing which was conducive to therapy. She had already acknowledged her suffering and had declared her desire for healing and change. Her openness about the nature of her difficulty also allowed my initial reflection of my own suitability, essential in PCT. One process issue was that the nature of her experience touched on my research and might generate a personal agenda which could interfere with process and drive the therapy in a direction only **I** wanted it to go. I had to be convinced that my allegiance to the core conditions of person centred therapy could withstand such drivers.

A further aspect of very early assessment in person-centred work revolves around the need to offer the client an empathetic understanding and unconditional positive regard for the issue, their subjective experience of it and for them as individual people. This draws the practitioner into a self-dialogue and reflection on how they feel they would

be with the client. Any difficulties would be seen to limit the potential to offer positive regard and would thus corrupt the process of congruency and empathy so vital to client change. This is quite different to those approaches which rely more on tools and strategies than on relational depth (Mearns & Thorne, 2000). In this case, I felt able to offer Jenny an empathetic approach, although I was aware that exploring her experience would be highly emotional and distressing.

Assessment beyond this will also include the nature of the difficulty without attaching assumptions about how the client has experienced these or should deal with them. I conceptualise my work as something akin to restoring a building (the client's well-being). I bring scaffolding in terms of personal and academic knowledge and skill while the therapeutic relationship can be seen in terms of the bricks and other materials. All the while, the client remains the architect and project manager. How the building looks and the speed and how it is constructed remains within their control. What we call it as it grows is most often immaterial. Assessment fits as a means of establishing a willing, proficient building team and, in allowing the client to share their story, offers the practitioner a first insight into the themes that will shape and structure the build. Thus, unlike many other approaches, assessment is a growing understanding, contextualised within the emerging relationship and not a way to identify with preconceived notions of why the building is under threat, a particular programme of works or how the rebuild should look. As a consequence, this report will discuss themes arising from the course of the therapy rather than have a single formulation section.

1.5   SUMMARY OF BIOGRAPHICAL DETAILS

Jenny was fifty-four years old and had been married to Iain, a business man eight years her senior, for eleven years. Iain had been a divorcee without children when they met. Jenny had not been married before. Together they had two children, Simon, nine and George, who would have been seven had he lived. Jenny had worked in the caring services but had resigned her post when the extent of George's disability became clear. On this first visit, I found the family lived in a large, modern home in a village in a wealthy and affluent part of middle England.

Jenny disclosed that she had not wanted children and it had only been through Iain's persuasion that she had tried for a baby at all. Although forty-four, she had become pregnant and miscarried soon after they had married. She believed the sense of loss and disappointment she had felt at the time had reassured her that motherhood was indeed what she wanted. Nevertheless, even then, she had never dreamt that she would be a 'stay at home mum' but she felt motherhood 'suited' her and she had enjoyed her life until George's death.

1.6   NEGOTIATING A CONTRACT AND AGREED THERAPEUTIC AIMS

Part of the process in PCT is to 'demystify' therapy for the client, so, at the beginning of our first session and following the usual discussion around boundaries and confidentiality, I explained the rationale behind Person Centred Therapy using the same building metaphor outlined above. We agreed a contract for eight weeks with a review session after the sixth. We would meet at Jenny's home by arrangement each week.

Toward the end of the session I also discussed the possibility of using our work as the client study for my portfolio. I explained the reasons I felt it fitting but also reiterated that she was under no obligation and that it would not influence me if she chose not to agree. Jenny had contacted me as a potential therapist because she had been told of my involvement with families with children with severe disabilities and shared my desire to relate the experiences of the mother so others could understand. She was therefore very keen that her story be told to a wider audience. We agreed that we would revisit this decision at the end of our work together.

PART B   THE DEVELOPMENT OF THERAPY

2.1   THE THERAPEUTIC PLAN

I felt Jenny needed a place in which to verbalise her difficulties. Often grieving clients have told me that such a space allows them to be selfish, to think solely about how the death has impacted on them, something they feel unable to do within their usual network of support also affected by the loss. This is especially so in the case of bereaved parents where different ways of mourning and adjusting can place additional pressure and strain on their relationship (Rogers, Floyd, Mailick-Seltzer, Greenberg & Hong, 2008). Therapy also allows the proclamation of words and thoughts that cannot easily be said in other venues or to other people because they may shock or upset. I have found a number of long term carers who admit a relief that had never been expressed outside the therapy room.   PCT offers an empathy, congruence and unconditional positive regard that allows the client to explore and attach meanings to such feelings. In addition, it seemed Jenny had no vision of what 'moving on' might look or feel like. I was confident that within that accepting relationship, the process of change and growth, motivated and driven by the inherent actualising tendency, would offer Jenny the means to move from her current turmoil toward holistic readjustment.

2.2   KEY THERAPEUTIC THEMES

This section will identify the theoretical understandings of the main therapeutic themes that arose from my initial meetings with Jenny. These will be viewed in relation to the Person Centred Model and the implications for therapy will be discussed

2.2.1   MOURNING

Jenny had been traumatically bereaved and was struggling to cope. In the second session she disclosed that she had had other recent bereavements. Her mother had died about ten months before George. She appeared to carry some fond memories of the days before her mother's death, remembering them having a cream tea together in

a quaint country tea shop which was fun even if she had been quite petrified that her mother would 'pop her clogs' at any minute.

Jenny also spoke of a younger brother Terry who had died suddenly about three years ago. He had been playing football, a favourite past time and had died on the field as the result of a heart attack. She said that although his death was a great shock, she recalled being 'relieved' that he had died doing something he loved rather than the long painful illness her mother endured. Jenny also told me that at that moment Iain's step father was in hospital, not expected to survive through the night. But she said he was ninety five and had had a 'good innings' unlike Terry and George, who had 'died before their time'.

Theories of mourning include the Stage or Phase (Kübler-Ross, 1969; Parkes, 2001), Dual Process (Stroebe & Schut, 2010), Meaning Reconstruction (Neimeyer, 2006) and Attachment & Loss models (Field, Gao & Paderna, 2005). Recent thought emphasises an oscillating, dynamic grieving process that attends to the relationship with the deceased rather than a linear, fixed model of detachment and recovery. Allowing for a continued, if transformed, relationship between the bereaved and the deceased seems to facilitate a more positive view of survivor experience (Gamino, Sewell and Easterling, 2000) where the individual can maintain the best and most constructive aspects of the relationship they have lost through psychological restructuring and reintegration (Neimeyer, 2000).

Although there is a lack of specific research around the experiences of parents bereaved of a child with disabilities (Reilly, Hastings, Vaughan & Hews, 2008; Reilly, Huws, Hastings & Vaughan, 2008), other studies confirm that bereaved parents report significantly more intense and prolonged grief related feelings than other bereaved individuals (Rando, 1986) and often 'feel alone' in the uniqueness of their loss (Toller, 2007). Oscillation and relational grief models seem particularly pertinent to bereaved parents who not only lose their 'child as was' but also their aspirations and visions of their 'future child' (Jeffreys, 2005, p125; Talbot, 2002). They, perhaps more than most, will have to contend with reminders and triggers of that loss throughout their life. To this end, Rando (2009) usefully distinguishes the 'psychological, behavioural, social, and physical reactions to the perception of loss'

are best thought of as *grief* while the efforts of the bereaved to cope and realign represent the *mourning* process.

A person centred approach to grief counselling accepts uniquely individual responses to bereavement rather than a universal process. The therapeutic relationship is seen as a vehicle for the bereaved person to explore their situation and to move toward understanding. No credence is given to the notion that grief is something to be conquered or that the person should maintain connections with the deceased. Neither are assumptions made about the nature of the elements of grief. Probing may give a depth of insight into their experiencing but essentially the grieving person is facilitated to find balance without being judged as being in denial or having unresolved grief (Horowitz et al., 1997). The therapist trusts that the self actualising tendency and greater insight will shape appropriate change, and has no inclination to drive the client through stages of acceptance or to equip them to cope in any socially or culturally defined way.

2.2.2   TRAUMA

I also construed that Jenny's disorientation could be heightened by the circumstances of George's death. She spoke of the many 'near misses' George had had throughout his life and yet each time the medics had managed to save him. He was something of a celebrity survivor. So it felt an even greater shock when one anonymous Tuesday night, without warning, she had simply found him dead in his cot.

Janoff-Bulman (1992) suggests we establish protective assumptions that our world is essentially a benevolent place, that our life has meaning and that we ourselves are worthy and ought therefore to experience only good things. She believes any undermining of such constructs can attack our sense of self efficacy and leave us feeling vulnerable. Such 'loss of the assumptive world' (Kauffman, 2002), seemed to fit particularly well in Jenny's situation as not only had she experienced the death of a child at home, she had also lost him in traumatic and as I understood, instantaneous, circumstances. The assumption that we can protect our family, that we are safe in our own home or that we die before our children were now all lost to Jenny (Matthews & Marwitt, 2004).

It also seemed to me that Jenny's recent experiences could give rise to fragility in her understanding and constructs of what her life was about. This would appear evident in her description of her existence as aimless and empty and her difficulty in imagining herself 'moving on' without George. However, theory also posits post traumatic growth whereby the individual is able to attach a meaning, control and order to the challenge that besets them thus reducing dissonance and incongruence and generating personal growth (Janoff-Bulman, 2004). It is proposed that in creating meaning, the individual is required not just to resist damage, but to generate a new way of thinking about the situation, one which alters old values and priorities and draws strength and existential meaning from the circumstance (Davis & McKerney, 2003).

Such tenets fit well with the assumption of the actualising tendency that drives individuals to respond to challenging experiences in a way that will strive for regulation and accord. Jenny's previous experience had exemplified this in that she had accommodated losses and framed them in very positive terms: a valuable strength. She viewed her miscarriage as providing her with the recognition that she wanted to be a mother. Her mother's death had allowed her to move into real independence. Her brother's passing had added a quality to her life through increased contact with his children. Her father in law had 'earned his rest'. A new interpretation of her reality (Harvey & Mills, 2000, p150) could come if Jenny was to scrutinise the ways in which her circumstances actually had challenged the totality of her 'assumptive world'. Currently the process had stalled, but tapping into this natural drive once again could encourage the post traumatic growth recognized in other bereaved parents (Engelkemeyer & Marwitt, 2008).

2.2.3 IDENTITY

The observations around bereavement and trauma fit well with a third theme arising from our early sessions. Jenny gave an account of a fragile identity, apparent in her aimlessness, isolation and lack of vision. She had grown to define herself through George and what she did for him; a transformational experience similar to that experienced by the women in my research. Now, suddenly, she faced the prospect of not only having to cope with life after the loss of her beloved child but also having to

negotiate the threat to her identity now that he was gone (Breakwell, 1986). Talbot (2002) proposes that when a child dies the parent experiences 'identity disintegration' and this seemed to be the case with Jenny who could not see what she could do or be, without George and felt stalled in her progress to accommodate his death.

Toller (2007) discusses grieving parent's struggle to establish a new identity without having to relinquish the validity of their previous parenthood. In this research, the parents had been left childless following the bereavement. For Jenny it was rather different in that her claim to mother status remained intact with Simon. What Jenny had lost was her identity as a parent of a child with complex disabilities. Reilly et al., (2008b) highlights the experience of mothers in a similar position and identifies both the intrapsychic and social struggles these women face in trying to adapt. To cope and accommodate, Jenny was having to address a major secondary loss, her identity as a mother of a child with complex disabilities. Engendering change, understanding this alternative self that now included Jenny prior to George; Jenny, mother to George and Jenny bereaved of George, was proving difficult (Brabant, Forsyth & McFarlain, 1997).

2.3   KEY CONTENT ISSUES

Jenny had initially spoken of feeling that things 'should' be getting a little better for her and yet it was still all so painful and raw. She identified that she felt left behind while others moved on. She talked about their garden and how they had just begun to have it landscaped to accommodate George's wheel chair in the weeks before he died. Now she could not bear to even look at it and could not understand how Iain took solace sitting there in the evenings. It felt the same with the bedroom with Iain feeling ready to change the decor and put George's belongings away, while Jenny struggled to let go and found that her place of solace. This gave cause for a discussion about other people's expectations about how she should be managing and feeling. As we progressed through the therapy, it became apparent that some of the difficulties Jenny was experiencing in this respect were grounded in her belief that she was not in charge of the pace of change. She was experiencing other people to be in control of the markers to George and they had been moving too fast. She felt she had to be how

they thought she should be after eight months but it really did not feel right. This frightened and disorientated her and caused her to become entrenched for her 'self protection'.

On one occasion, she explained that she and Iain had taken Simon to a favourite country park the previous weekend and she had parked in the disabled bay before realising she no longer needed to. She told me she had had a 'Mobility car' for George: one that would take his wheel chair in the back of it. She described how she had received a letter shortly after his death and the car had been 'unceremoniously' returned. She had not understood why that had been so painful as she did not need the 'bloody thing' any more. Her choice of words seemed enlightening and when drawn to her attention, she realised that the car had symbolised who she was –the mother of a child with disability. She recognised that she had lost it too soon and had really needed the event to be marked as a rite of passage or as a major transition since, as she now understood, she was relinquishing a little more of George and giving up part of her identity along with the car.

