The journey of becoming and being a mother raising a disabled child – The transformations between and across social positions

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Abstract

Although the experiences of mothers raising disabled children has been studied, their experiences are often still negatively interpreted (Beresford, 1994), or marginalised by professionals, prevailing discourses of motherhood, and debates within disability studies (Ryan and Runswick-Cole, 2008; McLaughlin, 2006; Brett, 2002; Green, 2001). This thesis seeks to provide new insight into the lives and perspectives of such mothers. The main concern is what mothers learn from their journey of changing social position from being a non-disabled person to being a mother raising a disabled child and what we can learn from them. The analysis focuses on three topics, how mothers construct their motherhood in the context of disability; how mothers manage issues around disability in their practices of motherhood; and mothers' reflections of professional knowledge and lay expertise. Sixteen mothers from the North East area were interviewed and the detailed data has been gathered by using qualitative methods including semi-structured interactive interviews.

The main arguments are generated from the respondents' experiences within their daily lives. Although surrounded by various social actors who provide diverse types of support, I will argue that mothers still experience an isolated type of motherhood. This then leads to discussions about issues related to care, dependence, and the boundary between the private and public spheres. Rather than being fixed within the binary discussions between the medical model and the social model, the respondents worked with an understanding of disability which recognised its social construction, alongside the specific practical and medical needs of their child. In doing so they approached discourses of need, impairment and care flexibly so that they could manage issues around disability in ways appropriate to they and their child's social position.

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Chapter One

Introduction

The goal of this research was to explore what mothers with disabled children had learned from their experiences of caring for their children and what we can learn from their experiences. Rather than concentrating on parents' stress (Margalita and Kleitmana, 2006; Hastings and Johnson, 2001) or general coping strategies (Gray, 2003; Taanila et al., 2002; Wallander and Venters, 1995), the intention in this research was to focus on the expertise the mothers had developed. By gaining insights into their perspectives and experiences, it is hoped that the findings from this research will contribute to debates on contemporary understandings of disability, motherhood and the boundaries between professionals/state and mothers, while at the same time making it possible to improve support for disabled children and their families now and in the future, not only in the U.K. but also in Taiwan.

In this chapter the background to this research and the reasons for exploring the mothers' perspective are presented. The chapter also includes a discussion of related service programmes and legislation, focusing principally on those mentioned by the mothers in their interviews. The research questions and the structure of the thesis will also be described.

Background

After graduating from university, I worked in an organisation for visually impaired people and their families in Taiwan as a social worker. One of my roles was to organise a self-help group for the parents of visually impaired children. Although I was there to 'help' parents, I realised I had much to learn from their considerable practical expertise. I learned about the difficulties and sorrow the parents encountered. I was also touched by their strength in handling issues surrounding their children, usually with little statutory support. For example, we visited some existing parents' groups in order to learn from their experiences of organising a self-help group. A mother who was in her sixties said that although she had only attended primary school for one or two years, she had learned to read and advocate in order to help her son, who had Down's

syndrome. Now she was using her thirty years' experience of being a mother to help other parents.

Inspired by the difficulties parents experienced in their first few years of becoming the parents of a disabled child, I chose to explore the experiences of parents who were looking for a diagnosis in the early intervention programmes for children with developmental delay and disabled children in Taiwan as the topic of my master's dissertation (Shih, 1998). For the purposes of this study, I interviewed 110 carers, who were engaged in the screening process that formed the initial stage of the first year early intervention programme. All the interviewees were quite confused and asked me various questions about the complicated screening process and the system of services that would follow. As both a student researcher and former social worker, I chose to pass on knowledge I had acquired in my capacity as a social worker and that other parents had shared with me. As a result, although I had planned to interview them in thirty minutes, it sometimes took me more than an hour to exchange information with the interviewees. From the interviewees' feedback, I realised how useful other parents' experiences were for them, as other researchers have suggested (Landsman, 2003; Rapp and Ginsburg, 2001).

At the time when I was conducting my master's research, services for disabled children provided by the government were still being developed and were unsound. Aware of the limited statutory resources available, the parents also acknowledged that the priority of the government was to focus on their child. The practical problems associated with the limited services mentioned above have also influenced the focus of research in this area in Taiwan. Most research has only focused on the difficulties associated with caring for a disabled child, the negative impact of disability, and parents' coping strategies. Parents' personal needs, reflections, strengths and expertise have been underestimated and not paid sufficient attention.

The above experiences contributed to my current standpoint as a researcher. The parents I worked with and interviewed at that time had demonstrated to me their knowledge and expertise. Since very little attention had been paid to the positive aspects of caring for a disabled child, with the focus being on difficulties and needs, as Beresford (1994) suggests, I decided to investigate the expertise of the mothers of disabled children. Although both my experience as a social worker and researching for my master's dissertation had demonstrated how other parents' experiences could be helpful (Shih, 1998), their experiences were seldom stored up and passed on to other

parents in a similar position, partly because the parents were busy, and partly because of their lack of interaction with other people. The experience of acting as a middle-person in the interviews described above, thus enabling parents to exchange their experiences, further suggested a possible role for me as a platform or a bridge to help mothers transform their experiences into knowledge that could be shared and exchanged, and which would therefore endure or become signposts providing a short cut for other parents who had just had a disabled child. From my work experience, I realised there was a possibility of working with parents in a partnership, although our respective knowledge would have come from different sources: their knowledge being derived from their daily experiences, mine being more academic. Since I believe that a combination of academic knowledge and parent's expertise will make it possible to provide more appropriate services for disabled children and their families, in the current research, I wanted to explore possibilities that could connect professional knowledge and mothers' expertise. These are the basic premises of this research.

New frameworks

In the U.K., since the 1970s the understanding of disability has been transformed. Two influential models for understanding disability in British disability studies, the medical model and the social model, were developed by key disability writers such as Michael Oliver in the 1980s (Shakespeare, 2006). Generally, the medical model focuses principally on the individual's biological impairments, medical treatment and rehabilitation (Oliver, 1983). Medicalisation has been viewed as one of the mechanisms that affects disabled people's lives (Barnes and Mercer, 2007; Oliver, 1990). The unbalanced relationship between professionals and lay persons is criticised for leaving disabled people little space to be independent in controlling their own lives and making their own choices.

Moreover, a lack of consideration of the experiences of mothers can result in overlooking important aspects of the difficulties associated with raising a disabled child which are created by others. For example, research has drawn attention to the problematic relationship that exists between mothers and professionals. Since the impact of biological impairment is the main concern of professionals in the framework of the medical model, there is a risk of portraying mothers' perspectives negatively, assuming that they are influenced by a sense of personal tragedy. Mothers might feel

judged and unfairly labelled as unrealistic, overly emotional, exceedingly optimistic, confused and problematic (McLaughlin and Goodley, 2008; Carpenter and Austin, 2007; Todd and Jones, 2003; Brett, 2002; Larson, 1998). Since mothers are often viewed as lay persons, their perspectives are seldom valued by professionals.

By contrast, concepts developed by proponents of the social model have highlighted barriers caused by social arrangements, such as social oppression and exclusion (Barnes and Mercer, 2007; Finkelstein, 2001; Oliver, 1983). According to proponents of the social model, instead of correcting or normalising disabled people through medical interventions dominated by medical professionals, the focus should be on how society should be changed to accommodate them (Barnes and Mercer, 2007; Thomas, 2002; Finkelstein, 2001; Oliver, 1983).

Although the social model provides another angle from which to view experiences of disability, parents do not always benefit from it. Research has shown that even when the diverse influences of gender and race are taken into account, the experience of disabled children and their families continues to be marginalised in the context of the social model (Connors and Stalker, 2007; Brett, 2002; Dowling and Dolan, 2001). Ryan and Runswick-Cole (2008) suggest that the reason mothers occupy a contradictory and marginal position in disability studies and in the disabled people's movement is because they themselves are not disabled. In the context of highlighting disabled people's own voices, it has been suggested that parents perform a similar role to professionals, in trying to normalise or overprotect their disabled children in ways that might prevent them from taking control of their own lives (Barnes and Mercer, 2007; Finkelstein, 1998). However, scholars have argued that it is not helpful to exclude all non-disabled people, because some disabled people need other people to speak for them: for instance, young disabled children or those who have severe disabilities (Ryan and Runswick-Cole, 2008; McLaughlin, 2006; Shakespeare, 2006; Kittay, 2002b).

The British sociological debates on disability provided me with new perspectives, not only because most of the information I obtained while studying at university in Taiwan came from America, but also because there is a difference between the perspective of social work and that of sociology. Rather than focusing solely on the individual's needs and difficulties, British sociological discussion has guided me also to become aware of the issues of social structure and led me to re-examine my experiences in Taiwan.

The early intervention programme I worked on might be viewed as one of the first programmes in Taiwan that tried to take into account the needs of the family. The idea of the early intervention programme was that the sooner young, developmentally delayed children are treated, the better are the chances of rehabilitation. Parents, especially mothers, were expected to learn skills and knowledge in order to practise activities in their home rather than depending on the limited support of professionals. Hence, increasing parents' abilities was viewed as one of the important strategies in the early intervention programme in Taiwan.

I embraced the ideas of early intervention for three reasons. As the findings of my master's research indicated, because of the lack of an established health and social welfare system, parents were the key people who decided if their child would access resources or not (Shih, 1998). I believed if parents were more aware of their child's development and better informed and supported, this could help their children to obtain the diagnoses and services they needed sooner. Moreover, when I interviewed the carers, they affirmed their desire to learn and help their children; hence I believed this was what carers needed. As a social worker, I was persuaded that it was essential to enable parents in order to promote their child's welfare in the context of limited resources and support. Second, I assumed that the early intervention programmes in Taiwan were an opportunity for the social welfare system to see the difficulties encountered by the carers, rather than focusing solely on their disabled children. Third, the American discussions I had read emphasised both the strengths and the weaknesses of the families concerned, their strengths having seldom been valued before. I hoped these new perspectives could make an impact on services for disabled children and their families in Taiwan.

After reading British literature, however, I started to doubt if the early intervention programme could help carers' situations to be fully recognised or appreciated. I perceived the risk of viewing carers as merely instruments for ensuring the welfare of disabled children, instead of truly acknowledging them as social actors who also deserved support. I also learned from the literature about the negative impact of 'medicalising' the home (McLaughlin, 2006; Leiter, 2004). These debates inspired me to question what I knew and gave me a different perspective from which to develop my research questions. These experiences and reflections also became the motivation for and basic premise of this research that examines the experiences of mothers in North-

east England. By introducing British academic, policy and practice perspectives, I hope that my research will be of benefit to parents in Taiwan.

Why mothers?

Several factors contributed to my decision to explore the experiences of mothers in particular. My interest in mothers with disabled children grew gradually and was based on diverse aspects of my experiences in Taiwan, my personal experiences and a review of the related literature. First, most of the parents I worked with and interviewed for my master's research were mothers. These incredible women nurtured my concern for an interest in disabled children and their families. The experiences they shared with me became the foundation of this research. The experiences of working with them motivated me to continue exploring mothers' experiences in particular.

After I myself became a mother, I found the demands of motherhood much more complicated than I had previously thought. As an overseas student, I encountered different and even conflicting perspectives between Taiwanese and English culture. I have needed to compromise, modify and choose the way that I think best for my children at the moment. Sometimes one's own values are not always obvious until one is confronted by opposing values (Goffman, 1968), and one's own values can also change over time. Hence, I concerned myself with the mothers' journey from being a non-disabled person to becoming a mother with a disabled child. I was interested in their motherhood in the context of disability and how the mothers responded to these challenges.

Another reason for choosing to explore the experiences of mothers in particular was that, not only in Taiwan, but also in the U.K., many mothers are the main carers of their disabled child. Using data from the 2001 census, Cares UK (2011) indicates that 99.1% of sick or disabled children in England and Wales live at home with their families. 64% of their carers are women and 36% are men. Contact a Family (2011) also notes that only 16% of mothers with disabled children work, compared to 61% of other mothers, which suggests that mothers are more likely to assume the main caring role for their disabled child; this supports the findings of academic research (Read, 2000; Traustadóttir, 1991). Since mothers are the persons who actually take care of their child on a daily basis, we cannot fully ensure the welfare of disabled children without

acknowledging the mothers, their main carers (Kittay, 2002b). However, mothers' experiences are normally marginalised.

When disability is portrayed as something pregnant women should try hard to avoid, it is easy for a mother and her disabled child to be viewed as 'others', as something which differs from normal social expectations (Ryan and Runswick-Cole, 2008: 203). Since it is assumed that their disabled children will not grow up to be independent and productive citizens, their experiences of motherhood are seldom included in dominant discussions about motherhood; rather, they can be viewed as exceptions, being judged or blamed, or else being praised for 'mother-valour' (Blum, 2007: 202). The experiences of these mothers have been excluded not only from mainstream discussions on motherhood but also from debates concerning disability, as presented earlier.

Moreover, scholars have argued the importance to acknowledge the gender issues. Some researchers suggest that not only the fact that mothers are not professionals but also gender issues contribute to the unbalanced relationship between mothers and professionals (McLaughlin and Goodley, 2008; Callery, 1997). Research has indicated that mothers are expected to carry out traditional caring roles when they have a disabled child. Since men and women do not receive equal pay for the same work, in many disabled children's families the father is chosen to be the breadwinner (Gray, 2003; Traustadóttir, 1991). Research has also suggested that mothers are normally put in the frontline when confronting social expectations and judgement because it is assumed that it is they who are responsible for the care of their child and for their child's behaviour (McLaughlin, 2006; Singh, 2004; Gray, 1997).

Although parents' experiences have been studied, after reviewing American and Canadian English journals focusing on the needs of parents with chronically sick children from 1985, Fisher (2001) argues that most research interviewees have been mothers, although the term 'parents' has been adopted. Other research has revealed the differences between mothers and fathers when managing issues surrounding disability (Graungaard and Skov, 2007; Hansen and Hansen, 2006; Read, 2000), or the different expectations of the fathers and mothers of a disabled child on the part of other people (Leiter, 2004; Singh, 2004). It is therefore important to acknowledge the difference between mothers and fathers (Ryan and Runswick-Cole, 2009).

Accordingly, mothers' experiences might be framed and interpreted negatively or distorted by the existing models because they are not professionals, nor are they

disabled, and they are women and mothers with disabled children. As feminist standpoint theory suggests, I believe that, given their marginalised social position, mothers' experiences can offer a unique perspective on the issue of disability (Jaggar, 2008; Harding, 1993). For all the above reasons, in this research I decided to concentrate on the experiences and perspectives of mothers, rather than on those of fathers or of both parents.

In this research, I have elected to use the term 'mothers with a disabled child' in this thesis, in order to emphasise the subjective experience of both the mothers and their children. I have chosen to view mothers as social actors who can construct their own understanding of their experiences (Young et al., 2002). Being the mother of a disabled child is only one of their roles. Additionally, several mothers in this research did not simply view their child as their property; they were aware of their children's individual subjectivity and therefore encouraged their participation in making sense of their world and themselves.

Policies, legislation and service programmes

During the interviews, the mothers did not talk a great deal about policies and legislation. Instead they were concerned with the practical services related to their child's needs and their family lives. Here I will provide some background information concerning the services the mothers mentioned in the interviews and which are described in chapters four, five and six.

In the U.K., services for disabled children and their families, including legislation and education, health and social care policies, are interwoven in a complex fashion. According to Contact a Family (2004), the importance of user participation has been emphasised by several items of legislation and guidance to health and social care in England, including the Health and Social Care Act 2001, the NHS Plan 2000, the Carers and Disabled Children Act 2000 and the National Service Framework for Children, Young People & Maternity Services. The issue of parents' participation in decisions about their children's care has been viewed as a crucial aspect of policies which offer support for disabled children: for instance, Improving the Life Chances of Disabled People, issued by the Prime Minister's Strategy Unit in 2005, Aiming High for Disabled Children: better support for families, published in May 2007, and The National Parent Partnership Network. The SEN Green Paper (which was introduced

after my fieldwork was completed), Support and Aspiration: A new approach to special educational needs and disability - A consultation', published in March 2011, not only continues to emphasise the partnership between parents and professionals, it further highlights the principle of giving parents control over support for their child and the rest of their family (DfES, 2011). Although the importance of parents' participation and of their voice has been emphasised in policies, however, research continues to reveal problems in the relationships between professionals and parents (McLaughlin and Goodley, 2008; Runswick-Cole, 2007; McLaughlin, 2006; Swain et al., 2003; Brett, 2002; Dowling and Dolan, 2001).

Concerns about the process of obtaining a statement of special educational needs were mentioned by most of the mothers who participated in this research, since it is this statement that will get their children educational support. According to Directgov, the first step is for relevant professionals to make a statement of the educational needs of the child. This statement specifies the child's needs and the help he or she should receive. If a child's needs cannot be satisfied by the existing services, an assessment made by related professionals can be arranged either by service providers or at the parents' request (Directgov, 2011b). After the assessment, the local authority concerned will let the parents know if the information obtained in the assessment will be written into a statement of special educational needs. Parents will be able to review the draft statement, have the right to disagree with its contents, have a meeting with the local authority, and make comments after the meeting. If the parents do not agree with the statement, they have a right to appeal to the Special Educational Needs and Disability Tribunal (SENDIST), an independent organisation (Directgov, 2011c). The statement will be reviewed annually to ensure the child receives the support he or she needs. According to the mothers interviewed for this research, the process of obtaining such a statement is complicated.

Several mothers talked about the issues related to respite care, which is sometimes known as short-term breaks. The aim of these is to give carers a rest from their caring duties (Directgov, 2011d), or to provide disabled children with opportunities to 'have enjoyable experiences which help them become more independent and form friendships outside their family' (Short Breaks Network, 2011). Options include a short-term place in a care home for a disabled child; or a paid care worker in their own home so that carers and the disabled child's family can have a break (Directgov, 2011d).

The services related to parents' participation, the statement and respite care are viewed as responsibilities of the local authority. According to The Children Act 1989, local councils have a general duty to provide a range of services to 'children in need' in their area, such as short break services, holiday play schemes, care at home, some aids and adaptations, financial help, or direct payments. Local councils are expected to identify the extent of need in their area and make decisions about the levels of service they provide.

Another service the mothers mentioned is the Disability Living Allowance (DLA). According to Directgov (Directgov, 2011a), the DLA is a tax-free benefit given to disabled people to help with extra costs. It has two components: 'a care component - if you need help looking after yourself or supervision to keep safe; and a mobility component - if you can't walk or need help getting around'. The entitlement and the amount of DLA are based on the information applicants give to the Pensions Disability and Carers Service (PDCS). It is the applicants' responsibility to give information and to inform the PDCS when their circumstances change. Rather than being an entitlement, these services can only be obtained through application; hence making the efforts to obtain the support their child needs is viewed as an important task for mothers (McLaughlin, 2011).

The recently formed Conservative/Liberal Democrat government has said that changes are going to be made in policies governing services for disabled people and their families. Although it is still not clear what kinds of change will be implemented, growing concern was evident at the Disability Studies conference in which I participated in 2010.

Research questions

Both my experiences in Taiwan and the literature I have read in the U.K. suggest that mothers' experiences are neither recognised nor respected by service providers, disability activists, or even by the mothers themselves, from the perspective of either the medical or the social model. Rather than applying existing discourses which are narrated by a variety of social actors, I have chosen to examine how mothers interact with these discourses, and what mothers have learned from these experiences.

Since I believe that the experiences of mothers can enrich our understanding of disability, I hope to help mothers to store up their experiences, so that these experiences can be transformed into knowledge that can then be shared with other parents in need of help. As well as the difficulties mothers encounter, their strength and their responses when facing challenges are also themes that I am concerned with. Motherhood, how mothers manage issues surrounding disability, and the relationships between mothers and professionals were chosen as the primary topics of this research. The following two main research questions were developed for this study:

1. What do mothers learn from their experience of moving from being a non-disabled person to becoming the mother of a disabled child?

2. What can we learn from them?

A series of sub-questions were also devised, as follows:

- How do mothers develop their motherhood? Since they are themselves social actors, what impact do external forces have on their motherhood? Since they are themselves active agents, how do mothers negotiate with related discourses suggested or monitored by others?

- How do mothers deal with issues surrounding disability? Apart from the explanations offered by medical perspectives and the social model, how do mothers construct, modify and put into practice their understanding of disability in their daily lives, including how they interact or negotiate with others and their disabled child?

- How do others, especially service providers, influence their motherhood and their understanding of disability? Why are the experiences and knowledge of mothers important?

Thesis structure

This thesis is composed of seven chapters. The literature review in chapter two establishes a connection between the findings of previous studies and the research questions presented above. The literature related to childhood, motherhood, disability and professionalism is examined. The framework and themes of this research have been generated on the basis of the discussions on these subjects found in the literature.

However, not all the ideas for this research were derived from the literature on disability. The valuable experiences of the mothers who took part in this study led me to read more widely, on issues that at first did not seem directly related to the subject of this thesis. This additional reading provided additional themes and further influenced how the data were analysed. It was thus an interweaving process.

In chapter three the methodology employed for this research is discussed in detail. An explanation is provided of why and how the research was conducted by presenting the conceptual framework, research design, methods of analysis, approach to ethical issues, and the limitations of the study. The chapter will also illustrate how my personal and work experience and my social position as an overseas student and outsider influenced this research.

In the three subsequent chapters (chapters 4, 5 and 6), the findings of the current research are presented. In chapter four, various elements that influenced the development of my respondents' motherhood are described, including dominant social expectations of motherhood, the impact of their child's disability, and the mothers' experiences of interacting with family and friends, other mothers with disabled children, and professionals. Although surrounded by these other social actors who provide diverse types of support through their relationship, I argue that mothers might still experience an isolated type of motherhood. This then leads to discussions about issues related to care, dependence, and the boundary between the private and public spheres.

In chapter five the discussion positions motherhood in the context of disability and illustrates how mothers handle issues surrounding disability. Rather than being fixed within the binary discussion between medical perspectives and the social model, this research uses mothers' daily experiences in the context of interpersonal relationships to demonstrate the complicated nature of disability. In the mothers' daily lives, they might encounter various discourses from other parties: for instance, medical perspectives, the social model, or the cultural norms of motherhood and childhood. These discourses are not fixed but negotiable, changing and interwoven. In the first part of the chapter various topics which are of concern to the mothers are used to illustrate how the mothers flexibly adapt discourses in order to manage and construct their understanding of disability while interacting with service providers, their child and others. In the second part the ways in which both their present lives and the mothers' imagined futures influence their choices for their children are described. The mothers' efforts to cultivate their children's participation in society are illustrated using examples of

educational arrangements, their lives at present and their child's possible life in the future.

Unexpectedly, it was found that ten of the sixteen mothers in my sample had various levels of experience with disability as service providers for disabled people and their families before having their disabled child. Chapter six focuses on the experiences of these ten mothers and discusses their reflections after having their disabled child. The first part describes how the mothers employed their knowledge and experience as professionals to manage challenges related to raising their disabled child. The limitations of their knowledge and the boundaries between themselves and others caused by their professional identities will be indicated in the second part of the chapter. In part three, the mothers' reflections on how their experiences as mothers influenced their careers as professionals after having the experience of raising a disabled child are presented. In the last part of the chapter an attempt is made to argue the necessity for acknowledging the importance of mothers' experiences and expertise.

The final chapter contains the conclusions and recommendations made on the basis of the findings. It includes a brief overview of the findings and outlines the contribution of this research to our contemporary understanding of motherhood and disability. On the basis of the findings of this study, I argue that the expertise which these mothers have developed as a result of their specific social position should be acknowledged and made use of. The mothers who participated in this research demonstrated the importance of recognising the issues of diversity in diverse contexts, and this could be useful when designing and delivering support. Accordingly, the more dialogue takes place between professionals and mothers, the more we will understand about disability and the more able we will be to provide suitable services for disabled children and their families.

Chapter Two

Literature Review

In this chapter the contexts in which this research is embedded and the theories and models that have shaped the directions and themes of this thesis are introduced. I will also show how contemporary concepts of disability, childhood and motherhood are socially constructed. The first section will illustrate how our present understanding of disability has been affected by the development of medical perspectives and by civil rights movements, including the disability movement in Britain. In the second section issues involving professionals who are concerned with the treatment and care of children with disabilities will be outlined. The influence of professionals has been identified as significant in the construction of concepts relating to disability, childhood and motherhood. The third section will contextualise and discuss issues related to motherhood, which has been transformed greatly in the past few decades, in line with a changing understanding of what constitutes childhood. The ways in which mothers with disabled children respond to social expectations will also be described in this section. In the last section, the discussion will expand to include other relevant issues related to care.

How disability is understood

Since the 1960s, the causal relationship between impairment and disability has been challenged. The discussions on issues surrounding disability have expanded the contemporary concepts of disability. Apart from the sociology of health and illness that is concerned with individuals' subjective experiences of impairments and disability, debates on disability studies have examined how the concept of disability is constructed in social, medical, economic and historical contexts and has generated strategies for dealing with the problems identified. This section will present influential perspectives and models which address how we can understand disability.

Sociology of health and illness

The findings of scholars working in the field of the sociology of health and illness have contributed to an increased understanding of individuals' experiences of illness/impairment in their daily lives (Williams, 2001). The concept of the 'sick role', proposed by Talcott Parsons (1951 cited in Barnes et al., 1999), has been identified as influential in the development of medical sociology (Lawton, 2009). This concept of the sick role is built on viewing impairments as a deviation from normality that allows patients to escape temporarily from their social roles and expectations (Barnes and Mercer, 2007; Fawcett, 2000). The concept of the sick role is criticised by Bury (1982: 168) for being oversimplified; he argues, 'the notion of adaption is often linked to a view of disablement as a relatively stable entity. In fact, the conditions which underpin most forms of disablement involve fluctuating symptoms and uncertain outcome'. However, this concept has continued to inspire scholars. Lawton (2009) indicates two approaches that have been generated from this influence. The first of these focuses on how people use their subjective narratives to construct meanings. Following Gareth Williams' work in1984, Lawton highlights how discussion of 'health beliefs' has changed to include individuals' 'accounts' of their experiences; and that the narratives can now be viewed as 'factions'. As Alan Radley and Michael Billig (1996: 222 cited in Lawton 2009) suggest, people's accounts are used as strategies to 'make themselves accountable to others and to articulate for others their own position in the world'. Furthermore, introducing related research, Lawton draws attention to the ways in which people's accounts are examined as a form of self-presentation that is formed in new contexts, such as the development of their illness, and is influenced by the cultural and historical factors.

The second approach is concerned with the impact of illness on the lives and identities of individuals. For example, Bury (1982) proposes the concept of 'biographical disruption'. He demonstrates how the experience of becoming a patient with rheumatoid arthritis not only undermines one's self-concept by shifting one from 'a perceived normal trajectory … to one fundamentally abnormal and inwardly damaging' (1982: 171); he also points out that this painful and often disabling condition may disrupt one's relationships with others.

Based on knowledge generated by the sociological study of health and illness, the definition of International Classification of Impairments, Disabilities and Handicaps (ICIDH) was proposed by Philip Wood, Michael Bury and Elizabeth

Badley (World Health Organisation 1980: 27 cited in Shakespeare, 2006). Impairment is defined as 'any loss or abnormality of psychological, physiological or anatomical structure or function'; disability is defined as 'any restriction or lack, resulting from impairment, of ability to perform an activity in the manner or within the range considered normal', while handicap is described as 'a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual'(World Health Organisation 1980: 14 cited in Shakespeare, 2006).

However, writers of disability studies have found the sociological definition of disability unsatisfactory. One of the problems is that it does not challenge the medical perspectives on disability and considers only the ways in which individuals cope with impairments (Oliver, 1990). Although social and cultural contexts are acknowledged in the ICIDH definition, and the revised ICIDH-2 definition even tries to incorporate the concepts of the social model into a new 'biopsychosocial' approach, this definition is still criticised by writers of disability studies for adopting biological impairment as the main cause of disability and for ignoring the role of social and cultural contexts (Barnes and Mercer, 2007; Thomas, 2004; Oliver, 1990).

Overall, sociology of health and illness approaches are questioned by activists and scholars in disability studies in three ways. First, although it may be impossible to distinguish illness from disability, Scully (2008) argues that there remain substantial differences between them. The influential concept of 'biographical disruption' may explain the significant change of an ill person's life or a person who becomes disabled later in his/her life when certain levels of identity have developed. However, it is different from persons who are born with an impairment who grow up with awareness that they are different from others (Scully, 2008). Second, when the impact of the illness and individuals' coping is highlighted, illness is therefore ranked as the main problem, leaving other difficulties caused by social and cultural factors ignored. Third, this focus on personal experience leaves the impact of medicalisation unquestioned (Barnes and Mercer, 2007; Oliver, 1990). Scholars have expanded the physical effect of illness and impairments to the overall impact when medical perspectives dominate the way we understand problems. In general, medicalisation is defined as the dominance of medical approaches and medical experts (Shakespeare, 2006).

Disability studies has given greater consideration to the role of medical institutions and frameworks in the production of 'disability'. The claim is that the category of 'the

disabled' was gradually created after the nineteenth century which was supported for several social conditions (Scully, 2008). The interpretation of being punished by moral or religious reasons has been progressively replaced by biomedicine, supported by its claim to offer better explanations and treatments to illness and disability (Scully, 2008). The way to view social deviance shifted from badness to medical judgements of biological deficit (Barnes and Mercer, 2007). In the nineteenth century the U.K. government administration started drawing support from medical professionals to categorise people by quantifying deviation into groups of unable/unwilling to work and worth/not worth helping in order to solve problems caused by the industrial revolution and capitalism (Oliver, 1990; Finkelstein, 1981; Scully, 2008; Braddock and Parish, 2001).

The medical influence has further increased, alongside the development of medical knowledge and technology. After World War Two, the development of medicine and science increased still further the potential for medical intervention to cure and correct, with corrective surgery being performed on disabled children (Priestley, 2003; Borsay, 2002; Finkelstein, 1981), or to prevent impairment or illness by using genetic technologies (Scully, 2005). Impairments were viewed as abnormal, and correcting the deficit or rehabilitating has become a primary goal of medicine in order to help disabled people to approximate normality.

In the present service system, medicine not only defines, categorises, measures and treats impairments (Barnes et al., 1999), but also, the services or benefits disabled people can get are mainly dependent on the measurement and evaluation of the impact of their impairment by technologies manipulated by medical specialities (Williams, 2001). The difficulties disabled people encounter are narrowed into medical issues that leave other aspects of their social circumstances unconsidered. Hence, scholars in disability studies have argued that, although medicine helps disabled people in many ways, it can only deal with the biological impairment and cannot solve all the problems in disabled people's lives: for instance, those caused by inappropriate social arrangements such as social exclusion (Barnes and Mercer, 2007). The issue is not only about viewing biological illness and impairment as the main problems, but also about how medical approaches dominate how disabled people should live their lives, while their accounts and wishes are not fully recognised and respected. In contrast to an exclusive focus on biological impairment from medical perspectives, many researchers in disability studies instead argue that disability is not only a medical problem.

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Social model

In Britain, the most influential model in disability studies is the social model that focuses on resisting medical control and removing barriers caused by inadequate social arrangements so that disabled people can control their own lives (Shakespeare, 2006). In this section the contexts which contributed to the development of the social model are first described. This will then enable us to examine the contribution made by the social model and critiques of this model which have arisen from various perspectives.

The British disability movement is embedded in its social context. Before the disability movement, a large number of disabled people lived in institutions. Oliver (1990) argues that these institutions not only provided care but were also strategies for ensuring social control in a capitalist society. However, the inadequacy of this system of institutional care had become one of the important forces that gave rise to the disability movement in Britain. From the late 1960s, disabled people, especially those who were forced to live in residential institutions, started to organise themselves and this had a profound effect on the disability movement (Barnes and Mercer, 2007).

Several organisations, such as Disablement Income Group (1966), Disability Alliance (1974), the British Council of Organisations of Disabled People (1981) and Disabled People's International (1981), were established and started to express their views on disability (Shakespeare, 2006). One of the most influential definitions of disability in Britain was proposed by the Fundamental Principles of Disability, published in 1976 by The Union of the Physically Impaired against Segregation (UPIAS). It provided the foundation on which the social model has grown:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976: pp.3-4).

One of the remarkable achievements of the disability movement was that disabled people recognised the potential of generating their own discourses and models to reinterpret their experiences of disability and to divert the focus of debates, rather than

allowing themselves to be passively defined by others (Braddock and Parish, 2001; Fawcett, 2000). Both Oliver (1990) and Barnes and Mercer (2007) highlight the importance of definitions because these influence both how a problem is framed and the subsequent solutions, that in turn will profoundly affect disabled people's lives.