She also described a similar event when in the weeks following his death: she received a notice from the local hospital addressed to the 'parents/carers of George Stevens' which informed her that he had now been delisted as he had died. The thoughtlessness had upset her greatly but she had also suffered a huge shock when, only at that moment, did she realise that relationships with professionals, some of whom she liked very much, would now be closed to her. She felt such appointments had almost 'structured' her life: if it was the audiologist it was summer, the neurologist meant it was nearly Christmas. Interestingly, Reilly et al (2008b) suggest that professionals should continue to make themselves available to bereaved parents as this was identified as a restorative factor in mothers' coping. In engaging with her discomfort at how quickly others were able to 'forget' him, Jenny started to construct an understanding that she was holding on to what she could of him in order to compensate and stabilise herself.

Essentially, Jenny was surviving by accommodating how others wanted her to be while at the same time recognising that she was not capable of such rapid change. This incongruence seemed also to have seeped into those aspects of her behaviour that

were conducive to growth so that she was attaching a negative meaning to positive behaviours.

2.4   EMERGING THEME – POWER AND CONTROL

As mentioned previously, PCT will take account of social and cultural influences on subjective experience. Each society has accepted and expected markers, protocols, ceremony and symbolism and often engendered accounts of how the bereaved should respond (Aiken, 2001).   Similarly, in Jenny's case there were various social understandings of disability, not all positive, which could influence how George's death was perceived by some (Barnes, Thomas, French & Swain, 2004; Carson, 2009). The phenomenological importance of this and the impact it was having on Jenny became clear as therapy progressed. It seemed she felt there were expectations of how she should be feeling and behaving and a sense that people were becoming tired and impatient with her. In many instances, events and individuals were causing her to address issues and changes for which she did not feel prepared. Person centred theory suggests that psychological and emotional incongruence is generated by the need for positive regard often corrupted by conditions of worth. I grew to recognise that much of Jenny's difficulties lay in the fact that while she recognised the demands from other people and watched how they managed their grief, she did not feel ready or able to move so quickly but in many instances was pretending she had.   The embedded and social nature of her existence meant this was an ever present struggle, leaving her feeling powerless and out of sync.

Although some might perceive her to be stuck in a lost identity in terms of the retained toys, bedroom and her charitable efforts, I felt she was probably biding time and protecting herself quite effectively. She had experienced an event that threatened her very core. She had 'battened down the hatches' in order to prevent any more damage. Her 'stuckness' was not about refusing to move on –it was about not knowing how to in a way that would keep her safe. I believed she could reconstruct her identity once she knew the pace at which she felt comfortable and asserted her own control over the actual events that lead her there. In the early stages of therapy, she was construing endeavours like her charity work as negative. Empowerment would come when she

understood her needs. Gentle challenges facilitated her to see she was labelling such efforts as she thought other people would see them. In turn she began to value them outside their connection to George.

2.5 DIFFICULTIES IN THE WORK

A sense of power also proved to be important within the actual therapy process although not as one might expect. The emotional content of the work was hugely draining and sharing Jenny's pain and fear very difficult indeed. Neither of us could bring George back and whilst our work was designed to bring some positive change, the one thing that could remedy all of the pain was beyond our reach. Thus, our work took me beyond the usual considerations of power within the relationship, having less to do with playing 'the expert' or being directive and more about the existential frailty of the person and the limitations of our command no matter who we were. At times I felt feeble, all knowledge and skills rendered impotent. But to assert anything else, to pretend that I felt anything else or could do something miraculous, would go against the very core of PCT. In neglecting or denying my own feelings I would corrupt congruence, threaten our relationship and Jenny's understanding of her experience. So I sat with my disempowerment and on occasion we talked together about it. It seemed to support Jenny that I could feel powerless in this situation and yet remain capable in other ways.

My feelings of powerlessness also lead to moments where I experienced what Rogers (1990) called 'presence' and others have labelled 'tenderness' (Thorne, 1991) and the 'fourth condition' (Wilkins, 2010). 'Presence' is seen as being at one with the client, a transformational experience of relational depth, which Mearns (1994, p7 – 8) suggests comes from a blending of the real therapist congruence, unconditional positive regard, empathy and resonance with the client's situation. Jenny's description of the circumstances of George's death, being so sudden, so final and without choice was acutely painful and at one point in the session I became aware of hot, stinging tears running down my face and suddenly realised that I had lost all sense of the environment we were in or the task that we were involved with. I had been completely immersed in Jenny's experience. I had been taken to the place she had

been. I felt her horror and agony in finding his lifeless body and the helplessness in the finality of it all. For all the empathy I imagined I had shown, it was really only in that moment that I could meet Jenny where she was, not because of any technique but because even as a therapist, I was as powerless as she had been.

2.6 CHANGES IN THE THERAPEUTIC PROCESS OVER TIME

Change for Jenny came when she realised that her experience and consequences of the loss of George were unique to her and she could own it as such. Perhaps one of the most significant moments came when Jenny recognised the enormity of change that George's death had brought her and how that separated her experience from anyone else's. Reflecting on her experiences of previous loss and her understanding of her current desire to exercise control over 'moving on' allowed Jenny some insight into how the loss of George was different for her. She described how she had felt both anchorless and liberated when the 'umbilical cord' was finally cut when her mother died. In voicing these feelings, Jenny began to explain George's death in terms of the umbilical cord being severed before **she** was ready. She detailed how, although he was six, George's physical and sensory disability had meant she still carried him, fed and changed him as one would a toddler. George would always have needed that kind of support. He would always have been her baby. She had been his life line and everything she had done had been to that end. In exploring the notion that she had transformed her life in response to his needs allowed Jenny to see George's death as changing everything. ''It _**all**_ changed' she proclaimed 'and I don't have anything to put in his place'. Jenny reasoned she was also mourning the death of part of herself, and that her striving to do things that kept George 'alive' was because in letting go 'Jenny', as she knew her, just wouldn't exist.

Jenny's understanding of her block to growth and movement was supported by our exploration of the pressure she felt to put mourning behind her and move on. She came to realise she could readjust if she could make changes at her own pace. Gradually she began to engage in her new world in a controlled and managed way. Doing so allowed her uncertainty and lack of coherence to ebb and she began to slowly build a new understanding of Jenny, bereaved mother of George. As often

happens, Jenny's growth came from applying her understanding from the sessions to situations beyond. One significant event was having her friend, Sal, also the mother of child with complex disabilities over to lunch. She had broached the topic in a previous session and in reflecting on it felt that she could cope with having Sal but not Amy her daughter. Jenny had explained her feelings to Sal and was delighted when she had understood. Jenny felt in control and although she acknowledged that at times she had physically ached for George, she celebrated that she and her friend actually had much more in common than just their children. Jenny felt this was a very, very important juncture for her.

I used the success of her lunch to highlight just how far she had journeyed and to extract the positives and strengths she could take forward. When asked, Jenny identified a number of strengths that had been rediscovered in her meeting with Sal. She was a good listener, she could be funny, she was a problem solver, she had good life experience and a maturity that could be supportive to others. She also identified the development of new strengths. For example, she felt she could manage her sorrow both physically and emotionally when she had been talking to Sal. Yes, there had been tears when she had first opened the door but after that one charged moment, she had been able to assimilate how much she missed George without it interfering or detracting from her time with Sal. Up until now, contact with people had essentially been as George's mum and about George: she had now dipped a toe into her social circle as Jenny and it had gone well.

By the twelfth session, Jenny had reasoned that the imbalance she felt previously was as much about her and the gap left in no longer caring for George. She was toying with the idea of working with families with children with disabilities. She explored her motivations in the session and she was assured that it was to provide them with the benefit of her experience not as a substitute for George. She marvelled at herself as she processed that this felt like 'moving on'. She believed she had begun to separate her loss of George and consequences that had had on her role in life. She could not change that George was gone but she could use the understanding and strengths having him had given her to change how she was and what she was doing after his loss. She was still scared but she gave herself permission to back off if things became overwhelming.

PART C   THE CONCLUSION OF THERAPY AND THE REVIEW

3.1   THERAPEUTIC ENDING AND EVALUATION OF THE WORK

Following reviews at the sixth and twelfth sessions, Jenny and I concluded our work on the fourteenth. In our penultimate session, I suggested we create a metaphor that she could hold to remind her of her journey. By the end of the last session we had depicted Jenny's coping in bereavement through driving. George's death had been like a crash where her car had been written off and her confidence in her ability to drive shattered. She had been left motionless and traumatised at the scene. Over the months she had acquired the courage to get into the car again and she was gradually venturing to drive further and further from home. Some days she would get through the journey without any significant hitches and increasingly, as she ventured back into life, that is what would happen. But equally, as she did begin to engage with the world as Jenny again, she would meet new situations where she might have to manoeuvre through reminders of George and his loss. These would be effortful days and she would no doubt be left feeling low again. Similarly, there would be times when, no matter how hard she prepared, reminders of her loss would come like a near miss traffic accident with her senses left heightened and her emotions raw. However in all these situations she now knew that she had the strength not only to get herself home but to try again tomorrow. Jenny embraced the metaphor with relish and said she would use it to support her.

Coping with bereavement of any kind has the potential to damage health and wellbeing (Stroebe, Schut & Stroebe, 2007). Mothers who have lost children are particularly vulnerable, with evidence to show they have increased risk of stress related illness, depression and even death in their bereavement (Li, Precht, Mortenson & Olsen, 2003). While in many ways the most perilous period had passed, and Jenny had many recognised safeguards in terms of self awareness and social support (Wijngaards-de Meij et al., 2005), I still felt it important to make sure that Jenny

would continue to care for herself, that she was aware of her mood and knew to discuss any issues with her GP. At the end of the last session we spoke about self help and support groups I had identified in the area and agreed that she could contact me in the future if she felt she needed further support.

I feel my work with Jenny was successful. She has made great progress towards creating a meaningful life without George. She is in a healthier place with a greater understanding of her strengths and a sense that she is worthy and empowered.

I was, however, left concerned that there was so little professional support or research around the specific experience of losing a child with complex disabilities and would hope to identify and pursue fulfilling the need in the broader arena when my Doctorate is complete. It had also became clear that Jenny was not eligible for support from local Mental Health or IAPT services as, in both cases, Jenny's experience of bereavement would not be considered severe enough to fit their criteria for support. Further the learning disability service that had provided support for George could not support Jenny since his death meant she was no longer a carer. I have since supported a review of this in my service and parents bereaved of young or adult children with disabilities will now have receive our support.

3.2   WHAT I LEARNT ABOUT THERAPEUTIC PRACTICE

My work with Jenny has allowed me to deepen my understanding of bereavement experienced as a fracturing of identity. Jenny's was a traumatic loss, out of kilter with the natural order. Her loss was devastating and disorientating. One of the major learning points was sitting with the powerlessness described earlier. The temptation to **do** something for the client rather than **be** with them as required in PCT, is very real in such circumstances but doing something would have been about resolving my discomfort not Jenny's. Yet there is something of a conflict in being the 'helper' and not 'helping'. Working with Jenny allowed me to experience moving beyond feelings of incompetence and to learn to trust that being was enough at that moment.

The work also allowed me to experience the power of person centred therapy. Our relationship provided not only the space to reflect but the conditions for growth that were unavailable to Jenny elsewhere in her life. While she felt others pressured her and misunderstood her responses, something which compounded her distress, I was able to offer unconditional acceptance and trust in her experience. My empathetic attending allowed her to feel secure enough to begin to process her challenges and restructure her self concept and identity from a safe place.

3.3 MAKING USE OF SUPERVISION AND LEARNING ABOUT MYSELF AS A THERAPIST

One of the first issues I took to supervision was the possibility that this might be a potential client study. Asking a client to allow their therapy to be used in a study has always been difficult for me, raising issues of power, choice and exploitation. This all seemed particularly pertinent in Jenny's case as I was reminded of the mothers in the study who recognised those professionals who only showed real interest when the child afforded them academic opportunities. How could I manage to protect our work from being corrupted by any desire to test the outcomes of my study? While my supervisor did not advise either way, the space to reflect and be challenged assured me I took a decision that was well considered and ethically sound.

The importance of how the person centred therapist **is** in the relationship rather than the tools or strategies they use, affords a professional duty for them to attend their own welfare. The emotional demands in the work with Jenny meant it was essential that I used supervision as a means to monitor how I was feeling. One element was my moment of unguarded weeping. This was not the first time I had shed a tear or shared feelings of anger with a client but this felt wholly different. I wanted to make sure that there was not too much of Joy, the mother, in the room. I appreciated being reassured that my work as a person centred counselling psychologist is relational and built on a congruence that can result in being vulnerable and sharing such emotional affect (Wolsket, 1999). Even in my powerlessness, Jenny taught me much; about love, about loss, about motherhood and about the resilience of the human spirit.

REFERENCES

Aiken, L.R. (2001). *Dying, Death and Bereavement.* Mahwah, NJ: Lawrence Erlbaum Associates.

Barnes, C., Thomas, C., French, S. & Swain, S. (Eds). (2004). *Disabling Barriers, Enabling Environments.* London, UK: Sage.

Barrett-Lennard, G.T. (2005). *Relationship at the Centre: Healing in a Troubled World.* London, UK: Whurr.

Brabant, S., Forsyth, C.J. & McFarlain, G. (1997). The impact of the death of a child on meaning and purpose in life. *Journal of Personal and Interpersonal Loss, 2*(3), 255 – 266.

Breakwell, G. (1986). *Coping with Threatened Identities.* London, UK: Methuen & Co.

Cain, D.J. (2002). The paradox of nondirectiveness in the person-centered approach. In D.J. Cain (Ed.), *Classics in the Client-Centered Approach.* Ross-on-Wye, UK: PCCS Books.

Carson, G. (2009). *The Social Model of Disability.* Retrieved from http://www.ukdpc.net/site /images/library/Social%20Model%20of%20Disability2.pdf.

Carson, G. (2009). *The Social Model of Disability.* Retrieved from http://www.ukdpc.net/site/images/library/Social%20Model%20of%20Disability2.pdf

Cutts, L.A. (2013). Considering a social justice agenda for counselling psychology in the UK. *Counselling Psychology Review,* 28 (2), 8-16.

Davis, C. & McKerney, J. (2003). How do people grow from their experience with trauma or loss? *Journal of Social and Clinical Psychology, 22*(5), 477 – 492.

Egan, G. (2002) *The Skilled Helper A problem –management and opportunity-development approach to helping.* Wadsworth Group California

Engelkemeyer, S. & Marwit, S. (2008). Posttraumatic growth in bereaved parents. *Journal of Traumatic Stress, 21*(3), 344 – 346.

Field, N.P., Gao, B. & Paderna, L. (2005). Continuing bonds in bereavement: An attachment theory based perspective. *Death Studies, 29,* 1 – 23.

Gamino, L., Sewell, K. & Easterling, P. (2000). Scott and White Grief Study: Phase 2 Toward an Adaptive Model of Grief. *Death Studies, 24,* 633 – 660.

Grant, B. (2002). Principled and instrumental nondirectiveness in person-centred and client-centered therapy. In D.J. Cain (Ed.), *Classics in the Client-Centered Approach.* Ross-on-Wye, UK: PCCS Books.

Harrison, K. (2013) Counselling Psychology and power: Considering therapy and beyond. *Counselling Psychology Review,* 28 (2), 107-117

Harvey, J. & Mills, E. (2000). *Loss and Trauma.* Hove, UK: Brunner-Routledge.

Haugh, S. (2012). A Person-Centred Approach to Loss and Bereavement. In J. Tolan & P. Wilkins, *Client Issues in Counselling and Psychotherapy.* London, UK: Sage Publications Ltd.

Hore, B. (2013). Is homelessness a matter of social justice for counselling psychologists in the UK? A review of the literature. *Counselling Psychology Review,* 28 (2), 17-29

Horowitz, M.J., Siegel, B., Holen, A., Bonanno, G.A., Milbrath, C. & Stinson, C.H. (1997). Diagnostic Criteria for Complicated Grief Disorder. *American Journal of Psychiatry, 154*(7), 904 – 910.

Janoff-Bulman, R. (1992). *Shattered Assumptions: Towards a New Psychology of Trauma.* New York, NY: Free Press.

Janoff-Bulman, R. (2004). Posttraumatic growth: Three explanatory models. *Psychological Inquiry, 15*, 30 – 34.

Jeffreys, J.S. (2005). *Helping grieving people: When tears are not enough; A handbook for care providers.* New York, NY: Brunner-Routledge.

Kauffman, J. (2002). *Loss of the Assumptive World: A Theory of Traumatic Loss.* New York, NY: Brunner-Routedge.

Klass,D., Silverman, P. &Nickman, S. (1996) *Continuing Bonds: New understandings of grief.* Taylor and Francis Washington

Kübler-Ross, E. (1969). *On Death and Dying.* New York, NY: Macmillan.

Lagrand, L. (2006) *Love lives on;Learning from the extraordinaryencounters of the bereaved*. Penguin New York

Li, J., Precht, D., Mortenson, P. & Olsen, J. (2003). Mortality in parents after death of a child in Denmark: A nationwide follow up study. *The Lancet, 361*(9355), 363 – 367.

Liiceanu,A. (2000) Parallel Selves as the End of Grief Work in Harvey, J. & Mills, E. (2000) *Loss and Trauma* Brunner-Routledge, Hove Ch.7

Matthews, L. & Marwitt, S.T. (2004). Examining the assumptive world views of parents bereaved by accident, murder and illness. *Omega: Journal of Death and Dying, 48*(2), 115 – 136.

McCormack, J. (2007) *Recovery and Strengths Based Practice.* SRN Discussion Paper Series. Report No.6. Glasgow, Scottish Recovery Network.

Mearns, D. (1994). *Developing Person-centred Counselling.* London, UK: Sage.

Mearns, D. & Cooper, M. (2005). *Working at Relational Depth in Counselling and Psychotherapy.* London, UK: Sage.

Mearns, D. & Thorne, B. (2000). *Person-Centred Therapy Today: New Frontiers in Theory and Practice.* London, UK: Sage.

Natiello, P. (2001). *The Person-Centred Approach: A Passionate Presence.* Ross-on-Wye, UK: PCCS Books.

Neimeyer, R.A. (2000). Searching for the meaning of meaning: grief therapy and the process of reconstruction. *Death Studies, 24*(6), 541 – 558.

Neimeyer, R.A. (2006). Complicated grief and the reconstruction of meaning: Conceptual and empirical contributions to a cognitive-constructivist model. *Clinical Psychology: Science and Practice, 13,* 141 – 145.

Osterweis,M., Solomon, F. & Green, M. (1984) Bereavement; Reactions, Consequences and Care. From the Committee for the Study of Health Consequences of Stress and Bereavement Ch. 4 http://search.nap.edu

Padesky,C. (2008) Uncover Strengths and build resilience with CBT; A 4 step model Workshop attended May 2008 London

Parkes, C.M. (2001). *Bereavement: Studies of grief in adult life* (3rd Ed.). Philadelphia, PA: Taylor & Francis.

Proctor, G. (2002). *The Dynamics of Power in Counselling and Psychotherapy: Ethics, Politics and Practice.* Ross-on-Wye, UK: PCCS Books.

Rando, T.A. (1986). *Parental Loss of a Child.* Illinois, USA: Research Press.

Rando, T.A. (2009). *12 Tenets of Working with Loss Today.* Warwick, RI: The Institute for the Study and treatment of Loss.

Rando, T.A., (2009) *12 Tenets of Working with Loss Today*
http://www.stfrancishospice.ie.images/Kal_09_handouts/Rando-handout

Rando,T. (1993) *Treatment of Complicated Mourning* Research Press Illinois

Reilly, D., Hastings, R., Vaughan, F. & Huws, J. (2008a). Parental bereavement and the loss of a child with intellectual disabilities. *Intellectual and Developmental Disabilities, 36*(1), 27 – 43.

Reilly, D., Huws, J., Hastings, R. & Vaughan, F. (2008b). 'When your child dies you don't belong to that world anymore' – Experiences of mothers whose child with intellectual disability has died. *Journal of Applied Research in Intellectual Disabilities, 21*(6), 546 – 560.

Rogers, C., Floyd, F., Mailick-Seltzer, M., Greenberg, J. & Hong, J. (2008). Long-Term Effects of the Death of a Child on Parents' Adjustment in Midlife. *Journal of Family Psychology, 22*(2), 203 – 211.

Rogers, C.R. (1959). A theory of therapy, personality, and interpersonal

    relationships, as developed in the client-centered framework. In S. Koch (ed.),

    Psychology: A Study of a Science, 3. Formulations of the Person and the

    Social Context. New York, NY: McGraw-Hill.

Rogers, C.R. (1980). *A Way of Being.* Boston, MA: Houghton-Mifflin.

Rogers, C.R. (1990). In H. Kirschenbaum & V.L. Henderson (Eds). *The Carl*

    Rogers Reader. London, UK: Constable.

Rupani, P. (2013) Social justice and counselling psychology training: can we learn

    from the US? *Counselling Psychology Review,* 28 (2), 30-38.

Sanders, P. (2006a). Why person-centred therapists must reject the medicalisation of

    distress. *Self and Society, 34*(3), 32 – 39.

Sanders, P. (2006b). *The Person-Centred Counselling Primer.* Ross-on-Wye, UK:

    PCCS Books.

Sexton, L. (1999) Vicarious traumatisation of counsellors and effects on their

    workplace. *British Journal of Guidance and Counselling* 27 (3)393-403

Simms, J. (2011). Case formulation within a person-centred framework: An

    uncomfortable fit? C*ounselling Psychology Review, 26*(2), 24 – 36.

Stroebe, M. & Schut, H. (2010). The dual process model of coping with

    bereavement: a decade on. *Omega: Journal of Death and Dying, 61*(4), 273 –

    289.

Stroebe, M., & Schut, H. (1999). The Dual Process Model of coping with

    bereavement: Rationale and description. *Death Studies, 23*, 197-224.

Stroebe, M., Schut, H. & Stroebe, W. (2007). Health outcomes of bereavement. *The Lancet, 370*(9603), 1960 – 1973.

Talbot, K. (2002). *What Forever Means After the Death of a Child: Transcending the Trauma, Living with the Loss.* Hove, UK: Brunner-Routledge.

Thorne, B. (1991). The quality of tenderness. In B. Thorne, *Person-centred Counselling: Therapeutic and Spiritual Dimensions.* London, UK: Whurr.

Toller, P. (2007, November). *Bereaved parents' negotiation of identity following the death of a child.* Paper presented to the Family Communication Division at the annual meeting of the National Communication Association, Chicago, IL.

Wijngaards-de Meij, L., Stroebe, M., Schut, H., Stroebe, W., van den Bout, J., van der Heijden, P. & Dijkstra, I. (2005). Couples at risk following the death of their child: Predictors of grief versus depression. *Journal of Consulting and Clinical Psychology, 73*(4), 617 – 623.

Wilkins, P. (2006). Being person-centred. *Self and Society, 34(*3), 6 – 14.

Wilkins, P. (2010). *Person-Centred Therapy: 100 Key Points.* East Sussex, UK: Routledge.

Wolsket, V. (1999). *The therapeutic use of self.* London, UK: Routledge.

Worden, W. (1991) *Grief Counselling and Grief Psychotherapy* Routledge New York pg.16

SECTION D

A Critical Literature Review

'JUST COUNSELLING PSYCHOLOGY'

A review of social justice and its place in Counselling Psychology

1 OVERVIEW

This review is designed to explore how Counselling Psychology can best support clients who, like the mothers in the study, feel they face systemic barriers in achieving just recognition, respect and treatment. It begins with an overview of current models and theories of social justice and its implications for psychological well-being. The relationship between Counselling Psychology and social justice is then considered and perceived barriers to drawing on this in practice are discussed. The review ends with the description of the model adapted by American Counselling and Counselling Psychology and explores how this may be the way forward, not only rejuvenate British Counselling Psychology's (British CoP) commitment to social justice, but also to re-establish and revitalise its unique contribution to psychology in the UK.

2. WHAT IS SOCIAL JUSTICE?

Generally, the term social justice is associated with notions of equality within the populace of any given society and, more recently, across societies (Pearce & Paxton, 2004; Widdows & Smith, 2011). However, the construct continues to lack a universally agreed definition, model or vision (Bankston, 2011; Jost & Kay, 2010) maintaining philosophical, academic and popular debate regarding the nature of equity and fairness, how a just world would look, how demands, benefits and responsibilities are defined, what achieving social justice goals might involve, and whether there is a need for particular professions, organisations or systems to service its implementation (Deneulin & Shahani, 2009; Stiglitz, Sen & Fitoussi, 2009; Tikly & Barrett, 2009).

Perhaps in some ways the lack of agreement is to be expected given the historical smorgasbord of theories and strategies that exists (Barry, 2005; Nussbaum, 2011; Sen, 2008) and the kaleidoscope through which the array of agencies, communities and commentators view what they each characteristically define as justice and injustice (Dwyer, 2000; HM Government, 2012; International Labour Organization, 2008; Miller, 2012). While space here prohibits the depth of commentary and analysis such questions deserve, there is a vast literature available to outline and discuss the various conceptualisations of social justice and its application (Capeheart & Milovanovic, 2007; Cramme & Diamond, 2009; Jost & Kay, 2010).

3. MODELS OF SOCIAL JUSTICE

In the absence of a clear definition, it seems appropriate to briefly consider the development of the concept and outline some of the foremost models representing current understanding. Burke (2011) comments on the irony that while the concept was long before established in religious and philosophical thought, the term itself is attributed to Luigi Taparelli D'Azeglio (1793-1862), who used it to defend feudal systems, arguing for a natural order in society with 'men' equal in terms of rights in respect to their humanity, but treated differently and afforded power as individuals, with disparate knowledge, character and breeding (p31). However, while initially grounded in a discourse that accepted unequal distribution of power, opportunity and commodity, over time, and with an infusion of socialist principles, social justice became synonymous with the fair distribution of resources, opportunity and treatment (HM Government, 2012; Miller & Kirkland, 2010; Robinson & Scherlen, 2008).