As mentioned in chapter one, in the 1980s, two influential models, the medical model and the social model, had been generated in disability studies (Shakespeare, 2006). Michael Oliver (1983: 15) called the medical approach that views an individual's impairment/illness as a personal tragedy and as the main cause of disability the 'individual model', in order to differentiate it from the social model (Shakespeare, 2006). Nowadays, in general, the medical model refers to the view of disability as an individual pathology or tragedy that is caused by biological defects and dysfunctions; hence the emphasis is on medical treatment and rehabilitation in order to help disabled people to approach normality (Barnes and Mercer, 2007; Thomas, 2002).

Rather than being an individual tragedy or an inescapable biological destiny, scholars have argued that disability is caused by social oppression, social exclusion, social barriers and power relations (Barnes and Mercer, 2007; Finkelstein, 2001; Oliver, 1983). It is the society, not disabled people, which should be changed (Barnes and Mercer, 2007; Thomas, 2002; Finkelstein, 2001; Oliver, 1983). Apart from discussing how disability is constructed by medicine, as mentioned earlier, forerunners of the social model such as Finkelstein (1981) and Oliver (1990) explain how concepts of disability have been constructed in historical contexts. They demonstrate how from a Marxist/materialist perspective disability is seen as a form of dependency in an industrial and capitalist society (Thomas, 2002; Oliver, 1990; Finkelstein, 1981). Since it is difficult for disabled people to meet certain standards which are required in such a society, such as the productivity rate, disabled people are normally excluded from the labour market, leaving them stigmatised as dependent (Oliver, 1990; Finkelstein, 1981). Accordingly, the supporters of the social model have tried to establish disability as being a result of disabling social arrangements, and the contemporary modes of understanding disability are socially and historically constructed.

According to social model, since disability is not caused only by biological impairment, medical treatments that focus on correcting or normalising disabled people performed by medical professionals will not solve all the problems of disabled people (Thomas, 2008; Barnes and Mercer, 2007; Oliver, 1990). Since it is the inappropriate social arrangements that disable disabled people, what should be focused on is the political

strategy that emphasises problems of social structure and makes efforts to remove social barriers. Simultaneously, according to forerunners of the social model such as Oliver and Finkelstein, the discussion of feelings and experiences related to impairment is only relevant at the individual level, and is thus a useless and passive approach (Barnes and Mercer, 2007). Therefore, the impact of impairment is normally excluded from debates related to the social model.

Shakespeare (2006) provides three explanations about why the social model became crucial to British disability movements and academia. First, as the slogan 'disabled by society, not by our bodies' indicates (Shakespeare, 2006: 33), the social model identifies social factors, such as prejudices and discrimination, as the cause of disability, and then indicates a clear political strategy: barrier removal. Second, it reverses the traditional deficit approach to a social oppression framework. Rather than feeling sorry for or ashamed of themselves and relying on charity or goodwill, disabled people were given a framework in which they felt able to be angry and demand their rights (see also Shakespeare and Watson, 2002). The social model contributes to a stronger sense of identity for disabled people. Third, in academia, the social model has inspired researchers to look at the influences of broader social and cultural contexts, such as discrimination, and the influences of industrial capitalism, which go beyond the traditional focuses of the medical sociology of disability on, for instance, modes of adjustment to being disabled and to what extent disability determines the identity of disabled people.

Since then, this approach has generated a wealth of literature that has examined various issues surrounding disabled people's lives, such as social oppression, inequality and exclusions that 'disable' disabled people (Barnes and Mercer, 2007; Thomas, 2004). Changes to society are advocated, such as independent living, removing social and environmental barriers or discriminatory attitudes, and promoting the idea that disabled people should have control over their own lives (Barnes and Mercer, 2007; Fraser and Greco, 2005; Thomas, 2004). However, the number of criticisms of the social model from various perspectives has been steadily increasing, including that the social model is not inclusive enough; the need to bring the body back; the way in which subjective experiences and interpretation are neglected; and how it does not pay enough attention to the diversity among the disability community.

The first main criticism of the social model is that it is not inclusive enough. In order to discuss this criticism, it is necessary to understand the contexts which gave rise to the

social model. Thomas (2004) indicates that the perspectives of the forerunners to the social model, like Finkelstein and Hunt, reflect their own experiences of being disabled in the 1970s, living in residential care, with minimal benefits, excluded from employment and the educational mainstream, and effectively prevented from gaining access to buildings, so these issues are important in the application of the social model.

In Oliver's (1990: 63) description of disabled people, the group he refers to is that of people who have become disabled later in their lives and who are expected to be able to approach normality again through medical treatment, rehabilitation and psychological adjustment. Finkelstein's (2001) explanation of why wheelchair users predominated in the UPIAS and why people with cerebral palsy were not represented also gives us a clue about what type of disabled people are involved more in political activities:

> There are, I believe, good historical reasons why people who used wheelchairs did predominate in UPIAS. They tend to be less isolated and so had greater awareness of significant social changes that were already taking place in the health and welfare services as well as political struggles and the general state of the economy. Many had been able-bodied and were familiar with social movements. On the other hand when we ask why people with cerebral palsy were so absent from self-help organizations of disabled people it may be that because they were born with an impairment they were often 'overprotected' by caring parents and consequently isolated from active contact with radical social movements. They tended to be more passive, having been indoctrinated with the understanding that people with abilities will always look after their needs (Finkelstein, 2001: 4).

According to Oliver and Finkelstein's descriptions, physically disabled adults, especially those who had become disabled later in their lives, were influential participants whose experiences became important references when the social model was developed. According to Finkelstein's explanation, rather than inclusion, distinctions are suggested, such as the differences between people who used wheelchairs and people with cerebral palsy, and between people who were once able-bodied and those who had been born with an impairment.

Finkelstein (2001: 4) also states, 'some people were critical of who joined UPIAS - mainly people using wheelchairs. We made no effort to recruit any specific group of disabled people but insisted that members shared a common perspective'. It might be an essential strategy to ensure that an organisation's members are committed to the mission of that organisation. However, it will be problematic if only a certain kind of voice is included. When certain groups of disabled people and certain perspectives are especially highlighted, it can imply exclusions rather than inclusion. Problems can also arise when the concept of the social model generated from particular groups is applied to all disabled people and claims to refer to all disabled people (Fawcett, 2000). Although discussions of the social model that used to be led by physically disabled adults have subsequently been extended to include sensory and cognitively disabled people, the criticism remains that some categories of disabled people are still not included or benefited, for the reasons described below (Barnes and Mercer, 2007; Campbell and Oliver, 1997).

Although the call for removing social oppression has been a powerful and useful strategy, it has not provided solutions to all the diverse problems disabled people encounter. Not every disabled person can benefit from the political strategies the social model proposes. For instance, even if all social barriers are removed, some disabled people would still be unable to obtain employment because of their impairments (Shakespeare and Watson, 2002), such as people with learning difficulties (Kittay, 2002b).

Second, although applauding the social model for offering a vision of a changed society in which disabled people might be free from oppression, some writers, based on their own experiences of disability, indicate the problem of ignoring impairment and assert the importance of 'bringing the body back' (Shakespeare, 2006; Shakespeare and Watson, 2002; Crow, 1996). For example, Crow (1996) disagrees that bringing the implications of impairment back into consideration will undermine or weaken the civil rights movements or disregard the types of oppression disabled people encounter. Because, for some disabled people, the experiences related to their body or impairments are important. The impact of their impairment is still embodied in their daily lives that can not be eliminated through removing the social barriers (French, 1993). If the impact of body/impairment is neglected, the experiences of these disabled people may continue to be excluded and their needs not fully recognised (Williams, 2001).

Scully (2008: 28) further argues, 'if social-relational approaches have nothing to say about impairment, then biomedicine will have everything to say about it'. Scully's argument highlights the problems of leaving issues related to impairment aside. Giving up the debates related to impairment may only leave the dominating discourses unchallenged; continuing to influence disabled people's lives profoundly. Moreover, Scully (2008) suggests, there are various approaches in medicine, and not every medical professional holds the same view. Although under the umbrella of 'the medical model', it is still possible for some medical professionals to hold similar ideas about disabled people's welfare providing insights from the medical perspective. Ruling out all the influences of medical perspectives and medical professionals may therefore lose opportunities to cooperate with these kinds of medical professionals. Although it may seem politically essential to separate disability from impairment, this approach may lose them their battlefield both in private and public sphere.

Third, the social model is criticised by sociologists of health and illness as being over-socialised, and for neglecting personal and subjective meanings and experiences (Thomas, 2004). For example, if disabled people do not want to espouse a political approach, do not want to view themselves as disabled people or as part of the disability movement or celebrate being disabled, but want to minimise their disability in order to integrate into society, they are often viewed as representing 'internalised oppression or false consciousness' (Shakespeare and Watson, 2002:20; Barnes and Mercer, 2007, Scott-Hill, 2004). On the other hand, according to the sociology of health and illness, disability is complex, since the dynamic interaction between disabled people and social structural factors can affect their subjective interpretations of their experiences of disability and their identities as a disabled person (Barnes and Mercer, 2007). Williams (2001: 132) argues that the unitary assumption of social oppression ignores disabled people's identities and social positions: 'theorizing disability is not merely about abstractly conceptualizing the relationships between impairment and situations- it is about how those relationships work for people in dynamic and complex personal and social processes'.

Therefore, Crow (1996) is concerned that if the experiences described above are excluded, the disability movement could become a movement for an elite group that does not include all disabled people. Therefore, scholars such as Crow (1996) and Shakespeare (2006) suggest including multiple dimensions of disabled people's lives. Crow (1996) proposes renewing the social model by highlighting the subjective

experiences of disabled people and how this can be influenced by their functional limitations and personal situation, such as race, gender, financial conditions, time and changing circumstances. Crow suggests, when the experiences of the impairment are integrated into disabled people's autobiography, a better sense of themselves can be established. It can be viewed as the first step towards empowerment. Shakespeare and Watson (2002) argue that disabled people should be allowed to have multiple identities. Shakespeare (2006: 58) further suggests putting the social model aside, and defines disability as 'the outcome of the interaction between individual and contextual factors - which includes impairment, personality, individual attitudes, environment, policy and culture'.

The last critique of the social model comes from groups such as feminists, postmodernists and the anti-racism movement who emphasise diversity, and their ideas have also expanded the discussions of the social model (Fawcett, 2000). They have done so by expanding our understanding of the social divisions between and within categories that used to be taken for granted (Barnes and Mercer, 2007; Fawcett, 2000). The assumption of the homogeneity of disabled people's experiences has also been challenged (Barnes and Mercer, 2007; Thomas, 2002; Vernon and Swain, 2002; Fawcett, 2000), although some disability activists and academics, such as Oliver (1996) and Barnes and Mercer (2007), are wary of these calls to emphasise diversity, since this could have a negative impact on the unity of collective action and blur the differences between disabled people and non-disabled people, thus causing fragmentation, which would make it hard to present a clear political message (Fawcett, 2000).

Although the assumed collective identity has been challenged, Scully (2008) acknowledges it still has positively affected understandings about disability for both disabled people and non disabled people that therefore have transformed disabled people's status and lives. Although the assumed collective identity may be distorted, it provides a foundation to reflect on, and therefore be improved for the better. Drawing from arguments of Nancy Fraser and Iris Marion Young about the political recognition of minority groups, Scully (2008) agrees that the positive aspect of being recognised as a legitimate group is helpful to being socially recognised, enhancing the possibility of making changes. For individuals, a collective identity that is different from what the dominating discourses can offer may provide individuals other perspectives to develop their subjectivity and moral agency. However, following Lindemann Nelson's (2001) discussion about damaged identities, Scully is also aware of the limitations of the

master discourses including the newly developed template, 'the strong social model'(2008: 25). This is because it can be simplified or homogenised, as other scholars have presented earlier. Rather than arguing if the political collective identity has worth or not, or if we should stress subjective individual interpretations or structural social barriers, Scully instead suggests a disability community where various identities and narratives can be emerged, described, discussed, and may be able to further support the development and discussion of ongoing collective identity. These narratives are not necessarily political, echoing the proposed collective one, or limited by the assumed disabled identity, instead, the diversity may therefore be respected in this disability community.

The diversity among disabled people is increasingly recognised in disability studies: for instance, the impact of gender, race, class and culture (Fraser and Greco, 2005; Thomas, 2002; Fawcett, 2000; Shakespeare, 1996). For example, Disabled writers on disability have highlighted the absence of the voices of disabled women and have made an effort to shed light on the perspectives, experiences and needs of disabled women (Thomas, 1997; Morris, 1991). Begum et al. (1994 cited in Fawcett, 2000) use the term 'double oppression' to describe disabled black people, and 'triple oppression' to describe disabled black women. Drawing on Braham's (1997) and Gilroy's (1992) work, Fawcett (2000) argues that although these labels describe the type of oppression experienced by individuals, the stereotypes of these categories might devalue or mask the complex nature of the lives of disabled people. Moreover, disabled people might become overwhelmed if they see themselves as victims of all these types of oppression, making resistance more difficult. Scully (2008: 143) provides an explanation for the reason of being overwhelming. While claiming for the oppressed political identity, individuals may feel the need to take on the 'victim' role. Although the 'sense of victimhood' may be useful to provide another perspective, it may cause other problems while viewing it as the only explanation or having negative on the development of their self-concept. Although the types of diversity caused by gender, race and class is now receiving more attention, some groups are still being marginalised: for instance, older disabled people (Zola, 1991 cited in Williams, 2001) and disabled children (Connors and Stalker, 2007; Brett, 2002; Dowling and Dolan, 2001).

One of the reasons that the experiences and needs of disabled children are marginalised is because they are not only 'disabled' but also 'children', who are assumed to depend on adults, including non-disabled and disabled adults, and their parents or carers are left

to speak for them. The problem is that parents/mothers are often placed in a marginal position in both disability studies and the disabled people's rights movement, because they are non-disabled people, and this weakens their voices when speaking for their child (Ryan and Runswick-Cole, 2008). Parents are often viewed as potential barriers that keep their disabled children from independent living by overprotecting them, or as being in the same camp as the professionals, whose aim is to 'normalise' the disabled child (Barnes and Mercer, 2007; Finkelstein, 1998; Campbell and Oliver, 1997). However, scholars have argued that it is not useful to assume that a binary opposition exists between disabled and non-disabled people (McLaughlin, 2006; Shakespeare, 2006). Ryan and Runswick-Cole (2008) further argue that we need to pay more attention to both disabled children and other family members.

Stigma

Stigma, as acknowledged by Erving Goffman (1990) who is generally viewed as a symbolic interactionist, has been applied and discussed widely in different social issues, including within work examining disability. Goffman proposes three types of stigma, abominations of the body, blemishes of individual character, or the tribal stigma. According to Goffman (1990:15), how these various types of attribute are viewed is influenced by and negotiated within the social interaction between 'the normal' and those with a spoiled identity. How 'the normal' understands the stigma is affected by the social and cultural contexts that generate attitudes and behaviours towards people with a stigma. The power of the dominating group, 'the normal', to define what is undesirable is an essential element in the process of stigmatization (Brown, 2010). On the other hand, being aware of the particular way that stigma discredits them, people with a spoiled identity will try to manage the stigmatization and influence its consequences, such as ''passing' (hiding the stigma) and 'covering' (reducing its significance) (Barnes and Mercer, 2007). Management and strategies can be different between the 'discredited' who has a significant stigma; and the 'discreditable' whose stigma is less visible (Goffman, 1990: 14). Therefore, for Goffman, stigma is not a fixed idea but a dynamic negotiation between people with and without the spoiled identity. When exploring issues related to disability, both sociology of health and illness and disability studies draw on the ideas about stigma proposed by Goffman in various ways. One approach is more concerned with individuals' subject experiences. In the case of mothers with disabled children, it is generally agreed that they may experience what

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Goffman (1990: 44) defines as 'courtesy stigma'. Gray (2002: 735) suggests, the courtesy stigma refers to 'a stigma of affiliation' when parents associate with their disabled child. The courtesy stigma is not only about face-to-face interaction within situational contexts when their child is present as previous research has revealed. Gray (2002) instead argues that the influences can expand to the relationship between parents and their child, and parents' identity as a parent of a disabled child. Green (2003b) suggests that the life style of mothers themselves and how they provide for their disabled children will also be influenced by mothers' experiences related to 'courtesy stigma'. Hence, feeling stigmatised is commonly reported by parents in empirical research (Blum, 2007; Brett, 2002; Green, 2002). Goffman's concepts of stigma are also used to explore parents' accounts about how they cope or manage issues related to the impact of disability (Green et al., 2005; Green, 2003; Gray, 2002).

Another approach that is more likely to be found in disability studies pays attention to how stigma is constructed, such as how professionals categorise people into groups of unable/unwilling to work and worth/not worth helping by adopting scientific and medical perspectives as presented earlier. This approach also argues that the process and result of stigmatisation is one of the social barriers that disable disabled people. For instance, the distinction between unable/unwilling to work and worth/not worth helping, according to Oliver (1990) l leads disabled people to be stigmatised as dependent and a drain on society.

Although an individual with a stigmatised and spoiled social identity might find him or herself cut off from society, according to Goffman (1968), there are two groups of sympathetic others who are able to accept such an individual as 'human and "essentially" normal in spite of appearances and in spite of his own self-doubts' (Goffman, 1990: 31). The first group is that of 'the own': those who share the same stigma and who therefore might be able to suggest 'tricks of the trade' and allow the individual to feel accepted as a person. The second group is that of 'the wise', who Goffman defines as 'persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of acceptance, a measure of courtesy membership in the clan'. The 'wise' may be divided into two types:

> *The first group includes those whose wisdom comes from working in*
> *an establishment which caters either to the wants of those with a*

particular stigma or to actions that society takes in regard to these
persons; the second type includes people who are related to the
stigmatised individual through the social structure - a relationship
that leads the wider society to treat both individuals in some respects
as one (Goffman, 1990: 42-43).

Although Goffman's theory about stigma is normally mentioned in the discussion within disability studies, it is seldom viewed as one of the main frames in disability studies. This is for a variety of reasons including, as Oliver (1990:66) suggests Goffman's model draws to heavily from psychological models. What this means is that institutionalised practice is ignored while attention is paid mainly to process and individual interaction. Therefore, although there are a lot of debates about professionals' power, the limitation of professional knowledge, and the legitimacy of parents' voices within disability studies, connections are seldom made to Goffman's category of the other, the wise, and the own. Although the distinction between 'the own' and 'the wise', and two groups of 'the wise' are only one sub ideas to support Goffman's concepts of stigma. It is useful for this research to think about the relationship between the two groups of 'the wise', the professionals and the mothers with disabled children. It is also interesting to rethink the different 'wisdom' that 'the wise' may possess.

To sum up, this section has presented how the category of disability is defined. It was first created for medical and administrative purposes that have a profound impact on the contemporary comprehension of disability, how disabled people are viewed, and it also affects the services and treatments designed for disabled people. The definition of the category of disability that is based on individual biological impairment has been reversed by activists and scholars in disability movements and disability studies through redefining disability as a result of inappropriate social arrangements. This redefinition has provided disabled people with another perspective to develop their self-concept. It also has enhanced the social recognition of the disabled community and has demonstrated disabled people's abilities and moral agency. The newly defined interpretation about disability has been used as a tool to develop its legitimate claims, removing the inappropriate social arrangements that disable disabled people.

Although the binary distinction between the medical and the social model offers a useful framework for understanding experiences of disability, both the medical model

and the social model have been criticised by scholars for being over simplified and not leaving enough space for disagreement and diversity among disabled people's subjective experiences and interpretations. It may be time to put the debate aside regarding which frame can explain social issues better or how much it can explain, and to think instead about how to move on from these existing foundations. Lindemann Nelson's (2001:6) argument about the 'master narratives' provides another perspective to see the function and limitations of the existing frames. Lindemann Nelson (2001: 6) indicates the problems of existing 'master narratives', by which she means, 'the stories found lying about in our culture that serve as summaries of socially shared understandings', therefore, it is an essential 'cultural store' (p152) for individuals to recognise their positions, their relationships with others, and to be recognised. Lindemann Nelson suggests, in the 'abusive power system', members of certain groups may be forced to take on damaged identities that set up inappropriate assumptions about how the members with damaged identity should act or what they are allowed to do, which she named 'deprivation of opportunity (2001: xii)'. Simultaneously, members with damaged identity may internalise the problematic assumptions as part of their self understanding which Lindemann Nelson calls 'infiltrated consciousness'. The alternative way to deal with the issues of damaged identity, Lindemann Nelson suggests is by using 'the counterstory' for retelling narratives; filling the gap between master discourses and the real life with unnoticed detail; and repairing, resisting, or replacing the damaged descriptions, and therefore supporting individuals to exercise their moral agency. For the dominating groups, their understanding about the damaged identity may be changed so that more opportunities for the members of the damaged groups to exercise their agency may be increased. For the individuals, they may start resisting the problematic comprehension and developing their own self understanding.

It could be argued that the social model began as a 'counterstory' which offered a framework for resistance. However the critiques which have been made of it suggest that over time it has instead become a master narrative that only highlights certain values, while excluding others. Therefore, encouraging and respecting new counterstories may be an important strategy for moving on.

For Scully (2008), the counterstories are not only about modifying or creating a new more inclusive master narrative. It is not only the prevailing discourses that can be inappropriate; if the new master narrative is idealized it will not lead to better comprehension about the marginalised group. If this occurs it will lead to

misunderstanding and cause pressure to members of the marginalised group to live up to the new narrative. For example, if a disabled person does not match the new praised template of the 'supercrip' they may be unfairly judged as not working hard enough. Therefore, apart from the inappropriate or toxic discourses, Scully (2008) further indicates another problem; there may be no single appropriate discourse for disabled people to understand their experiences through. Nevertheless, Scully suggests using counterstories emerging and shared in the disability community can be a tool to repair distorted and damaged assumptions about their disabled identity. Through providing more details of real life, especially how they manage their impairments, may enhance opportunities for disabled people to exercise their moral agency. Therefore, this research intends to present mothers' counterstories with details about how they manage issues around disability, and how they develop their own motherhood in order to provide other perspectives to understand mothers' experiences.

Professionals

The modern welfare state and health care has enabled a range of professionals to have a significant influence on the lives of disabled people (Williams, 2001; Finkelstein, 1981). It is not only the medical treatments they offer, but also their assessments and evaluations of the needs of disabled people that have a direct impact on the benefits to which a disabled person is entitled, and this in turn has an effect on every aspect of that person's life (Barnes and Mercer, 2007; Oliver, 1990). In this section, the development of professionalism, issues surrounding professionals and the impact of the professional approach on the lives of disabled people will be discussed.

Turner (1995) indicates two approaches in sociology to discussing 'professionalisation'. The first views professionalisation as an accumulation of traits. For example, drawing on the work of several scholars, Millerson (1964 cited in Williams, 1993) identifies several features of a 'profession', as follows: skill based on theoretical knowledge; provision of training and occupation; tests of the competence of members; organisation; adherence to a professional code of conduct, and altruistic service. The second approach, according to Turner (1995), concerns the role of professionals in maintaining social order. For example, Talcott Parsons argues that from the perspective of functionalism, professionals can help to maintain a stable social order (Evetts, 2003; Turner, 1995). Rather than taking the traits and functions of professionals for granted,

recent scholars are concerned with the making of professionals, how they make themselves into professionals, and how they prove themselves as professionals.

Claiming possession of knowledge is one of the most significant strategies professionals use to distinguish themselves from others (Fournier, 2000; Turner, 1995). Professional knowledge is normally presented as obscure, unintelligible, objective and mysterious (Fournier, 2000) and is claimed to be evidence-based, generalisable, or scientific (Henderson, 2010). Professional knowledge is also characterised as being objective (Woodward and Watt, 2004; Callery, 1997). Fournier (2000) suggests, based on the claim of exercising scientific knowledge objectively, that professionals see themselves as altruistic and as making decisions for the public good.

Another of the key defining characteristics of professionals suggested by Friedson (2008:255) is that of organised autonomy, by which he means that professionals have control over their work. Organising and operating within various organisations and institutions is one of the tactics professionals use to prove their competence. Professional knowledge is viewed as being produced or learned only through specific procedures in recognised institutions. Evetts (2003: 397) suggests, 'professions are essentially the knowledge-based category of occupation which usually follow a period of tertiary education and vocational training and experience'. Licences are only given when members prove their competence by passing the required tests (Friedson, 2008; Fournier, 2000). Codes of ethics are used to control the quality of professionals' products and are viewed by Turner (1995: 131) as one of three necessary dimensions of professionalism, the other two being knowledge and power. By using the strategies described above, professionals claim to be self-regulated (Fournier, 2000). Fournier (2000) indicates that through proving they are self-contained, professionals establish their professional field and can claim to be autonomous. Moreover, Williams (1993) argues that these strategies, including the content of the training, tests, ethical codes and licences, are all defined and operated by professionals themselves through organisations. In other words, when professionals use these strategies to prove they are competent and can be self-controlled, it is also a tactic to reduce external influences and ensure they are the ones who decide the rules for constructing their professional fields. Because of these tactics of constructing their own professions, professionals occupy a different social position from lay persons. Moreover, professionals also distinguish themselves from other professionals (Turner, 1995).

Fournier (2000) argues that professionals not only occupy their particular field, they also turn that field into a place where only their own and no other professionals' interventions are legitimate. The possession of legitimacy is viewed by Friedson (2008) as one of the most significant characteristics of professionals; by this he is referring to both those who can do the work legitimately and the way it is done being legitimate. Through establishing and maintaining the boundaries, an exclusive division of labour is secured, and this, as Turner (1995) suggests, could be viewed as occupational control. Other scholars also suggest that these tactics of excluding other professionals and lay persons serve the purpose of maintaining professionals' privilege and status (Friedson, 2008; Deverell and Sharma, 2000; Fournier, 2000). Once the professional field is established, professionals need continuously to maintain and negotiate with others and respond to other social forces in order to demarcate their identities and assure their status (McLaughlin, 2003).

Since the late twentieth century, the development of the approaches to professional knowledge and self-regulation have helped fuel a broad critique of their power in society. The legitimacy of professionals has become increasingly challenged (Bolton, 2000; Fournier, 2000). The assumption that knowledge is neutral, isolated, objective, or altruistic was questioned (Skeggs, 1997; Harding, 1993). Instead, scholars became concerned with the impact of social, economic and cultural factors on professionals and suggested that professional knowledge and status are influenced by such external circumstances (Woodward and Watt, 2004; Fournier, 2000; Harding, 1993).

Some, especially Marxists, further suggest that professionalism does not always work equally for the public good and that some groups will benefit more than others (Fawcett, 2000; Turner, 1995; Oliver, 1990). Owing to the social problems caused by the industrial revolution and the rise of capitalism, the U.K. government drew support from professionals to provide strategies and solutions that contributed to the development of professions (Evetts, 2003; Hays, 1996). Since the development of professionals is related to the problems of the capitalist society, and since they try to ensure a certain level of social order, Friedson (2008) indicates that elites' values have been given more weight.

Although professionals claim to be 'altruistic' in their provision of services, contemporary critiques of their power stress that there is usually some sort of price to pay on the part of the service users: for instance, agreeing to follow the professionals' suggestions or conforming to their values. While acknowledging the benefits derived

from treatments, services and support following a medical diagnosis, several researchers in disability studies emphasise the impact and social control of medicalisation and the increasing power of medical professionals (Barnes and Mercer, 2007; Oliver, 1990; Finkelstein, 1981). The power of medical professionals to define normality and identify others as deviants from normality is highlighted (Braddock and Parish, 2001; Oliver, 1990). Oliver (1990) argues that institutions are a mechanism of social control creating stigma and social segregation.

Furthermore, the reach of medical professionals' power extends beyond the medical field to include various aspects of disabled people's lives. Several writers draw on Foucault's work, which highlights this feature of medical surveillance (Singh, 2004; Borsay, 2002; Oliver, 1990). In addition to identifying a deviation from normality, professionals can further invade the privacy of individuals through suggesting how they should live. The positions and choices offered to disabled people are either work hard to overcome disability or accept disability through physical rehabilitation, medical intervention and psychological adaptation (Shakespeare and Watson, 2002; Fawcett, 2000). If disabled people are unable to achieve goals set by professionals, they are viewed as not coping well (Oliver, 1983). Hence, Barnes and Mercer (2007) also refer to medicalisation as being a key strategy used to control disabled people.

Moreover, people with a privileged social position have a better chance of being viewed as having 'real' experiences and have more opportunity to participate in the process of shaping discourses or knowledge (Skeggs, 1997 :24). Since those experts or professionals who participate in policy making or academic debates might not have experience of being a woman or a disabled person, it is difficult for them to understand the needs and circumstances of these marginalised groups, or to make decisions based on their standpoints and interest (Mackenzie and Scully, 2007; Gottlieb, 2002; McKie et al., 2002). Accordingly, rather than being seen as objective, neutral and isolated, knowledge is now gradually becoming recognised as socially constructed and situated (Skeggs, 1997; Harding, 1993).

Recognising that individuals' experiences are not all given equal weight in the production and practice of knowledge, and since their experiences are often neglected, distorted or disparaged by the dominant discourses or by privileged groups, feminists and others emphasise the value of the knowledge of marginalised groups (Harding, 1993). Therefore, the 'lay' expertise of patients or service users has been increasingly emphasised. For example, rather than being grateful for altruistic help, following the

efforts made by the disability movement, disabled people now view it as their right to receive support (Shakespeare and Watson, 2002). Finkelstein's (2001: 8) assertion that it is time for disabled people to 'intervene in restructuring service provision' also reflects the challenges professionals face in the late twentieth century. In order to deal with the crisis in professional legitimacy, one of the strategies proposed in the last two decades is to be patient-centred (Henderson, 2010; Prior, 2003).

One of the strategies of being patient-centred is to encourage patients' participation in decision making in their partnership with professionals (de Geeter et al., 2002; Sloper, 1999; Williams, 1993; French, 1988). New demands are now being made on how professionals should work with service users in order that they respect their perspectives and develop a partnership with them. Professionals are expected to be sensitive, empathic, and to respect their clients' choices more when interacting with them (Bolton, 2000; Deverell and Sharma, 2000; Fournier, 2000). This practice has been emphasised in policies related to disabled people and their families, such as Aiming High for Disabled Children: better support for families (DeFS, 2007).

However, research continues to reveal difficulties in mothers' relationships with professionals. The choices and roles available for parents are still largely defined by professionals (Rixa and Paige-Smith, 2008; Leiter, 2004; Murray, 2000; Callery, 1997). For example, Kirk (2000) argues that although most parents agree with the principle of parental participation in order to ensure the welfare of a child with complex health care needs, they are not given the opportunity to negotiate or discuss what kinds and levels of participation they want or are able to engage in based on their diverse and changing circumstances. Instead, expectations, responsibilities and caring tasks are loaded onto the parents' shoulders without consultation. In a study of American mothers, Leither (2004) found that although more value was attached to mothers playing an active and key role after their cooperation with professionals in promoting the American early intervention programme, what constitutes a good mother is still shaped by the professionals' expectations. In other words, the strategy of parental participation is still not put into practice in the patient-centred context. It might also imply that under the mask of parental participation, the power relationship between professionals and parents might not have truly changed.

Although the expertise and experience of lay persons are attracting more attention and have started to be appreciated, lay persons' abilities are still questioned (Prior, 2003; Lowton, 2001). Callery (1997) found that maternal knowledge is viewed as a private

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and intimate understanding that is based on closeness and everyday contact, so that it has less authority than professional knowledge. Prior (2003) indicates that the experience of lay persons might be unfairly examined by adopting professional standards; on the basis of such standards it could be criticised for not being objective, for being impossible to generalise, and as consisting of partial and restricted individual experiences. As a result, the differences between lay persons and professionals are still emphasised and maintained (Fournier, 2000; Popay and Williams, 1996). It is difficult for mothers with disabled children to participate on an equal basis when their perspectives are not respected.

Accordingly, in the late twentieth century, in order to respond to the legitimation crisis in which the competence of professionals was being questioned, strategies such as the patient-centred approach and parental participation in decision making grew in importance (Henderson, 2010; Prior, 2003; de Geeter et al., 2002; Fournier, 2000). However, although the relationship between professionals and their clients has changed over the last few decades, the boundaries and distance professionals try to maintain leaves little space for lay persons to participate on equal terms in the decision making process. Professionals are frequently viewed as a type of social barrier by disabled people and the mothers of disabled children, whose choices and perspectives are still not accorded sufficient attention, appreciation or respect. The fact that previous research confirms that the maternal perspective differs from that of professionals and that this perspective is still being neglected, indicates the paramount importance of examining the experience and knowledge of mothers. The findings of this study will therefore make an important and original contribution in this area of disability studies.

Professionals and lay persons are normally viewed as separated groups, and the overlapping part does not get enough attention. However, some research does examine such overlaps, for example research which examines doctors' experiences of being ill. This work examines how doctors in such a position reconsider various aspects of their practice, including, their reflections on a good relationship between them and their patients, and what does being a good doctor mean (Fox et al., 2009; Malterud et al., 2009; Kay et al., 2008; Klitzman, 2006; Jaye and Wilson, 2003; Ingstad and Christie, 2001). The doctors in the research used their insight gained from their social position both as a patient and a doctor. Both Klitzman (2006) and Fox et al. (2009) used the doctors' experiences in their research to discuss how to teach empathy in medical education. They also recognised the power issues between doctors and patients and

suggest that doctors listen, are sensitive and that they encourage patients to engage more in matters regarding their treatment. Instead of following the traditional assumptions about interactions between doctors and their patients, positive aspects of doctors' self-disclosure are also raised by Malterud et al. (2009) and Ingstad and Christie (2001). The advantages and disadvantages of being a doctor before being a patient are also revealed. Although having the privilege of knowing how to interact with medical professionals (Jaye and Wilson, 2003), Ingstad and Christie (2001) indicates that doctors may be restricted to their medical knowledge and start to learn from the embodied experience of illness. The knowledge lay people developed has been recounted as valuable by the doctors. However, except for some rare research (Cole, 2005; Klein, 2007), those who occupy both the social positions as professionals and mothers with disabled children are not yet explored in disability studies, which will be an important theme of this research.

Contextualised motherhood and care

In the last few decades, both sociological ideas about motherhood and the practices associated with it have changed. This section will first examine how the contemporary understanding of childhood and motherhood is constructed socially. Why motherhood is portrayed as essential for women, why it is women, not man who are expected to take care of their children, and how the content and elements of motherhood is produced and delivered will also presented. The difficulties mothers with a disabled child encounter in conforming to social expectations about motherhood and how mothers develop the various aspects of their mothering will then be discussed. In the last part the discussion will be extended to include other relevant issues related to care.

Childhood

Sociologists suggest that we cannot fully comprehend motherhood without acknowledging children (James and James, 2004; Lawler, 2000), because how children are seen will influence the expectations of motherhood (Cunningham, 2005; James and James, 2004; Hays, 1996). The following paragraphs will demonstrate the ways in which the comprehension of and expectations regarding childhood are socially constructed.

The view that children have special needs is a concept that has gradually emerged over time. From the seventeenth or eighteenth centuries in Europe, first the bourgeoisie and then the aristocracy started to view children as valuable, innocent, dependent, vulnerable, needing to be cared for, and having special needs which were different from or even opposite to those of adults (Cunningham, 2005; James and James, 2004; Hays, 1996). One of the significant responses to this recognition of children as constituting a category in their own right was the introduction of efforts to protect children.

To this end, from the end of the nineteenth century and the beginning of the twentieth century, in the U.K. the state began to play an increasingly important role in children's lives, first by making policies and laws that set limitations on children's working conditions and establishing compulsory schooling for children: for instance, the Education Act of 1880, the Prevention of Cruelty to Children Act of 1889, the Factory Acts of 1864 and 1874 and the Children Act of 1908 (James and James, 2004). Rather than working as individuals performing an economic function as they had previously, children were supposed to be educated in schools or cared for in families (Walzer, 2004; Chodorow, 1978).

Researchers have argued that children were not only protected, but also that the category of children was formally formed, defined, assumed, or designed by adults through laws and policies which regulated what children were supposed or allowed to do (Cunningham, 2005; Priestley, 2003; Pinkney, 2000). However, James and James (2004: 23) refer to the differences in expectations concerning children between generations: for instance, they suggest childhood is 'the outcome of sets of discourse produced by adults, seeking to preserve or recreate the childhoods they remember'. As a result of social changes, children may no longer be what they are assumed or imagined to be by adults. Moreover, adults' expectations concerning what kind of adults children are supposed to grow up to be in the future will also influence how children are treated and what is expected of them in their childhood (Cunningham, 2005). Furthermore, according to James and James (2004), the assumption that there is only one set of conditions which constitutes a normal/ideal childhood can cause problems because it neglects the diversity among children.

However, children may not have the opportunity to participate in the construction of the category of children based on adults' memories or expectations, as James and James (2004: 34) argue that the concept of protection simultaneously imposes restrictions on children that mean they do not possess 'full social personhood', and thus excludes them

from adult spheres, creating an unbalanced power relationship between children and adults. Accordingly, the category of children does not exist alone but has a close relationship with that of adults.

A fundamental consideration in the sociology of childhood is the significance of class to constructions of what childhood is assumed to be (O'Brien, 2007; Cunningham, 2005). Hay (1996) points out that the target of compulsory schooling and the limitations on child labour were targeted at working class children, since children of the middle classes were already educated and did not need to work. Through compulsory schooling, social order and values associated with the middle class became dominant (Cunningham, 2005; Lawler, 2000). Another reason why middle class values became dominant was that the people who were devising the policies relating to children at that time were themselves middle class, and thought that their values were right, while working class values were wrong (Hays, 1996; Ribbens, 1994).

Cunningham (2005) also suggests that the so-called best interests of children referred not to their individual well-being but was actually closely related to the best interests of the state that expects children to be brought up to be moral, productive, independent, autonomous and even compliant citizens of the future. Hence, the relationships between parents and their children are no longer private. The concerns of the state are embodied in the policies and laws it introduces.

Although the state has become more involved in the process of child raising, parents, especially mothers, are still expected to shoulder most of the responsibility for protecting and controlling their dependent and vulnerable children (Cunningham, 2005; James and James, 2004; McKie et al., 2002; McCarthy et al., 2000; Skeggs, 1997). Good parenting, especially good mothering, is viewed as important in the process of children's development (Lawler, 2000; Hays, 1996). Motherhood is not only about providing care and letting children grow up - how to 'bring up' children has become a new challenge of motherhood (Ribbens, 1994: 1). Moreover, the goal of producing a good citizen has become a powerful force that influences the strategies suggested for raising children and the standards used to evaluate maternal success (Lawler, 2000; Hays, 1996). Alongside this transformation in the understanding of childhood, the expectations of motherhood were also influenced by other social changes.

Motherhood

With the advent of feminism, the view of women began to change, as did the exclusive emphasis on their role as mothers. Different factions of feminists responded differently to this emphasis on motherhood, and various strategies were developed at different times. In the nineteenth century, some feminists accepted the differences between men and women, extolled the tenderness and compassion expressed by women in their domestic feminine role and sought to establish an 'equality in difference' (Richardson 1993: 111). In contrast, from the 1970s onwards, the gendered expectations that support the discourse of an inseparable relationship between women and child rearing started to be challenged and deconstructed. Attention was also drawn to the social, economic, cultural and historical contexts in which motherhood is embedded.

The impact of the industrial revolution and the rise of capitalism have been identified as influencing various social arrangements that contributed to women playing a caring role in their families. When children were excluded from the labour market, they were either expected to be educated in school or be cared for in families, and it is normally assumed that the mother will take on this responsibility (Walzer, 2004; Chodorow, 1978). Raising children was no longer the joint responsibility of both parents as it had been in the eighteenth century; the gendered roles of women as mothers or carers responding to the needs of children and family members were emphasised and often portrayed as their natural duty and as a source of satisfaction, pride and identity that enriched their lives and was seen by them as desirable (Walzer, 2004; Traustadóttir, 1991; Stanworth, 1987). Since the family was no longer the basic economic unit, women had fewer opportunities to participate in productive activities (Walzer, 2004; Hays, 1996; Chodorow, 1978). Like children, in the name of protection, women were at first restricted or excluded from participating in the labour market by policies and laws that regulated their working hours (Hays, 1996; Rich, 1977). If women did go out to work, they often received lower pay than men doing the same job (Radnedge, 2011; Arendell, 2000; Traustadóttir, 1991). These social arrangements pushed women into playing caring roles, including unpaid caring and domestic work.

The ways in which gender roles are formed and reproduced is one of the interests of the feminist movement. Chodorow (1978) argues that human behaviour is not instinctually or naturally determined but culturally mediated. Motherhood, as a part of the sexual division of labour, is influenced by gendered institutional arrangements. According to Chodorow (1978: 214), the sexual division of labour, social relationships and social

structures are rationalised, and sexual inequality is reproduced through the 'internalization of their mothers' gender identities', and passed from mothers to daughters. Walzer (1998 cited in Walzer, 2004) claims that women and men carry their understanding and others' assumptions about gender roles while raising their children, hence, women become not parents but mothers. However, scholars suggest that changes in family size from an extended to a nuclear family have affected mothers' social networks and resources within kin and communities (Payne, 2000; Richardson, 1993). The knowledge of how to raise a child may no longer be passed on from generation to generation, from mothers to daughters, and instead they rely increasingly on experts (Hays, 1996; Ribbens, 1994).

The influence of experts has also been identified as influential in shaping the modern concepts and practice of motherhood (Cunningham, 2005; Hays, 1996). Apple (1995: 161) names this approach as 'scientific motherhood' by which he means, 'the belief that women require expert scientific and medical advice to raise their children healthfully'. Mothers are expected to update their knowledge about their child's physical and mental development in line with the suggestions of experts (Miller, 2007; Cunningham, 2005; Hays, 1996; Ribbens, 1994; Richardson, 1993). Mothers are also expected to be sensitive, selfless, self-sacrificing or child-centred, and concerned with their child's development (Carpenter and Austin, 2007; Lawler, 2000; Richardson, 1993; Stanworth, 1987; Rich, 1977). Hay (1996) indicates that strategies suggested by experts such as demonstrating unconditional love, being child-centred, expert-guided and labour-intensive are particularly influential in present concepts of motherhood. Hay calls this 'intensive motherhood', which she defines as 'a gendered model that advises mothers to expend a tremendous amount of time, energy, and money in raising their children' (1996: px). With the increasing emphasis on the best interests of children, motherhood is no longer seen as the inevitable outcome of maternal and biological instinct but as something mothers need to learn by following expert guidance (McCarthy et al., 2000; Hays, 1996). As a result, expert advice has became a source of anxiety and stress to mothers, and something which requires a great deal of confidence on the part of a mother to resist (Cunningham, 2005).

The views of the state are also influential in contemporary society. As mentioned earlier, in the nineteenth century, as a result of state intervention through policies and laws, children and women were excluded from the labour market. The state's intervention has not only shaped general views of the category of children, but also

expectations concerning motherhood. Moreover, as Hay (1996) suggests, it is partly as a result of state support that experts have gained the legitimacy to explain problems, suggest solutions, and shape expectations of motherhood. Although the state governs, monitors and influences private lives and claims to intervene when families are in need, the care of children is still generally seen as mothers' responsibility, one of their moral roles (McKie et al., 2002; Ribbens, 1994).

Morality has also gradually come to be seen as an essential ingredient of motherhood, leading to the concept of 'the moral mother' (O'Brien, 2007; Hays, 1996). Women are expected to regulate themselves so that they can be role models and set an example for their children (O'Brien, 2007; Lawler, 2000; Hays, 1996; Chodorow, 1978; Rich, 1977). According to McCarthy et al. (2000: 789), putting children's needs first is an 'unquestioned and unquestionable' moral notion. They argue that children's development is viewed as the mothers' responsibility and suggest that 'it is these adults who are thus held morally accountable for the actions of children in their care and are required to demonstrate their acknowledgement of their moral obligations through having tried to control their charges' (McCarthy et al., 2000: 788). Hay (1996) demonstrates the shift in mothers' moral roles in American society from being monitored to being the keepers of morality. Skeggs (1997) also argues that women, especially working class women, are not only expected to regulate themselves in order to pursue respectability, but also that the caring courses attended by the women in the North-west of England who participated in her research had transformed them even further so that they were able to monitor not only themselves but also those in their care. Accordingly, women, especially working class women, are normally viewed by the state as both the reasons for and the solutions to social problems, which means that if they can first regulate themselves and then go on to control their children and their husband effectively, there will be fewer problems in society (Lawler, 2000; Skeggs, 1997).

Accordingly, these notions and expectations suggested by experts, policies and laws have profound influences on what constitutes a good mother at a practical level. Some feminists go further and explain women's plight as being a result of oppression, asking the question, who benefits from this discourse? (Ribbens, 1994; Richardson, 1993) The group of white, middle class, heterosexual men is identified as especially benefiting from the contemporary discourses of motherhood (Cunningham, 2005; Arendell, 2000; Hays, 1996; Ribbens, 1994; Chodorow, 1978). Some scholars have highlighted the fact

that although white, middle class, heterosexual male employers, policy makers, professionals, experts or advice book authors might not have experiences of child rearing, they have more opportunities and legitimacy to shape the discourses of motherhood than women (Walzer, 2004; McKie et al., 2002; Ribbens, 1994). Hence, being a mother has been viewed as a barrier that obstructs women in their efforts fully to develop their abilities and potential and serves the aim of continuing to privilege men (McKeever and Miller, 2004; Walzer, 2004; Hays, 1996; Chodorow, 1978). In other words, the gendered issues are interlaced with other social characteristics, such as class and social positions, and are hidden within the so-called 'objective' knowledge proposed by professionals.

Feminists have also developed various approaches in order to understand the experiences of women. While at the same time encountering and interacting with social expectations and discourses about motherhood, some feminists have documented their reflections on their own experiences as mothers (Walzer, 2004; Richardson, 1993). They argue that the romanticised mask of motherhood as the identity most desired by women, an identity that gives them pride, reward and satisfaction, can actually leave women with negative emotions such as dissatisfaction, disappointment, anger and frustration (Miller, 2007; Arendell, 2000; Richardson, 1993). If women cannot adapt to such an identity, they might be blamed by others or even by themselves, and end up seeing the difficulties as somehow being their own fault (Lawler, 2000; Richardson, 1993). Hay (1996: 156, cited in Miller, 2007) argues that the assumptions that define motherhood as natural and instinctive ignore the 'circumstances, power relations and interests that have made women primarily responsible for mothering'.

Some feminists have searched for alternative strategies for dealing with women's difficulties. According to Mclaughlin (2003: 84), radical feminists focused on freeing women from the burden of raising children by technologies and communal living. Liberal feminists suggested providing childcare facilities so that women could participate in the public sphere. Socialist and Marxist feminists argued that people who provide care should be paid. Finally, feminists of ethics of care believed it was essential to acknowledge care rather than expecting others, such as technology or government, to take over the job. Feminist psychologist Chodorow (1978: 16) suggests separating 'child care from childbearing, nurturing as an activity from pregnancy and parturition' and proposes non-gendered care, in order to free women (Morris, 1991). These feminist approaches try to break the irreplaceable connection between mothers and child rearing

and the assumptions about what women should do. However, Miller's (2007: 347) recent empirical research on first-time motherhood finds that women continue to struggle with the notion that mothers will know what their baby needs/wants by nature/instinct, before finally realising that 'it didn't come naturally'. This implies that a gap between dominant discourses and contemporary motherhood experiences still exists. Despite the efforts of feminists in the last few decades to break the link between women and child rearing, being a mother is still an important identity for many women and certain assumptions about motherhood remain (O'Brien, 2007; Ribbens, 1994).

One of the possible reasons could be that being a mother is one of the most socially praised identities available to women that is a complicated and interlaced hybrid composed of various discourses such as the social expectations of a promising citizen of the future, the best interests of a child, the gender assumptions, and class values as presented earlier. As Lindemann Nelson (2001: 162-4) proposes, natualizing, privatising, and normalizing an oppressive identity are all used as tactics to rationalise the oppression so that the power relationship remains. Therefore, the oppression is not easily recognised. Moreover, the complicated intertwined hybrid can be difficult for oppressed individuals to resist. Meyer (1994: 54 cited in Lindemann Nelson 2001) precisely points out the struggles individuals have, she states 'even people who are victimized by these very figurations have reason to hesitate to overturn them. Insofar as members of socially excluded groups share the dominant culture's world view, their world view hangs in the balance, as well'. Even if oppressed individuals decide to refuse what dominating discourses offer, they may encounter another plight, there is no discourse available for them to understand their experiences and develop their own self concept, as Scully (2008) illustrates about disabled people's difficulties while trying to develop their own identities. Furthermore, it may be difficult for others to recognise these new narratives since they are different from the prevailing ones (Scully, 2008; Lindemann Nelson, 2001).

Rather than arguing about whether or not motherhood is an essential part of a woman's destiny, some feminists instead highlight the diversity of the experiences women derive from their social position as mothers and believe we could learn from their perspectives (Harding, 1993). Some researchers have examined the differences between women's approaches to motherhood on the basis of differences in their social characteristics and status (Miller, 2007; Lawler., 2000; Skeggs, 1997). Attention has been paid to the influence of social characteristics such as race, class and culture on the everyday lives

and diverse experiences of women (McKie et al., 2002; Arendell, 2000; Richardson, 1993; Chodorow, 1978). Scholars have also stated that both mothering a disabled child and the motherhood experiences of disabled women should be included in discussions on motherhood (Rapp and Ginsburg, 2001; Landsman, 1998; Thomas, 1997; Morris, 1991).

To conclude, ideas about what constitutes a good mother have been transformed over time (Hays, 1996). Generally speaking, motherhood is socially constructed and seen as being an irreplaceable caring role. Any difficulties involved in child rearing are seen as the sole responsibility of women in the private domain. One of the main reasons some women resist taking on responsibility for care is the lack of value attached to care by society; however, the downgrading of care or the severing of the link between mothers and child rearing is not the only or the most suitable approach for every woman owing to the diversity among women. In the following section the experiences of mothers with a disabled child are discussed.

Although feminists have successfully challenged some of the assumptions about women and motherhood, what they have suggested has been questioned by women from diverse backgrounds for the gap between their lives and the new discourses proposed by white, middle class, non-disabled women. It again highlights the importance of acknowledging the diversity within the category, in this case, motherhood. It will be useful to look at how mothers interact with these social norms that are designed to serve dominating groups, not only men, but also non-disabled people and professionals, while mothers occupy a social position as a mother with a disabled child.

In spite of the diversity among women that has been gradually recognised, it does not necessarily lead to inclusion. Instead, these various narratives are often viewed as a deviation or exception that is different from normality. This may provide a possible explanation for why mothers' experiences of raising their disabled child are still not included in prevailing discourses. However, the boundary between mothers with or without a disabled child may not be that distinctive. For example, mothers may not only be a mother of a disabled child but also a mother of a non-disabled child. Or, before getting the diagnosis, they are not viewed as a mother of a disabled child by others and themselves. Moreover, it is impossible to draw a line from the moment of getting a diagnosis that straight away separates them as two different kinds of motherhood. I do not mean that there is no point in acknowledging the differences, what I am arguing is the distinction that is taken for granted is not as clear as may be assumed. Although it

may be useful to discuss things theoretically through giving different groups various labels, the distinction may cause problems due to the categories given to people, such as 'mothers with a disabled child'.

Mothers with a disabled child

The adult assumptions that children are innocent, vulnerable, dependent and valuable have different implications when applied to disabled children. At the end of the nineteenth and beginning of the twentieth centuries, disabled children were categorised as unable to learn, and were often placed in special schools and institutions on the assumption that they would have no opportunities to participate in society (Cunningham, 2005). In the 1960s and 1970s, deinstitutionalisation and normalisation became important principles when designing services for disabled people; hence, disabled people started to live within their homes or communities instead of living in institutional settings (Barnes and Mercer, 2007; Rehm and Bradley, 2005; McKeever and Miller, 2004). Now, the majority of disabled children are growing up with their families and are cared for mainly by their parents, especially their mothers (Contact a Family, 2011; Leiter et al., 2004).

Although most disabled children receive better services than before, the negative assumptions concerning disability still exist. Disabled children are still presumed to be dependent or are seen as a burden because of the impact of their disability (Rehm and Bradley, 2005; McKeever and Miller, 2004; Larson, 1998). Since raising a child towards independence is considered one of the most important goals of motherhood, mothers of disabled children might be seen as failures, or as 'producers of defective merchandise', as Landsman (1998: 77) puts it. This kind of perception is built on the stigma and stereotypes associated with disability. In this section, research about experiences and perspectives of mothers with disabled children will be focused on. I will illustrate that although mothers with disabled children may be viewed as 'others' rather than only being different, as Lindsman (1998) suggests, the new set of expectations and assumptions waiting for these mothers are still influenced by the prevailing discourses, such as discourses about disability and motherhood suggested by the social norms, and the views of professionals and the state. On the other hand, mothers with disabled children may find it difficult to fit in with dominant social and

cultural norms and expectations that suggests it can be difficult for them to find a suitable discourse to make sense of their experiences (Scully, 2008).

Although it is often assumed that disabled children will not grow up to become independent, productive and autonomous citizens, this does not mean that their mothers are exempt from the pressure of social norms and expectations. Instead, research has revealed that the role of mothers of disabled children in particular can be narrowed down into the traditional caring role. As mentioned earlier, since men and women do not receive equal pay for the same work, therefore, many disabled children's families choose the fathers as the breadwinners, while mothers play the role of main carer (Gray, 2003; Traustadóttir, 1991). Both O' Brien (2007) and Leiter et al.'s (2004) research found that no matter what social positions the mothers occupied, they were all expected to take more responsibility for their children. Traustadóttir (1991) indicates that if a mother refuses to give up her job in line with the social expectations of a mother with a disabled child, she might be judged as deviant. Moreover, the notions of what constitutes a good mother are often distorted because of the impact of disability.

Generally accepted characteristics of a good mother such as selflessness and dedication are seldom questioned by mothers of disabled children (Hays, 1996). These ideas are also found in empirical research about experiences of mothers with disabled children that such mothers always tend to put their children first and hardly ever talk about their own problems or needs because they do not want to be viewed as selfish, or as competing with the needs of their children (Blum, 2007; Todd and Jones, 2003; Young et al., 2002). Furthermore, research has revealed that trying to help their child to achieve his or her maximum potential is an endless challenge and an important goal for many mothers and that this is expected by professionals (Landsman, 2005; Prussing et al., 2005; Leiter, 2004). However, some American researchers have questioned where this endless effort should end (Blum, 2007; Green, 2003b; Gottlieb, 2002), since there are always other expensive treatments on the market in America that parents can expend money and energy in pursuing (Rapp and Ginsburg, 2001). Furthermore, unlike other mothers, who can expect the selfless, child-centred nature of their motherhood gradually to decrease, mothers with disabled children may instead face an increasing number of challenges within their extended motherhood because they are getting old, their disabled children are growing up, and their other non-disabled children may have left home and thus no longer be able to assist with some of the caring tasks (Todd and Jones, 2005). Although it is assumed that parents will try to help their children to achieve the 'infinite

worth of the soul' (Gottlieb, 2002: 229), Gottlieb argues that the limitations on parental resources need to be recognised and respected rather than solely emphasising selfless, child-centred dedication.

Gradually (as research has illustrated indicated), mothers of disabled children find they no longer have a map or a predictable trajectory either for their lives or for how to bring up their child owing to the uncertainty surrounding the raising of a disabled child (Ryan and Runswick-Cole, 2008; Graungaard and Skov, 2007; Kearney and Griffin, 2001). This uncertainty can lead mothers on an unexpected journey that is different from social expectations (Rapp and Ginsburg, 2001). Since their understanding of motherhood, or what they imagined motherhood to be, is not applicable, such mothers start negotiating with dominant discourses in order to make sense of who they should be and how they should care (Ryan and Runswick-Cole, 2008)

In cases where the dominant discourses on motherhood have been found not useful, other mothers with disabled children have become important references for some mothers (Clavering, 2007; Poltorak et al., 2005; Fisher, 2001; Green, 2001; Beresford, 1994). However, because of the diversity among mothers, not all mothers will be able to obtain suitable support from other parents (Ryan and Runswick-Cole, 2008). At the same time, not every mother finds it necessary or useful to interact with other parents (Ryan and Runswick-Cole, 2009).

Apart from other parents with disabled children, professionals and experts have been identified as the most influential forces when mothers of disabled children are developing their motherhood. The medical perspective is the first interpretation of their child's disability most mothers encounter (Landsman, 2005). However, rather than feeling positively supported, some mothers have found being given a diagnosis a negative experience (McLaughlin, 2005; Kearney and Griffin, 2001). Rather than receiving support, mothers may encounter the problematic aspects of professionals' services.

Although researchers, especially medical service providers, might have good intentions in exploring mothers' experiences in order to provide support for such families, research has suggested that the gloomy outlook of the mothers of disabled children is often magnified and highlighted by professionals when they adopt the frame of personal tragedy to explain the mothers' experiences (Todd and Jones, 2005; McKeever and Miller, 2004; Beresford, 1994). While the bond and the relationship between mothers

and their children and the mothers' influence are viewed as the keys to their children's development, these are seldom discussed in the literature on disabled children's mothers; instead, the negative impact of disability is highlighted in the experiences of mothers with disabled children (Leiter et al., 2004; Taanila et al., 2002; Wallander and Venters, 1995). The more positive experiences of mothering a disabled child are either ignored or are interpreted as unrealistic or as denial from professional perspectives (McKeever and Miller, 2004; Larson, 1998).

Professionals not only identify, interpret and emphasise the 'special needs' of disabled children, they also evaluate and judge the mother's ability to respond to her child's needs and to follow the professionals' suggestions (Prussing et al., 2005). As Blum (2007: 202) states, mothers with disabled children might find themselves in a 'mother-valour/mother-blame binary' dilemma. The professionals expect mothers to make efforts, and if mothers refuse to give up or make 'too much' effort, or behave differently from the way the professionals suggest, they might be pathologised as not understanding the extent of their child's impairments or be judged as in denial, unrealistic, overly emotional, exceedingly optimistic, confused, or problematic (McLaughlin and Goodley, 2008; Carpenter and Austin, 2007; Todd and Jones, 2003; Brett, 2002; Larson, 1998). Although strategies of protection and control are viewed as necessary because their child is dependent and vulnerable, the behaviour of some mothers might be seen as overprotective (Ryan, 2005; McKeever and Miller, 2004; Todd and Jones, 2003). When disability is seen as being simply a case of biological impairment, the mothers' personal abilities and coping strategies, instead of social structures, become targets to be examined (Prussing et al., 2005).

Moreover, mothers with disabled children might find that their motherhood has been 'medicalised' (Case, 2000). They not only play the role of mothers, but are expected to play multiple roles assigned by professionals or created by their need to interact with professionals such as case workers, advocates and image managers (Blum, 2007; Kelly, 2005; Prussing et al., 2005; Ryan, 2005; McKeever and Miller, 2004; Todd and Jones, 2003; Beresford, 1994; Traustadóttir, 1991). Mothers with disabled children might be overwhelmed by these expectations on the part of professionals. Their private life may need to be opened up and examined (Read, 2000).

Some research has demonstrated that mothers do in fact resist the expectations and interpretations of professionals at various levels, for example, how their child is categorised and understood is questioned. One of the similarities among the empirical

research is mothers continue to argue that professionals cannot see beyond the mask of disability and 'written off' predictions to the unique individual their child is, so they make efforts to demonstrate their child's value and abilities and prove the doctor wrong (Graungaard and Skov, 2007; McLaughlin, 2006; Landsman, 2005; Green, 2003a; Green, 2001; Kearney and Griffin, 2001; Landsman, 1998). Other research has demonstrated mothers' resistance to assumptions that mothers are only mothers or a resource such as 'a pair of hands' (Brett, 2002: 833), rather than an individual human being whose voice needs to be heard (Carpenter and Austin, 2007; Dempsey and Dunst, 2004; Leiter et al., 2004; Brett, 2002). When encountering difficulties, strategies are generated by mothers, such as learning how to interact with professionals, including making a good impression and being prepared beforehand (Green et al., 2005; Prussing et al., 2005; McKeever and Miller, 2004; Todd and Jones, 2003).

For mothers of disabled children, the state's role is significant and some mothers even demand that it should take more responsibility and provide greater support and services for their child. In the U.K., the state does in fact provide more benefits and services to families with disabled children, compared to other families. However, raising a disabled child is still seen as being the mother's personal duty. As Hillyer (1993) indicates, mothers are not only expected to be responsive, but also responsible. How to share the care responsibility between mothers and the state is thus a contentious issue and is one of the main battlefields for mothers (McLaughlin, 2006; Gottlieb, 2002; Kittay, 2002b).

Although the social model provides another perspective from which to view experiences of disability, parents have not really benefited from this change. Instead, in some disability studies debates, they are viewed as one of the barriers that keep disabled people from having control over their lives. For example, Barnes and Mercer (2007: 62) state,

> People born with congenital or who acquire an impairment very early
> in life experience unrelenting socialization to low expectation or an
> 'abnormal' life-style while a few positive role models exist to
> demonstrate a contrary picture. Families and special schools may hide
> children with congenital impairment to protect them from
> discrimination, perhaps until early adolescence. The majority of
> disabled children grow up in households and communities where there

is no other disabled person. A variety of factors, including the actions of parents and close family members, lengthy periods of hospitalization, segregated special education, and a largely inaccessible physical environment, ensure that many of these children assume a conventional 'disabled identity'.

According to Barnes and Mercer (2007: 62), these disabled children will not be aware of the 'full impact of impairment' until they look for work, because they are shielded, probably overprotected, or have low expectations from their families. However, their argument is not consistent with findings of recent empirical research. While the families of disabled children are viewed as worked along with hospitalisation, segregated special education and inaccessible environments, research that is concerned with parents' experiences instead has demonstrated mothers' constant battles with the inappropriate arrangement involved with these institutions (Runswick-Cole, 2008; Clavering, 2007). The assumption about parents' low expectations is certainly not consistent with a critique from professionals' perspectives about parents who tend to be unrealistic or exceedingly optimistic in their expectations about their disabled child (Larson, 1998; Miller, 2007). In addition, without defining what counts for a normal life-style, parents are accused of offering an 'abnormal' life-style, which I think is confusing and unfair. While disabled adults are demanding to be integrated into mainstream society and to be enabled to live independently in the community, ironically, disabled children are described as being 'hidden' in a community. Therefore, continuing to adopt assumptions about the 'disabled identity' parents create can be problematic especially when recent empirical research has provided a quite different picture about the lives of mothers and their disabled children. It may mislead the ways in which to explore contemporary relationships between parents and their disabled child.

Moreover, as mentioned in chapter one of this thesis, parents have been viewed as being in league with the professionals and as trying to 'normalise' their disabled children (McLaughlin, 2006). For instance, for Finkelstein (1998), parents are 'non-disabled' competitors whose main goal is assimilation; therefore, they occupy a different position from disabled people. He notes,

It is obvious that the duel between 'care' and 'support' involved a number of players. Apart from the expanding body of professionals the main non-disabled contender for the right to determine the direction of facilities and services in the community were parents of disabled children. Parents, however, are already in a 'care' relationship with their children and, as well-intentioned and responsible adults, want the best for them. For the vast majority this will mean that they want them to be like themselves, as 'normal' as possible. Unlike their disabled children, however, parents are actively pursuing the goal of 'assimilation' into mainstream society (Finkelstein, 1998: 5).

It is understandable that disabled adults try to avoid allowing non-disabled people, including professionals and parents, to control their lives (Shakespeare, 2006; Barnes et al., 1999). However, in the case of some disabled children and some disabled adults, it is neither useful nor realistic to exclude the voices of parents and carers, since young disabled children and some disabled adults do need their carers or parents to speak out or fight for them (McLaughlin, 2006). Even if the mothers are not disabled themselves, research has indicated that they also suffer from the stigma attached to disability and the social barriers caused by unsuitable social arrangements, especially when they interact or negotiate with service providers (Green, 2003b; Gray, 2002). Mothers also make great efforts to remove social barriers for their children as the social model suggests (Runswick-Cole, 2007; Brett, 2002; Green, 2001). However, their experiences are rarely recognised but are marginalised in disability studies (Dowling and Dolan, 2001).

Researchers have started to attach a higher value to parents' experiences over the last few decades (Beresford, 1994). Not all mothers are passive receivers but exercise various levels of agency to resist discourses they encounter based on their personal situations (Beresford, 1994). Additional research has revealed the complexity of the mothers' worlds. The paradox of mothers' experiences has been documented to show the changeable and complex meanings of disability and the corresponding motherhood (Kearney and Griffin, 2001; Landsman, 1998; Larson, 1998). These discussions have established alternative perspectives to understand mothers' experiences.