The work of Rawls (2001) provides a model that represents this inherent aim to redress social injustice through redistribution. Arguing against the maximum freedoms of Libertarianism and the partiality of Utilitarianism, he promotes a justice of fairness whereby, through social contract and remedial intervention, basic equalities of liberty, rights and opportunity are maintained in a way blind to historical, political and social factors. Inequalities in resource distribution would only exist if they benefitted the most disadvantaged in society. In Rawls' model, anything which disputes or disrupts these essential rights and the fair, restorative distribution of resources is socially unjust.

Miller (2004) on the other hand, advocates a pluralistic and circumstantial model with justifiable inequalities. Focussing on need and just reward, he posits a fair sharing of both benefits and burdens of society whereby citizens understand what they are due and what they owe to others. For Miller, social justice is a virtue with outcomes determined and secured within contextualised situations and relationships and achieved when every citizen profits and contributes depending on their capacity,

opportunity and effort. A society is unjust if one group is advantaged or disadvantaged more than others with equitable hardships or requirements.

The reciprocity, negotiation and contextualisation of 'fair' inequalities of Miller's approach broadens the scope of social justice concerns beyond distributive justice, into procedural justice; the preservation of equal voice, power and opportunity, and to relational and interpersonal justice; the entitlement of all to be respected, treated and valued as equals (Jost & Kay, 2010). As a consequence, concerns now stretch from issues such as food and employment to those of opportunity, quality of life, social engagement and, increasingly, to environmental and ecological concerns (Dowler & O'Connor, 2012; Greenleaf & Williams, 2009; Lucas, Walker, Eames, Fay & Poustie, 2004; Nussbaum, 2011; Raworth, 2012).

Feminist and Multicultural thought has also contributed to the debate, arguing that inequalities, their meaning and negotiation, should not be considered solely in the light of individual circumstance and misfortune but examined as consequences of systemic privilege, power and oppression. They illuminate the shaping intersectionality of multiple identities, social contexts and particular injustices in the modern world and how these can compound and mediate the experience of both oppression and privilege (Crethar, Torres-Rivera & Nash, 2008; Gill & Anitha, 2011; Malloch & McIvor, 2012; Reynolds & Constantine, 2004).

Activists posit attention must be paid to both interpersonal and macro systems which determine resources and position in order to identify and deconstruct processes which devalue, sanction or silence particular populations on the basis of, for example, their gender, sexuality or social position (Ayers, Quinn & Stovall, 2008; Craig, Gordon & Burchardt, 2008; Sheppard, 2002; Zammit, Berik & Van der Meulen Rodgers, 2008). For Feminist and Multicultural advocates, a just society is one which appreciates, accommodates and promotes diversity while injustice occurs when such diversity is used to discriminate, persecute or censure.

The notion of a subjective social justice is further developed within the Capability and Opportunity approach which, while not promoted essentially as a social justice model, does much to operationalise the current emphasis on individuality, diversity and

context (Burchardt, 2004; Clark, 2009; Nussbaum, 2004; Robeyns, 2005). The approach asserts that having particular rights, perceived as those things required to support 'capabilities', in itself is not sufficient to benefit from a just society. Instead it is suggested that the citizen must have an enabling environment to exploit their rights and capabilities in a way that allows them to achieve functionality, that is to be and to do what it is they value being and doing. The enabling environment is construed to include having choice voice, agency, resources and support that are not only adequate but appropriate to pursue goals and fulfil potential (Alkire & Deneulin, 2009; Bruni, Comim & Pugno, 2008; UNICEF, 2007).

Like Feminist and Multicultural theories, Capacity models highlight that social justice processes will be clouded by previously established notions of what is moral, fair, deserved and changeable (Miller & Kirkland, 2010, p28). For those assuming this approach, social justice is achieved in the space between the individual's capabilities and function. Conversely, social injustice occurs when, through purpose or neglect, individuals are denied the opportunities they require to fulfil their potential (Robeyns, 2008, p90).

Social injustice, then, is now viewed as structurally, relationally and contextually influenced, an individual as well as communal concern, built upon pluralities and shaped through reason and democracy (Burke, 2011; Lindgreen & Swaen, 2010; Lukes, 2005; Sen, 2008). There has been a move away from aspirations of collective concord and generic remedy towards giving credence to multiple perspectives and meaning. So, while there is the understanding that established institutions such as civic government continue to influence and shape social action, the spotlight also falls on first level instrumental relationships which facilitate individual and collective awareness and self determination in social justice issues (Beck 2012; Miller, 2001, p11; Pearce & Paxton, 2004; Rocco & Suhrcke, 2012; Van der Walt & Potgieter, 2011).

In light of this, social justice will be defined in this paper as:

... a dynamic virtue focused on common interest, which is taken to include the good of the individual as well as the good of humanity at large. This common good is

*dependent on a fair and ongoing distribution of benefits and responsibilities in society
and is based on the integrative application of the principals of equity, access,
participation, and harmony* (Crethar, 2004, p7).

4 SOCIAL INJUSTICE AND PSYCHOLOGICAL DISTRESS

Prilleltensky (1999) declares:

*Psychological problems do not exist on their own, nor do they come out of thin air;
they are connected to people's social support, employment status, housing conditions,
history of discrimination, and overall personal and political power...promoting
complete health means promoting social justice for there cannot be health in the
absence of justice* (p99).

There is general acceptance of a health gradient associating poor mental and physical
well being to social injustices in everyday life experiences (Egan, Tannahill, Petticrew
& Thomas, 2008; Graham, 2007; Marmot Review, 2010).   Evidence suggests for
example, that experiences of impoverished housing and homelessness (Broussard,
2010; Stafford & McCarthy, 2006), poverty (Theodossiou & Zangelidis, 2009) and
unemployment (Office of National Statistics, 2004, p6; Thomas, Benzeval &
Stansfeld, 2007), as well as fractures in equal citizenship arising out of social position
and exclusion (Gamarel, Reisner, Parsons & Golub, 2012; Singh, Marcus, Rabbatts &
Sherlock, 2012) all have negative and detrimental effects.

One major contribution to the understanding of the psychological consequences of
distributive inequalities lies in the literature around stress. The suggestion is that, as a
survival orientated response, stress will be elevated when individuals or groups
experience barriers or threats to their basic needs, development or personal integrity
(Friedli, 2009; National Institute for Health and Clinical Excellence, 2007; Sapolsky,
2004; Steptoe, 2005). Further, Christopoulos, Crosier, McVey, Bell and Porritt (2009)
and Lynch, Smith, Kaplan and House (2000), purport evidence that suggests even
relative deprivation, such as the 'fair' differences described by Miller, may be
negatively internalised as unjust, generating pessimism, anger or resentment. As

described earlier, others draw attention to the limited explanatory power distributive justice holds in relation to wellness (Mirowsky & Ross, 2003). They instead argue that given the influences of race, gender, education, age, environmental and social contexts on mental health for example, oppressive, discriminatory and stigmatising procedural and relational experience must also be implicated (Almeida, Dolan-Del Vecchio & Parker, 2007; Ballou & Brown, 2002; Bowleg, 2012; Clay-Warner, 2001).

While Friedli (2009) highlights the 'invisible' barriers such processes pose for growth and well-being, others propose they also generate a 'social pain' and point to the broad body of literature exploring the internalisation of negative social experiences and their impact on identity (Albee & Joffe, 2004; Christopoulos et al., 2009; Scheier, Carver & Bridges, 2001; Smart-Richman & Leary, 2009; Teti, Bowleg & Lloyd, 2010). Other work has illuminated how such painful effects may be transmitted inter-generationally resulting in harmful behaviours and psychological distress of those who did not experience the injustice but whose lives nevertheless carry the scars (Calma, 2005; Duran, Firehammer & Gonzalez, 2008; Kabeer, 2011).

5. SOCIAL JUSTICE AND COUNSELLING PSYCHOLOGY

Mirowsky and Ross (2003) argue that there would be no need to address social justice issues if "the poor, powerless and despised were as happy and fulfilled as the wealthy, powerful and admired" (p3). That they are not challenges us to attend to such concerns in order to comprehend and eliminate associated psychological suffering. Counselling Psychology has evolved from such pursuits (Fouad, Gerstein & Toporek, 2006; Milton, Craven & Coyle, 2010, p66). In utilising psychological theory and focussing on relational processes it has enshrined social justice as a defining feature so that the Division of Counselling Psychology's Practice Guidelines require practitioners to:

… recognise social contexts and discrimination and to work always in ways that empower rather than control and also demonstrate the high standards of anti-discriminatory practice appropriate to the pluralistic nature of society today (British Psychological Society (BPS), 2005, p2).

... challenge the views of people who pathologise on the basis of such aspects as sexual orientation, disability, class origin or racial identity and religious and spiritual views (BPS, 2005, p7).

... consider at all times their responsibilities to the wider world. They will be attentive to life experience, modes of inquiry and areas of knowledge beyond the immediate environs of counselling psychology and seek to draw on this knowledge to aid communication or understanding within and outside of their work (BPS, 2005, p7).

Unsurprisingly then, Counselling Psychology has much in common with the principles, values and ideologies that underpin current social justice models (Cooper, 2009; Kanellakis, 2009; Moller, 2011). The perception of the conscious, reflective individual and an emphasis on the subjective meaning making between them, their relationships and society, nestles distress, wellness and recovery within the dynamics of their engagement with the world (Cooper, 2009; Health & Care Professions Council (HCPC), 2012, p28; Kinderman, 2009; Milton, 2011). Further, Counselling Psychology embraces equality, diversity and difference, facilitating feminist and multicultural orientations, while its focus on well-being, strength, resilience and empowerment echo the ideologies and practice of the Capacity and Development models currently making their mark within the literature (Eleftheriadou, 2010; Hutchinson & Pretelt, 2010; Milton et al., 2010).

Moreover, Counselling Psychology views justice not only as a desired social outcome for clients but as part of the therapeutic alliance itself (Caldwell, 2008; Chi-Yi Chung & Bemak, 2011; Sue & Sue, 2007). For example, the client is asserted as the authority on their own experience with the practitioner not assuming "the automatic superiority of any one way of experiencing, feeling, valuing and knowing" (BPS, 2005, p2; HCPC, 2012, p6). Similarly, practitioners are charged to remain mindful that their own social experiences will afford particular values and allegiances that may result in power imbalances, oppressive dogma and social positioning entering the therapeutic relationship (BPS, 2009, p22; HCPC, 2012, p8). While individual therapy, personal development groups in training and supervision in practice underpin the commitment to this kind of reflective practice (Moore & Rae, 2009), it is recognised

that even with precaution, no alliance will be value free and therapists are called upon to establish their own personal "social justice compass" (Lee, 2007, p2).

One example of the influences of the social justice agenda in Counselling Psychology can be seen in its understanding of psychological distress itself. It has been argued, for example, that dominant medical models, institutionalised within UK mental health services, generate unhelpful narratives around individual inadequacy that allow the negative impact of social injustices to go unchallenged (Biggs, 2010; Boyle, 2007; Galbraith & Galbraith, 2008; Joseph, 2007). Counselling Psychologists dispute such models, instead conceptualising mental suffering and distress, not as pathology but grounded in legitimate survival responses to the challenges and barriers that arise in relating to the social world (Larsson, Brooks & Loewenthal, 2012; Woolfe & Strawbridge, 2010). They point to how such constructions are used to establish social capital for the well, stigmatise help seeking and contribute to further injustice by way of discrimination and disadvantage that, for example, reduces social integration and employment opportunities to the individual and their family (Biggs, 2010; Department of Health, 2003; Dillon, 2011; Mason, Carlisle, Watkins & Whitehead, 2001; MIND, 2007).

For Counselling Psychology then, poor mental health at once becomes a consequence of social injustice and a social injustice in itself: both aspects being equally important to any intervention.

6. THE SOCIAL JUSTICE AGENDA IN BRITISH COUNSELLING PSYCHOLOGY

Despite a recognition of the need some time ago (Milton & Legg, 1999; Strawbridge, 1994), it would appear that British CoP has yet to effectively incorporate its social justice agenda into practice. For example, at the time of writing, a search using the term 'Social Justice' within the Divisions journal, The Counselling Psychology Review (CPR), offered no results. Further scrutiny of 165 items from the past two years of CPR revealed only one paper, Edge & West (2011) that could be seen to be promoting, albeit an unidentified, intervention informed by social justice principles. An additional primary search of The Psychologist, revealed only three occasions when

the phrase social justice was identified in relation to an article or research (MacKay, 2008; Webster & Robertson, 2007; Wilkinson & Kitzinger, 2005). It is also worth noting that Community Psychology, traditionally endowed with a social justice prospectus, has only had a BPS special section since 2010. While such findings raise questions with regard to the position of social justice in UK psychology generally, they have particular implications in respect to Counselling Psychology, which declares social justice as a guiding principle.