To sum up, motherhood is portrayed as important; however, the example of mothering a disabled child implies that only the result or the product of motherhood matters. Since disabled children are considered incapable of developing into the stereotypical promising productive citizen of the future, their mothers' motherhood is viewed and treated differently. Although debates about mothers' experiences exist and are continuing to develop, there is still a gap between mothers' real lives and the prevailing frameworks or discourses, such as the assumptions and expectations raised by social norms, professionals or the state, and the new templates proposed by feminists. New angles such as the social model in disability studies have been developed, however, mothers with disabled children seem not to benefit much from these developments. Instead, an emphasis on the legitimacy of speaking only from the position of being disabled may become another frame that misunderstands, distorts or excludes mothers' experiences. Rather than adopting these existing frames, recent research has started to reveal more diverse or subjective experiences and interpretations from mothers' marginalised social positioning, of being women who are not disabled or professionals. Scholars such as Landsman (1998) and Gottlieb (2002) argue that mothers' experiences are valuable in that they give the mothers' perspective on living with disability. These researchers believe that such experiences can give prospective parents another angle when making a decision about their embryo if it has been diagnosed as possibly being disabled in the future which is lacking in the prevailing discourse. In the current research mothers are viewed as active agents in managing their difficulties surrounding issues related to disability and in exploring the complex meanings of disability and motherhood.

Care

Care is a contentious issue for both disability studies and feminism. From the end of 1970s, the concept of 'community care' gradually replaced the institutionalised service provision (Johnstone, 1998) in the UK. For feminists, the idea of community care refers to care provided by families, especially women. Therefore, feminists were attempting to emancipate women from their caring duty, those the women were caring for were sometimes portrayed as a burden or as a barrier that restricted women's opportunity to be independent (Walzer, 2004; Richardson, 1993). On the other hand, researchers in disability studies argued that disabled people were being ignored while attention was being paid to the oppressed situation of the carers (McLaughlin, 2006; Morris, 1991).

They became concerned with how disabled people can be oppressed in the unbalanced power relationship that operates between them and their carers. Kröger (2009) suggests that it is partly because disabled people are referred to as a burden both by the state and by feminists that the issue of care is rarely discussed in disability studies; instead, the emphasis is on issues of independence, justice and rights. Various strategies are employed: for instance, words like help, support and assistance are chosen to replace the word 'care'; or, instead of family care, contract care is suggested by disability activists. In this context, carers and disabled people occupy opposing standpoints in their relationships.

The conflict over care between carers and those they care for might be influenced by assumptions about what constitutes a moral and independent citizen, which is presumed to be the opposite of dependence (Gottlieb, 2002; Kittay, 2002b; Hillyer, 1993). Gottlieb (2002) indicates that moral subjects are supposed to be rational, autonomous, healthy and empathic so that they can participate in society and make moral decisions. However, meeting these standards can be difficult both for women who might need to take care of others and for disabled people. When individuals cannot meet these standards, personal capability is questioned, instead of structural factors. The other person involved in the caring relationship is viewed as a barrier to individuals seeking their moral independence. Hence, strategies such as trying to free women from caring duty, or insisting on disabled people's independent living are proposed. Care is devalued in the eyes of both the carers and those who need care.

Instead of trying to free women from the responsibility for care, another branch of feminists, including people like Carol Gilligan (1982), Nel Noddings (1984) and Eva Feder Kittay (2002), confront the inevitability of care in human society and recast the meanings and nature of care (Kröger, 2009; Fine and Glendinning, 2005). These scholars have diverted the debates that used to situate care to the private arena, and argue for recognising caring values, such as reciprocity, interdependence and empathy and generating this into an alternative approach of 'ethics of care' (McLaughlin, 2006).

This approach of ethics of care tries to challenge traditional moral theory that stresses notions of rights, justice, individualism and autonomy (Kittay, 1990; Kröger, 2009). The forerunner of this approach, Carol Gilligan, challenges the view that women are morally inadequate based on a theory of moral development stages established by research on boys which she believes cannot reflect women's experiences (McLaughlin, 2003; Shakespeare, 2006). Instead, she suggests that the moral frameworks women and

men adopt are different (Kröger, 2009). Gilligan proposes, relationships and care play significant roles in women's moral activities, 'the ideal of care is thus an activity of relationships, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone (Gilligan 1984:73 cited in Fine 2005)'.

However, the arguments proposed by the approach of ethics of care are challenged among feminists. McLaughlin (2003) illustrates several responses towards the ethics of care that criticise it as problematic. The problem several feminists have identified is how it frames care as a difference between women and men and that care is identified as the core concept in women's moral development. If moral development is varied between men and women as Gilligan suggests, instead of validating the dissimilarity, what should be asked is what the causes the differences. In addition, the ethics of care presents care as something which occurs within relationships. However, this understanding limits care and the responsibility to care to being amongst those we have relationships with. To respond to these criticisms writer such as Selma Sevenhuijsen place questions of care within questions of the social organisation of care and issues of citizenship (McLaughlin, 2003).

Kröger (2009) indicates how this psychological original approach has been drawn into social policy and citizenship by Joan Tronto (1993) and Selma Sevenhuijsen (1998). Not only focusing on the dichotomy of justice and care, the complicated nature of care has been considered, such as the problems of disempowerment (Shakespeare, 2006), and the various care patterns in contemporary society which are beyond the assumptions of heterosexuality (McLaughlin, 2003). Sevenhuijsen (1998:12 cited in Shakespeare 2006) uses 'the shadow of virtue' to refer to some carers who do not necessarily care with kindness but try to control those under their care. Moreover, Tronto (1993b:103 cited in McLaughlin 2003) reminds us, concentrating on individuals within relationships will 'dismiss from the outset the ways in which care can function socially and politically'. Instead of focusing on the individuals within care relationships, the emphasis is on the 'lake of care in public' as Jagger (1991 cited in McLaughlin 2003) highlights. Among the scholars engaged with the debates about care, this section will focus more on the arguments proposed by parents of disabled people, Eva Feder Kittay, Barbara Hillyer and Roger S. Gottlieb since they are more related to the issues of disability.

Kittay (2011: 52) disagrees that care should be stigmatised or denigrated. Instead, she argues that 'the ability of a being to give and receive care is a source of dignity for

humans no less than the capacity for reason'. Scholars in this branch try to divert the debate from who should provide care to an acknowledgement of individuals' interdependence, valuing care as being at the core of society and having positive meanings, rather than meaning a negative burden (Fine and Glendinning, 2005).

According to this approach, some form of dependence is unavoidable in everyone's life. Even when not being dependent because of being young, old, or on specific occasions in their life course, everyone still relies on others in their daily lives: for instance, for an electricity supply (Kittay, 2002a). Kittay (2002b) argues that it is not useful to insist on the binary poles between independence/productive and dependence/burden. Hillyer (1993: 216) adds, 'the alternative to the dependence/independence dichotomy, then, is not interdependence in the sense of an exchange of dependencies, but an acknowledgement of "the way lives intertwine"'.

The unbalanced relationship between carers and people who are cared for is one of the main concerns when discussing caring relationships. Rather than care being fixed and moving in a one-way direction from the carers to those they care for, researchers have found that over time the nature of the care relationship is diverse, shifting and complex (Kröger, 2009; Fine and Glendinning, 2005; Morris, 1991). Fine and Glendinning (2005) use an example of the care provided by an old male spouse to argue that it is not only women who provide care. This care relationship was built on and remained a long-term interdependent and reciprocal relationship between the couple. Kittay (2002b) indicates that care is often supplied by women or servants who do not necessarily have more power than those they care for. Both Thomas (1997) and Morris (2001; 1991) argue that the assumption that disabled women are dependent ignores how disabled women can also be carers who offer diverse forms of support in their reciprocal relationships with their family members.

Moreover, in their relationship, carers and the people they care for do not necessarily assume opposing or confrontational positions. Instead, the relationship could be viewed as a symbiosis. Scholars have highlighted the fact that carers themselves can also require care, and thus fall into the category of dependence (Kittay, 1999; Richardson, 1993; Rich, 1977). Fine and Glendinning (2005: 614) argue that while providing care, carers can become a 'second level of dependency', since in order to be able to provide care, carers might be unable to engage in productive work and thus end up having to rely on the support of others, especially men. Simultaneously, their care duties can result in reducing the carers' opportunities to participate as citizens in society

(McLaughlin, 2011; Todd and Jones, 2005; Gottlieb, 2002). Hence, not only are dependents viewed as not being entitled to the rights of a citizen, but carers themselves might also fail to achieve the standards of a good citizen who participates in society as an independent, productive, rational and moral actor. This situation weakens the voices of carers, who could be important advocates for those under their care (Gottlieb, 2002; Kittay, 2002b).

The boundaries between public/private are not stable, and scholars have paid attention to how these boundaries are experienced, constructed and negotiated and how they can either constrain or enable women depending on their circumstances (McLaughlin, 2006; Ribbens, 1994). Generally, care is positioned in the private domain and relies on an individual's competence. When support is not available for carers, it is difficult for them to satisfy all the needs of those they care for. Such a situation could damage their relationship, and is one possible cause of conflict between carers and those they care for.

The unpaid or low paid situation of most carers is viewed by Kittay (2002b) as exploitation by gendered institutions or by the state. She suggests paying more attention to this issue, not only for the sake of the well-being of carers, but also that of disabled people, because she believes that unless carers receive appropriate support, they cannot provide good quality care for their dependents. Hence Kittay (2002a: 242) suggests carers should be supported from a 'triadic concept of reciprocity' that highlights the importance of public involvement. Other scholars also argue that care should not be anyone's personal responsibility, but that it should be a collective responsibility and that it is important to support carers and those they care for based on our recognition of our interdependence (Kröger, 2009; Gottlieb, 2002; Kittay, 2002a).

Therefore, mothers/ carers are not necessarily the oppressive part in the care relationship. They may also be the oppressed due to the external factors. This research will try to reconsider issues of care, mothers' relationship between mothers and professionals/the state, and their care relationship with their disabled child from their point of view. When located as a carer that undermines mothers' moral role and how they are expected by others, how this will affect mothers' agency and strategies and how they think about themselves will be interesting theme to look at in this research. Issues related to dependency within the care relationship will also be explored from mothers' perspective.

Conclusion

Previous research has indicated several forces that influence how mothers and their children are understood. These political, economic, cultural and historical contexts contribute to the contemporary environment in which motherhood and childhood are embedded. The guidance provided by both experts and the state's laws and policies not only offers support or information, but also becomes social norms that imply moral responsibilities for mothers to reach the expectations established by these authorities. These factors are not independent but are interwoven with each other in order to achieve their aim of producing productive, independent, amenable and autonomous citizens of the future for the capitalist society and the state. The discourse of a good mother is not fixed but changeable and socially constructed.

Mothering a disabled child is shaped by discourses of contemporary motherhood, childhood, medical perspectives and the social model. However, this chapter also shows the gap between the discourses and mothers' lives. Mothers are framed differently in the diverse perspectives of these discourses. Mothering a disabled child might be viewed as a deviation that is unrelated to mothering a non-disabled child. From medical perspectives, mothers are 'only mothers' - lay persons without professional knowledge or skills. For supporters of the social model and disabled people, mothers are non-disabled people who can be potential barriers and competitors who keep disabled people from being independent. Rather than being included and respected, mothers' experiences are normally viewed as exception or others, therefore easily being ignored or distorted. As a result, appropriate notions about raising a disabled child normally lack mothers' perspectives on their experiences. The experience of not having a map when one has a disabled child suggests that the experience of mothering a disabled child is not included or available in dominant discourses on motherhood and childhood. As research has revealed, although mothers' experiences have been studied, their experiences as unique individuals do not receive enough attention by professionals and scholars in disability studies in Britain.

Based on previous researchers' suggestions, this research chooses to acknowledge mothers' unique but marginalised experiences. Rather than viewing mothers as potential barriers, I choose to view them as disabled people's allies, although from different positions and perspectives. I am interested in what mothers learn from being the mother of a disabled child. Through mothers' counterstories, I believe mothers' experiences can fulfil the gap that is lacking in prevailing discourses and enrich our understanding of

disability, motherhood and childhood, and thus help us to design more suitable services for disabled children and their families. They could also provide references for parents with disabled children in the future.

Chapter Three

Methodology

As described in the previous chapter, mothering a disabled child can be understood from a variety of perspectives. From a medical perspective, which emphasises the negative impact of impairment, mothers are often seen as suffering from a tragic burden. From the perspectives of professionals, mothers are lay persons who need their guidance. In the field of disability studies, mothers are often assumed to be potential barriers or oppressors, preventing disabled people from having control over their lives. The similarity between all these frames is that mothers of a disabled child are identified as 'others' and outsiders, different from mothers who do not have a disabled child, different from professionals, and different from disabled people. It is easy for the experiences of such mothers to be overlooked or distorted by these assumptions. Rather than employing these existing frames to examine mothers' experiences, in this research I have chosen to use them as reference points when examining the mothers' perspectives and generating ideas from their experiences.

In the first part of this chapter, several concepts that I found useful, especially when attempting to locate the mothers in the social context, are presented. I will explain how these concepts influenced my standpoint as a researcher while conducting this research and also how my personal background affected this research. I shall then go on to explain why and how this research was conducted, through presenting the conceptual framework, research design, the methods of data analysis employed, consideration of ethical issues, and the limitations of the study.

Standpoints

Several of the issues raised by the mothers who took part in this study led me to study theories with which I was previously unacquainted: feminism, postmodernism and the sociology of professions. Learning to view the data from the different perspectives offered by diverse theories was an interesting but sometimes confusing journey that shaped and reshaped the themes and framework of this research over time. Simultaneously, my standpoint was influenced by the interlaced issues arising from the

mothers' narratives, by the literature I read, and by my own personal history and work experience. In this section, I will first present concepts I found useful in order to position both the mothers and me as a researcher, who each had situated knowledge (that is, knowledge derived from our particular social positions). I will also discuss the issue of insiders and outsiders as it relates to my research.

Locating mothers

Since the 1970s, how knowledge is produced has been questioned in contemporary sociology, in particular, experience and how it is attached to social positions and identities has been increasingly seen as significant (Ali et al., 2004; Harding, 1993). Both feminists and postmodernists have questioned the contemporary prevailing discourses and values from which knowledge is generated.

In the 1970s, some feminists started to challenge existing epistemology that legitimated men's experiences alone (Kitzinger, 2004). Influenced by Marxism, feminist standpoint theory indicates the close relationship between social location and epistemic privilege (Jaggar, 2008; Harding, 1993). Harding (1993) asserts, 'knowledge claims are always socially situated' (p. 53), and 'one's social situation enables and sets limits on what one can know' (pp. 54-55). For example, my knowledge is not my knowledge only, but is influenced by my social position as affected by my age, race, gender and culture. Harding continues to argue that it is difficult for dominant discourses fully to explain the situations and experiences of marginalised groups, because these prevailing discourses are constructed by dominant groups, who are different from the marginal groups. The reality presented in these discourses is therefore distorted. Hence, it is essential to acknowledge the knowers' social position and pay attention to the voices of subordinated groups which have previously been suppressed and ignored (Harding, 1993). Jaggar (2008) describes the contribution of standpoint theory as follows:

> Standpoint theory offers an approach to assessing the credibility of particular knowers in particular subject areas. Typically, it asserts the epistemic authority of individuals who have been discredited as knowers, especially those who are economically dispossessed, politically oppressed, and socially marginalised, and whose status as

knowers is therefore likely to be doubted as unreliable, uneducated, and uninformed (2008: 307).

As mentioned in the previous chapter, mothers of disabled children may be viewed as a marginalised group whose perspectives can easily be neglected, since they are not men, not mothers of non-disabled children, not disabled persons, or not professionals. Standpoint theory provides a useful and much-needed frame for locating mothers' experiences and knowledge within their relationships with others. Although Harding (1993: 60) proposes that every standpoint is important and 'a good place' for us to learn from, standpoint theory is often questioned for its inability to demonstrate whose story is the more valuable, owing to the diversity among whichever standpoints are being considered (Jaggar, 2008; Ramazanoglu and Holland, 2002).

Although postmodernists also emphasise the fact that knowledge is socially constructed and situated, hence an individual's knowledge is shaped by his/her social position, they question the assumption of a unified reality. Instead, postmodernists suggest individuals' understanding of their world, identity and subjectivity will be constituted and limited by available and changing discourses, hence their perspectives could be partial, distorted and discontinuous, and their social identities could be multiple, overlapping and contradictory (Obsborne and Neale, 2009; Jaggar, 2008; Mann, 2000). This makes the assumption of similarity within a category or the possibility of the universality of an experience such as being disabled less likely (Jaggar, 2008; Fawcett, 2000; Skeggs, 1997). From this point of view, it is also not useful to adopt binary distinctions to discuss complex reality (Fine and Glendinning, 2005; Fawcett, 2000).

Furthermore, unlike standpoint theory, which emphasises the inevitable connection between social position and the knowledge attached to it, as Jaggar (2008) indicates, the postmodern feminists' emphasis on subjectivity means that not only experiences, but also the knowledge individuals possess is generated from their interpretation of reality. Accordingly, both the influences of discourses related to childhood, motherhood and disability, and how mothers interpret their experiences will affect mothers' motherhood and their comprehension of and attitudes towards disability (Obsborne and Neale, 2009; Jaggar, 2008). Since identities are multiple, the mothers' other roles and identities should be examined in order to shed additional light on their situation.

As Jaggar (2008: 345) states, 'researchers can aspire only to tell a story acknowledged to be partial in perspective, one story among others'; the postmodernists' arguments could thus provide mothers with the legitimacy to speak and contribute to reality related to disability through dialogue with others based on their experiences, rather than having to make efforts to prove they are insiders, also disabled and experiencing stigma, not oppressors, or are lay experts (Blum, 2007; Brett, 2002; Gray, 2002; Green, 2002). Since every standpoint contains its own particular world view, the perspective of mothers of disabled children regarding disability should be acknowledged.

Apart from the experiences and knowledge attached to social positions, scholars are further concerned with the social structure in which individuals are embedded. Mann (2000) worries that the postmodernist emphasis on differences will ignore the impact of social oppression emphasised by Marxists. She cites Harding's critics, who state that the danger in claiming every viewpoint to be legitimate is that the views of the dominant groups are likely to prevail (Harding, 1993: 61, cited in Mann, 2000), or unconsciously taken for granted (Lewis, 2007). Therefore, the influences of the social structures which formed the context of the mothers' lives will also be recognised in this research. The first-person narratives by the oppressed are especially highlighted as strategies to confront or compete with dominant discourses. Jaggar (2008) describes feminist intentions as follows:

> They emphasized listening to women's first-person narratives, and
> they were interested not only in experiences of victimization but also
> in women's agency, creativity, and resistance to oppression.... So
> often the focus on women's experience revealed not only unhappiness
> hidden beneath the bland surface of masculine accounts but also
> hitherto unrecognized resistance to oppression (Jaggar, 2008: 269).

Therefore, the arguments presented in this thesis will also highlight the mothers' agency, creativity and resistance to the challenges they encountered. Rather than being passive receivers, mothers can be positive social actors (Beresford, 1994). As Skeggs (1997: 27) also argues 'it is not individuals who have experience but subjects who are constituted through experience'. She explains that experience is created by an individual's participation and practice. Through the construction of subjectivity, we know and are

known. Rather than viewing mothering a disabled child as a fixed experience, this research will use mothers' first-person narratives to demonstrate how the mothers constantly transform their knowledge into experience, and their experiences into knowledge, and how they modify their comprehension of what constitutes a good mother based on what they learn from their experiences.

These discussions were also useful for this research when investigating the relationship between mothers and others, and the different types of knowledge possessed by mothers and professionals: for instance, in explaining how this recognised knowledge is created and possessed by particular groups such as professionals (Fournier, 2000), and how reason and objectivity have become the generally accepted approach to creating knowledge that is recognised as legitimate and that has authority (Jaggar, 2008; Harding, 1993). Not only was it important to acknowledge the marginalised group's epistemological privilege, it was also essential to acknowledge my social position and standpoint.

Locating researchers: insiders or outsiders?

In social science, it has been generally acknowledged that it is difficult for a researcher to be neutral or value-free (Mason, 1996). Ali et al. (2004: 26) indicate that the 'research process is not the production of objective knowledge but is produced by knowers who are situated in the social world and whose knowledge reflects its value. These values are not a neutral frame for research but reflect a social world in which certain groups dominate and have powers over others'. Therefore, these social factors not only influence how and what researchers know; a researcher's position, value and experience will filter information and influence the ways in which he or she accesses, conducts, generates, or interprets the research. Therefore, Griffith (1998) highlights the importance of a reflexive relationship between the researcher and the subjects of his or her research concerns, and of how the research is constructed across social boundaries. Here I will discuss the issue of the boundaries of insiders and outsiders.

One response to the recognition of marginalised groups' voices and researchers' possible bias is to ensure that these marginalised groups speak for themselves; this will reduce the risk of misunderstanding or the reinforcement of the oppression resulting from the unbalanced relationships between those who speak and those they speak for (Lewis, 2007). Trebilcot (1988 cited in Alcoff, 2008) argues that those who claim to

speak for less privileged individuals can have a negative influence on the marginalised individuals' willingness to participate. For example, although mothers might speak on behalf of their child, some disability activists have questioned whether a mother can fully represent her child, partly because parents tend to be 'overprotective' of their disabled child and partly because the power relationship between mothers and their children can be unbalanced (Finkelstein, 2001). The importance of listening to the voices of disabled people is especially highlighted by disability activists. Not only professionals, but also non-disabled researchers are not really trusted by disabled people because they might not be able to present the disabled person's standpoint and produce credible and valid knowledge. Their concern includes whether non-disabled researchers may further exploit disabled people for their own career advantage (Fawcett, 2000). Research conducted by insiders is thus suggested in line with highlighting marginalized groups' right to speak for themselves.

Together with highlighting personal experiences as a foundation for constructing knowledge, some feminists and minority group researchers state that when a researcher is an insider, he/she might be able to claim 'epistemological privilege', on the basis of sharing similar experiences with his/her interviewees (Almack, 2008; Green, 2003a; Deverell and Sharma, 2000; Griffith, 1998). Mason (1996) suggests that this approach recognises the connection between location, position, experiences and oppression. Lewis (2003:65) also notes, 'sharing some aspects of cultural background or experiences may be helpful in enriching researchers' understanding of participants' accounts, of the language they use and nuances and subtexts'. According to Almack (2008) and Green (2003a), being insiders themselves helped them to build trust, develop rapport and have political awareness when conducting their research.

Researchers may not only possess this epistemological privilege, they might also choose to allow themselves to be recognised as insiders by the subjects of their research, hence they choose to reveal their identities (Kombo, 2009; Green, 2003a). In disability studies, several researchers have not hidden their identity as a mother with a disabled child when conducting research related to disabled people and their families (Ryan and Runswick-Cole, 2008; Runswick-Cole, 2007; Green, 2002; Rapp and Ginsburg, 2001; Avery, 1999; Landsman, 1998) . As a mother with a disabled child, Green (2003a: 2) argues that the 'objective stance' and 'privileged voice' prevalent within academic practices often unintentionally marginalises, alienates or even pathologises the people being studied. Rather than hiding safely behind professional distance, Green chooses to

identify herself as a mother with a disabled child. She claims it is important for interviewees to understand that she is an insider and for the reader to understand how her experiences influence her interpretations.

Instead of simply categorising the researcher as either an insider or an outsider to their research focus, recent debates have broadened discussions on this subject, acknowledging its complexities. Some researchers have found that identifying themselves as an insider is not enough. This is not for the researcher to decide. Instead, they need to create or assert their identities in order to be viewed as an insider by those they study (Kombo, 2009; Almack, 2008; Mason, 1996)

Moreover, the criticism has been made that being an insider does not necessarily lead to good research. Although an insider might be familiar with the cultural context, things might be ignored or taken for granted (Almack, 2008; Lewis, 2003; Griffith, 1998). Although benefiting from insider knowledge resulting from personal experiences which have given them an epistemological privilege, at the same time, the limitations on the researcher's knowledge, which is restricted to his/her personal experiences, is highlighted; thus no researcher would be able to know or understand everything about the people he/she studies (Styles, 1979 cited in Griffith, 1998; Mason, 1996). Or, even if the researcher is a member of the same group, his or her experiences can still be different from those of his or her subjects because of the heterogeneity within the group. One of the explanations for this heterogeneity is that the identity the researcher shares with his/her interviewees is only one of the identities possessed by the interviewees, and may not even be the identity most important to them (Almack, 2008; Lewis, 2003). Ramazanoglu and Holland (2002) further argue that no matter who the researcher is, he/she is an outsider because of his/her role as a researcher.

Sometimes it is advantageous to allow outsiders to do the research. Lewis (2003) suggests that interviewees might prefer outsiders or might contrarily hold back because the researcher is an insider. For some groups, it is not possible for them to conduct research by themselves, and they need the help of others to make their voices heard; this applies, for instance, to groups such as people with learning difficulties and young children (Shakespeare, 2006). Moreover, both Merton (1972 cited in Griffith, 1998) and Styles (1979 cited in Griffith, 1998) remind us of the risk of overemphasising the privileged nature of insiders' knowledge since this could lead to the claim that only a particular group has the legitimacy to conduct research, to the exclusion of other

possibilities. The following suggestion by Rubin and Rubin was very useful when considering a way forward in my research:

> Unlike some schools of feminist research, our approach to qualitative interviewing emphasises the ability to go across social boundaries. You don't have to be a woman to interview women, or a sumo wrestler to interview sumo wrestlers. But if you are going to cross social gaps and go where you are ignorant, you have to recognise and deal with cultural barriers to communication (Rubin and Rubin, 1995: 39, cited in Lewis, 2003: 66).

Although it is essential to highlight the barriers and the risk associated with speaking for others, Alcoff (2008) disagrees that researchers should retreat from their social responsibilities to resist oppression and to speak for less privileged groups. Alcoff believes what researchers could do is try to 'do it better' (p. 491). Hence, she suggests that researchers should speak with rather than only speak for others, and that they should always be responsible and accountable for their form of speaking. Echoing other researchers' appeals (Jaggar, 2008; Lewis, 2007; Harding, 1993), Alcoff also believes reflectivity is a good start for a researcher. In the following paragraphs I will reflect on my own standpoint as a researcher.

In the process of conducting this research, I found the notion of objective knowledge produced by value-free researcher was less possible. Many decisions in this research were made based on my experiences, values, and standpoints, for example, I took my side to stand with mothers with disabled children and my attempt to help their voice be heard has affected the possibility to being an "objective researcher". In addition, unlike my research for my master's dissertation in which I was in the position of a service provider focusing on the difficulties being encountered by carers, my initial intention in this research established me as an apprentice who hoped to learn from the mothers, and who was prepared to be a bridge that supported the mothers in sharing their experiences and reflections with others. The assumption of this standpoint was a choice I was able to make. However, there were also aspects of my social position that were not open to choice, but which had to be taken into account when conducting my research.

As a female and a mother, I was an insider to my interviewees. We discussed certain things we had in common during the interviews, such as how we interacted with our

children. We chatted about my pregnancy, since I conducted the first five interviews during the last four months of my pregnancy with my second child. Several of the mothers saw my children before the interviews, possibly helping to strengthen their perception of me as a mother. However, I was obviously an outsider in other ways: to them I was a postgraduate student, a former social worker from Taiwan, I came from another country and another culture, and I was not a mother of a disabled child.

The power imbalance between researcher and respondent has been an important consideration in research methodology (Almack, 2008; Opie, 2008; Ramazanoglu and Holland, 2002). However, scholars argue that the issue of the researcher being an outsider from another country has not yet received a great deal of attention (Winchatz, 2006). Ali et al. (2004: 24) suggest that cross-cultural research is normally about 'advanced' nations trying to document and categorise 'others' within the hierarchical relations of power; it is about colonialism and imperialism. This suggests that the problem of the imbalance that exists in the relationship between researchers and researched can be exacerbated by the power relationships between cultures.

However, in this piece of research the situation was different. Although I had been a social worker in Taiwan, and although I was a postgraduate student and a researcher, my other social position might reduce the mothers' worry about being judged. As a new mother, I was less experienced than my interviewees. As a student and a mother without a disabled child, I was not an insider at all. In this research the researcher came from a developing country which is attempting to follow in the footsteps of Western countries, and which has less experience of providing suitable services for disabled children and their families than the U.K., where the research was carried out.

During the interviews, the mothers were aware of the limitations on my English language skills and my lack of familiarity with British cultural and social contexts. Since I made it obvious that I wanted to learn from them, because of these conditions, the mothers might not necessarily feel as though they occupied a weak position in our relationship, which might differentiate the relationships in this research from usual research relationships. The experiences of this research echo Winchatz's finding. Winchatz (2006) also demonstrates how the deficit in her language skills contributed to her research. When the participants found out about Winchatz's linguistic inadequacies, they took on the role of language teachers; this led to two results. Although Winchatz thought her knowledge was being called into question, albeit mildly, she actually obtained more data because her participants explained in more detail. So she started to

embrace moments of misunderstanding as an ethnographic tool. Since the roles of researcher and researched alternated, the power relationship was not particularly unbalanced. Moreover, in the current research, qualitative, semi-structured interviews were chosen as the research instrument, which gave the mothers more opportunity to participate in or lead the conversations during the interviews. It was hoped that this would enable the mothers to feel more comfortable when sharing their stories with me (Ramazanoglu and Holland, 2002).

Although knowledge is situated in social positions, this does not mean that it was not important to consider the reliability and validity of my approach and methods of analysis. For example, in order to ensure reliability in the application of the research instrument, I interviewed all the interviewees myself and asked for help from only one transcriber. Since validity is viewed as more important than reliability in qualitative research (Mason, 1996), I will focus on the strategies for achieving validity in this section. Triangulation, as advocated by Norman Denzin (1970 cited in Silverman, 2006), normally refers to using various methods to examine the data and thus produce a more accurate or objective representation. However, Mason (1996) questions the implication that there is only one objective unitary reality that could be examined from diverse angles. Marvasti (2004) suggests,

> Piecing several perspectives together does not mean that at the end the errors cancel each other out to produce a net effect of 'Truth'. A more theoretically enlightened approach to triangulation is to see it as a way of adding complexity and depth to the data and analysis. In this way, social phenomena are approached as multi-sited narratives, each narrator's account is worthy of analysis in its own right (Marvasti, 2004: 114).

Rather than being viewed as strategies for identifying a unitary reality, these strategies were seen as tools to help me to understand and interpret the data. In addition to generating data from interviews, I adopted several strategies to increase my understanding of my topic. My experience of working with disabled children's families in Taiwan and the knowledge generated from the research I carried out for my master's dissertation formed the foundation of my understanding (Shih, 1998). I drew concepts

and ideas from literature reviews. During the research process, I narrowed down my interests and shaped my research questions based on the goals of the research. I refined the research questions and designed the interview questions to collect responses and experiences related to my research questions.

A flexible, semi-structured type of interview was chosen that would give the mothers more opportunity to participate in the interviews, with the aim of increasing the validity of the data obtained. I also made efforts during the interviews to develop the conversations on the topics I planned to discuss. I used a tape recorder to ensure the accuracy of the interview data. Some of the interviewees had quiet voices or spoke too fast, and there were sometimes uncontrollable factors in the interviewee's house, such as noise, which interfered with the clarity of some parts of the recordings. However, none of these factors had a great impact on the data I needed to quote. I also took field notes including observations of non-verbal information and dynamic interactions. These field notes and observations were used as backgrounds for contextualising the data and increasing the validity while understanding the narratives.

In order to acquire a broader comprehension of the subject, I made efforts to familiarise myself with related social policies and organisations around Newcastle, and used this as background information. I also participated as an observer in a Parents Forum held by a local authority in order to become more knowledgeable about issues surrounding families with disabled children in the North-east of England. I also used my experience of raising two young children in Newcastle as a way of increasing my comprehension of issues such as education, childcare services, medical health services and leisure activities. These strategies provided me with broader and more diverse foundations to understand the data in the cultural or social contexts from which they were derived.

As Barrett and Cason (1997) suggest, a researcher's nationality, ethnicity, gender and class will influence his or her assumptions. I was aware of the boundaries that define me as an outsider. I was aware of being an outsider, hence I tried to be reflexive while generating and sorting the data for the purpose of reducing any bias or risk of misunderstanding on my part. I analysed data from the bottom up, extracted themes and developed my interpretation through comparing the mothers' experiences within the research with related theories and other research. The logical relationships between the data were considered. The mothers' contexts and their social positions were acknowledged in order to reveal the structural factors behind the scenes. During the process of analysis, I gradually learned to compress the themes arising from the data,

and tried to make connections with my research questions and conceptual frame in order to answer the research questions.

To sum up, I chose to acknowledge the mothers' social position and epistemic privilege. I intended to value the knowledge they had acquired from their unique positions, which were different from those of disabled people, professionals and other mothers without disabled children. I chose to view the mothers' experiences as material for a dialogue that would increase our understanding of disability. The mothers' subjectivities, strength and resistance when encountering difficulties would be highlighted. It was not, however, the intention to romanticise the mothers' experiences but rather to present an alternative perspective to the prevailing frame in which mothers are viewed as passive recipients. Although the focus in this research was on the mothers' voices, the impact of social structure factors was also considered. Being an outsider, I chose to reflect constantly on the interpretation I made, whilst remaining aware of the possible effects of my own experience and standpoint, making an effort to be responsible and accountable for the arguments I put forward. These choices influenced how I conducted this research.

Research Method

This part will explain how the research was conducted by presenting a description of the changing conceptual framework, the research design, methods of analysis, ethical issues, and limitations of the study.

Conceptual Framework

In order to achieve validity of interpretation, Mason (1996) suggests tracing the route by which the interpretation was reached. She also suggests allowing research designs to be flexible, since subsequent research decisions are likely to have an impact on the initial research design. This part will explain how the conceptual framework was transformed in three shifts that led to both great challenges and great benefits in this research.

The initial framework was based on the experience I had acquired in Taiwan. As a social worker in an organisation for visually impaired people and their families, I worked with the parents of visually impaired children. These work experiences supported the research for my master's dissertation, which focused on the needs and

difficulties of carers of developmentally delayed or disabled children. I interviewed them while they were taking part in the early intervention programmes in Taiwan. Once in the U.K., the framework for the current study was increasingly influenced by what I was learning here, including through disability studies, especially those related to parents' experiences.

Because my scholarship was for only three years, to begin with I chose my own country as my field. I thought that being able to use both my network and my previous work experiences would help me to conduct this research more easily within an environment I was already familiar with. However, after reading and getting to know more about the debates in the U.K, my interest in the situation in Britain increased. In Taiwan, most of the information on the subject came from America: for instance, the early intervention programme that was one of the most important social policies for disabled children was drawn from America. The British approaches and frames adapted to understanding disability were new to me. I had never heard of the social model when I was studying in Taiwan. Hence, I was really interested in how these arguments were generated from and applied in the U.K. Since I was already here in Newcastle, rather than reading about mothers' experiences in books and journals, I had the opportunity to interact with and learn directly from mothers here in the U.K., which could be of great benefit for parents in Taiwan. I therefore changed the field to North-east England.

The initial conceptual framework was influenced by my experiences when conducting research for my master's dissertation (Shih, 1998). The carers who participated in my master's research talked about how they managed difficulties within their families. They expressed their feeling of uncertainty about the new world of professionals, and a 'disabled world' that their children and their families were going to interact with and become part of. They also talked about the change from their old world. In order to distinguish among these factors, the initial conceptual framework for the current research separated a newly recognised world related to disability, that included service providers, other disabled children's parents and disabled people from the mothers' family life, and from the mothers' old world, which included her family, social network, or career (see Figure 3.1). Motherhood, the meanings of disability, and the mothers' relationships with professionals were selected as the main topics of this research.

Several themes were developed and kept in mind. These involved the idea that disability might affect the mothers' family life and their motherhood; the idea that the

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newly recognised disabled world might not be the same as that experienced or suggested by disabled adults; the fact that having a disabled child could influence the mothers' motherhood and their understanding of disability; and the idea that the mothers' old world would have changed and might not necessarily support them.

The main research question designed for this research is: what do mothers learn from their transformation from being a non-disabled person to being a mother with a disabled child? Motherhood and the meanings of disability are the core themes of this research. Among the various social actors who might have an impact on the mothers' journeys, I was especially interested in the influence of professionals, based on the findings of my master's dissertation and those of previous researchers (Brett, 2002; Green, 2001; Case, 2000; Shih, 1998). I wondered in what way mothers' experiences of working with professionals could influence their construction of their motherhood and their comprehension of disability.

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│                                                 │
│     ┌─────────────────────────────────┐         │
│     │  A: within their families:      │         │
│     │  a mother with her              │         │
│     │  disabled child.                │         │
│     │                                 │         │
│     └─────────────────────────────────┘         │
│                                                 │
│     B: a world related to disability that       │
│     might have been invisible before,           │
│     but now living in it.                        │
│                                                 │
│           C:  mothers' old world.               │
└─────────────────────────────────────────────────┘
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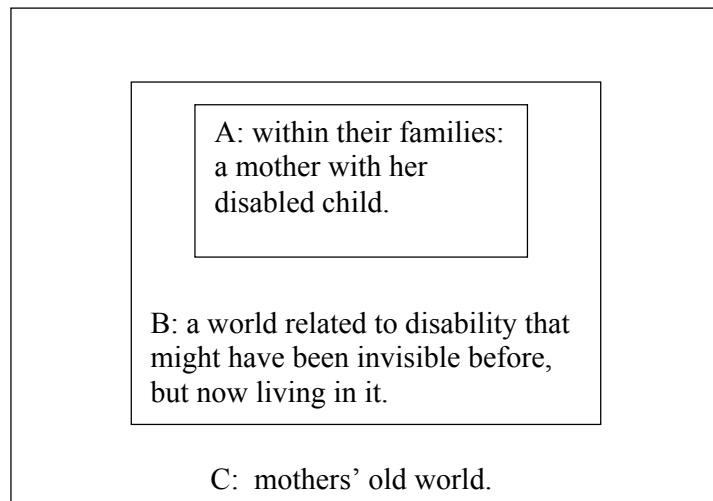
Figure 3.1: Conceptual frame

The second shift in the direction of this research was related to my maternity leave. After I had interviewed five interviewees in the North-east England between May and September 2006, I gave birth to my daughter and took maternity leave for six months. After this interruption, it took me a while to get back to my trajectory and I had to build up all the recruitment networks all over again. The other eleven interviews were conducted from May to September 2007. My role changed to that of being a mother with two young children, and this in some ways led to additional challenges in finishing

this research. It also led to the third shift, which by contrast made a positive contribution to this research.

Because of the interruption, I was able to re-examine the first five interviews; this helped me to fine-tune my interview questions and focus after my maternity leave. I worked on the transcriptions of the first five interviews while recruiting new interviewees. As Bryman (2008) states, one possible result of flexible qualitative interviewing is that the issues raised by the interviewees might lead the researcher to change the emphasis of the research. These five mothers' interviews became akin to 'pilot' interviews that caused me to re-think my conceptual frame, the themes I was concerned with, the themes I had developed initially and helped me to transform the focus of this research. The conceptual frame became a reference but not a complete guide for the analysis because several unexpected issues were raised and some presumed issues were not really of concern to the interviewees.

Although some of the mothers recognised that there was a 'disabled world', others tended to integrate disability into their ordinary world (Fisher, 2001). Hence, less emphasis was placed on the concept of the disabled world in both the subsequent interviews and the analysis process. Rather than distinction, integration and participation were recognised in the process of analysis. Moreover, the first five mothers did not confirm the assumption that service providers were the most important factor in shaping their motherhood and in understanding disability. Instead, they talked about the influence of other parents of disabled children, of their family members or friends, and of unknown others in the public realm. When discussing the difficulties of working with professionals, contrary to expectations, the mothers referred more frequently to educational than to medical professionals. Therefore, the later interview questions about relationships with others not only focused on professionals but opened the field up for the mothers to talk about whom and what had supported or frustrated them most on their journey.

In addition, I made a similar assumption about mothers to that made by other researchers who have focused solely on their role as a mother, neglecting their other roles and identities (Brett, 2002). I was fortunate that the first five mothers showed me that they were more than just mothers (Lindblad et al., 2005); they also had experience with disability as a nursing auxiliary, a teacher for children with special needs, a teacher for adults with learning difficulties, and a therapists' assistant. This wide range of understanding generated from their backgrounds and work experience with disability

allowed them to reflect on their motherhood, their comprehension of issues surrounding disability, and their relationship with professionals. Hence, the subsequent interviews focused more on mothers' previous experiences of disability and the influence of these experiences. The reflections, especially from mothers who were professionals, became one of the main topics of the current study. These unexpected data contributed a new basis for discussions on the relationships between mothers and professionals. The mothers' experiences broke through the boundaries I had assumed existed among their families, the disabled world, and the mothers' old world. This new recognition showed me that the mothers' experiences were complex. It was thus difficult to use fixed concepts to frame their experiences. It also suggested the limitations of researchers' understanding of their interviewees, and the potential risk of making fixed assumptions or devising hypotheses in advance.

Mason (1996: 36) chooses to use the phrase 'generate data', because she argues that the data are not simply there to be collected but that it is 'a data generation process involving activities which are intellectual, analytical and interpretive'. Therefore, she suggests that the various stages of research are interwoven with each other. For example, the process of analysis does not occur only after generating the data but all the time. The process of interpretation and analysis in this research, as Mason suggests, did not only take place after all the interviews had been completed. Instead, it was interwoven with the literature review, and with the research design and interview processes and was influenced by the shifts that took place in the direction of the research.

Although these three shifts resulted in enormous challenges and difficulties for this research, they also led to a journey full of new and interesting issues and debates that I never imagined would be useful before I embarked on this project. These new concerns had a great impact on the data I generated, and later on the structure and focus of the research. In the end, the research focus was extended to include issues including motherhood in the context of disability, how mothers managed issues related to disability in the context of motherhood, and the relationship between mothers and professionals based on the reflections of those mothers with professional backgrounds.

The research design

In this section, the research design, including the research instrument, sampling and recruitment, interview process and data analysis, will be presented.

Qualitative interviews and interview questions

In the research for my master's dissertation, using a questionnaire, I interviewed 110 carers taking part in Taiwan's early intervention programme for developmentally delayed and disabled children at the stage of obtaining a diagnosis. Many of the carers I interviewed were frustrated or confused and asked me questions during, after or even before their interviews. Since I had worked as a social worker with parents of visually impaired children, I had some knowledge of the medical and social service system. Instead of simply collecting their responses, I offered them information about resources if they required them. These interactions and exchanges of information helped me to build trust with my interviewees and they shared with me a great amount of information beyond the scope of the questionnaire. These interactions became the foundation for my analysis and explanation of the quantitative data, but I still found it hard to include and present all that I had learned outside the questionnaires because of the limitations of the research method.

One generally accepted advantage of qualitative research is that it reveals the perspectives of interviewees (Bryman, 2008). Snape and Spencer (2003:3) describe the qualitative approach as 'a naturalistic, interpretative approach concerned with understanding the meanings which people attach to phenomena (actions, decision, beliefs, values etc.) within their social worlds'. Since the current research concerned mothers' understanding of motherhood and disability in their social contexts, the qualitative method was deemed to be an appropriate method for exploring the questions in which I was interested.

Semi-structured, open-ended, interactive and qualitative in-depth interviews were further chosen based on the following consideration. Byrne (2004: 182) asserts that qualitative interviewing is a useful and flexible medium because it allows interviewees whose experiences have been ignored or misrepresented in the past to express their attitudes and perspectives in their own voices and language. According to Coombes et al.(2009), the in-depth interview is a suitable instrument for sensitive or relatively little known topics because researchers can ask for clarification or additional responses that help them to acquire a better understanding of the interviewees' perspectives and increase the validity of the findings. Moreover, they suggest that using in-depth interviews might allow unexpected but important issues to emerge, something which was proved correct in this research. For similar reasons, qualitative data, especially

those obtained from in-depth interviews, have been viewed as useful in feminist social science research for presenting women's voices (Kitzinger, 2004; Bryman, 2001). Additional issues involved in undertaking interviews include issues related to the roles of interviewees and the researcher, and the influence of those roles in the interview data (Fontana and Frey, 2005; Almack, 2008). Fontana and Frey (2005: 712) do not agree that researchers are invisible within the research interview because they are the ones who decide what data is acknowledged while others are excluded. Scholars have further indicated that interviewers' age, race, gender will influence how a researcher conducts his/her research (Barrett and Cason, 1997; Harding, 1993). Rather than a unbiased researcher, Fontana and Frey (2005: 720) indicate a new approach that is politically involved, 'empathetic interviewing' by which they mean, an interviewer/ a researcher can be a advocator who makes effort to speak for the marginalized group, for example, feminists may try to 'use interviewing for ameliorative purposes' (Fontana and Frey, 2005: 720). However, Ramazanoglu and Holland (2002) remind us that even though researchers try to help the voices of marginalized groups to be heard, it is important for the researcher to recognize the different positions between the researchers and the interviewees since the researchers are the ones who decide how to present and interpret the data.

Drawing from Kong and colleagues' (2002: 254) argument, Fontana and Frey (2005) also highlight that when a researcher's perspective is affected by historic, politic, and social change, the way he/ she analyses and interprets his/her data will be different. For example, when disability is not viewed as the result of biological deficit but the result of social barriers, how to consider the solutions of the problems will be different.
In addition, interviewees are not only viewed as an object but an 'equal participant in the interaction' Fontana and Frey 2005: 718). Rather than viewing interviewees as the people to provide information, Silverman (2006) suggests that interviewers and interviewees are always actively engaged in constructing meaning. Fontana and Frey (2005: 696) portray the interview as 'two (or more) people are involved in the process and their exchanges lead to the creation of a collaborative effort called the interview'. Therefore, how interviewees locate themselves, such as a learner (Wax 1960 cited in Fontana and Frey, 2005) can have great impact on the interview.

Accordingly, I believe that using qualitative interviews helped me to increase the validity of my comprehension and reduced misunderstandings through direct interaction and exchange of thought and information during the interviews. For example, it gave

me opportunities to clarify my questions if the mothers did not understand them. I could ask for more details if I did not understand or if I wished to know more, for instance about something that was taken for granted by the mothers but was new to me. For example, unlike mothers in Taiwan who highlighted their financial difficulties due to the lack of statutory support, mothers in this research seemed to have better level of financial security, partly because of the welfare system, such as the Disability Living Allowance, and paid employment. It also enabled me to ask about something I had assumed based on my own experiences but which was different from the mothers' narratives. For these reasons, qualitative and interactive interviewing was chosen as the instrument for generating data in the current research.

A semi-structured guideline composed of prepared interview questions was developed in advance for the purpose of concentrating on issues I was interested in with the help of my supervisors, in order to ensure that the questions were expressed in a clear, appropriate and grammatically correct way. The interview questions were generated from the research questions and the conceptual framework (see Appendix 3-1). The conceptual framework was utilised as a boundary marker to identify the fields in which the research questions were embedded: within families, in a world involving disability, and in the mothers' old world. Several themes were developed in order to determine the possible relationships between topics and fields. Key questions were identified first and some related sub-questions were grouped under the key questions. The key research questions were viewed as topics, but grouped questions were used flexibly in the interviews in order to follow the natural development of the interviews.

Before entering the field, I used pilot interviews to pre-test my interview instrument to see if there were any potential problems in the questions. I also used these pilot interviews to practise my interview skills and to obtain a clearer picture of the structure of an interview: for instance, how long it would take, or whether I should reduce the number of questions. I did a rehearsal with a senior PhD student and a mother of a disabled child. After the interviews, I asked them for feedback on the clarity of the interview questions and my expression: could they understand my English, was it clear enough, and were the questions hard to answer? After this trial, I discussed my interview skills with my supervisors, modified the interview questions, avoiding ambiguous questions, and also reduced the number of questions (Teijlingen and Hundley, 2001). The positive responses from these two practice interviews gave me more confidence in conducting a qualitative interview in English.

The initial criteria for choosing the sample of participants were that they should be mothers of young disabled children who lived around Newcastle and who had had a diagnosis for more than one year. According to Beresford (1994), research has suggested that it can take over a year for families to settle into a pattern of adaptation to disability. Since the adaptation experience and process was one of the concerns of this research, the criterion of having had a diagnosis for more than one year was set to help to find suitable participants.

It has been generally accepted that that different types of disability will lead to different experiences (Shakespeare, 2002; Fawcett, 2000). I was also aware of how various needs are affected by different types of impairment from my experiences in Taiwan. Because of the different limitations of the impairment, services needed are also diverse, for example, the training of self-help skills will be different between a visual impairment person and people with physical impairment. Therefore, scholars have argued that even all the social barriers are removed; it is still difficult for some disabled people to be employment because of their impairment, such as learning difficulties (Shakespeare and Watson, 2002; Kittay, 2002b). Moreover, the types of impairment can make influences on mothers' relationships with their child and others. My experiences of working with parents taught me that the communication between mothers and their children can be profoundly affected due to their child's conditions such as learning difficulties or autism that influences mothers' caring tasks. Research has also illustrated mothers' perspectives while comparing their experiences with their children with 'low visibility' impairment with other children with significant impairment (Gray, 2002: 742). Although they may not experience such as social awkwardness or pity, they can be blamed and experience separation (Green, 2005). Blum (2007) suggests that some mothers may envy medical certainty because the can lead to blame and stigma. However, this research did not make a specification about types of disability. According to my experiences when researching for my master's dissertation, mothers could share similar experiences although having children with different types of disability (Shih, 1998). From a practical point of view, as an overseas student, I wanted to obtain a broader picture of families with disabled children in the U.K. At the same time, I was also concerned that it would be more difficult to recruit interviewees if I set limitations on the types of disability.

At first, I intended to interview mothers with young disabled children around Newcastle upon Tyne, following on from my master's dissertation about early intervention

programmes for disabled children and their families. I used the Internet to search for service providers who supplied services for families with young disabled children such as parent and toddler groups, for two purposes. I wanted to find out more about the existing services for families with young disabled children and to research potential access to recruiting interviewees. Using telephone and email, I successfully accessed seven related organisations and institutions, included a playgroup, voluntary organisations, a mainstream school, a local library, and day nurseries. After visiting these organisations and institutions, I found that there was no playgroup designed especially for young disabled children as I assumed there would be, and as is the case in Taiwan. Instead, great efforts had been made to support disabled children within the local childcare services. This new understanding led to a shift in my recruitment strategy: I extended the age range of disabled children in my sampling criteria, and contacted more diverse sources than I had originally intended. The large age range of the disabled children provided rich data for this research by showing mothers' diverse consideration in different stages of their lives, such as the issues related to transformation between primary schools and secondary schools, or mainstream schools and special schools; how mothers discussed issues related to disability and their children's future with their older children; and how mothers imagined their own future with their disabled child.

Having become more familiar with my target group, an information sheet was designed to explain the purpose and process of this research (Appendix 3-2). A letter for the mothers was also attached if the sheet was sent or handed out by organisations or institutions (Appendix 3-3). In order to recruit potential interviewees, I tried various ways to access mothers. The North-east branch of Contact a Family, one of the biggest U.K. organisations for families with disabled people, allowed me to insert a paragraph advertising my research in their newsletters in 2006 (Appendix 3-4). Although two mothers contacted me, only one became my interviewee in 2006. All the six organisations and institutions I had visited earlier agreed to distribute my information sheets for me, although I do not know exactly how they processed the sheets. I was able to contact two mothers through these channels. I also contacted two other voluntary organisations and a public support team for disabled children by email and they too agreed to send out my information sheets, and two more mothers joined the project. One organisation for people with impairments that I visited sent out 106 letters, but I only got one reply. Fortunately, the person who had co-organised a conference with my

supervisor had personal details of three participants in the conference who were all mothers of disabled children. She mentioned my research to them and asked their permission for me to contact them. After they had agreed to this, I contacted these three mothers, who all became my interviewees. After my maternity leave, some mothers in the parents' forum became eligible after removing the limitations on the children's age, so I invited them personally after the forum and three mothers agreed to participate. I also visited another two playgroups and one toddler group. I tried to contact the organisations I had visited previously. However, no interviewees were obtained through these channels. When I encountered difficulties in recruitment in 2007, I again asked Kathy Rist, the Contact a Family's regional manager, for help. As a result of her help, I received two replies from mothers in the North-east.

I also used a strategy of snowball sampling in order to increase opportunities to access other potential interviewees (Bryman, 2008). Although all the mothers said they were happy to talk with me at the end of the interviews and were happy to pass on the information 'if possible', only one mother successfully convinced two other mothers to join the project. A few mothers admitted that they did not know whom they could pass the information on to but they would keep it in mind. This implies that although the mothers were in some way included in a social network, which was how I reached them, they did not have very intimate or intense connections or relationships with other mothers and might actually be quite isolated.

Although my aim was to interview twenty mothers, in the end, I interviewed sixteen for this research because of the difficulties in recruitment, the limitations of time, and the richness of the data I obtained. Therefore, although I also asked Judith Lane, who worked for Parent Partnership Special Education Needs in Newcastle, for advice, I did not ask her for further help (Appendix 3-5: Table of interviewees' demographic data and recruitment sources).

There are several possible explanations for the difficulties in the recruitment. The age range of the disabled children was from five to nineteen years old and all were still at school. Beresford (1994) suggests that schools are a form of respite care, offering mothers an acceptable way of having a break from caring for their child. This could explain why all the children in this research were of school age - their mothers had more free time. Furthermore, these mothers might have had time to think through their experiences while their children were at school and have clearer perspectives, awareness and attitudes toward raising a disabled child. In addition, after my son started primary

school, I realised that the timing of the two interview periods - May to September in 2006 and May to September in 2007 – could be problematic, since it would be difficult for mothers to attend meetings during the summer holidays. Another possible reason for the recruitment difficulties was that mothers may not have been interested in talking to an 'overseas' 'student', especially as I made it clear that I wanted to learn from their experiences and take this information back to Taiwan instead of helping them directly.

Although several organisations and individuals generously helped to distribute the information sheets, the recruitment process did not go smoothly and it took me a long time to recruit all the interviewees. However, these difficulties ultimately turned out to be a valuable benefit. Using a variety of sources for the recruitment produced a sample with great diversity (Lewis, 2007; Ritchie et al., 2003), but at the same time, although the mothers were heterogeneous, they demonstrated various similarities regarding the impact of impairment, which could contribute to producing sharable knowledge for other mothers with disabled children. Probably because of the combination of self-selected sampling and the diversity of the accessing approach, several mothers with professional backgrounds participated in this research. This had not been expected and would not have been easy to achieve if this research had focused on a single disability or had recruited interviewees from only a few access points.

Interview process

After receiving the information sheets, the mothers contacted me for further information. Since most of them had read the information sheets before contacting me, most mothers were willing to discuss a date and place for interview straight away. Most mothers used email and some used the phone to exchange information with me. For those who had not seen the information sheet in advance or wanted to know more, I provided the information requested and waited for them to contact me to make further arrangements. The times and places for the interviews were chosen by the mothers. Thirteen interviews were carried out at mothers' houses and three mothers were interviewed in a room at Newcastle University.

Before the interview, I always briefly introduced myself, the aims of the research, the expected length of the interview, and then asked the mothers' permission to use a tape recorder. I also explained that my English was not very good so I might need them to slow down their speed or say more when I could not understand. I explained that

because of the limitations on my English language ability, I might need my supervisors or one or two colleagues to help me when transcribing the recordings, so I also asked their permission for only a limited number of other people to access the tapes in order to ensure confidentiality (Israel and Hay, 2006). After the mothers had asked questions or discussed any concerns they might have, I asked them to sign the Consent Form (Appendixes 3-6) before the interview started.

The interview questions constructed in advance were used as a guide. In the first five cases, I tried hard to follow the guide and asked all the questions, but I missed a lot of opportunities to follow up issues raised by the interviewees. After discussing my interview skills with my supervisors, a more flexible strategy was adopted and I engaged more in issues the interviewees were concerned about. Most of the time, I started from a topic that I was interested in and gave the mothers more freedom to talk about their experiences. Rather than leading the interview strictly, I tried to follow what the mothers had spoken about and probed or connected these subjects to questions which I had intended to ask. Both the interviewees and I were actively engaged in constructing meaning (Silverman, 2006). Through the interaction, I benefited from having opportunities to ask for more details about things I had not thought about beforehand.

The interviews were between 90 and 120 minutes long. Although the time I had suggested was 90 minutes, some mothers insisted that they did not mind talking for longer about their experiences. Several mothers were happy to have the chance to reflect on their years of bringing up a disabled child as they had never had the opportunity to do so and no one had ever asked or cared about their opinions before.

After deciding to focus on the mothers' backgrounds related to disability, I emailed two mothers in the first five interview group. I asked more about their jobs and how they were related to disability. Two mothers emailed back some details and generously stated that I could contact them with further questions.

Analysis

Because of the limitations on my English, I encountered difficulties when transcribing the tapes. Funded by my supervisor, Dr. McLaughlin, a senior PhD student helped me to transcribe the recordings. She was highly experienced in transcribing data and when she

encountered problems with the transcribing, she discussed them with me. In order to ensure consistency, she was the only person to transcribe the tapes. After she had transcribed the data, I checked each of the transcriptions myself.

After checking the transcriptions, I read them through several times in order to familiarise myself with each interview. I was aware that my understanding of English cultural and social contexts was limited, hence although it was time-consuming (Ritchie et al., 2003), I chose to categorise my data fully instead of sorting them by theories or conceptual frameworks, in order to reduce the possibility of misunderstanding and increase my comprehension of the data.

While reading, I marked both interesting quotes and recurring ideas, and wrote down my thoughts in footnotes. I then wrote down my initial analysis of each interview through identifying themes, and connecting or comparing these themes with other interview data, my experiences in Taiwan, and the literature I had read. After finishing the first rough analysis, I outlined and indexed themes I thought would be interesting.

The data were grouped into three categories related to motherhood, the meanings of disability, and relationships with professionals, which were the three main areas of interest in the research. I developed a new outline and used sub-headings to draw attention to relevant points drawn from the data. With my supervisor's guidance, themes that I wanted to focus on were developed, and these dictated the form of the three data chapters. As a result, the first data chapter focuses mothers' journey of developing motherhood and discusses issues of diversity, dependence and care. The second explores how mothers consider issues surrounding disability, not only for their present circumstances but also for the future. Based on the experiences of mothers with professional backgrounds, the third data chapter presents knowledge generated from different social positions, and also reflects on issues related to the relationship between mothers and professionals. Partly because the initial framework did not work well, and partly because unexpected data had been obtained, the three topics of the data chapters were developed gradually. Some concepts were recognised as particularly useful when analysing the data.

The debates between the medical model and the social model have had a crucial impact on how disability is understood in the last few decades. These two models provided frameworks for this research to explain the mothers' experiences of both motherhood and their management of disability. At the same time, in this thesis the mothers'

perspectives and experiences are linked and compared with the concepts proposed by these two models in order to extend our understanding about disability beyond these two models.

Apart from the issues related to disability, I found myself poorly equipped to understand many of the interesting themes emerging from the data. I therefore started to read theories and discussions before attempting to conduct an analysis. Debates raised and contributed by feminists gradually became an important thread running through this research. Some postmodernist arguments, especially those concerning respect for diversity, were taken into account when attempting to understand the mothers' varied experiences. The theory of 'capital' proposed by Pierre Bourdieu was also useful for explaining how the mothers managed challenges by employing resources derived from their other social roles. Goffman's concepts relating to stigma, especially the categories of 'the own' and 'the wise', were very useful when looking at the mothers' management of issues surrounding disability and how individuals generate their comprehension when their social position shifts. Discussions about professionals and knowledge became important references when analysing the relationship between the mothers and professionals. These concepts, models and theories influenced how the data were viewed, analysed and interpreted.

When writing up the three data chapters, I first grouped the related quotes together, then categorised them or compared them in order to understand the relationships between them, thus identifying similarities, differences and any contradictions within the data. After writing each chapter, the structure of all three chapters was modified again in order to put arguments together and avoid repetition. My first two attempts at writing these chapters were fragmented; they included too many things but did not discuss the data deeply and accurately. I also struggled when attempting to conceptualise themes I had extracted bottom-up from the data and when attempting to integrate them into my conceptual frame. In addition, having been trained as a social worker in Taiwan, I had difficulty analysing the data from a sociological perspective; hence the analysis focused more on individual situations and was overly descriptive. Because of the historical and social contexts of Taiwan, when I was at university students were neither expected nor encouraged to engage in critiques or take sides. I am still practising how to construct and develop arguments logically and clearly. Because of the difficulties described above, each chapter was redrafted more than three times. As a result of these challenges, there was an obvious improvement in my research skills.

Limitations

One of the critiques of qualitative research is that it is too subjective and that it is difficult to generalise the results (Bryman, 2008). Although I made various efforts to overcome this problem by recruiting mothers from different networks, it remained a small-scale sample of sixteen mothers recruited by convenience sampling, making it difficult to generalise the results to a wider population of mothers with disabled children. However, achieving generalisability was not the main purpose of this research. Rather, the emphasis was on the diversity among the mothers that highlights the knowledge generated from their particular subjective social position, and I believe that although the mothers' stories are only partial, the findings from this research will enrich our understanding of mothering a disabled child and of disability in general. This research has given mothers a voice and amassed material that may be used for further dialogue.

The language barrier was one of my main difficulties when conducting this research. As Silverman (2006) indicates, the semi-structured interview requires skills such as probing, rapport with interviewees, and understanding the aims of the project. The language limitation did have an impact on the quality of the interviews, in that I was unable to respond as accurately as I would have liked to the interviewees' answers and I missed some opportunities to ask for additional or more detailed information on the themes which interested me. It also had an impact on my comprehension during the interviews. For the same reason, the quality of the transcription was affected, as were the speed, understanding and quality of my reading and writing. However, it also brought some benefits. The mothers in this research were aware of my limited English skills and cultural understanding, so they were willing to explain in more detail when I could not follow what they were saying.

Being a mother myself also had a great impact on this research. Although my duties as a mother delayed the progress of this research, at the same time this contributed to the research in two ways. It enriched my knowledge of motherhood. It also helped to increase my comprehension of the cultural and social context of this research. For example, after living in Newcastle for seven years, I started to understand the British sense of humour a bit better. Unlike reading the relevant literature, this development of my cultural comprehension was slow and took a long time. Many aspects of this comprehension are minor details, but they are important. I still learn new things every

day. Hence, I will be more aware of the cultural context in the future, especially when I take these experiences back to Taiwan.

The limitations described above prolonged the time it took to complete this project, and resulted in a long gap between conducting the interviews and writing up this thesis. However, limitations of time made it impossible to update the information initially obtained from the mothers. Although these limitations did have a profound impact on this project, I also benefited from them in the ways described above. The experiences of this research suggest that it might be worth paying more attention to the benefits derived from overcoming limitations, rather than viewing them solely from a negative perspective.

Ethical issues

This research followed basic ethical principles, such as minimising harm to participants; adopting a policy of informed consent; being careful about the invasion of privacy, and not using the strategy of deception (Bryman, 2008; Israel and Hay, 2006). In the information sheets I explained the aims of this research, informed potential participants that the principle of anonymity would be adopted by, for instance, changing the mothers' and children's names, and offered the mothers the freedom to withdraw at any time. The interviewees signed a consent form before the interviews.

When interviewing, I encountered two events related to ethical issues. One of the interviewees cried several times during the interview, and although I gave her tissues and suspended the interview until she felt able to continue, on reflection I did not deal with it as appropriately as I should. For example, I did not offer her the chance to withdraw, or set another time. Another case involved that of an interviewee who said she felt isolated. I told her that one of the other interviewees lived nearby, and offered to ask this other interviewee if she would like to make friends with her. Although I did not reveal where the other mother lived, there was still a risk of revealing the other mother's identity by indicating she lived nearby, and it would have been better to ask the first interviewee before making an offer to the second.

There were other ethical challenges to which I believe I responded much more positively. During two of the interviews, a child with cerebral palsy was in the same room with us. This had some impact on these two interviews because the mothers

needed to respond to their child's needs regularly (Barrett and Cason, 1997). Although these could be viewed as interruptions and they did have an influence on the process of the interviews, I still viewed it as a positive thing. I had a chance to meet their children and observed the interaction between mother and child. It helped to embed the interviews in their regular lives and made their accounts come alive. It also reminded me that as a researcher I should be grateful for the fact that these mothers were generously sharing their private lives with me, allowing me to enter their homes and meet their children.

Some mothers said in the Parents' Forum that some parents did not believe that their participation in research could make any difference, so they did not bother to do it and rather focused on looking after their child. This could imply that the mothers doubted whether their voices were really going to be heard. The mothers realised that their expectation of social change could never be guaranteed by a research report (Kombo, 2009). It might also suggest that mothers share a similar concern to disabled people that their families could be exploited for researchers' own interests or to further their careers (Israel and Hay, 2006; Fawcett, 2000).