Moller (2011) declares that the failure of British CoP to fulfil such social commitments results from attaching too rigidly to humanistic and phenomenological philosophies. She believes this has generated an insularity which has stunted the growth of the discipline and its ideals by reducing employability, weakening research validity and rendering British CoP politically ineffectual. Moller is not alone in her observations regarding the lack of development, application and dissemination of the social justice underpinnings of British CoP, however others interpret her perceived consequences somewhat differently.

For instance, there is some agreement that the desire for employability has influenced the shape and content of British CoP practitioner training (Douglas & James, 2010; Mollen, 2009) with most courses now Doctoral level and sharing many competencies with Clinical Psychology (HCPC, 2012; Kinderman, 2009; Larsson et al., 2012; Martinelli, 2010). However, rather than be a positive for the discipline, some believe, the 'professionalisation' of Counselling Psychology, the blurring of speciality lines and the teaching of approaches not necessarily akin to its core philosophy, may weaken the group's values and challenge established practice (Clarkson, 1998, p7; Hammersley, 2009; Ward, Hogan & Menns, 2011) leaving practitioners in an epistemologically "uncomfortable place" (Bellamy, 2003, p2).

Other observers comment on how employment contexts themselves may reduce opportunity for Counselling Psychologists to apply their understanding of social influences. The "streamlining" of workforce training and services, professional isolation and the predominance of the medical model may lead practitioners to use a language and approach quite alien to their roots (Blair, 2010; James & Bellamy, 2010, p413; Larsson et al., 2012; Moore & Rae, 2009). Further, it is argued that employing

institutions such as the National Health Service and Her Majesty's Prisons are increasingly shaped by political and economic agendas that disguise or ignore social content, thus locking practitioners into the dominant discourses Counselling Psychology evolved to dispel (James, 2009, p65; Rafalin, 2010; Strawbridge & Woolfe, 2009).

Thus, while the voice of counselling psychologists may be silenced and their socially based model lost, this may not be because they adhere too rigidly to their epistemological roots as Moller (2011) suggests, but because their allegiance to them has not been strong enough to resist the 'in group' (Cooper, 2009; Moore & Rae, 2009; Orlans & Van Scoyoc, 2009).

Moller's second criticism around research is echoed by Kasket & Gil-Rodriguez (2011) who remonstrate that "uncertainties and debates around Counselling Psychology's identity, distinctiveness and contribution have affected research" (p20). Again, their argument is the reverse of Moller's in that they believe trainees' lack of knowledge and application of the core principles of Counselling Psychology resulting in "confusion, anxiety and crisis of identity" (p21), that often leads to research that offers little development of the discipline's unique approach, something previously recognised a decade ago (Strawbridge, 2003).

Such argument contrasts sharply to the research of Moore and Rae (2009), who suggest interviewed Counselling Psychology trainees celebrated themselves as non-conformist Outsiders/ Mavericks, who challenged established practice and constructs, in a way previously likened to the rebellious adolescent (Strawbridge, 1992; Woolfe, 2006). The authors note that maintaining such an identity and approach may be easier in training than when trying to gain employment or fitting into a team. Like Moller, they also notion that identity issues impede practitioners in the workplace. However, again, in contrast to her argument of rigidity, they suggest that in drawing on a mix of often contrasting epistemologies and methods, for example embracing both the scientist and reflexive practitioner models (BPS, 2005, p1) and in 'attempting to span different world views', what Counselling Psychologists do and stand for is not always understood. The diversity and pluralism of the approach in practice they suggest, may

well work against British CoP, diminishing its position and reducing the power capital upon which it might exploit the social justice model (Rizq, 2006).

It is interesting to note that thirty years ago, one of the founding members of the division, Sheelagh Strawbridge (1992) fretted that she might not like Counselling Psychology when it reached mature adulthood. Similarly, Milton's (2011) response to Moller has a sense of looking back to the 'early days'. Perhaps there is something in the notion that individuals attracted to British CoP recognise its social justice identity and sense of mission, but lose the vibrancy and conviction of youth in a lived practitioner reality (Blair, 2010; Kasket, 2012; Rafalin, 2010; Rizq, 2006). Such analysis would seem to spotlight the need for a particular vehicle through which British CoP could preserve its youthful commitment to social justice, resist deconstruction and represent its unique beliefs and values more robustly in the real world. Moller (2011) posits, the Multicultural Social Justice Counselling and Advocacy Model advanced by American Counselling Psychology in the last decade, has the potential to fulfil such requirements.

7. SOCIAL JUSTICE AS A THERAPEUTIC PARADIGM

Social justice counselling is said to augment humanistic and phenomenological traditions by drawing on constructionist, liberation and critical community theory, building on the argument that issues of power, privilege and oppression generate unfair social barriers that underpin psychological distress and recovery (Goodman et al., 2004a; Lillis, O'Donohue, Cucciare & Lillis, 2005; Smith, Reynolds & Rovnak, 2009; Sue & Sue, 2007). The movement argues that whilst there is a general acceptance of such links in psychology and counselling, traditional practice fails to challenge them (Fouad et al., 2006; Smith, Baluch, Bernabei, Robohm & Sheehy, 2003; Vera & Speight, 2007).

Further, it is suggested that in expecting individuals to adapt and cope with the injustices of their social world, practitioners support the forces that perpetuate them *(*Albee, 2000, p248; Joseph, 2007*; Prilleltensky & Prilleltensky, 2005, p89). Social Justice counselling, while holding fast to the strength based ideals of humanistic approaches, seeks also to address unfair constraints in society, thus enmeshing "the

role of healer with social change agent" (Moe, Perera-Diltz & Sepulveda, 2010, p106). The operationalisation of social justice counselling is underpinned by advocacy (Lewis, Toporek & Ratts, 2010, p4) and social action (Crethar et al., 2008, p274) so that Vera & Speight (2007) suggest "[a] commitment to social justice requires a redefinition of our roles to include advocacy and other forms of social action-orientated intervention" (p374).

Hunsaker (2008), although writing to dispute its relevance, outlines the aims of the model well: "a doctrine of counsellor as activist, it exhorts counsellors and therapists to leave their offices, de-emphasize individual psychotherapy and become lobbyists for special interest groups" (p1).

Those who uphold the approach argue that counselling practice has always been concerned with social change (Hof, Dinsmore, Barber, Suhr & Scofield, 2009; Ratts, 2009) and any paradigm shift comes from addressing "equity, access, participation and harmony" (Crethar et al., 2008, p270) not only with the client, but through community, systems and socio-political action (Chi-Yi Chung & Bemak, 2011; Vera & Speight, 2007). Thus, Almeida et al (2007) suggest the social justice model offers "a reformulation of service delivery system and process of therapy in an effort to make therapy the journey of liberation and healing instead of a journey toward renewed compliance and acquiescence to society's everyday oppressive expectations" (p179).

The underpinning philosophies and principles of the approach still mean an individual approach. However, there is a move way from a neutralising "remedial, medical model" towards the development of critical consciousness (Vera & Speight, 2007, p373). Thus, the client becomes aware of the influence of social, economic and political context on their well being, liberating them from notions of pathology and empowering them to address the issues at the core of their distress (Goodman et al., 2004a, p804). Therapists too are challenged to assert a critical consciousness of their own socio-political context and their "taken-for-granted realities about how the way the world operates" (Almeida et al., 2007, p186).

Social justice advocates reason that sustainable client well-being cannot be attained within the therapy room (Arredondo, Tovar-Blank & Parham, 2008).   Thus a cornerstone of social justice counselling is an onus, indeed a professional and moral 'imperative' for practitioners not only to acknowledge but actively address the social injustice befallen on their client (Lee, 2007).   As a consequence, therapists move outward beyond a sole focus on the clients' inner lives, to purposefully attend to the negative impacts of the social systems within which they live (Aldarondo, 2007; Toporek, Gerstein, Fouad, Roysircar-Sodowsky & Israel, 2006).   So practitioners work in clinical, community, civic and political arenas and are encouraged to personally serve the community in their efforts towards change (Fouad et al., 2006; Greenleaf & Bryant, 2012, p18).   It is perhaps this shift from the micro to the macro that sets the approach apart and identifies social justice counsellors, psychologists and other mental health workers as social advocates.

Research is also seen as an essential element of the approach, both as a means to illuminate and address social injustice.   However, the research process itself is considered to have the potential to be unjust.   Questions are raised about the objectivity, purpose and power within empirical enquiry and how communities may be affected by the outcomes (Craig et al., 2008; Goodman et al., 2004a). Goodman et al (2004a) suggest following particular process principles that implicitly address such concerns.   These involve on-going researcher self-examination, the need to share power with participants, giving voice, raising consciousness, a focus on strengths and finally the need to leave the tools of self-determination with those who have been involved**.**

Perhaps a suitable example of the social justice approach might be the support of those who experience domestic violence.   While individual therapy may be useful, it also has the potential to promote victim and blame narratives, locates solution and change within the abused and fails to address the part played by oppressive discourses and social injustices (Alhabib, Nur & Jones, 2010). Taking the issue into the social world has not only facilitated understanding of the nature and causes of abuse, it has generated awareness of hitherto silent groups of male and elderly victims (Simmons, Lehmann & Collier-Tension, 2008; World Health Organization, 2008). In this instance, social justice practice might involve utilising a preferred model to attend to

previously unresolved trauma and anxiety within the client, developing self-advocacy, choice and assertiveness, challenging dominant discourses in a culturally and power sensitive way through self help and community groups and becoming involved in academic or action research to inform practice and understanding and to challenge dominant discourses within the profession and wider society.

The development of the social justice approach in America has been underpinned by training, supervision and leadership (Toporek et al., 2006). Specific training is considered especially vital in developing the understandings, competencies and strategies required for practice (Odegard & Vereen, 2010; Ratts & Wood, 2011; Toporek, Lewis & Crethar, 2009). Components are considered to include affective, intellectual and skill based learning (Bemak, Chi-Ying Chung, Talleyrand, Jones & Daquin, 2011; Vera & Speight, 2007). This will include raising trainee awareness of personal privilege and oppression via 'dialectical meaning making' activity akin to Freire's (1974, p132) decoding process. While potentially a painful process, it is thought essential in growing motivation and confidence in applying social justice principles in practice (Chang, Crethar & Ratts, 2010; Manis, 2012; Murray, Pope & Rowell, 2010).

Skills and strategies are also purposively taught and practiced in order to move the model from the abstract into the real world (Ali, Liu, Mahmood & Arguello, 2008; Vera & Speight, 2007). These are developed through in situ experience with trainees having opportunities to apply and develop their advocacy, outreach and preventative work within communities and organisations that suffer or address social injustice (Almeida et al., 2007; Dickson & Jepsen, 2007; Goodman et al., 2004a). In this way, the trainee meets their own resistance, facilitated to reconceptualise client issues in terms of social factors and enabled to develop meaningful community relationships (Chang, Hays & Milliken, 2009). Research projects in training are also generated from a social justice perspective (Goodman, Laing, Weintraub, Helms & Latta, 2004b; McWhirter & McWhirter, 2007).

Supervision that allows the "fusion of scholarship and activism" (Lewis, Ratts, Paladino & Toporek, 2011, p5) is percieved to be a lynch pin in the successful application of the approach. Thus supervision is not only utilised to identify and

manage social justice issues in the formulation and process of therapy, it is also designed to help the committed supervisee integrate their personal world view, professional identity, therapeutic role and social agent function (Chang et al., 2009). Supervision is further viewed as a means to mindfully reframe traditional practices and support excursions into novel, multi-level social action activities for those who are novice. This may be particularly important as practitioners adapt to the differences in the quality and nature of the therapeutic relationship (Almeida et al., 2007, p185; Falendar & Shafranske, 2004; Glosoff & Durham, 2010).

Leadership too is seen to have a duality of purpose in promoting social justice as a goal within the discipline and in providing a bridge between practitioners and policy makers (Constantine, Hage, Kindaichi & Bryant, 2007; Fox, 2003; Kiselica, 2004). Leaders therefore function as advocates not only in terms of those who suffer (Hof et al., 2009), but also in promoting the ideologies and principles of the social justice model in public, professional and legislative forums (Myers, Sweeney & White, 2002). Arredondo and Rosen (2007) highlight the importance of leaders modelling the principles of social justice as they work and offer Spears' (1998) ten characteristics of the 'servant leader'; listening, empathy, healing, awareness, persuasion, conceptualisation, foresight, stewardship, commitment to the growth of people and building community to depict the quality of the role.

8. LEARNING FROM THE AMERICAN EXPERIENCE

It could be argued that, given previous discussion regarding the philosophical commonalties between Counselling Psychology and social justice theory, there would be little difficulty in including social justice advocacy as part of the curriculum of British CoP training, as a research model and as a framework through which practitioners could utilise their preferred approach. However, any plan to develop the greater application of the social justice agenda within British CoP will have to address the criticisms already levied in the US (Nelson-Jones, 2002; Smith et al., 2009; Weinrach & Thomas, 2004).

For example, Kiselica (2004) suggests that social justice work brings its own challenges in employability. For example, she suggests those who work in social

justice initiatives are often not in full employment nor economically compensated to the same level as those who maintain more traditional practice, that some social actions may be seen to breach ethical and professional guidelines and that the financial and institutional support for social justice research may not be forthcoming.