As Israel and Hay (2006) assert, researchers should make efforts to provide benefits to the participants and the group they belong to. As Bryman (2008) illustrates, feminist researchers advocate an interview that emphasises the interviewee's perspective, in which there is a high level of rapport and reciprocity between interviewer and interviewee, and a non-hierarchical relationship. As a researcher, I chose not to just 'take and run'. At the end of the interviews, I would ask the mothers if they wanted to add anything or if they had any questions to ask. With some of them I discussed the experiences of parents of disabled children in Taiwan and exchanged some thoughts on the differences between the two countries. Two mothers said that they would like to hear news of my progress, so if I went to conferences related to their situations, I would email them. If I obtained information related to their situations, I informed them of it through email. Even now, I still send the mothers Christmas cards in order to express my gratitude.

I appreciated the fact that the mothers were prepared to share their private experiences with me and with parents in my country in the future. Hence, I am aware that it is my responsibility to protect them when talking about their experiences in public. Although I might not be able to give these mothers direct feedback, I still view it as my responsibility to have an influence on the public sectors in my country in the future in

order to promote the welfare of disabled children and their families in Taiwan. I also hope to contribute the expertise they shared with me through presenting papers in conferences or journals in order to make their voices heard.

Conclusion

The experiences of this research have confirmed that the qualitative, semi-structured in-depth interview is a very useful instrument for exploring a marginalised group or a group that a researcher is not very familiar with. Since all knowledge is situated, a researcher might never be able to anticipate what kind of data he/she will collect. Although this research was not guided by a strong conceptual theoretical framework, the approach of learning from the mothers' experiences led to an interesting and unexpected journey that enriched my comprehension of many related issues.

In this research, the issue of the distinction between outsiders and insiders was an important one for the mothers, who are easily identified as 'others'. In the following three chapters, I will show why mothers' experiences are invaluable and how they can expand our understanding of disability, motherhood and care, and help to promote benefits for disabled children and their families.

The issue of outsiders and insiders was also significant for me as a researcher. As an outsider, my personal background influenced how this research was conducted, how the data were collected and analysed, and how the mothers' experiences were interpreted, and therefore influenced the validity of this research. In order to achieve validity and respect ethical principles, I remained constantly aware of my standpoints. I derived both limitations and benefits from being an overseas student, and an outsider. Throughout this research, I was aware of the importance of recognising and choosing one's standpoint. It has been a long journey and I am still constantly searching, modifying and reflecting on my past, present and future. Having recognised the profound influence of cultural and social contexts, I will have to think carefully when introducing the experience and information I have acquired in the U.K. to my country on my return.

Chapter Four

A journey of developing motherhood- Diversity and Dependence

Motherhood has been identified by feminists as a crucial element that influences the socialisation and reproduction of social relations and social structure: for instance, in the training of gender roles (Richardson, 1993; Chodorow, 1978; Rich, 1977). In contemporary society, one of the main goals of motherhood is to bring up the independent, moral and productive citizen of the future who conforms to the interests of the state and a capitalist society (Lawler, 2000; Hays, 1996). As other research has highlighted, although having a disability can lead to the assumption that these children will not fulfil these expectations, their mothers are not thereby freed from the influence of social and cultural norms (Ryan, 2010; Ryan, 2008; Blum, 2007), hence such mothers and their children are still intimately involved in relationships with various social actors in cultural and social contexts. Although they appear to be surrounded by various support systems, I will propose that taking care of a disabled child continues to be deemed principally the mothers' responsibility, and that mothers with a disabled child can experience an isolated type of motherhood. Issues related to dependence will be discussed in considering the boundary between families and society when sharing the care of disabled children.

The impact of disability was found to be one of the main factors that shaped the motherhood of the respondents in this study. Many of the issues surrounding the care of the child discussed by the respondents involved practical matters related to their child's impairments. Their motherhood was intensive because not only their physical but also their mental strength was challenged daily, 24 hours a day. Many respondents gave illustrations of their extended motherhood, such as changing nappies for their teenage children. It was hard for them to imagine a gradual decrease in their maternal duties along their life trajectory, as described in previous research (Todd and Jones, 2005; Leiter et al., 2004; Landsman, 1998). Several mothers described themselves as dominated/controlled/taken over/occupied by the needs of their child. Debbie used the metaphor of a 'cocoon' to portray her life with her daughter: '*If the parent, living in the world of a disabled child and not having able-bodied children, you, you are in your own little cocoon really, you're in your own little world. What we do with Jenny is influenced by what she is interested in, what our friends are doing, and most of them have got children with disabilities anyway. So we don't often venture into the world of*

the normal child'. Many of the respondents expressed great sorrow about how the impact of disability obstructed their relationship with their child, so that the relationship was different from the one they had imagined or planned. For example, some mothers felt sad that they were unable to share activities they enjoyed with their child, such as walking in the Lake District.

However, the impact of their child's impairment was not the only factor that had given rise to the extended and intensive nature of the respondents' motherhood. Respondents spent more time talking about how external contexts were as significant, if not more so, in the care of their child than the specific issues their child had (Hodge and Runswick-Cole, 2008). This section will examine other, external social elements that have influenced the development of the respondents' motherhood, including prevailing social expectations of motherhood, and the influence of families, friends, other parents with disabled children, and professionals. After becoming a mother, the women in the study began to develop their own approaches to motherhood through contemplating the discourses and expectations suggested by others and their own life experiences. They also reconsider the meaning of dependence and care.

The social image of a good mother

> *When I was having Ben, I had an idea in my head… I knew how I*
> *wanted to bring him up so it wasn't difficult to think of what I wanted*
> *to do. It was just not practical because obviously he was born with*
> *difficulties (Cathy).*

Lindemann Nelson's (2001: 6) arguments about what she calls 'master narratives' is useful to explain Cathy's claim to know 'how' to bring her son up. Lindemann Nelson views the master narratives as a cultural store from where stock characters and plot templates are used as a shared foundation for individuals to make sense of what they encounter. Lindemann Nelson also suggests (2001: 137),that master narratives both shape who should take care of children – women- and also provide job descriptions about 'how' to do it properly. Within an 'abusive power system' (Lindemann Nelson, 2001: 137), these master narratives that are frequently shaped by white middle-class

men, are normally presented as something that can/should be taken for granted as feminists have challenged. Although these master narratives are influential, individuals still have some level of agency to examine and adjust their comprehension drawing from the master narratives.

Social expectations and social images of women/mothers were used as references by some of the mothers in this study. Miller (2007) indicates that first-time mothers find that assumptions or discourses about motherhood do not resemble reality, and the mothers in this research similarly had realised that social expectations of good women/mothers could be unrealistic and a source of pressure. This view is illustrated in the following comment by Wendy:

> *I do think that women are expected to do an awful lot now…You're expected to have a perfect home that looks like it's just come out of a magazine, you're expected to earn a living that pays for that perfect home and you're expected to bring up perfect children who are well-behaved and grow up to be clever and you know are beautiful and all of these things and, and the reality for most people is just so stressful trying to achieve all of that. And I don't think, in reality, I don't think it ever really works. I think people kind of get by, and make the best of it.*

As a women in Traustadóttir's (1991) research who refuses to give up her career after being a mother of a disabled child because she is a feminist, Wendy also highlighted the influence of feminism, she indicated: '*I can understand why women would be dissatisfied…it is hard to think that you would have to give all that up just because you had children and that you stopped existing as a person yourself, just to be their mother. So the sort of feminist side of me thought well why should I have to do all of that?*'

Feminist arguments about gender issues may have had an impact on contemporary social expectations of mothers; however, as pointed out by other researchers (O'Brien, 2007; Leiter et al., 2004), women are still expected to take care of the needs of their family members. Although their children were viewed as being unable to meet the social requirements for being a good citizen because of their impairments, society's

views of what is a good mother and social norms regarding what makes a good citizen were still significant references for the respondents' expectations and components of their motherhood. For instance, Debbie described her experience as follows:

> *I wanted to be a mother who... taught their child... right from wrong, to be very, a good citizen, to be very upstanding and... well-behaved, polite... a good child who was mischievous and naughty as a young child but learnt right from wrong and, ya and was a good citizen and gave, gave back to society what she took really...a good mother is, is the person that teaches them those things and is a good role model...I try to teach Jenny right from wrong. I don't always succeed cause she takes no notice of me... she only understands things up to a sort of age of two and a half to three. ...they're still at the age of hitting people and pulling hair and stuff like that, you know. She doesn't have the concept to, to know better. Can't teach that really.*

After comparing the social expectations and assumptions about motherhood with the reality they themselves experienced, several mothers said they had realised that they could never satisfy every social expectation and be perfect; hence they had developed their motherhood in line with what occurred in their daily lives. Cathy recalled her journey of recognition, '*if you don't reach them or if you don't manage to do them then maybe you feel like a failure... I think I've just learnt not to do that now, and just sort of lighten up not to put too much pressure on myself... I'll just do what I can when I can*'. These reflections on discourses related to motherhood did not come easily; the respondents had generated them from their experiences of feeling self-doubt, judgement or blame. Moreover, the mothers had also realised that the dominant ideas about motherhood were inadequate to help them raise a disabled child, as were the practical maternal experiences passed on and shared among them in the mothers' existing social support system.

Existing informal social support system

Research has indicated that socialisation is one of the important influences on motherhood. By this is meant the way in which gender roles or identities that pass from mothers to daughters reproduce patterns of how to be a good mother (Richardson, 1993; Chodorow, 1978; Rich, 1977). In this research, four mothers stated that their ideas about motherhood were nurtured by how they themselves were raised. Cathy stated, '*to be a good mother just depends on…obviously on what your experiences have been when your mother's been, you know, raising you and I think it all depends on that*'.

However, some respondents indicated that the special needs of their child arising from his or her disability went beyond their own experiences of being brought up. According to Jackie, '*being the mother of a child with ADHD, I would say, was different from how my mother mothered me*'. Rather than passing on experiences, some of the grandparents instead apparently relied on the mothers' information to understand and interact with their grandchildren.

Furthermore, the understanding of disability and what was viewed as an appropriate placement for disabled children was different between generations. For example, two grandmothers mentioned the option of putting their grandchild into an institution. However, the mothers disagreed and rejected these suggestions. On the other hand, some grandparents showed a great deal of sympathy with and understanding of the mothers' situations because they had acquired some experience of disability from their friends, their partners or themselves. Gradually, they could become a generation able to understand issues related to illness and disability and become members of 'the wise' or 'the own' groups, to use Goffman's terminology (Goffman, 1968: 31).

Normally, family members, kin and friends are important information sources that offer role models or exchanges of maternal experience for mothers, a group we can think of as 'the own'. In this research, however, the respondents had found that not only was what they had learned from their own mothers invalid, but also their existing support system often failed to support them. Several mothers reported a great grief when losing their intimacy with existing social networks because of their child's impairments. A few mothers stated that their relationships with their siblings had been damaged. Wendy recalled, '*me and my sister, had sort of drifted apart…he was an unhealthy baby, she didn't really know what to do…we lost touch, and haven't really recovered that actually, our relationship is still quite damaged because of that time*'. Milly was angry

with her family; she recalled, '*we were in hospital for a week, having tests. And none of my family came to visit. None of the family, none of them…and my sister who is a social worker… She phones me after 3 weeks and said 'oh I'm sorry I haven't phoned, I didn't know what to say'*.

Some mothers reported that they and their children had been excluded from occasions and interactions they used to be included in, such as not being invited to a wedding. Jackie's sister did not want her own sons associating with Jackie's sons who had ADHD. This separation dashed Jackie's hope that the boys could support and be there for each other. Although Jackie tried to educate her sister to deal with her unease about disability and illness, the effort seemed only to push her sister further away. This suggests that the mothers had found that the boundary between insider and outsider had suddenly shifted because they had a disabled child: it was no longer clear who their 'own' were. These notions confirm the suggestions of previous research that families with disabled children may feel excluded, isolated or angry because of the negative responses from family and friends who are supposed to provide care or support but instead choose to withdraw from and marginalise them as 'others' outside normality (McLaughlin, 2006; Kearney and Griffin, 2001).

Several mothers also reported that they had needed to review their relationships with their friends. Only two mothers noted that they still had good relationships with their old friends and only two mentioned reciprocal support and friendship from their neighbours. Jackie noted, 'y*ou find out who your friends are and who your friends aren't. A lot of people don't want to know you. And they just you know, they don't bother with you anymore*'. Gradually, tensions started to emerge in the mothers' relationships with their friends. Sometimes this was because the differences between their child and those of their friends were spotted, which led to unease and embarrassment on the part of mothers of non-disabled children. Angel recalled, '*my friends came to us, and her little girl started to walk, she felt so guilty. They keep away because you know their children are, you know, developing the way they should*'. The mothers' own previous experiences when encountering impairments might have helped them to understand their friends' embarrassment. Many respondents recalled that they did not know how to act when meeting disabled people before having their disabled child or doing their jobs as service providers within NHS or educational settings, as Anita recalled*, 'I didn't know a disabled person until I left school and started my career'*. It was something they were not familiar with, an experience outside of social

norms. Moreover, if the prevailing discourse involves the notion of personal tragedy, this could be another explanation for the guilt as Angel indicated. The tension caused by such differences also affected the mothers with disabled children, as shown in the following comment by Mary:

> *All my brothers and sisters are sort of academics and doctors and doctors of philosophy...sometimes, I do really struggle, sometimes, because again, they're very competitive and you know Adam is playing the violin and Tracy is playing the flute and blah, blah, blah, blah, blah...and then it's like, ok, I can't really compete like that but, I'm really, really proud of her. I'm really, really proud of her achievements because I'm, you know, when you see her or, how much she's had to overcome, and she does it and she manages to still keep a smile on her face, you know, it's great.*

Most of the mothers were aware of the differences between their child and others' children. Although all the mothers in this research appreciated their child's unique values, some admitted that it was still not pleasant to listen to the achievements described by other proud parents. Hence, their relationships with other parents changed. In addition, the mothers found that their priorities and interests differed from those of other parents. Wendy explained the change in her friendships as follows:

> *It became more obvious that the friendship was becoming strained because obviously, we were having totally different experiences of being a mother and mine was very medical and I'd a lot of involvement with medical people and a lot of our conversation was about that and I think she just sort of thought 'she doesn't really want to know'... (lol) 'I don't want to talk about this, this isn't a conversation for me'.*

Although none of them denied that their children were different in many ways from other children, the mothers who participated in this study felt that it was because the

emphasis was always placed on the differences, rather than acknowledging similarities between the children, that they were marginalised as 'others'. Both they and their child were defined by other people according to the disability the child had. Wendy illustrated the differences in the types of maternal exchange she had with other mothers:

> *The only thing they would ask me about is 'oh so why is he on oxygen? What's, what's this? Why has he got these tubes on his face?' And he had his hearing aids at the time so 'oh so he's deaf, so, um, it's nothing being deaf these days is it, there's loads of things they can do' and get really stupid thoughtless comments and I stopped going (the class her health visitor was teaching) because it was just so unpleasant. It was just, I just thought well if you haven't got a perfect little baby, you know, they don't want to know you, all they wanted to talk about was his disability. Nobody wanted to ask if he'd got nappy rash or whether he got a, you know whether he slept through the night…and all these other mothers were asking questions about weaning…the only sort of questions that I got asked like I say were related to his disability. And I just thought you know, on top of all of this, he's a regular baby, he does the same things that most other babies do. And you're all talking about these problems with breast-feeding and all of this sort of stuff. And nobody asked me at all about anything like that.*

Green (2001) describes an experience similar to Wendy's. When her daughter contracted chicken pox, she finally had something in common with the other mothers and could share her experiences with them. However, after that, she was on her own again. The focus on differences excludes mothers and their children from normality. As research has indicated, having a disabled child might become the border that divides the insiders, who also had a disabled child and who hence understood, from the outsiders who did not (Bennett, 2007; Green, 2001).

One of the reasons that the mothers' informal social network could not understand and support them, or that experiences shared with their existing social network were not useful for the respondents, was because the experience of mothering a disabled child is

not valued or included in dominant discourses on motherhood. Instead, in most books for pregnant women or mothers, disability is portrayed negatively as something to be avoided (Ryan and Runswick-Cole, 2008). Therefore, as the experiences of the mothers who participated in this study have demonstrated, many non-disabled persons are fearful of disability and do not know how to act in the company of a disabled person. Sadly, not many of the relatives and friends of these mothers had shifted their position from that of 'others', who have little or no personal experience of individuals with stigma, to that of 'the wise'. They did not make an effort to understand the mothers and their disabled children but continued to exclude or marginalise them as 'others'. As a result, the friendship and relationship with others were changed, as Libby noted, '*when you have this child with disability who doesn't fit in with what everybody else is doing then they're (friends) often gone*'. The previous understandings of where they belong had to be examined and altered.

New sources of templates for a mother with a disabled child

When mothers in the study talked about a lack of support for mothers of disabled child, I asked them what could change that, Wendy suggested '*…trying to think of different ways to solve their problems and different ways to overcome barriers…be able to sort of see around the problem, you know you have to be able to kind of work problems out and not be afraid of trying new things and ask for help*'. Debbie added,

> *As a, the mother of a child with special needs you have to actively go out and look for somebody to support you. Where you go for that it depends on who you are…it (motherhood) can't be developed by yourself, you can't learn and be the best mother who you can be if you, if you don't have…support, role-models, whatever you want to call the people around you.*

Among the various kinds of help, professionals and other mothers of disabled children were identified as influential sources by the respondents. However, although in theory these two groups will provide support or services, the reality is much more complex. The following section will illustrate how these two communities supported the mothers

who took part in this study and how they could cause problems as well as support on the mothers' journey.

The influence of the professionals

As indicated in the findings of previous research, how to interact and cooperate with professionals was identified by most of the mothers as one of the most significant elements of what they saw as their altered maternal role (Carpenter and Austin, 2007; Clavering, 2007; McLaughlin, 2006; Prussing et al., 2005; Rehm and Bradley, 2005; Leiter, 2004; Leiter et al., 2004; Green, 2003a; Brett, 2002; Green, 2001; Bower and Hayes, 1998; Larson, 1998). The following paragraphs will focus solely on the professionals' influence on motherhood.

Especially in the early stages, suggestions and information from professionals were welcomed by the respondents because they were one of the main sources of information that could help them to understand and take good care of their child. For instance, through diagnosis and prognosis, medical professionals framed the ability/disability of their child. However, the influence of professionals was much more complicated in mothers' lives. In this section, I will first suggest the information professionals provide may not be necessarily helpful, instead sometimes it can be problematic. Second, I will demonstrate the impact of medicalisation on mothers' maternal practice. Last, I will illustrate some strategies mothers generated and mothers' reflection on these strategies.

Scholars have indicated how the information or diagnosis professionals provide and present can be influenced by their own values. For example, Oliver (1996) argues, the medical perspective adopted by most professionals places an emphasis on the child's biological deficits, and is thus predominantly negative. Professionals may fail to give mothers of disabled children any hope or encouragement when they communicate a diagnosis as tantamount to passing on bad news (McLaughlin, 2005; Kearney and Griffin, 2001). Research has also revealed how insensitive ways of delivering a diagnosis can have a negative impact on mothers' understanding of disability (McLaughlin, 2006; Green, 2001). Similar experiences were reported by the respondents in the current study. Since the mothers' negative views or stereotypes of disability were unchallenged or even compounded by the medical prognoses and explanations, some respondents recalled that they felt sad, in shock, and on their own at the beginning of their journey.

Following the diagnosis, an assortment of service providers entered their lives. The mothers who participated in this research had varied experiences of these encounters. Three of them said they appreciated the support of professionals in the early stages. Others, especially those whose children were diagnosed with autism or ADHD, reported that they were left alone with limited information instead of being fully supported. Sherry described how, '*you get this diagnosis but you don't know what to expect… Nobody actually tells you anything. You have to learn it on the way*'. Even mothers who reported professional support was helpful in early days gradually recognised some problems while interacting with professionals.

The mothers were expected to follow the advice and guidance of these professionals, but this proved very complicated in practice. The instructions they received from the professionals were useful guidelines, but could also be a source of confusion. One reason for this was that the suggestions made by the various professionals were not consistent with each other. Mary described how, 'sometimes you're given conflicting advice as well about sort of, you know, and they're very, very rigid'.

Although the support professionals provided was not always useful, their guidance and expectations could have a profound impact on the practice of the respondents' motherhood, which could be viewed as the influences of medicalisation, impacting their maternal roles and tasks, and the surveillance of these. Progressively, the mothers found that the professionals not only defined the meanings of their child's disability but also circumscribed their maternal tasks and roles. Since the suggestions were given by different professionals, the mothers were expected to play multiple roles (Leiter et al., 2004), such as those of a therapist, a nurse and a teacher, as Jackie stated: 'everything rolled into one (a mother)'. They were expected to perform a multiplicity of tasks, such as maintaining their child's health, giving their child medicine, and monitoring or improving their child's development in their daily life. Thus, mothers were not only the 'reserve army' as McKeever and Miller (2004: 1188) suggest, but were also the ones who actually performed some highly complicated and technical tasks.

As Kirk (2000) argues, the norm is for the duty of care to transfer from professionals to mothers. The number of tasks and duties imposed on the mothers increases constantly over time, while the support from professionals is reduced. As Cathy, one of the respondents in the current study, noted, she only saw the professional once every six months. The mothers were left alone between the visits of the professionals and were expected to carry out complex tasks and take responsibility for their child's

development. Left alone and without appropriate support, it was easy for the mothers to feel they were failing to meet their child's needs and the demands of the professionals. Angel described the difficulties she faced, '*you're trying so hard, you want them, you want them to think you're doing your best, you know, and you've got to admit that you're not doing something, and you haven't done something and you know, you're a bit...that makes me think, I am not such a good mother after all*'. Angel's notion echoes Leiter's (2004) finding that mothers do not have the knowledge to judge the effectiveness of the exercises which therapists tell the mothers to do at home with their children and cannot maintain distance when things do not go well. Additionally, as Angel added, the services normally focused on their child and their impairments, and seldom took into account the support the mothers would need in order to perform these tasks, or their personal needs. Debbie also illustrated the narrow focused service professionals offered seldom included the needs mothers needed.

> *Professionals are only, only interested in that little area... If they're a physiotherapist they're just interested in giving you that physiotherapy support that you need. ...you can get that package but you don't get emotional support beyond you know the, the, the physiotherapy package or the occupational therapy package, or whatever.*

Since the boundary between typical childcare and atypical health care is blurred, Leiter (2004) suggests viewing care duties performed by mothers that include health components as the exception, or as an extension of mothers' caring tasks. However, as Kirk (2000) argues, the boundary between professionals and mothers is taken for granted rather than being the result of negotiation. Mothers might find that they are expected to participate and contribute more in their child's development by professionals, instead of being invited to participate. Kirk continues to argue that the power relationship between mothers and professionals is unbalanced, and that mothers occupy a weak position when negotiating with professionals about when and where the extensions to their duties end.

These extra expectations and responsibilities can affect a mother's role and reduce the amount of time and space she has available for being a mother. Angel found her life was taken over by the professionals' demands on her: '*if she's been in the water I've been*

trying to exercise her legs…you're constantly thinking, is this actually doing her any good, whereas you know, a child without a disability you enjoy watching them because they're having fun'. As a result, Angel found '*sometimes they just want to sit on your knee and you just want to give them a cuddle but this is a bit of a waste of your time'*. Recognising the invasive nature of the professionals' expectations, four mothers specifically asserted that what their child needed was a mother rather than a therapist or a nurse. With some mothers their awareness of the professionals' invasion of their privacy, their life and their house arose gradually. As Mary described, '*you have so many people in your life, as I said there's about 28 different professionals around Siobhan. But, you know, sometimes you do just want to, feel like shutting the door and saying, 'go away everyone, and just leave us alone' '*. Hence, five mothers noted that they were happy when therapies took place at school, which meant that their home remained their private domain as Read (2000) has suggested.

In addition to the professionals' tangible influence on the mothers' caring tasks and roles, some of the respondents were also aware of the effect of 'medical surveillance', as indicated in the findings of previous research (McLaughlin and Goodley, 2008; Carpenter and Austin, 2007; Todd and Jones, 2003; Brett, 2002; Larson, 1998). Angel described experiencing the pressure to fulfil the professionals' requirements and expectations: '*y*ou do feel as if you're being, you know, under scrutiny, as though you're being watched…there's somebody watching all the time… and questioning what you're doing with them and why you're doing it and what you should be doing and what you shouldn't be doing'*. These tasks and expectations could turn the mother's view of her child into a medical 'gaze' on his or her body, as in the case of Wendy's view of her son Sam's disability:

> *I had been really focused on his disability before then, really focused on our lives as parents of a disabled child and looking forward with a very bleak picture if you like, of what his prospects were, and what our lives were going to be like, and how tied we were going to be to his needs, rather than being able to just be a normal family, that everything that we did was going to have be centred around his needs.*

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Both Wendy and Angel's notions reflected other researchers' arguments concerning the efforts to control illness and how these can evolve into full medical surveillance (Barnes and Mercer, 2007; Borsay, 2002; Oliver, 1990). This surveillance can turn into self-monitoring, not only of the impairment, but also of other aspects of mothers' daily lives, especially the content of their motherhood.

In addition, as Williams (1993) suggests, this relationship is more likely to be a one-way transmission of knowledge from service providers/experts to mothers. The respondents were expected to follow professionals' guidance and try to adopt the professionals' rigid standards. Wendy gave the definition of a good mother from the professionals' perspective as being '*somebody who doesn't ask too many questions…their (professionals') knowledge is you know unquestionable…they want somebody who does what they're told*'. With mothers being viewed as lay persons who are just 'a pair of hands', as Brett (2002: 833) suggests, it is not surprising that they are expected to do as they are told, and that their voices are not heard (Carpenter and Austin, 2007). In this context, if mothers adopt other approaches, such as refusing to accept the medical assumptions, it is common for them to be tagged as unrealistic, optimistic or in denial as previous research has indicated (Kearney and Griffin, 2001; Larson, 1998). For instance, Mary disagreed with the doctors' gloomy prognosis regarding her daughter and insisted on maintaining her high expectations of her; this was labelled as unrealistic.

Moreover, the dynamic of professional control can also be seen in the fact that the mothers' observations drawn from their daily life were viewed as less valuable and were excluded from the service providers' views of what constituted reality when assessing their child's condition and needs (Fisher, 2001). For example, when Maggie shared her observation that her daughter, who had been diagnosed as blind, could actually see, she had been regarded as still being at the bereavement stage, and pathologised as angry or frustrated. She recalled, '*they said she cannot see at all…I said 'look, if I line all the Milky Bar buttons up along the floor and she would go and pick them all up and eat them'… They said, 'No, that's just your imagination…you want her to see, it's in your mind'*'. After seeing her daughter pick up the chocolate buttons, the professionals did admit that she might be able to see a little bit. Libby offered another example involving her son Carl, who had difficulty sleeping. After trying various different strategies, she had found that it helped if she let him sleep in a buggy seat. However, a respite carer had questioned this. Libby told the respite carer, '*I'm telling you as a parent, that's*

what works, and I don't think it's right for you to question what I've found works'. Libby's explanation for the difficulties in getting her views across was that it was because '*they (professionals) are seeing you in a negative light'*. As suggestions of previous research, in the unbalanced relationship between mothers and professionals, there was little opportunity for the mothers' experiences to be taken into account (McKeever and Miller, 2004; Kearney and Griffin, 2001; Larson, 1998).

In confronting the influence and expectations of professionals, the mothers had developed diverse tactics based on their personal situations to allow more flexibility and open up more possibilities for their children and themselves. Some mothers preferred less overt resistance and adapted the professionals' suggestions and expectations to suit their own approach to motherhood. Maggie admitted that '*(I) believed in what I thought um, I didn't exactly listen to all of that. I didn't honestly. I cheated quite a few times actually'*. Angel echoed, '*I got to a stage where I thought, right, I've got to listen to the physio…but I'm going to decide what I do, when, and how I'm going to do it'*.

Other mothers chose more overt ways to resist or confront the service providers. Most of the mothers interviewed for this study stated that when interacting with service providers it is essential to be well prepared, make yourself heard, ask questions, stand up or fight to show disagreement, and be strong, stroppy, bossy, hard, or persistent as needed. This finding is in line with the findings of previous research (Clavering, 2007; Runswick-Cole, 2007; McLaughlin, 2006; Prussing et al., 2005; Todd and Jones, 2003; Beresford, 1994; Traustadóttir, 1991). Some mothers, especially those with professional backgrounds, identified fighting with professionals as the result of structural problems in the organisation of welfare, as illustrated in the following comment by Milly:

> *I think the services often create what they call 'difficult parents'…you have to fight for everything. I think it makes you exhausted, having to deal with a child, having to fight for everything, not having the right information, not having any support going through the different stages, I think it just creates a very difficult situation, for all families. I don't know any families that haven't found it difficult.*

It should also be pointed out here that the mothers' tactics were constantly being transformed. After a few years of fighting, both Mary and Lisa had decided to scale down their fight with the service providers because it was having a negative impact on their families. Mary questioned the function of fighting by asking 'w*hat's the point? Who is it damaging?*' She explained,

> *Pretty much you can almost fight all the time and it's not healthy, I don't think it's very good for you as an individual or as a person…there are times, when ya, the door is slammed in the face, but if that happens then we also, we always try and challenge, if it's blatant discrimination then we do challenge it. Um, but as far as possible you, you don't want to be in, in that challenge mode all the time.*

Several respondents claimed that fighting was not in their nature, although fighting for their child's rights was identified as essential by many mothers. It was not what they had expected. They had been brought up to be nice, easy-going, pleasant people, and some were shy and quiet. In order to negotiate more efficiently with the service providers, many of the mothers in this research claimed that they had had to abandon their upbringing. For example, Wendy explained, '*you're brought up to be nice; you've got to be very nice. If you're not nice then you don't get what you want. It's just not true. It's like often you get things especially difficult if they want to get rid of you (lol). It's hard…the balancing act*'. Some mothers stated that they had been forced to change their personalities, as in Jackie's experience: '*I'm not a, a vocal person, but I've had to get over my shyness to be able to be vocal. And stand up there and say what I want*'. None of the mothers enjoyed this kind of transformation. Debbie was struggling to be the mother she thought her daughter needed:

> *I wish I had more power and I wasn't quite as emotional. I wish I could take that step back out of the situation, and, and you know, and then step back into it…I would like to have the verbal skills to go in, and just say, I want this, this, this and this…I'd like to be a parent who didn't go into some meetings and interviews and cry…. I wish I was one of these powerful executive people that you knew them, you know,*

you knew some people and they say exactly the right thing, don't they,
at the right time.

The image of a tough mother described by Debbie was different from the dominant discourse on what constitutes a good mother. When negotiating in the public sphere, a more rational (not crying), objective (could step in and out) or powerful (saying the right thing at the right time) individual was preferred by other social actors in the public sphere. It also suggested an emotional cost. Debbie added a description of how other people would respond to an emotional woman, '*well, just nod our head and say yes, yes, yes, yes. And then she'll go away, weeping little woman. And people do treat you like that…'oh my God! She is again she's going to cry' '*. Sherry believed it was essential to be prepared or you might be ignored as a mother. She said, '*I'll have reasoning behind it, so they can't just say, 'oh she's a paranoid mother' '*. The labels mentioned by the respondents that had been attached to them when they had different perspectives from the professionals, such as paranoid, neurotic or imagining, are more likely to be used in describing women (Todd and Jones, 2003). It implies that a person's account could be included or excluded depending on how he/she expresses it, or on whether it is expressed in a female way. This gendered framework also partly explains why the mothers' perspectives were often viewed as subjective or emotional and were not taken seriously. It could also explain why the mothers reported that they had had to change their personalities. This finding confirms the findings of previous research that mothers' perspectives are denigrated not only because they are not professionals, but also because they are women (McLaughlin and Goodley, 2008; Callery, 1997).

Although the mothers might not have been able to pass on what they had planned to pass on to their children, some of them had had other, unexpected achievements. For example, Sherry's physically disabled adult daughter had asked her to fight for her grandson in the future if needed. This suggests that her daughter did appreciate the fight her mother had engaged in on her behalf and that she wanted to pass it on. It is also possible to argue that the actions of those mothers who fought, who became stronger and more vocal, or who walked away from how they themselves had been raised will provide alternative templates for their children, templates that are less limited by social norms or gendered expectations.

The findings of this research confirm those of previous research, which suggest that professionals can have a profound impact on mothers' self-identity, roles and duties (Leiter, 2004; Leiter et al., 2004; Todd and Jones, 2003; Brett, 2002). However, it was also found that the respondents developed their own strategies to manage related issues. Although the mothers had struggled in their battles with the professionals, there had been benefits. The professionals might provide an example of how to do things properly according to their methods, but the mothers also realised that there were a few approaches that they would never choose, such as using a medical prognosis to limit how they imagined their child's future. The comparisons, competition, resistance, and fighting the mothers engaged in with the views and recommendations of the professionals produced important references for the mothers that helped them to relocate themselves and generate their new identity, and construct their motherhood (Jenkins, 2004; Scott-Hill, 2004) .

The influence of other mothers of disabled children

When interacting with others, mothers of disabled children can find themselves feeling inadequate and alienated (Bennett, 2007; Green, 2001). Many of the mothers in this research stated that they preferred to make friends with parents who had disabled children because they 'understood' what they were experiencing. Hence, they suggested that other mothers could get support through contacting other parents with disabled children or by participating in groups for parents of disabled children. Five mothers especially indicated that most of their new good friends were parents, especially mothers of disabled children, and said that the support and advice they received from other parents was extremely helpful, because they could share strategies and information that could help them deal with difficulties they were encountering, which is a feature of 'the own' group proposed by Goffman (1968: 31). Wendy illustrated the differences between women and men when interacting with other families with disabled children they sometimes went out with:

> *My husband says that he finds it more difficult to talk to other*
> *fathers…because men don't like to talk about how they feel about*
> *things… He finds it difficult to socialise with the fathers of the*
> *children who Sam's friendly with, and I'm very friendly with the*

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> *mothers. He finds it difficult to take part in like a bigger group there.*
> *So, generally speaking, it's mothers who get together and mothers*
> *who get the support from each other and I think dads do get a raw*
> *deal really, it's harder for them I think to get the support they need.*
> *And you need to be in a good relationship I think, to get the, that*
> *support.*

This suggests that mothers can have different experiences from fathers when interacting with other parents. Most of the experiences the respondents referred to were their interactions with other mothers with disabled children. Therefore, in the following discussion the experiences presented will be located in the context of the interactions between mothers. Compared with the vague and negative medical prognoses, the experiences of interacting with other families with older children could provide mothers with some degree of certainty about what their lives could be in the future. In Wendy's opinion, the experiences of these women were invaluable in enabling her to look ahead and know where she was going next:

> *Particularly from mothers who've got slightly older children, they*
> *kind of steer you through the system as well, so you get advice that*
> *helps you onto the next stage, you know. So you, you're always*
> *looking ahead, where you're going next…her experience has been*
> *completely invaluable, you know it's really been a lifeline to us.*

Interacting with other mothers could also help mothers to gain courage and increased their confidence. According to three of the respondents, going out together as a group had given them courage to face others in public and break down barriers together. They had more opportunities to have fun and positive experiences, rather than feeling stressed and frustrated if they had gone on their own. As Libby described, '*if I'd have been on my own, it's very embarrassing…on your own, you'd have been mortified, really upset. Two of us we were wetting ourselves, we were really laughing cause it's funny*'. Wendy also stated:

Getting involved with local support groups and meeting other parents and making friends with, with other families who you can socialise with and do nice things with the kids, so you don't feel like it's all doom and gloom…get out with other families who are more confident maybe than you are or they've got more experience than you have and then you just sort of, you develop that confidence from them…if they can take their kids swimming I can take my kids swimming. Then you do go and then you realise that you can do it and it was good for them, and it was hard work, but it was good fun and worth doing it and so you do it again.

Therefore, interacting with other mothers not only creates a pleasant atmosphere within the parents' groups, it can also extend mothers' comfort zone outside these groups. Through acting together, they can explore and experiment with possibilities and alternatives in their approach to managing disability. When they had built a shared identity or sense of belonging to this community, the mothers had felt less alone. Relationships with other mothers of disabled children might therefore offer something which is not available from mothers who do not have a disabled child. Other mothers with disabled children could become new role models, and new sources of information and suggestions. These experiences can influence the mothers' understanding of disability, how they practise their motherhood, and their sense of being a mother with a disabled child. However, sharing a similar social position as a mother with a disabled child does not mean mothers will go through homogeneous experiences.

Although more than half of the mothers interviewed for this research suggested that it was a good idea to interact with other parents of disabled children, nearly half of the respondents did not consider it a good idea, as suggestion of previous research (Ryan and Runswick-Cole, 2009; Read, 2000). One of the reasons for this was the different needs of the various mothers. Two of them claimed that they did not have time to just have a cup of tea and talk about their feelings. What was important for them was to find practical strategies for solving problems, so they preferred to learn from books, the Internet or workshops which could target their needs.

Other respondents illustrated how their changing needs in different stages influenced their relationships with other mothers. For example, when their child had grown older or

they were more confident about managing their life, some mothers chose to leave the parents' groups. On the other hand, after becoming more confident or more committed to their role as the mother of a disabled child, some mothers made more connections with other parents through organising parents' groups or working for organisations for disabled people and their families. Since they had not received enough support themselves, they tried to use their own experiences to support other families that is also found in Ryan and Runswick-Cole's (2009) research. As Klein and McCabe's (2007) research shows, when mothers start to play new roles as service providers or organisers, they may have different views about the interactions and their identity as a mother with a disabled child. Further discussions about mothers playing both the roles as a professional and a mother will be presented in Chapter Six. The respondents showed that mothers not only search for help, they also offer their help when they can.

It was interesting to find that more than half the mothers, especially those with professional backgrounds, believed they were different from other mothers with disabled children. Scholars have highlighted how the influence of class and race can lead to very different experiences of disability (Barnes and Mercer, 2007; Vernon and Swain, 2002; Fawcett, 2000; Crow, 1996). The experiences of the mothers in this research also showed that aspects of their existing identities, such as their class or their occupation, had a great impact on the way they managed their new identity as the mother of a disabled child. As Skeggs (1997) suggests, the social position one occupies will influence how different kinds of values are weighted, the possible relationships with others, and individuals' opportunities to access various kinds of capital. The ways in which the mothers defined problems were influenced by their values and by the resources available to them. It was found that these elements could lead to very different approaches to motherhood. For example, two mothers with greater financial security were able to reduce their difficulties by employing a nanny or a personal assistant, and this allowed them more choices in their personal lives. Mary was quite confident about her skills to question and resist people saying no to her, based on her previous experience and role as a trade unionist and trade union representative: '*I was very used to, be against people saying to me, 'no, the rules say you can't'. I'm not one of these people who say 'oh, right, ok, ya, I'll accept that'. I'm going to be going 'why? Why do the rules...?' ...I'm going to question*'.

The weight the mothers attached to different values also affected how they accessed different kinds of resource and their relationships with others. Libby and Claire reported

that they did not make friends with others just because they were parents of disabled children; they chose friends who shared similar interests and values to them. Moreover, most respondents with a professional background also distinguished themselves from others, and this will be discussed in more detail in chapter six. Therefore, a new identity like that of a mother is not just given or added, but will be interwoven or incorporated into individuals' biographies that are sustained through continuity and consistency (Jenkins., 2004; Giddens, 1991). Since mothers have multiple identities and roles, the assumption that being a disabled child's mother is their only or main identity can be problematic.

In addition, there was a particular group of mothers that the respondents in this study especially distinguished themselves from. They talked about a group of mothers who were not able to fight for their child, did not bother to do their job, and who were not able to manage issues in the way they themselves were. Cathy described how she imagined professionals distinguished between a good and a bad mother: '*they (professionals) think oh you know, obviously she's a good mother, she, she's wanting to find out these things about her child, she's, she's found out all this information, she really cares, as opposed to somebody…who's not bothered and who doesn't know or understand*'. Sherry showed her sympathy for such mothers by stating, '*whether it be intellectually, emotionally, whatever, not everyone has the ability to do that (fight for their child)*'. Although the respondents used this group of mothers to identify themselves as good mothers, none of them specifically claimed to know a mother like this. Although this researcher was unable to discover where this picture of bad mothers came from, it was obvious that these images of less willing or capable mothers were present in the mothers' minds when defining their own motherhood and identities. It also showed that they could make social judgements about mothers too, and they were determined to distance themselves from the figure of the 'bad mother'.

Although interacting with other mothers with a disabled child might be useful in breaking down social barriers, some mothers found they encountered viewpoints from other parents which they found problematic. Two of the respondents were told by other parents that because they were carers now, they should not go back to work (Traustadóttir, 1991). In addition to the prevailing discourses on what constitutes a good mother, the mothers in this study also encountered new expectations of what a mother with a disabled child should do put forward by other parents (Traustadóttir, 1991). Anita said she had resisted conforming to assumptions about a 'disabled family' suggested by

another mother with a disabled child: '*I very much didn't want to be like that… I didn't want to become a disabled family because we had a disabled child*'. Although the views of these experienced mothers might be right for their own situation, this did not mean they would be right for all mothers. The stereotype or expectations of a disabled child's mother produced by other mothers of disabled children could leave little space for mothers to pursue their own identity.

Therefore, although other mothers of disabled children might be helpful in many ways, it was just as important to acknowledge the differences as it was the similarities between them. Although the mothers in this study were viewed as falling into the category of mothers with a disabled child, they did not necessarily have a sense of belonging to this category or of being homogeneous. Instead, many of them claimed to be different from other mothers with disabled children. For various reasons, mothers might choose to maintain some distance between themselves and other mothers with disabled children instead of embracing their new identity and new friends unconditionally.

As Lindemann Nelson (2001) suggests, the function of the master narratives is not providing solid examples or evidences, but a conventional sense of the world for individuals to understand the world surrounding them and then further locate their position within it (Lindemann Nelson, 2001). Thus, the idea of the 'bad mother' can be a mixture composed by fragmented elements drawn from the master narratives that is related to good mother versus wicked woman as Lindemann Nelson (2001) proposes, or the prevailing assumptions of tragedy about the mothers who suffer from having a disabled child. Although the master narratives may be influential, both Lindemann Nelson (2001) and Scully (2008) highlight the individuals' agency to modify their comprehension based on their situation or even resist certain ideas. Through developing 'counterstories', Lindemann Nelson believes this may not only serve the purpose of replacing pernicious narratives, but also be able to repair the damaged identities, fill in details that the master narrative fails to present, and correct what has been distorted. Therefore, both the comprehension of dominated groups and groups/ individuals with damaged identities may have opportunities to change the inappropriate assumptions and understanding about the groups/ individuals with damaged identities. And this is the reason why these mothers' experiences are extremely valuable. Next I will move on to presenting how mothers generated their own route after negotiating with the related master narratives.

Generating their own route

 Having a disabled child was a turning point for the respondents' assumed or planned trajectory, resembling a form of 'biographical disruption' as proposed by Michael Bury (1982). Bury (1982) uses the example of becoming a person with rheumatoid arthritis to illustrate how being disabled/ill undermines one's trajectory and affects one's self-concept and one's relationships with others. In the case of mothers with a disabled child, previous research has illustrated the impact of disability affected their relationship with others and how they view themselves as a mother who no longer have a clear map to direct them (McLaughlin and Goodley, 2008; Ryan and Runswick-Cole, 2008; Kearney and Griffin, 2001)

The mothers interviewed for this research had formed their approach to motherhood gradually, based on what they had learned from their experiences, and had tried to find their own route that suited their particular situation. There was no straight, simple or unified answer for the question of what constitutes a good mother of a disabled child. Their strategies were not fixed or always right. Instead, the mothers shifted their attitudes and strategies not only because of their changing situations but also because they were continuously learning from their experiences.

As a result of their increasing experience and confidence, the mothers progressively came to realise that the doctors did not know everything. Some began to argue that professionals did not have an adequate appreciation of their child's individual conditions. Instead of strictly following professionals' suggestions, mothers started to adapt what they were told by professionals to suit what they thought was better for their child, although they knew they might be questioned and judged. Maternal instinct was referred to by the respondents as being in contrast to the authority of the professionals.

Maternal instinct is a disputed issue in different contexts. The notion of the maternal instinct is not popular with feminists who are trying to break the assumed irreplaceable relationship between women and the responsibility for raising children (Chodorow, 1978). The definitions of motherhood as being something natural and instinctive have been criticised for ignoring external factors such as power relationships and interests (Hay 1996 cited in Miller, 2007). Moreover, in contemporary society, the possession of a maternal instinct is not regarded as sufficient for motherhood, so mothers are expected to follow the guidance of experts (Cunningham, 2005; Hays, 1996; Apple, 1995).

However, in this study the respondents referred to the maternal instinct in a different context.

Nearly half of the mothers suggested that other mothers should follow their instinct, believe in their heart or go with their guts as a mother in the context of competing with professionals. Prussing et al. (2005) obtain similar findings and indicate that parents value personal intuition as a source of wisdom that can surpass professionals' knowledge. The reason the mothers in the current study employed the word 'instinct' might simply have been because it was a phrase or discourse that was familiar to them. According to their notions, it was their intimate knowledge of their child and their lay expertise that they relied on when managing difficulties. Based on their experience, the respondents had more confidence to claim that they knew their child best (Brett 2002). They started to develop strategies such as resisting the prevailing social expectations and creating their own map. These were generated from their experience rather than from the maternal instinct that comes simply from being a mother. However, by using the term they were drawing on a culturally recognised term to validate that experience.

The importance of flexibility was also highlighted by several mothers from various perspectives. Wendy and Debbie suggested that mothers should be flexible and open-minded when searching for and trying out different ways to solve problems and overcome barriers. This implies that there is no strategy that can be applied in every situation and that will meet the needs of every child and their families all the time. Since uncertainty was part of their daily life, as several mothers reported, Suzy identified flexibility as an essential practical principle of life because it was nearly impossible to carry on as planned. Moreover, the mothers modified their plans according to the current situations and the resources available and in line with their imagined future. Another reason they needed to be flexible was because they had to respond to changeable problems. Their children's needs were not fixed but would continue to change; as Anita said, when she got over one problem, another emerged. Several mothers stated that they were aware of the necessity to modify their expectations according to the development of their children. Two mothers used the terms 'swings and roundabouts' and 'roller-coaster' to describe how they shifted between good and bad times. This implies that instead of being a stable role, the mothering of a disabled child was on a dynamic continuous scale that was constantly being influenced by the changeable nature of their children's needs (Ryan and Runswick-Cole, 2009).

Since taking care of their child was a long-term job, several respondents had gradually realised the importance of taking good care of themselves. Seven out of sixteen mothers highlighted the importance of having 'me time' in order to recharge themselves. They further argued that mothers should look after themselves first in order to be able to take care of their child as Kittay's (2002b) argument to pay more attention on carers so that they can provide better quality of care. Maggie asserted, '*you always think of yourself last, which is wrong because if you're not all right your child wouldn't be all right*'. Two of the mothers further emphasised that a good mother was a happy mother. Cathy explained, '*A good mother is obviously a happy mother so…time-out is very, very limited but even just getting a bit of a break or, you know, feeling good about yourself then obviously you're going to bring that into the home and be happier for your child*'. The reasons they gave for taking good care of themselves were different from the prevailing discourses of a good mother. They modified the notion about unconditional, child-centred love and unselfishness in order to save some space for themselves in the long-term interests of their child. This reflection was embedded in the belief that they were the only one their child could rely on.

As revealed in this section, my respondents' experiences gave various indications that motherhood is a socially constructed and shaped product. The institutional order, as proposed by Jenkins (2004), had a significant influence on the mothers' journeys to develop their identity as a mother, including the discourses on disability, how they were raised, the mothers' previous social network, social and cultural norms concerning mothers and children, the power of professionals, and the category of mothers with disabled children. As Jenkins (2004: 20) indicates, 'not only do we identify ourselves in the internal-external dialectic between self-image and public image, but we identify others and are identified by them in turn'. By making comparisons between social expectations, the additional roles and duties proposed by others and those that they themselves believed their child needed, several of the mothers had modified these expectations and redefined their positions, and they had adjusted and chosen which values they wanted to emphasise when making decisions. However, although the mothers might have developed better ideas about how they wanted to practise their motherhood, they still needed to negotiate with service providers and the state about the shared care of their child.

Dependence and interdependence

As shown in the literature review, care remains a contentious issue in both disability studies and feminism. From the point of view of the independence of women, feminists try to release women from their caring duty (Walzer, 2004; Richardson, 1993), and writers of disability studies emphasise the issues of independence, justice and rights, and claim the right of disabled people to control their lives and live independently (Kröger, 2009; Barnes and Mercer, 2007). In this context, carers and disabled people view the other social actors in their care relationships as having a potentially negative impact when they are striving for independence. This conflict between carers and disabled people can be viewed as a personal matter. However, in this section I will argue that it is important to place that relationship in context and to explore why a caring relationship can lead to isolation for both carer and cared for. I will also show how experiences of caring for their child could lead the mothers to alter their perspectives on dependency and how this had influenced the ways in which they practised their motherhood.

The experience of mothering a disabled child is normally viewed as irrelevant by others. Landsman (1999) suggests that mothers with disabled children might be viewed according to two frames: that of a 'bad' mother or that of a 'chosen' mother. She explains that if a mother does not have a healthy baby, there is a common assumption that she has done something wrong during her pregnancy for which she can be blamed (Landsman, 1999). One example was noted by Anita: '*if he's (her son) cross with me about something or he's just cross in general, he will say things like he hates me because he grew in my tummy therefore it must be my fault that he's disabled... I'm very sad that he thinks that*'. Another notion Landsman (1999) mentions is the idea that God gives special children to special parents. This notion separates mothers who do everything they can during their pregnancy from the so-called 'bad' mothers (Landsman, 1999). The mothers who took part in Landsman's (1999) research found this notion comforting in their early days, but they gradually came to reject it as candy-coating because it separated them from normal people. It also diminished both their child's personhood, and the parents' hardship and effort. Five mothers in this research shared a similar resistance to this notion. Mary further questioned, '*so what, if I don't cope and I don't have a child with a disability?*'

Blum (2007) further suggests that trying either to avoid mother-blame or to be praised for mother-valour can result in the mothers policing themselves or in their being

policed. The distinction between a bad mother and a chosen mother may perpetuate the construction of stereotypes for mothers with disabled children and leave little space for acknowledging their diverse experiences or identities. Moreover, any difficulties mothers have in raising their disabled child are seen as a result of some deficiency in the mothers' capability. Nor does focusing on either a mother's incompetence or her heroic capability take into account the contexts in which the mother operates or environmental factors; instead, the mother herself is the sole focus. Accordingly, both the above notions can result in excluding and marginalising the experiences of mothers with a disabled child by positioning them as exceptions to normality.

Although surrounded by various social actors and services, as described in previous sections, the respondents still experienced an isolated type of motherhood. Their existing social network did not necessarily offer them adequate support. They were also aware that there were many differences between them and other mothers with disabled children. Although the mothers carried out a large number of caring tasks, their perspectives were often ignored or labelled as unrealistic if they did not follow professionals' suggestions. Mothers who fought with service providers might earn themselves a label, that of a difficult mother, which further marginalised the mothers from the mainstream. Mothers who took part in this research suggest that their experiences were marginalised and excluded. Hence, some of them sometimes decided to secede from the groups they used to participate in, like the examples of Wendy (p97), and Claire (p178). The findings echoed what researchers have suggested, these experiences of exclusion can lead to a cycle of withdrawal and further isolation (Green, 2003b; Goffman, 1968). However, withdraw is not the respondents' only choice. Sometimes, they chose to withdrawal, sometimes, they were confronted their challenges. Rather than only concerning separation, several mothers instead rethought connection, as some scholars have argued.

Rather than continuing to emphasise independence as presented in chapter two, some scholars instead have called for a redefinition of the meaning of interdependence, connectedness and dependency in human society (Fine and Glendinning, 2005; Gottlieb, 2002; Kittay, 1999; Hillyer, 1993). Since human beings have to depend on others at different stages over the course of their lives: for instance, when they are young, old or sick, Kittay (2011) argues that dependency is an inevitable part of human life, because even if people are not in need, they may need to offer care to others, such as their children or their parents. Learning from their negative experiences and sorrow at

being excluded from their existing support network and intimate relationships after having a disabled child, the respondents realised the importance of connectedness. They started to cherish connection and interdependence within relationships in their lives. This recognition made some impact on how they viewed their child's independence in the future and how they practised their motherhood.

In contrast to the findings of Bower and Hayes's (1998) research, several of the mothers who took part in the current study stated that they did not want their non-disabled child to take responsibility for caring for their disabled sibling. However, my respondents tried to build networks for their disabled child that included their child's siblings, relatives and friends. They hoped this connectedness could offer their child a future with family and friends around, rather than an independent but isolated future. Jackie noted, '*I hope that he does keep his family around him and you know have that, closeness*'. Libby considered adopting again because, '*I'd want somebody to be there for Carl as an adult, even if it is only as a…say hello or to go to the pub for a drink now and again, I would still like him to have somebody to live with round and about*'. In order to achieve this goal, the mothers worked hard to enhance or maintain the relationships between their child and others, so that their child's independent living could be supported by the caring and love offered by other people, including siblings, relatives and friends.

Moreover, the type of independence that the mothers were helping their children to pursue and develop was independence with support. This was not only because of their child's disability but also because they knew it was essential for every human being to live within relationships. The mothers had gradually come to realise that having an independent life is not the only approach to having a decent life but that there should be diverse forms of independent living based on their child's disability/abilities, and their needs/wants. Compared to their consideration for their disabled child's welfare, how to deal with external factors was complicated, especially when related to their own independence.

Gradually, the mothers had come to admit to themselves that it was not possible for them to manage all of the difficulties on their own. In order to find possible resources, they maintained or created connections with relevant social actors. Accessing help was viewed by the respondents as a strategy to maintain their independence. This is illustrated in the following comment made by Claire: '*we're a happy family, but we do that because we get help. Take the help away and it would all come tumbling down. I need that help to be able to help us function like this*'. Although the respondents

identified being independent as their goal, which they worked hard to achieve, this did not keep them and their child from the stigma of being dependent. Fighting and making demands based on their child's rights, not on charity, as disabled adults have argued, did not reduce their feelings of discomfort when asking for help. Their efforts to become independent were not viewed as a form of independence by society.

Moreover, acknowledging needs and asking for help is not as simple as assumed by others. The mothers knew it was essential to reveal their deficiencies and weak points in order to access the support they needed: however, some mothers reported that they did not feel comfortable about revealing their private life. Claire stated, '*I just find it very demoralising having to sit and tell people how difficult it is…Why do I have to lay it out? That it's so difficult. They must be, they must understand that it's quite difficult*'. Emma also gave the following description of how she helped her disabled daughter to have a shower:

> *I used to stand in the shower and hold her (17 years old), hold her up*
> *and like wash her…I'm getting a, a chair now so she actually sits*
> *down, so that's much easier. But I've just started getting these things*
> *and I've just started asking for these things, which is stupid really. I*
> *should have asked ages ago for them but you just, you just think oh,*
> *it's just not worth it. I don't know, you just get on with things, I think.*
> *I think you do get on with things, cause it's easier that way, just to get*
> *on with it.*

Emma's example illustrates how asking for help can be difficult for some mothers, especially when taking care of their child was viewed as their individual duty and dependent mainly on their capability. Asking for help might mean that they have to lose something, such as their privacy; exchange something, such as their autonomy; or admit that they cannot cope, like a failure. It is not a pleasant process, hence Emma's feelings that it was not worth it and that it would be easier if she just got on with things herself.

When asking for help or being dependent is stigmatised and negatively valued, the action of asking for help can create difficulties for the mothers' view of themselves. It was different from how the respondents had been brought up and from what they had

expected, which was to be an independent and autonomous person, as Green's (2002) experience. They had found that not only their disabled child, but also the mothers themselves fell into the category of dependence (Fine and Glendinning, 2005). Several respondents reported that they did not like being in the position of having to rely on others and that they felt powerless.

It took some respondents a long time not to feel ashamed of needing others' support. As the American comedian Richard Pryor, who had multiple sclerosis, claimed, the best lesson he had learned was starting to trust others (Kittay, 2011: 57). The respondents in this study had also learned to trust others and to allow others, such as formal support workers, to become involved in sharing care for their disabled child. Wendy stated, '*I didn't trust other people to be able to do it (before) and I think that's something you've got to get over. I think you need to just be able to let go of that, and learn to trust other people*'.

The respondents were also making efforts to ensure that the relationship between the state and their child responded to their disabled child's needs. Based on the notion of rights, the mothers fought for their children's benefit on their child's behalf and demanded formal support. In order to access resources and support, the mothers made applications and allowed service providers to examine, evaluate or even invade their privacy, such as allowing professionals to go in their home. Moreover, mothers also developed their strategies to present the information while being examined or their family lives invaded. For example, Claire learnt to separate how she looked at problems positively and how to highlight and stress all the difficulties while applying support and negotiating with professionals. She stated, '*(I) think about all the positives, I think that's what makes the difference, tell them (professionals) all about the bad bits. I've learnt that lesson. And I'd take my make-up off*'. It is another example to illustrate mothers' practically strategies by selecting and presenting information in order to meet professionals' criteria so that they might get services they needed. As part of this process, the mothers also needed to negotiate with service providers for diverse reasons in the public sphere: for instance, by attending a meeting or a tribunal (Runswick-Cole, 2007; McLaughlin, 2006). Hence, their motherhood was not a private domain but involved public intervention and support.

Although the state offers its support through providing treatment, intervention, services and support, the respondents' experiences still showed that they were lonely fighters, and they reported a lack of appropriate services. Although the mothers had started to

trust others and make efforts to access support, most of the mothers in this research still believed that it was their duty to take care of their child; as Cathy said, '*you're the only person who can protect them in the world…you're the only person who will do it, nobody else will*'. This recognition was not only based on the idea of private maternal instinct. Instead, it was influenced by external elements. Both the informal and formal support systems had failed to provide full support for the mothers, with the result that the respondents had been obliged to assume one set role and duty, that of a mother of a disabled child.

Because of their view of the quality of care provided by formal services, five of the mothers found it hard to leave their children with others, especially with those who were not related to them. Milly noted, '*there's no respite facility that you would want your child to go to*'. She added, '*there is less care now. People are, a lot of people work for the voluntary sector, for different professions and they just do it for the money. They don't actually care. And obviously I as a mum, I want somebody to care for Joseph, and you know, like him, and get to know him, and you know, accept him first, the faults that he has*'. Doubts about the quality of the care provided by professional services could thus prevent some mothers from accessing formal support and oblige them to carry out their caring duty alone. Although they might be happy for their child to be cared for by a loving relative, the mothers' choices were limited since, as described earlier, they were often excluded from their previous network and communities. In this study, six grandparents were important sources of support, but the amount of help they could offer was limited because of their age, their own disability, or their duty as a carer for their partners.

Therefore, when considering their child's future, the mothers still viewed themselves as irreplaceable carers and assumed that the period of their motherhood would be extended alongside their child's independent life in the community. In Anita's case, she and her husband had promised their son with cerebral palsy that mum and dad would be there to help him sort things out and make sure he could live independently, and their son's plan was to live in a bungalow nearby. Sherry had offered to continue her maternal duties with her son who had ADHD to see how much independence he could achieve in the future. After finding her son an appropriate home to live in with other disabled people in the future, Milly was considering moving in order to be near him.

Most of the mothers were worried about their child's future when they were gone, as Maggie described: '*you don't know how long you're going to be bathing them for and*

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dressing them for... You think of the future, you think of what'll happen if you're not there, what will happen if anything happened to you'. Some mothers felt powerless to shelter their child safely from the influences of the outside world over time, especially in a future without them. Sherry noted, '*at the minute I can stand and fight, fight for him, but when he moves, then he's on his own kind of. And there's, there's still a lot of discrimination, a lot. Even though they say there's not. There is. There is'*.

Although the services were designed to support mothers, both the mothers themselves and the state continued to see the care of their disabled child as predominantly their responsibility, with some limited support being provided by professional services. Although recognising the importance of interdependence, the respondents were aware that taking care of their disabled child was viewed as their personal responsibility by society. Additionally, based on their experiences of accessing support, they believed that if they did not fight, their children would not get what they needed. Hence, both social expectations and the fact that they had to apply or even fight for formal services made the mothers irreplaceable. However, scholars like Kittay (2011) highlight the risks involved when the welfare of disabled people depends mainly on their carers.

The theory of justice that assumes individuals are rational, independent, autonomous and moral agents who participate equally in society has been challenged recently especially in feminist ethics as presented in chapter two. This section will continue to draw debates proposed by parents of disabled people (Gottlieb, 2002; Kittay, 2002b). Kittay (2002b) argues that even the perspectives of non-disabled people are not equally valued; it will thus be difficult for the voices of disabled people to be heard, especially those who cannot communicate or speak for themselves. And not only disabled people, it will also be difficult for their carers to meet the criteria of an independent and moral individual. Gottlieb (2002) suggests that being a carer might reduce a person's opportunity to participate in society, which conflicts with the theory of justice regarding the responsibility of a moral citizen; thus, their moral status may be questioned. Kittay (2002b: 261) also indicates that carers may not meet the criterion of being 'rational self-interested' agents because they can be altruistic and 'other-directed', hence they fall 'outside of conventional understandings of relationships between equals within liberalism'. When carers' voices are weakened by their social position as carers, Kittay (2002b) indicates that the welfare of those they care for will also be affected, since they might have to rely on their carer to speak for them. Considering the carer's responsibility and difficulties, Kittay (2002b) argues that if those who provide care are

not supported, they will never be able to provide good quality care for disabled people. She states that 'it is only with care, and care of the highest quality, that she (her disabled daughter) can be included, loved, and allowed to live a joyful and dignified life' (2011: 52). Accordingly, viewing disabled people and their carers as citizens in society, scholars have argued that not only the disabled people, but also their carers should be supported (McLaughlin, 2011; Gottlieb, 2002; Kittay, 2002b; Read, 2002). A 'triadic concept of reciprocity' is proposed by Kittay (2002a: 242) that acknowledges public involvement in order to ensure that carers are supported so that people in need will have better care and a better quality of life.

Their social position as mothers with a disabled child allowed the mothers in this research to recast their perspectives on dependency. Both the findings of previous researchers and the experiences of the mothers in this study highlight the importance of acknowledging interdependence, connectedness and dependence as essential aspects of people's lives. We might be able to create a better society if we pay more attention to the way dependence and independence intertwine, rather than focusing on the conflict between them (Hillyer, 1993). Better and more public involvement and support in the context of acknowledging interdependence will be helpful for both disabled children and their mothers.

Conclusion

The mothers' accounts support the argument that motherhood is socially constructed. Their comprehension about motherhood was influenced by the social and cultural expectation related to mothers, their children and disability. How they practiced their motherhood was further affected by related social actors, such as their mothers, professionals and other mothers with disabled children. Compared to mothers with non-disabled children, the mothers in this study appeared to receive more support and services from the public sector. However, rather than feeling supported and included, the respondents claimed to experience exclusion and isolation. Instead of sharing the caring responsibility, the mothers were expected to and actually did shoulder a large amount of this responsibility. It is essential for service providers to bear mothers' isolation in mind when designing services. The sharing of care between mothers and state/professionals should reflect the diverse needs and priorities of both the mothers and their children.

The mothers' experiences also suggest that the understanding of mothering a disabled child is absent from prevailing discourses on motherhood. Giving birth to a disabled child has often been portrayed as something to be avoided (Ryan and Runswick-Cole, 2008) and the issues surrounding the care of disabled children have been viewed either as irrelevant to the majority of people or as a potential burden to society; hence the subject has normally been excluded from prevailing discourses on motherhood. Therefore, the reasons that the mothers did not have a map were not only because of the uncertainty caused by impairment but also because there was no positive reference point for them in dominant discourses suggested by social norms and professionals. Moreover, even in the category of 'the wise', the experiences of the respondents show that their experiences were either excluded from professional knowledge or negatively framed in the context that viewed being disabled as a personal tragedy. If the experiences of mothering a disabled child remain marginalised, the stereotypes of mothering a disabled child will continue to be reproduced, although presented in diverse forms.

Rather than viewing disabled children and their mothers as a special or separate category; I want to highlight the fact that they are also citizens of this society and their experiences are valuable for and connected with the rest of the citizens. These mothers' experiences of mothering a disabled child could offer references for prospective parents and parents who have recently obtained a diagnosis for their child, instead of leaving them feeling disempowered and sad in the unnecessarily negative shadow of disability (Rapp and Ginsburg, 2001; Landsman, 1998). These mothers' experiences of taking care of others and their reflections on disability and illness might also be able to help us interact with illness or disability more easily when we find ourselves in need in the course of our lives, or when we have to take care of others in need. If we can start to embrace the inevitability of dependence in human life and appreciate the diversity among us, we might be able to create a better world with a caring system of justice (Kittay, 2002b).