A further highlighted difficulty is resistance to the ways of working expected within the model. Smith et al (2009) suggest that while therapists may be mindful of the social content of their clients' difficulties, the notion that social justice work should be a 'duty' bestows too heavy a burden of responsibility and accountability on practitioners who have not personally generated the injustice. Further, pursuing high visibility, politically enmeshed challenges may make practitioners in some contexts feel particularly vulnerable (Moore & Rae, 2009).

It is also suggested that an idealised objectivity and neutrality may lead some sections to resist asserting their personal ideologies or to advocate for one set of circumstances over another (Parikh, 2011; Smith, Ng, Brinson & Mityagin, 2008). It is argued that mandating practitioners to do so could be viewed as oppressive in itself (Canfield, 2008). Further, there is a recognition of the potential for elitism and privilege should such splits occur as those most strongly committed will be viewed as principled and altruistic, while those who resist, who prefer to change the world 'one person at a time' or who sit within the parameters of the dominant group may be marginalised, reduced in status or even considered in favour of the injustice (Johnson, 2010).

A related concern is that the ideologies and debates of the movement reflect academic and political rather than clinical concern (Canfield, 2008; Hunsaker, 2008; Lockhard & Stack, 2008). It is argued that these are generated in a vacuum and infuse the therapeutic literature with politicised doctrines and language around "rights, equality and isms" that contrast sharply with those of growth and resilience traditionally used (Mirowsky & Ross, 2003, p4; Smith et al., 2009, p485). Others have raised questions about who determines what is malevolent or just, who influences, monitors and controls social justice work delivered in the name of Counselling Psychology and how such action is prevented from being the imposition of one particular value base or supposition of being "the one who knows how to emancipate the oppressed" (Kiselica, 2004, p848).

A further challenge is the perception that the model undermines the proven helpfulness of therapy as it is traditionally understood (Moe et al., 2010; Newbury & Hoskins, 2012; Raskin, Bridges & Neimeyer, 2010, p253; Smith et al., 2009). Advocates point out that Social Justice could never be the only meaningful or appropriate intervention available to Counselling Psychologists, since, even in a just world, people will continue to experience personal distress. Likewise, the suggestion that the client remains a helpless victim until their world changes contradicts the ethos of individual potential in Counselling Psychology, while motivating the client to change their world without the resources or means to do so is equally questionable (Lewis et al., 2011; Newbury & Hoskins, 2012).

Promoting the notion that traditional therapeutic contexts can be used to develop individual critical consciousness of social processes may alleviate the kind of tensions experienced across the Atlantic, while training, supervision and leadership can be used to disseminate understanding and confidence to apply the model in broader contexts (Almeida et al., 2007, p185; Glosoff & Durham, 2010).

9. CONCLUSION

Social Justice has never been part of the mainstream of our society. Rather it is furthered by the courageous and inventive work of those willing to risk upsetting 'business as usual' in order to promote the making of a more just world (Almeida et al., 2007, p186).

Whether or not British CoP can rise to the challenge of re-establishing its social justice agenda remains to be seen (Farhy & Milton, 1998). This paper suggests that if it is to develop, the pitfalls experienced in America could be managed through a committed network of leaders, supervisors and trainers who can expand and disseminate social justice activity within British CoP.

Notice has already been taken of oppressive or marginalising practices and attitudes which have served to silence, devalue and marginalise Counselling Psychology, even within those institutions which declare support. This may be seen in financially

inequitable training pathways (Nowill, 2011), failure to include the discipline as part of the family of psychology (Coe, 2011; Davey, 2011; Douglas, 2011) and discriminatory employment advertising, even when extolling the worth of the discipline itself (Florance, 2012).

It may be that, in the same way as it aims to do with clients, a social justice approach could liberate British CoP in its entirety. It could, for example, offer a deeper understanding of the personal commitments of being a Counselling Psychologist, develop a sense of community within the discipline, raise consciousness of professional as well as personal injustices and empower practitioners to assert their principles and practices more forthrightly. Further, the model could be used to assert the validity of pluralism, of qualitative research and increase political influence through improved relevance, broader dissemination and increased dialogue between communities, researchers and policy makers.

Perhaps, in reviving the social justice mantle, British Counselling Psychology can progress from rebellious adolescent to the confident, risk taking adult Moller sees in its American cousin and of which Strawbridge would be proud.

Postscript

It is exciting to note that the Counselling Psychology Review (June 2013), produced at the time of final drafting of this portfolio contained a number of articles and references to social justice (Cutts 2013; Hore 2013; Rupani 2013). Cutts' article (pg. 8) outlines some of the points highlighted in this review, alongside three main issues that create barriers to growing social justice work –training, private practice and employment in the NHS. However, the conceptualisation of the nature of social justice is very limited and not strongly linked to the philosophies or practices of Counselling Psychology. While it is good to know that there are others of the same mind working to generate an interest in the place of social justice in British Counselling Psychology, it is somewhat disappointing that the emphasis is on what we as practitioners might have to give up to buy into the social justice approach. Hore's paper (pg.17), offers a much more dynamic approach that recognises what we could do and who we could do it with, in order to address social injustices such as homelessness. Rupani (pg. 30) &

Harrison (pg. 107) both draw theory into the practice of training and therapy respectively and robustly challenge practitioners to consider how a social justice agenda can be included in everyday practice. While rather frustrated that my own paper did not lead the way, I anticipate very stimulating and challenging times ahead and I look forward to it enormously.

References

Albee, G.W. (2000). The Boulder model's fatal flaw. *American Psychologist, 55,* 247 – 248.

Albee, G.W. & Joffe, J.M. (2004). Mental illness is NOT "an illness like any other". *The Journal of Primary Prevention, 24*, 419 – 436.

Aldarondo, E. (Ed.). (2007). *Advancing social justice through clinical practice.* Mahwah, NJ: Lawrence Erlbaum Associates Inc.

Alhabib, S., Nur, U. & Jones, R. (2010). Domestic Violence Against Women: Systematic Review of Prevalence Studies. *Journal of Family Violence, 25*(4), 369 – 382.

Ali, S.R., Liu, W.M., Mahmood, A. & Arguello, J. (2008). Social Justice and Applied Psychology: Practical Ideas for Training the Next Generation of Psychologists. *Journal for Social Action in Counseling and Psychology, 1*(2), 1 – 13.

Alkire, S. & Deneulin, S. (2009). The Human Development and Capability Approach. In S. Deneulin & L. Shahani. *An Introduction to the Human Development and Capability Approach: Freedom and Agency.* London, UK: Earthscan.

Almeida, R., Dolan-Del Vecchio, K. & Parker, L. (2007). Foundation Concepts for Social Justice Based Therapy: Critical Consciousness, Accountability and Empowerment. In E. Aldarondo (Ed). *Promoting Social Justice Through Mental Health Practice.* Mahwah, NJ: Lawrence Erlbaum Associates.

Arredondo, P. & Rosen, D.C. (2007). Applying principles of multicultural competencies, social justice, and leadership in training and supervision. In E. Aldarondo (Ed), *Advancing social justice through clinical practice.* Mahwah, NJ: Lawrence Erlbaum Associates.

Arredondo, P., Tovar-Blank, Z.G. & Parham, T.A. (2008). Challenges and promises of becoming a culturally competent counsellor in a socio-political era of change and empowerment. *Journal of Counseling and Development, 86*(3), 261 – 268.

Ayers, W.C., Quinn, T. & Stovall, D. (2008). *Handbook of Social Justice in Education.* New York, NY: Taylor & Francis Inc.

Ballou, M. & Brown, L.S. (Eds.). (2002). *Rethinking mental health and disorder: Feminist perspectives.* New York, NY: Guilford Publications.

Bankston, C.L. (2011). Social Justice: Cultural Origins of a Perspective and a Theory. *The Independent Review: A Journal of Political Economy, 15*(2), 165 – 178.

Barry, B. (2005). *Why Social Justice Matters.* Oxford, UK: Polity Press.

Beck, E. (2012). Transforming Communities: Restorative Justice as a Community Building Strategy. *Journal of Community Practice, 20*(4), 380 – 401.

Bellamy, A. (2003). Editorial. *Counselling Psychology Review, 18*(1), 2.

Bemak, F., Chi-Ying Chung, R., Talleyrand, R.M., Jones, H. & Daquin, J. (2011). Implementing multicultural social justice strategies in counselor education training programs. *Journal for Social Action in Counseling and Psychology, 3,* 29 – 43.

Biggs, S. (2010). Assessed Unit 4: An academic paper which examines the meaning and implications of anti-discriminatory practice in counselling psychology. *Counselling Psychology Review, 25*(3), 25 – 31.

Blair, L. (2010). A critical review of the scientist-practitioner model for counselling psychology. *Counselling Psychology Review, 25*(4), 19 – 30.

Bowleg, L. (2012). The problem with the Phrase Women and Minorities: Intersectionality – An Important Theoretical Framework for Public Health. *American Journal of Public Health, 102*(7), 1267 – 1273.

Boyle, M. (2007). The problem with diagnosis. *The Psychologist, 20*(5), 290 – 295.

The British Psychological Society. (2005). *Division of Counselling Psychology: Professional Practice Guidelines.* Leicester, UK: British Psychological Society.

The British Psychological Society. (2009). *Code of Ethics and Conduct: Guidance published by the Ethics Committee of the British Psychological Society.* Leicester, UK: British Psychological Society.

Broussard, C. (2010). Research Regarding Low-Income Single Mothers' Mental and Physical Health: A Decade in Review. *Journal of Poverty, 14*(4), 443 – 451.

Bruni, L., Comim, F. & Pugno, M. (2008). *Capabilities and Happiness.* Oxford, UK: Oxford University Press.

Burchardt, T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. *Disability and Society, 19*(7), 735 – 751.

Burke, T.P. (2011). *The Concept of Justice: Is Social Justice Just?* New York, NY: Continuum Publishing Corporation.

Caldwell, L.D. (2008). Counseling with the Poor, Undeserved, and

Underrepresented. In C.M. Ellis & J. Carlson, *Cross Cultural Awareness and
Social Justice in Counseling*. London, UK: Routledge.

Calma, T. (2005). *Social Justice Report 2005: Aboriginal and Torres Strait Islander
Social Justice Comissioner.* Sydney, Australia: Human Rights and Equal
Opportunity Commission.

Canfield, B.S. (2008). Valuing diversity of thought. *Counseling Today, 50*(7), 5.

Capeheart, L. & Milovanovic, D. (2007). *Social Justice: Theories, Issues and
Movements.* New Brunswick, NJ: Rutgers University Press.

Chang, C.Y., Crethar, H.C. & Ratts, M.J. (2010). Social justice: A national
imperative for counselor education and supervision. *Counselor Education and
Supervision, 50*(2), 82 – 87.

Chang, C.Y., Hays, D.G. & Milliken, T. (2009). Addressing social justice issues in
supervision: A call for client and professional advocacy. *The Clinical Supervisor,
28,* 20 – 35. doi: 10.10 80/07325220902855144.

Chi-Yi Chung, R.C. & Bemak, F.P. (2011). *Social Justice Counseling: The Next
Steps Beyond Multiculturalism.* Thousand Oaks, CA: SAGE Publications Ltd.

Christopoulos, A., Crosier, A., McVey, D., Bell, R. & Porritt, F. (2009). *Some are
more equal than others ...: Public attitudes to health inequalities and social
determinants of health.* Retrieved from
http://www.consumerfocus.org.uk/files/2012/09/Some_are_more_ equal-
_than_others.pdf.

Clark, D.A. (2009). Adaptation, Poverty and Well-Being: Some Issues and Observations with Special Reference to the Capability Approach and Development Studies. *Journal of Human Development and Capabilities, 10*(1), 21 – 42.

Clarkson, P. (1998). Counselling psychology: The next decade. In P. Clarkson, *Counselling Psychology: Integration of Theory, Research, and Supervised Practice.* London, UK: Routledge.

Clay-Warner, J. (2001). Perceiving procedural injustice: The effects of group membership and status. *Social Psychology Quarterly, 64*(3), 224 – 238.

Coe, C. (2011). Counselling psychology needs to take its 'proper' place. *The Psychologist, 24*(8), 559.

Constantine, M., Hage, S., Kindaichi, M. & Bryant, R. (2007). Social justice and multicultural issues: Implications for the practice and training of counselors and counseling psychologists. *Journal of Counseling and Development, 85*, 24 – 29.

Cooper, M. (2009). Welcoming the Other: Actualising the humanistic ethic at the core of counselling psychology practice. *Counselling Psychology Review, 24*(3 & 4), 119 – 129.

Craig, G., Gordon, D. & Burchardt, T. (2008). *Social Justice and Public Policy: Seeking Fairness in Diverse Societies.* Bristol, UK: The Policy Press.

Cramme, O. & Diamond, P. (2009). *Social Justice in a Global Age.* Cambridge, UK: Polity.

Crethar, H.C. (2004). A Definition of Social Justice. *CSJ Activist, 5*(1), 7.

Crethar, H.C., Torres-Rivera, E. & Nash,S. (2008). In Search of Common Threads: Linking Multicultural, Feminist, and Social Justice Counseling Paradigms. *Journal of Counseling and Development, 86*(3), 269 – 278.

Davey, G. (2011). *Applied Psychology.* West Sussex, UK: John Wiley & Sons Ltd.

Deneulin, S. & Shahani, L. (2009). *An Introduction to the Human Development and Capability Approach: Freedom and Agency.* London, UK: Earthscan.

Department of Health. (2003). *Tackling Health Inequalities: A programme for action.* London, UK: HMSO.

Dickson, G.L. & Jepsen, D.A. (2007). Multicultural training experiences as predictors of multicultural competencies: Students' perspectives. *Counselor Education and Supervision, 47*, 76 – 95.

Dillon, J. (2011). The Personal is Political. In M. Rapley, Moncrieff, J. & Dillon, J. (Eds), *De-Medicalising Misery Psychiatry, Psychology and the Human Condition.* New York, NY: Palgrave Macmillan.

Douglas, B. (2011). Don't forget counselling psychology. *The Psychologist, 24*(7), 476.

Douglas, B. & James, P. (2010). QCoP: The independent route in counselling psychology. *Counselling Psychology Review, 25*(3), 7 – 9.

Dowler, E.A. & O'Connor, D. (2012). Rights-based approaches to addressing food poverty and food insecurity in Ireland and UK. *Social Science and Medicine, 74*(1), 44 – 51.

Duran, E., Firehammer, J. & Gonzalez, J. (2008). Liberation Psychology Healing Cultural Soul Wounds. *Journal of Counselling & Development, 86*, 288 – 295.

Dwyer, P. (2000). *Welfare Rights and Responsibilities: Contesting Social Citizenship.* Bristol, UK: The Policy Press.

Edge, D. & West, W. (2011). Mental Health and 'The Big Society': Where do counselling psychologists and therapists fit in? *Counselling Psychology Review, 26*(2), 17 – 23.

Egan, M., Tannahill, C., Petticrew, M. & Thomas, S. (2008). Psychosocial risk factors in home and community settings and their associations with population health and health inequalities: A systematic meta-review. *BMC Public Health, 8,* 239.

Eleftheriadou, Z. (2010). Cross-cultural counselling psychology. In R. Woolfe, S. Strawbridge, B. Douglas & W. Dryden (Eds.), *Handbook of counselling psychology* (3rd Ed.). London, UK: Sage Publications Ltd.

Falendar, C.A. & Shafranske, E.P. (2004). Clinical supervision: A competency-based approach. Washington, DC: American Psychological Association.

Farhy, E. & Milton, M. (1998). Psychology, psychotherapy and paymasters: A cautionary tale. *Counselling Psychology Review, 13*(1), 35 – 38.

Florance, I. (2012). Opening up possibilities. *The Psychologist, 25*(5), 382 – 385.

Fouad, N.A., Gerstein, L.H. & Toporek, R.L. (2006). Social justice and counseling psychology in context. In R.L. Toporek, L.H. Gerstein, N.A. Fouad, G. Roysircar

& T. Israel (Eds.), *Handbook for social justice in counseling psychology: Leadership, vision and action*. Thousand Oaks, CA: Sage Publications Inc.

Fox, D. (2003). Awareness is good but action is better. *The Counseling Psychologist, 31*, 299 – 304.

Friedli, L. (2009). *Mental health, resilience and inequalities*. Copenhagen, Denmark: World Health Organization.

Freire, P. (1974). *Education for critical consciousness*. New York, NY: Continuum.

Galbraith, V.E. & Galbraith, N.D. (2008). Should we be doing more to reduce stigma? *Counselling Psychology Review, 23*(4), 53 – 61.

Gamarel, K.E., Reisner, S.L., Parsons, J.T. & Golub, S.A. (2012). Association Between Socioeconomic Position, Discrimination and Psychological Distress: Findings From a Community-Based Sample of Gay and Bisexual Men in New York City. *American Journal of Public Health, 102*(11), 2094 – 2101.

Gill, A.K. & Anitha, S. (2011). *Forced Marriage: Introducing a Social Justice and Human Rights Perspective*. London, UK: Zed Books Ltd.

Glosoff, H.L. & Durham, J.C. (2010). Using supervision to prepare social justice counseling advocates. *Counselor Education and Supervision, 50*, 116 – 129.

Goodman, L.A., Liang, B., Helms, J.E., Latta, R.E., Sparks, E. & Weintraub, S.R. (2004a). Training Counseling Psychologists as Social Justice Agents: Feminist and Multicultural Principles in Action. *The Counseling Psychologist, 32*(6), 793 – 837. doi: 10.1177/0011000004268802.

Goodman, L.A., Liang, B., Weintraub, S.R., Helms, J.E. & Latta, R.E. (2004b). Warts and all: Personal Reflections on Social Justice in Counselling Psychology. Reply to Kiselica, Palmer, Thompson and Shermis and Watts. *The Counselling Psychologist, 32*(6). doi: 10.1177/0011000004269276.

Graham, H. (2007). *Unequal lives: health and socioeconomic inequalities.* Maidenhead, UK: Open University Press.

Greenleaf, A.T. & Bryant, R.M. (2012). Perpetuating Oppression: Does the Current Counseling Discourse Neutralize Social Action? *Journal for Social Action in Counseling and Psychology, 4*(1), 18 – 29.

Greenleaf, A.T. & Williams, J.M. (2009). Supporting Social Justice Advocacy: A Paradigm Shift towards an Ecological Perspective. *Journal for Social Action in Counseling and Psychology, 2*(1), 1 – 14.

Hammersley, D. (2009). Counselling Psychology: What I see in the crystal ball. *Counselling Psychology Review, 24*(1), 5 – 9.

Health & Care Professions Council. (2012). *Standards of proficiency: Practitioner psychologists.* London, UK: Health & Care Professions Council.

HM Government. (2012). *Social Justice: Transforming Lives.* Retrieved from www.dwp.gov. uk/social-justice.

Hof, D.D., Dinsmore, J.A., Barber, S., Suhr, R. & Scofield, T.R. (2009). Advocacy: The T.R.A.I.N.E.R. Model. *Journal for Social action in Counseling and Psychology, 2*(1), 15 – 28.

Hunsaker, R. (2008). Social justice: An inconvenient irony. Retrieved from http://sjirony. blogspot.co.uk/2008/09/social-justice-inconvenient-irony.html.

Hutchinson, J. & Pretelt, V. (2010). Building resources and resilience: Why we should think about positive emotions when working with children, their families and their schools. *Counselling Psychology Review, 25*(1), 20 – 26.

International Labour Organization. (2008). *ILO Declaration on Social Justice for a Fair Globalization.* Retrieved from http://www.ilo.org/global/meetings-and-events/campaigns/voices-on-social-justice/WCMS_099766/lang--en/index.htm.

James, P. (2009). The centrality and consistency of Counselling Psychology: Before, during and after 2008. *Counselling Psychology Review, 24*(2), 64 – 73.

James, P.E. & Bellamy, A. (2010). Counselling Psychology in the NHS. In R. Woolfe, S. Strawbridge, B. Douglas & W. Dryden (Eds.), *Handbook of Counselling Psychology* (3rd Ed.). London, UK: Sage Publications Ltd.

Johnson, T.S. (2010). Practice What You Preach: A Personal and Pedagogical Social Justice Policy. In S.J. Miller & D.E. Kirkland, *Change Matters.* New York, NY: Peter Lang Publishing Inc.

Joseph, S. (2007). Agents of Social Control? *The Psychologist, 20*(7), 429 – 431.

Jost, J.T. & Kay, A.C. (2010). Social justice: History, theory and research. In S.T. Fiske, D.T. Gilbert & G. Lindzey (Eds.). *Handbook of social psychology (5th Ed.)* (p 1122 – 1165). Hoboken, NJ: John Wily & Sons Inc.

Kabeer, N. (2011). MDGs, Social Justice and the Challenge of Intersecting
Inequalities, Policy Brief 3, London. *Centre for Development, Policy and
Research, Policy Brief 3.*

Kanellakis, P. (2009). Counselling psychology and the next 10 years: Some
questions and answers. *Counselling Psychology Review, 24*(1), 22.

Kasket, E. (2012). The counselling psychologist researcher. *Counselling Psychology
Review, 27*(2), 64 – 73.

Kasket, E. & Gil-Rodriguez, E. (2011). The identity crisis in trainee counselling
psychology research. *Counselling Psychology Review, 26*(4), 20 – 30.

Kinderman, P. (2009). The future of Counselling Psychology: A view from outside.
Counselling Psychology Review, 24(1), 16 – 21.

Kiselica, M.S. (2004). When Duty Calls: The Implications of Social Justice Work for
Policy, Education, and Practice in the Mental Health Professions. *The Counseling
Psychologist, 32*(6), 838 – 854. doi: 10.1177/0011000004269272.

Larsson, P., Brooks, O. & Loewenthal, D. (2012). Counselling psychology and
diagnostic categories: A critical literature review. *Counselling Psychology Review,
27*(3), 55 – 67.

Lee, C.C. (2007). *Social justice: A moral imperative for counselors.* Alexandria,
VA: American Counseling Association.

Lewis, J.A., Ratts, M.J., Paladino, D.A. & Toporek, R.L. (2011). Social Justice
Counseling and Advocacy: Developing New Leadership Roles and Competencies.
Journal for Social Action in Counseling and Psychology, 3(1), 5 – 16.

Lewis, J.A., Toporek, R.L. & Ratts, M.J. (2010). Advocacy and social justice: Entering the mainstream of the counselling profession. In M.J. Ratts, R.L. Toporek & J.A. Lewis (Eds), *ACA advocacy competencies: A social justice framework for counselors.* Alexandria, VA: American Counseling Association.

Lillis, J., O'Donohue, W.T., Cucciare, M. & Lillis, E. (2005). Social justice in community psychology. In R.H. Wright & N.A. Cummings (Eds.), *Destructive trends in mental health: The well-intentioned path to harm.* New York, NY: Routledge.

Lindgreen, A. & Swaen, V. (2010). Corporate Social Responsibility. *International Journal of Management Reviews, 12*, 1 – 7. doi: 10.1111/j.1468-2370.2009.00277.x.

Lockhard, F.W. & Stack, C.L. (2008). ACA's role doesn't include supporting personal political agendas. *Counseling Today,* 4.

Lucas, K., Walker, G., Eames, M., Fay, H. & Poustie, M. (2004). *Environment and Social Justice: Rapid Research and Evidence Review.* London, UK: Policy Studies Institute.

Lukes, S. (2005). *Power: A Radical View* (2nd Ed). London, UK: Palgrave Macmillan.

Lynch, J., Smith, G., Kaplan, G. & House, J. (2000). Income inequality and mortality: importance to health of individual income, psychosocial environment, or material conditions. *BMJ (Clinical research Ed.), 320*(7243), 1200 – 1204.

Mackay, T. (2008). Can psychology change the world? *The Psychologist, 21*(11), 928 – 931.

Malloch, M. & McIvor, G. (2012). *Women, Punishment and Social Justice: Human Rights and Penal Practices.* Oxfordshire, UK: Routledge.

Manis, A.A. (2012). A Review of the Literature on Promoting Cultural Competence and Social Justice Agency Among Students and Counselor Trainees: Piecing the Evidence Together to Advance Pedagogy and Research. *The Professional Counselor, 2*(1), 48 – 57.

Marmot Review. (2010). *Fair Society, Healthy Lives.* London, UK: The Marmot Review.

Martinelli, M. (2010). Assessed Unit 6: An academic paper which critically examines the philosophical bases of counselling psychology and addresses in particular the relationship between its values and commitment to psychological enquiry. *Counselling Psychology Review, 25*(3), 39 – 46.

Mason, T., Carlisle, C., Watkins, C. & Whitehead, E. (2001). *Stigma and social exclusion in health care.* London, UK: Routledge.

McWhirter, B. & McWhirter, E. (2007). Toward an Emancipatory Communitarian Approach to the Practice of Psychology Training. In E. Aldarondo (Ed), *Advancing Social Justice Through Clinical Practice.* Mahwah, NJ: Lawrence Erlbaum Associates Inc.

Miller, D. (2001). *Principles of Social Justice.* Cambridge, MA: Harvard University Press.

Miller, D. (2004). What is Social Justice? In N. Pearce & W. Paxton. *Social Justice: Building a Fairer Britain.* London, UK: Politico's Publishing Ltd.

Miller, D. (2012). *Are Human Rights Conditional?* Oxford, UK: Department of
Politics and International Relations, University of Oxford.

Miller, S.J. & Kirkland, D.E. (2010). *Change Matters*. New York, NY: Peter Lang
Publishing Inc.

Milton, M. (2011). A response to Moller (2011): 'Diversity still requires
epistemological clarity'. *Counselling Psychology Review, 26*(3), 89 – 91.

Milton, M., Craven, M. & Coyle, A. (2010). Understanding the Nature of Human
Distress: Moving beyond the Concept of Psychopathology. In M. Milton (Ed),
*Therapy and Beyond: Counselling psychology contributions to therapeutic and
social issues.* Oxford, UK: Wiley-Blackwell.

Milton, M. & Legg, C. (1999). A challenge for Counselling Psychology: Engaging
with the political in client's materials. *Counselling Psychology Review, 14*(4), 12 –
18.

MIND. (2007). *Another Assault.* London, UK: MIND.

Mirowsky, J. & Ross, C.E. (2003). *Social Causes of Psychological Distress* (2nd Ed.).
New York, NY: Aldine.

Moe, J.L., Perera-Diltz, D. & Sepulveda, V. (2010). Are Consultation and Social
Justice Advocacy Similar?: Exploring the Perceptions of professional Counselors
and Counseling Students. *Journal for Social Action in Counseling and Psychology,
2*(2), 106 – 123.

Mollen, P. (2009). Our rich heritage – are we building on it or destroying it? (Or why are counselling psychologists not angrier than clinical psychologists?). *The Psychologist, 24*(3 & 4), 130 – 142.

Moller, N. (2011). The identity of counselling psychology in Britain is parochial, rigid and irrelevant but diversity offers a solution. *Counselling Psychology Review, 26*(2), 8 – 16.

Moore, T. & Rae, J. (2009). "Outsiders": How some counselling psychologists construct themselves. *Counselling Psychology Quarterly, 22*(4), 381 – 392.

Murray, C.E., Pope, A.L. & Rowell, P.C. (2010). Promoting counseling students' advocacy competencies through service-learning. *Journal for Social Action in Counseling and Psychology, 2,* 29 – 46.

Myers, J.E., Sweeney, T.J. & White, V.E. (2002). Advocacy for counseling and counselors: A professional imperative. *Journal of Counseling and Development, 80*, 394 – 402.

National Institute for Health and Clinical Excellence. (2007). *NICE public health guidance 6: 'Behaviour change at population, community and individual levels'.* Retrieved from http://www.nice.org.uk/nicemedia/pdf/PH006guidance.pdf.

Nelson-Jones, R. (2002). Diverse goals for multicultural counselling and therapy. *Counselling Psychology Quarterly, 15*, 133 – 144.

Newbury, J. & Hoskins, M. (2012). Seeking solutions without centering problems: A professional exploration. *International Journal of Child, Youth, and Family Studies, 3*(1), 20 – 45.

Nowill, J. (2011). Status of counselling psychology. *The Psychologist, 24*(9), 628 – 629.

Nussbaum, M.C. (2004). Beyond the Social Contract: Capabilities and Global Justice. *Oxford Development Studies, 32*(1), 3 – 18.

Nussbaum, M.C. (2011). *Creating Capabilities: The Human Development Approach.* Cambridge, MA: Harvard University Press.

Odegard, M.A. & Vereen, L.G. (2010). A grounded theory of counselor educators integrating social justice into their pedagogy. *Counselor Education and Supervision, 50,* 130 – 149.

Office of National Statistics. (2004). *Focus on Social Inequalities.* London, UK: HMSO.

Orlans, V. & Van Scoyoc, S. (2009). *A short introduction to counselling psychology*. London, UK: Sage.

Parikh, S.B. (2011). *Examining the relationship between belief in a just world, political ideology, religious ideology, socioeconomic status of origin, race and social justice advocacy attitudes of practicing school counselors*. Charleston, SC: Proquest, Umi Dissertation Publishing.

Pearce, N. & Paxton, W. (2004). *Social Justice: Building a Fairer Britain.* London, UK: Politico's Publishing Ltd.

Prilleltensky, I. (1999). Critical psychology foundations for the promotion of mental health. *Annual Review of Critical Psychology, 1*, 95 – 112.

Prilleltensky, I. & Prilleltensky, I. (2005). Beyond resilience: Blending wellness and liberation in the helping professions. In M. Ungar (Ed), *Handbook for working with children and youth: Pathways to resilience across cultures and contexts.* Thousand Oaks, CA: SAGE.

Rafalin, D. (2010). Counselling psychology and research: Revisiting the relationship in the light of our 'mission'. In M. Milton (Ed.), *Therapy and Beyond: Counselling psychology contributions to therapeutic and social issues* (p41 – 55). Oxford, UK: Wiley-Blackwell.

Raskin, J.D., Bridges, S.K. & Neimeyer, R.A. (2010). *Studies in meaning 4: Constructivist perspectives on theory, practice, and social justice.* New York, NY: Pace University Press.

Ratts, M.J. (2009). Social Justice Counseling: Toward the Development of a Fifth Force Among Counseling Paradigms. *Journal of Humanistic Counseling, Education and Development, 48*(2), 160 – 172.

Ratts, M.J. & Wood, C. (2011). The fierce urgency of now: Diffusion of innovation as a mechanism to integrate social justice in counselor education. *Counselor Education and Supervision, 50,* 207 – 223.

Rawls, J. (2001). *Justice as Fairness: A Restatement.* Cambridge, MA: Harvard University Press.

Raworth, K. (2012). *A Safe and Just Space for Humanity: Can We Live Within the Doughnut?* Oxford, UK: Oxfam Discussion Paper.

Reynolds, A.L. & Constantine, M.G. (2004). Feminism and multiculturalism: Parallels and intersections. *Journal of Multicultural Counseling and Development, 32*, 346.

Rizq, R. (2006). Training and disillusion in counselling psychology: a psychoanalytic perspective. *Psychology and Psychotherapy: Theory, Research and Practice, 79*(Part 4), 613 – 627.

Robeyns, I. (2005). The capability approach – A theoretical survey. *Journal of Human Development, 6*(1), 93 – 114.

Robeyns, I. (2008). Sen's capability approach and feminist concerns. In S. Alkire, M. Qizilbash & F. Comim (Eds). *The Capability Approach: Concepts, Measures and Applications.* Cambridge, UK: Cambridge University Press.

Robinson, M. & Scherlen, A.G. (2008). Open Access to Criminal Justice Scholarship: A Matter of Social Justice. *Journal of Criminal Justice Education, 19*(1), 54 – 74.

Rocco, L. & Suhrcke, M. (2012). *Is social capital good for health? A European perspective*. Copenhagen, Denmark: World Health Organization.

Sapolsky, R.M. (2004). *Why Zebras Don't Get Ulcers.* New York, NY: St Martin's Press.

Scheier, M.F., Carver, C.S. & Bridges, M.W. (2001). Optimism, pessimism, and psychological well-being. In E.C. Chang (Ed), *Optimism and pessimism: Implications for theory, research and practice.* Washington, DC: American Psychological Association.

Sen, A.K. (2008). The Idea of Justice. *Journal of Human Development, 9*(3), 331 – 342.

Sheppard, M. (2002). Mental Health and Social Justice: Gender, Race and Psychological Consequences of Unfairness. *British Journal of Social Work, 32*(6), 779 – 797.

Simmons, C., Lehmann, P. & Collier-Tension, S. (2008). Men's Use of Controlling Behaviors: A Comparison of Reports by Women in a Domestic Violence Shelter and Women in a Domestic Violence Offender Program. *Journal of Family Violence, 23*(6), 387 – 394.

Singh, D., Marcus, S., Rabbatts, H. & Sherlock, M. (2012). *After the riots: The final report of the Riots Communities and Victims Panel.* London, UK: The Riots Communities and Victims Panel.

Smart-Richman, L. & Leary, M.R. (2009). Reactions to discrimination, stigmatization, ostracism, & other forms of interpersonal rejection: A multimotive model. *Psychological Review, 116*(2), 365 – 383.

Smith, L., Baluch, S., Bernabei, S., Robohm, J. & Sheehy, J. (2003). Applying a social justice framework to college counseling center practice. *Journal of College Counseling, 6*, 3 – 13.

Smith, S., Ng, K., Brinson, J. & Mityagin, E. (2008). Multiculturalism, diversity and social advocacy: A 17-year content analysis of counselor education and supervision. *Counselor Education and Supervision, 47*, 249 – 263.

Smith, S.D., Reynolds, C.A. & Rovnak, A. (2009). A Critical Analysis of the Social Advocacy Movement in Counseling. *Journal of Counseling and Development, 87,* 483 – 491.

Spears, L.C. (Ed). *Insights on leadership: Service, stewardship, spirit and servant-leadership.* New York, NY: John Wiley & Sons.

Stafford, M. & McCarthy, M. (2006). Neighbourhoods, Housing and Health. In M. Marmot & R. Wilkinson (Eds), *Social Determinants of Health* (2nd Ed). Oxford, UK: Oxford University Press.

Steptoe, A. (2005). How stress gets under your skin: psychobiological studies of social status, stress and health. *Glasgow Centre for Population Health Seminar, Series 2: Paper 1.*

Strawbridge, S. (1992). Counselling psychology and the model of science. *Counselling Psychology Review, 7*(1), 5 – 11.

Strawbridge, S. (1994). Towards ant-oppressive practice in Counselling Psychology. *Counselling Psychology Review, 9*(1), 5 – 12.

Strawbridge, S. (2003). A question of identity. *Counselling Psychology Review, 18*(3), 45 – 48.

Strawbridge, S. & Woolfe, R. (2009). Counselling Psychology: Origins, Developments and Challenges. In R. Woolfe, S. Strawbridge, B. Douglas & W. Dryden, *Handbook of Counselling Psychology.* London, UK: SAGE.

Stiglitz, J.E., Sen, A. & Fitoussi, J. (2009). *Report by the Commission on the Measurement of Economic Performance and Social Progress.* Retrieved from http://www.stiglitz-sen-fitoussi.fr/documents/rapport_anglais.pdf.

Sue, D.W. & Sue, D. (2007). *Counseling the Culturally Diverse: Theory and Practice.* Chichester, UK: John Wiley & Sons Ltd.

Teti, M., Bowleg, L. & Lloyd, L. (2010). 'Pain on Top of pain, Hurtness on Top of Hurtness': Social Discrimination, Psychological Well-Being, and Sexual Risk Among Women Living With HIV/AIDS. *International Journal of Sexual health, 22*(4), 205 – 218. doi: 10.1080/19 317611.2010.482412.

Theodossiou, I. & Zangelidis, A. (2009). The social gradient in health: The effect of absolute income and subjective social status assessment on the individual's health in Europe. *Economics and Human Biology, 7*(2), 229 – 237.

Thomas, C., Benzeval, M. & Stansfeld, S. (2007). Psychological distress after employment transitions: the role of subjective financial position as a mediator. *Journal of Epidemiology and Community Health, 61*(1), 48 – 52.

Tikly, L. & Barrett, A.M. (2009). *Social Justice, Capabilities and the Quality of Education in Low Income Countries.* Bristol, UK: EdQual.

Toporek, R.L., Gerstein, L.H., Fouad, N.A., Roysircar-Sodowsky, G. & Israel, T. (2006). *Handbook for Social Justice in Counseling Psychology: Leadership, Vision and Action.* Thousand Oaks, CA: SAGE Publications Ltd.

Toporek, R.L., Lewis, J.A. & Crethar, H.C. (2009). Promoting systemic change through the ACA advocacy competencies. *Journal of Counseling and Development, 87,* 260 – 268.

UNICEF. (2007). Child poverty in perspective: An overview of child well-being in rich countries. Retrieved from http://www.unicef-irc.org/publications/pdf/rc7_eng.pdf.

Van der Walt, J.L. & Potgieter, F.J. (2011). How Citizens with Integrity Can Contribute to Social Justice in an Unequal Society. *Journal of Social Sciences, 28*(2), 77 – 86.

Vera, E.M. & Speight, S.L. (2007). Advocacy, outreach, and prevention: Integrating social action roles in professional training. In E. Aldarondo (Ed.), *Advancing social justice through clinical practice*. Mahwah, NJ: Erlbaum.

Ward, T., Hogan, K. & Menns, R. (2011). Perceptions of integration in counselling psychology training, a pilot study. *Counselling Psychology Review, 26*(3), 8 – 19.

Webster, A. & Robertson, M. (2007). Can community psychology meet the need of refugees? *The Psychologist, 20*(3), 156 – 158.

Weinrach, S. & Thomas, K. (2004). The AMCD multicultural counseling competencies: A critically-flawed initiative. *Journal of Mental Health Counseling, 26*, 81 – 93.

Widdows, H. & Smith, N.J. (2011). *Global Social Justice.* New York, NY: Taylor & Francis.

Wilkinson, R.G. & Kitzinger, C. (2005). Same-sex marriage and equality. *The Psychologist, 18*(5), 290 – 293.

Woolfe, R. (2006). A journey from infancy to adulthood: The story of counselling psychology. *Counselling Psychology Review, 21*(1), 2 – 3.

Woolfe, R. & Strawbridge, S. (2010). Counselling Psychology: Origins, developments and challenges. In R. Woolfe, S. Strawbridge, B. Douglas & W. Dryden (Eds)., *Handbook of Counselling Psychology* (3rd Ed). London, UK: Sage.

World Health Organization. (2008). *A Global Response to Elder Abuse and Neglect.* Geneva, Switzerland: WHO.

Zammit, A., Berik, G. & Van der Meulen Rodgers, Y. (2008). *Social Justice and Gender Equality: Rethinking Development Strategies and Macroeconomic Policies.* Oxfordshire, UK: Routledge.