As Lindemann Nelson (2001) proposes, when individuals draw the related fragmental parts from the mater narratives, it is not a master narrative anymore but an individual 'alternative' story. In this chapter, the process of drawing elements for constructing these mothers' own narratives demonstrated how the related master narratives were embodied in their daily lives, and how mothers negotiated with these master narratives. These kinds of negotiation and recounting not only happened between mothers and the

master narratives they shared with others, but within interpersonal interaction, which will be discussed in the next chapter.

Chapter Five

Managing Disability—Now and in the Future

In recent years, research has uncovered the diverse and changing nature of disability and opened up discussions on the causes of disability beyond the explanations offered by the medical/individual and the social model (Thomas, 2002). Alongside the quite rigid interpretations of disability provided by these two models, recent research has been concerned with the role of uncertainty. The findings of research in which mothers of disabled children were interviewed have suggested that mothers can at times adopt various discourses flexibly (Fisher, 2001; Kelly, 2005; McLaughlin and Goodley, 2008; McKeeve and Miller, 2004). McLaughlin and Goodley (2008: 324) propose an appreciation of parents' 'nomadic' approach of managing issues surrounding disability, by which they mean, 'what we see over time are adaptive and strategic claims of certainty around particular problematic, while at the same time embracing new forms of uncertainty in their lives and their visions of what the future may hold (p323)'. The positive aspect of this approach is it allows the existence of possibility through embracing the uncertainty, moving beyond the expectations imposed upon their social position related to disability, and choosing from various discourses depending upon time and space. In this chapter I will show how the participants in this study adopted this approach, illustrating how the factor of uncertainty influenced the strategies the mothers adopted to manage issues surrounding disability. The main argument of this chapter is that mothers are active agents who develop their own strategies to negotiate the construction of meanings of disability within interpersonal relationships with related parties (professionals, family members, their disabled child, other parents with disabled children, friends etc) in order to ensure their child's welfare.

The first section will focus on mothers' perspectives in order to demonstrate that the meaning of disability is not fixed but negotiable and changing. It was found that the mothers in this study attempted to influence people's understanding of their child's disability in social encounters. Three topics - the shadow of prognosis, explanations for others, and their child's awareness of being disabled - will be presented as examples to demonstrate how the mothers flexibly managed these challenges when interacting with service providers, their child and others. In the second section, educational arrangements and issues related to living in the community will be used as examples to

demonstrate how the mothers carefully considered their decisions in the context of wishing that their children were and would be able to participate in society now and in the future.

The shifting meanings of disability

In this section, I will argue that the meaning of disability is socially constructed. Although the changeable nature of and uncertainty surrounding their child's disability can increase mothers' challenges, it also becomes an important asset when they are managing issues associated with disability as McLaughlin and Goodley (2008) suggest.

The shadow of diagnosis

From the medical perspective, disability is an individual pathology mainly caused by impairments. The focus is on medical treatment and physical rehabilitation to correct or cure the impairment, together with the psychological adjustments necessary to come to terms with disability (Barnes and Mercer, 2007; Oliver, 1990). Mothers are expected to follow the experts' suggestions in order to prevent or correct impairments (Landsman, 2005). If mothers' approaches are different from those recommended by professionals, they can be branded as unrealistic or in denial (McKeever and Miller, 2004; Larson, 1998). Rather than viewing mothers as unrealistic, I shall suggest that mothers are realistic practitioners who evaluate situations and implement practical strategies in order to handle challenges in daily life. Moreover, it was found in this research that what the mothers challenged was not the medical diagnosis but the prognosis. What I mean by prognosis here is the wide range of preconceived ideas professionals have of what a child's abilities are and will become, based on that child's particular disability, and how these ideas influence their outlook and the way they deal with the individual children.

Most of the mothers in this research recognised the advantages of obtaining a diagnosis. The diagnosis not only provided them with explanations of their child's condition and increased their understanding of their child's impairment, but could also lead them to the services and support that their child needed. However, as time went by, many respondents in this research realised the limitations of medical knowledge in enabling them to solve all their difficulties (Barnes and Mercer, 2007), and also recognised the cost of having the label of 'disabled' attached to their child. Apart from the impact of

the impairment/ the diagnosis, next I will present that the problems related to the prognosis and that is what the respondents were fighting against.

For the respondents, it was essential to bear their child's conditions/diagnosis in mind, but it could be problematic when their child was only viewed through the prognosis, and the generalised understanding of the diagnosis, because it did not take the child's uniqueness and potential into account. Many of the mothers in this research were aware of the risk of viewing their child only through the lens of the medical diagnosis. Mary referred to the inappropriateness of services supplied on the basis of fixed categories/diagnoses, saying, '*why can't you go from where Siobhan is rather than you know trying to, he (the professional) always seems to try and sort of be fitting her into this kind of you know square peg*'. Lisa's son had been viewed through the frame of Down's syndrome, which became a barrier to detecting his other special needs resulting from autism. The mothers also argued that generalised knowledge based on categories/diagnoses failed to allow space for the development of their child's potential, which was what they endeavoured to cherish. Libby was challenged by service providers for her efforts to toilet-train her son with cerebral palsy:

> *I've started toilet-training and it had quite some success at home, and asked them to toilet train him at respite care, and they didn't contact me, they went to my social worker and contacted my doctor without asking me to find out whether he could be toilet trained, and the doctor said I don't know him well enough but children like Carl can't, usually, which I think is out of order completely... Who are they to question that? Also I thought it was a human rights issue, I thought it's you know, he has every right to be toilet trained like everybody else.*

Both Mary and Libby argued that professionals adopted the general understanding based on the category but failed to see past the diagnosis to their child. Instead of support, what awaited Libby was an 'emergency meeting' with respite carers at the social services office where they questioned her actions and approach to caring for her son. Moreover, the low expectations and imagined limitations attached to the prognosis were viewed as unnecessary and inappropriate by the respondents. The mothers found that

they had to fight for many things which other mothers took for granted before they could happen. As the case of Carl's toilet training illustrates, because Carl was a child with cerebral palsy, his toilet training became an issue worthy of an emergency meeting, something which would never happen with a non-disabled child, other mothers who also had other, non-disabled children were particularly able to see the difference in the expectations for their children. Mary described the following experiences with her two children:

> *When Phi was born, nobody sat me down and said 'oh my God, got a little boy, you know, they're going to break a leg when they're eight, because they're going to be into everything, and, oh Christ he'll probably become a drug addict when he's fifteen' and stuff like that, do you know what I mean? But with Siobhan that's what it was like, it was sort of 'she won't be able to do this, and she can't do this', and, and they just seemed to construct this really artificial world.*

Some respondents allowed their children to try things they wanted to do even though the professionals thought it was impossible. Angel argued that it was so easy to say no to a disabled child: '*the doctors say you're not going to be able to do that, so just forget about it… But I think you've got to give them a chance…how often will you be able to say to a normal child, would you?… I don't think it's fair, just because you've got a disability, and you can't do that and you can't try that*'. Mary and Angel's argument was that it was unfair to set out an unpromising future that rejected any possibilities for a disabled child and which basically wrote them off (Landsman, 2005).

Moreover, based on what they learned from their journey, mothers recognised the diversity within the category of disability as a whole and the prognosis and assumptions attached to the diagnosis. For the mothers in this research, the overall category of disability had been deconstructed after they had their disabled child. Several mothers admitted their ignorance and misunderstanding beforehand and said they had started to view the world through different lenses. This kind of recognition has been picked up by other researchers such as Green (2003b). Maggie described the growth in her understanding of disability: '*I used to think disabled people, people in wheelchairs who sat there and done nothing, and didn't know anything and were silly… I'm the total*

opposite now. I mean I meet that many disabled in different ways all different ways. And they're all lovely and they can all do things'. Many mothers also knew that there were differences among people in the same categories, as Anita noted: '*it (cerebral palsy) affected different people in different ways'*. However, they found that service providers did not make enough effort to take the differences into account.

As a result of their experiences of interacting with service providers and their increasing confidence concerning their knowledge of their child, the mothers had gradually realised that the professionals did not know everything. Sherry argued, '*even people that think they know, they don't know... they're all different, they all have different needs'*, while according to Maggie, '*they (doctors) are still right, they know, it's their job. But they need to listen to a parent... a mother always knows - if your child's sick, if your child's unhappy, if something's bothering, you always know. And a doctor will know the illness or bits around the illness but they don't know that particular person, do they?'*

Rather than adopting the professionals' perspectives in their entirety, the respondents started to make their own decisions. They also refused to allow the diagnosis and medical prognosis to become the main definition that guided their child's life. Many of the mothers rejected the restrictions suggested by professionals and endeavoured to ensure opportunities for their child's potential to develop, as other mothers do. However, their efforts were generally viewed as unrealistic. Libby, who used to be a residential teacher, argued that '*the kids there I worked with, between ten and fifteen year old were doing more things and had more expectations of them twenty years ago than what I find Carl's expected in like respite care and other places now... I couldn't believe that there were still people that still had that oh you can't do that. Why not?'*

Having high expectations did not mean that the mothers ignored their child's disability and needs. None of the mothers in this research denied the impact of the impairments, since they significantly affected their child's development and their caring tasks. Claire admitted that she resented the impact of her son's autism: '*I don't pretend it's not there. It's very in our face'*. Although they recognised the impact of disability, however, the mothers embraced the uncertainty which allowed for the existence of possibilities, the development of their child's potential, and their hope as McLaughlin and Goodley (2008) argue.

The respondents started to use their increasing experience to compete with or supplement professional knowledge, or to share information about their child's disability that they had acquired as a mother with the professionals, as in the case of a mother in Lowton's (2001) research who identified the side-effect of a medicine, thus helping the doctors to deal with the problem. Some mothers in this research did successfully modify the professionals' view of their child's impairment by proving their child's abilities according to their observation and understanding of their child, as Maggie used the chocolate buttons to prove her daughter could see (see p103). Accordingly, several respondents started to believe that it was only when their perspectives on their child's difficulties and needs were included, that the service providers could have sufficient understanding of their child's circumstances to offer suitable support for their child.

Furthermore, mothers may not only be able to provide detailed daily observations, they might further play a vital role that was overlooked by the professionals. Previous research has indicated some mothers may become case managers (Prussing et al. 2005; McLaughlin, 2011). In this research, suggestions from different professionals conflicted with each other according to mothers. Wendy pointed out that one of her tasks was to '*remember who said what and... People play each other off against each other*'. The inconsistency may be because professionals were trained to examine things through their specialised framework that only focused on certain aspects of their child's development. The professionals may hold diverse approaches or prioritise different points. Moreover, the professionals do not necessarily work as a team or communicate together for their clients. As a result, the mothers could become the essential pivot who held more information, acquired from the different professionals, about the various interpretations of their child's disability/abilities proposed by diverse professionals than any single professional operating in the system of the division of labour.

Many respondents viewed themselves as the guardian of and advocate for their child's rights. Several mothers decided to participate more actively and tried to influence the process of evaluating their child's needs and designing services for their child, although these efforts might not be welcomed by the professionals. Knowing that their comprehension of their child's disability was denigrated, the respondents used a variety of strategies to legitimate their perspectives when interacting with professionals. Some mothers became armed and prepared through educating themselves to approach the level of semi-professionals. Other mothers managed their presentation in order to fit the

image of a good mother so that they could have a better chance of being paid attention to by professionals as suggestion of previous research (Clavering, 2007; Green et al., 2005; McKeever and Miller, 2004). Some mothers drew from formal sources of expertise to legitimate their views as pointed out by other research (Fitzgerald, 2008; McKeever and Miller, 2004; Hillyer, 1993); for example, Sherry obtained a professional statement from an independent psychologist to help in her dispute with her child's school.

Although the respondents recognised the impact of impairment and had acknowledged the advantages of getting a diagnosis, they did not accept the medical perspective in its entirety. It was not the diagnosis of impairment but the medical prognosis, the expectations and the writing off of their child's future by the professionals that the mothers were fighting against. The mothers challenged the prognosis and expectations when they failed to allow space for the development of their child's potential and set unnecessary limitations on their child's opportunities. Although the diagnosis might be viewed as a medical fact, how the child develops is not wholly circumscribed by it. Embracing the concept of uncertainty, many mothers had decided to participate actively in the process of evaluating and interpreting their child's condition. They became a medium that bridged their child's needs and the supply of services and support, as McLaughlin (2006) suggests. Rather than being wholly guided by the professionals' prognosis, most mothers continually modified their targets and strategies based on their updated understanding of their child's ability/disability and what their child needed/wanted. Their comprehension of their child's disability was a continual process of balancing the medical prognosis and the maternal understanding generated from their daily experiences.

Explanation to others

Research has shown that mothers often need or are asked to explain their child's condition by others (McLaughlin, 2006; Ryan, 2005; Gray, 2002). How to control information about differences is complex, as Goffman (1968: 57) suggests: 'to display or not to display; to tell or not to tell; to let on or not let on; to lie or not to lie; and in each case, to whom, how, when and where'. Goffman also refers to strategies such as 'passing (hiding the stigma)' or 'covering (reducing its significance)' to demonstrate

how people manage their social presentation (Barnes and Mercer, 2007). Some of the respondents in this study chose similar tactics in order to avoid unpleasant encounters.

In the early days, most of the mothers in this research chose to explain when facing social judgements. Some felt sad because their child was masked by the impairment and was misunderstood because of the prejudices of others. Suzy said, '*he's really a clever little boy, so, but, because his behaviour can be a bit um, obscure, some people sort of get the wrong impression of him and they don't sort of see the other aspects to him*'. Hence, some respondents tried to defend their child as a protector (Landsman, 1998).

Gradually, the respondents realised how the different characteristics of their child's disability might affect their experiences. For instance, Sherry's family could accept her daughter's physical disability because it was tangible and undeniable. However, they thought her son's diagnosis of ADHD was something she had made up and were less tolerant of his behaviour. The respondents with children with a significant disability described social awkwardness such as rude staring, ignorance, or not responding to their child's friendly greeting in public places. If children had a less visible disability such as autism, ADHD, visual impairment and learning difficulties, respondents seldom encountered overt indications of the stigma associated with disability. Instead, they reported more social pressure or felt judged when their child's behaviour was viewed as not fitting in with the social or cultural norms, an issue other researchers have highlighted (Bennett, 2007; Blum, 2007; Green et al., 2005). Although some children with invisible disabilities were less likely to be identified as disabled, as Ryan (2005) indicates, their behaviour, which broke rigid social and cultural rules, could still lead to them being labelled as deviations from normality. Jackie's son, who had ADHD, was often labelled as a 'yob' for his behaviour, or as an '*uncontrollable teenager*'. It was nearly impossible for mothers to explain everything before other people had made their judgement, as Jackie continued to describe: '*people have already judged the situation before you got a chance to explain…they've got it in their mind*'. Therefore, several strategies were generated based on their situations.

Using a badge to highlight their children's impairment was considered by some mothers, especially for those with invisible impairments. Five mothers especially pointed to the symbol of a wheelchair and thought it might be easier for others to recognise these children's special needs, as reported also in Blum's (2007) study. Maggie suggested, '*I think people, it would be good if there was something visually impaired people could have on them to say 'I am visually impaired'. You know, just so that people won't bump*

into them…even a badge or symbol which means 'I have…' '. As Ryan (2008: 737) suggests, revealing the medical label does not equal putting their child in a 'degraded status' but provide others with an alternative framework to understand their child. Ryan (2010) further argues that this may also imply that the mothers did not necessarily view their child's disability negatively, as the prevailing notion suggests. However, for the mothers in this research it remained questionable whether it was better to reveal their child's disability and if it would actually serve the function the mothers expected it to.

If the mothers in the study found they needed to explain they found that the diagnosis or medical label served a limited function, a finding also identified in Singh's (2004) research. Many people had no idea what the medical label meant; hence, it did not help others to understand their child. Even if it was a better known medical label, the mothers still found that other people had only a limited understanding or even a misunderstanding or stereotypical image in mind. Sometimes, the label only led to thoughtless questions and useless suggestions based on others' stereotypes, with people failing to see their child behind the label or equipment, as illustrated by Wendy when she referred to comments about oxygen and hearing aids (see p97). Other respondents found that the medical labels and explanations were viewed as excuses by others. Some mothers also realised that other people simply did not care or were just ignorant, as they themselves had been before they had their child. Hence, rather than serving the function of helping other people to understand, using a label could instead be risky and lead to misunderstandings. At the same time, the mothers recognised that it was possible from them to mediate over the gap between the fixed medical explanation and the vague understanding possessed by others.

Landsman (1998) illustrates how, outside the medical diagnosis, there were numerous different ways to tell the story of her daughter, even though she was just a new-born baby, such as why she was disabled or what kind of miracle she had achieved simply by surviving. Like Landsman, who chose to relate different versions of the story to different people, the mothers in this research also developed strategies to manage the image of their child within social encounters. They would assess each situation and decide what kind of information or story they wanted to tell. For instance, Suzy chose 'learning difficulty' instead of autism when explaining her son's condition, because she thought other people would not know what autism was, as she had not before she had her child. On the other hand, believing that a stigma was attached to cerebral palsy,

Angel chose to use the label of hemiplegia, to give her the opportunity to explain that the condition only affected physical functions, not everything.

While Suzy selected a better-known label, Angel chose to use jargon to explain her child's disability. What other people might know or what stereotypes other people might associate with the label were important references when the mothers were considering what information they wanted to present. These examples show that mothers used the comprehension they shared with other non-disabled people as references when deciding on their tactics. Although it could be argued that they were merely guessing at what stereotypes others might have in their minds, it shows that the mothers used the understanding they had acquired from their positions as both a non-disabled person and a mother with a disabled child to manage the meanings of disability.

However, since it became obvious that their explanations were having a limited positive effect and were not helping to prevent the children and their mothers from being judged and stigmatised, Cathy likewise often held back: '*just let things develop, and then hope that he doesn't misbehave himself*. Some respondents stopped trying to explain unless it was seen to be necessary. Moreover, Maggie was not only concerned about the social judgement of unknown others, she also took Chris's feelings into consideration'. As she pointed out, 'y*ou can't stop everybody and go 'she can't see, sorry', you know. I don't. Because I don't like to intimidate Chris either, it wouldn't be very nice…I just have stay close to her and manoeuvre her around people*'.

As Gary (2002) indicates, the respondents tended to discuss their child's condition only with people who needed to know about it, especially service providers and those close to them. The respondents did not cease to act as a bridge between their family members and their child. Sometimes the mothers had to act as interpreters because the limitations caused by the impairment made interaction difficult. Many mothers played the role of an information manager who provided and updated information for others, for instance on their child's disability, needs, limitations and abilities. Mary noted, '*we try and keep people informed… We just try and tell people, you know, just being really open to people*'.

Simultaneously, several mothers revised their definition of normality after recognising the diversity in the spectrum. As Suzy described, '*I have been in Iceland after school and some of the children without learning disabilities behave horrendously in there*'. Realising that a child could behave badly with or without a medical label made the

disclosure unnecessary for Suzy. It also blurred the difference defined by the medical label between her son and other children. I do not know how Suzy could be sure that the children she saw in Iceland did not have special needs or if she judged these children in the same way as other people did. What Suzy's comment suggests is that as a member of society, she was aware of the social norms of what constituted good behaviour, a good child and a successful motherhood. This implies that although their disabled children could not be expected to fit in with social expectations owing to their impairments, the mothers were not exempt from the social norms and expectations regarding what constitutes and reflects a good mother who is bringing up her children properly. It might also suggest that Suzy unconsciously separated her son from other children and assumed that other children did not have special needs.

In addition, after having their disabled child, the mothers were much more sensitive in detecting these social judgements. As Goffman (1968: 12) indicates, 'typically, we do not become aware that we have made these demands or aware of what they are until an active question arises as to whether or not they will be fulfilled'. Singh (2004: 1201) argues, 'every individual is both a subject exercising the disciplinary gaze, and object of the gaze. Uncertainty as to whether one is subject or object leads the subject to internalize the disciplinary gaze and to continually reproduce a disciplinary power that has no external material centre'. Therefore, it did not matter whether the mothers really experienced the judgment or whether they imagined it; their reaction reflected the internalisation of the 'disciplinary power' referred to by Singh, so they tended to self-discipline or blame themselves.

These social encounters may put more pressure on women than on men (McLaughlin, 2006; Gray, 2002). It is generally assumed that mothers take more responsibility for child rearing than fathers (Lawler, 2000; Gray, 1997; Hays, 1996). Research has shown that parents with disabled children are no different. Because the father might get better pay, many mothers are the main carers of their child (Runswick-Cole, 2007; Traustadóttir, 1991). Gray (2003) also found that fathers were not significantly influenced directly by their disabled children, but that they were affected through their wives' experiences. Normally, it is mothers who are in the frontline facing the social pressure (McLaughlin, 2006; Singh, 2004; Gray, 1997). Singh (2004) further indicates that judgement or criticism in public venues often comes from other women and mothers, women become both the subjects and objects of surveillance by other women or by themselves.

When confronting this social pressure, it was the respondents' growing confidence that supported them. The mothers in this study described themselves as '*thick-skinned*' in the public sphere. Claire noted, '*I'm quite confident... I'm dealing with it the best way I can. And people have just got to accept that...if somebody challenged me I'd just say well, this is the situation, get on with it, it's not your problem, it's mine and I'm dealing with it*'. Jackie added, '*I don't care what people think any more. I know myself that I'm not (what other people think of me)*'. Ryan (2008: 734) highlights the nature of social encounters with unknown others as not involving the past or the future; rather than challenging the social norm or comprehension of disability, the mothers in her research chose to use a 'shorthand' for the diagnosis to manage 'the fleetingness and repetitiveness of public interaction'. Although these kinds of strategies can be viewed as mothers exercising their moral agency actively, Scully (2010) instead indicates the importance in recognising the unequal power relationship that explain how mothers needed to make great 'hidden' labour to manage these social encounters, such as considering others' feelings, evaluating the situation, being aware of the consequences of their actions. Scully further argues these various types of tactics involving selecting information and controlling personal emotions may have a great impact on an individual's sense of self and consume a great amount of energy that others do not have to spend.

Thus, in interactions with others the mothers played important roles as protectors, mediators, information managers and storytellers in order to help others to understand their child. In certain situations, they stopped trying to defend and explain their child to unknown others altogether. They became able to assess situations and decide if they needed to reveal their child's disability or not, and what 'mask' to choose. Sometimes they passively withdrew, sometimes they actively meditated, and chose their strategies according to the circumstances and their assessment of what would be beneficial to their child's welfare. Between the medical diagnosis and the stereotypes or vague understanding other people attached to the label of disability, the mothers found space to mediate and influence others' comprehension of their child. This suggests that the meaning of disability is negotiable. It also demonstrates the mothers' active agency when managing difficulties.

Explanations of their child

Their child's awareness of the impact of the disability was reported as one of the difficult tasks that required thoughtful management on the part of the mothers. Unlike previous studies that showed that disabled children were not encouraged to talk about impairment and disability in their family (Connors and Stalker, 2007), most of the mothers in this research did not avoid discussing disability with their child in various ways, since they knew that they could not hide the fact that they were disabled from their children, since it affected their daily lives.

Some mothers reported that their children were probably not really aware of being different because of their young age, or because of the impairment itself in the case of autism, learning difficulties or ADHD. Some mothers thought this lack of awareness was a good thing. However, others worried that their children could be vulnerable if they did not have a social awareness of what was at times an unfriendly environment. Their child's circumstances affected the strategies the respondents chose. Several mothers, especially those with young children, carefully chose phrases such as 'special' when describing and explaining their child's conditions and avoided making them negative. Some mothers tried to ease the situations through looking at the funny side or making jokes. Milly gave an example of the type of conversation she might have with her son: '*he'll say 'why do I have fits, why me', you know, 'why me?' And, what do you say? Ya, why him? ... I joke him through it. I make him laugh... I think...he is disabled enough to be not wholly aware*'. Other mothers chose to confront it. Mary insisted on giving her daughter opportunities to get involved: '*we always take the view that she understands everything...it's a lot better to involve Siobhan in what's going on around her. And if she doesn't understand, well, what have we got to lose? Whereas if we treat her like she doesn't understand anything when actually, I think, and I've seen, it caused quite a lot of damage to her*'.

With older children, there was more discussion and negotiation between the mothers and their children. Their mothers encouraged them to participate in the process of constructing comprehension of their disability. A few respondents provided factual information for their child to understand. Anita noted, '*I've always just been honest with Patrick. And with both of the children. If they ask me a question about anything I will answer honestly, and in a simple way. I believe that if a child is old enough to ask a question, they're old enough to hear the answer*'. When other people asked her about her son's condition, Anita suggested they should respect her son's ability to speak for

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himself: '*I used to say 'well ask Patrick, he will tell you'. So, it was, he didn't like it that, you know, people were asking me and not him*'. Following a psychologist's suggestion that she should not feel shame about disability, Angel was concerned that her daughter did not identify herself as disabled, although she did not hide her disability:

> *She (Cherry) likes to explain, not just hide it and I feel that's quite important, you know because I think if she can accept it like that and talk about it as just part of her, then, people will accept her more…she's very open about her, her disability. She doesn't call it a disability… She doesn't think of herself as being disabled…she'll say what, what's disabled, why have I got to use this word, she hates the word, because it sets them apart, doesn't it?*

Although how disabled people identify themselves is an important issue, it is beyond the scope of this research to investigate why Cherry did not view herself as disabled. However, Cherry's attitude echoes Shakespeare and Watson's (2002) argument that not every disabled person shares the same disabled identity. They further assert that everyone should have his/her right to choose his/her identity. Cherry's questions regarding what constitutes disability and what does being disabled mean reflects the postmodernist challenge to the essentiality of a category, and their emphasis on multiple realities and diversity (Barnes and Mercer, 2007; Fawcett, 2000). The meaning of disability will change over time. It could also have a different meaning for an adult and a child, between generations (Mayall 2000 cited in James and James, 2004). Should disabled children now be limited by the category or definition of disability constructed for the social model proposed by disabled adults a few decades ago? Or should they be allowed to develop their own new definition and identity beyond the label of disability? Therefore, I agree with Scully's (2008) argument about a disability community where diverse and subjective narratives can be merged and shared that do not necessarily fit in with political claims but may be able to support the development of the collective identity.

Connors and Stalker's (2007) research into disabled children's awareness of being disabled in mainstream schools could provide some explanation for Cherry's notion. They found that disabled children who attended mainstream schools tended to minimise

their differences and did not view impairment or disability as a part of their identity. These researchers suggest that this might be a result of schools' 'inclusive policies' that avoid acknowledging the differences. These findings reflect the social and cultural contexts in which disabled children live: for instance, living with their families and going to mainstream schools, which are significant changes that have occurred over the last few decades. Hence, it is essential to explore how disabled children view their identities and their relationships with others rather than simply adapting existing models. Moreover, it is also highly important to recognise the diversity among disabled children.

In addition, for the respondents in the current study, the meanings of their child's impairment required constant reassessment. Their understanding of their child's impairment and abilities influenced how they practised their motherhood. The need to set a boundary was highlighted by several mothers but used in different ways. Cathy's son's difficulties were diagnosed quite late, and she recalled, '*as we've sort of understood Ben's conditions a bit more…it's not like we let him get away with things but we make allowances because we understand why he behaves in a certain way*'. Wendy, on the other hand, was more confident about saying no to her son after acquiring a better understanding of Sam's condition:

> *There was a time you go through where you, you just want him to be happy all the time, so you give in, give in…and you realise that, you know, it's not working, he's not any happier than he would be if he had boundaries. And he has to have the same boundaries and understandable boundaries as other children do. So, so discipline and things like that were a big issue when he was small. I think he got to the age of two and I don't think I ever said no to him. Before he was two, I think he just got what he wanted all the time (lol). And luckily he wasn't, he wasn't spoilt as a result of it.*

Over time, the mothers obtained a better understanding of their child's impairment and abilities. Based on their comprehension, the respondents were aware of the boundaries related to who their child was and what they expected their child to achieve. This is illustrated in Jackie's comment that '*they're both teenagers, they've got hormones rushing through them and they're both ADHD and there's a lot of things that they can't*

control. But there's a lot of things that they can. And I know what they can control. And I know what they're trying to get away with as well'. However, their children might not always agree with the boundaries their mothers established for them.

Despite the awareness of being disabled, as time went by, the mother's bargain with her child concerning the permitted range of his or her activities might be questioned, which is probably an issue in the relationship between all mothers and their children. It was an endless process. Anita's son who had cerebral palsy used the word 'prison' to describe their home. Anita explained, '*he wants to be just like you know, any other little boy and he wants to go and play and he wants to have some independence from us but he, physically he can't do that'*. Maggie had a similar attitude toward her daughter who had a visual impairment and cerebral palsy: '*I don't let her play out, cause you can't. You can't let them play out because they can't see the road, they can't see cars. And that's probably what upset Chris more, and me, because she wants to go out with friends, but you can't, it's too dangerous... I let her in the garden and she plays by herself, you're watching in the garden'*.

It is understandable that most mothers cannot prevent themselves from protecting their child because of concerns over their impairment and the unfriendly environment. But protection was not the mothers' only concern. Several mothers were aware that they were conservative; hence they tried to compensate for the limitations they set. In order to make sure Chris had fun, Maggie turned her garden into a little park with various pieces of equipment and let Chris participate in a variety of activities designed for disabled children. It appears that the mothers in this study allowed their children freedom in a limited area where they could ensure their safety. However, as critiques from both professionals and disability activists suggest, over-protection might not always be what their children want (Finkelstein, 2001; Larson, 1998).

Mothers not only set boundaries for their children, they can also gradually learn to set some limitations on their maternal protective actions. Avery (1999) reflects on how she tried to delay the first wheelchair in order to keep her dream that one day her son might walk. However, when she saw how her son enjoyed his freedom in his wheelchair just like a teenager with his first car, she felt guilty for delaying his independence because of the social definitions of normality. Mary also modified her attitude after realising that '*sometimes, we were the biggest barriers to Siobhan making friends, because we are her parents and we look at things from a parents' perspective. Whereas, you know, you don't make friends in the playground with your mum on your shoulder'*. Although

worrying for Chris's safety, Maggie still stated that '*you have to put into perspective what they can do, what they can't do, what you're going to allow them to try and do. You need to let them try and do a little themselves, just little things. I think you need to try and learn them*'. Angel identified independence as one of the most important things that she tried to help her daughter achieve, saying, '*I think we've got to give them as much freedom as they can cope with*'. Moreover, the mothers did not intend to protect their child forever because they knew it was not possible and this was something that was a source of concern. Angel illustrated this when discussing the uncertainty of the future:

> *She's more concerned about the future, Things like if I can drive the car, when I, if I am able to have a baby, how would I manage to hold it, things like that and…you know, you haven't got the answer. When they're small you're just focused on getting them through this and getting them into a school, making sure they're in the right school, making sure…but I think now, you're sort of losing some of your control, it is more pressure.*

Bearing their child's future without them in mind, the mothers were making efforts to nurture their independence instead of trying to control or protect the child as they were accused of doing. Through constant assessment, they reflected on their experiences and modified their values and strategies. None of the mothers showed any joy in controlling their child's life but struggled to find a balance between their child's abilities and disability in the context of the environment their child would be in. The mothers might emphasise different elements in different situations within various contexts over time. However, although the positive nature of the mothers' efforts has been presented here, this does not mean that all their choices were necessarily right for their child from the child's perspective. The unbalanced power relationship between mothers and their children still needs to be highlighted.

To summarise the previous section, the mothers' experiences had gradually led them to see that the meanings of disability were not fixed or determined but were negotiable and socially constructed. After perceiving the possibility and importance of mediating or participating in this construction process, many mothers made efforts to contribute their

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influence in interpersonal relationships in order to safeguard their child's interests. The mothers' experiences indicated that they were the important figures in the process of shaping understanding about their disabled child, both for their child and for other social actors.

Unlike the mothers' negotiations for their children with service providers which were based on their child's rights, the mothers exhibited less confidence concerning how to handle issues surrounding their child's awareness of being disabled. This may be because the mothers recognised that they themselves were not disabled, and hence might not be able to have anything useful to offer but could only refer to ideas about identity suggested by professionals, disability activists, or related discourses. Although they might name their young child's condition to the child using words like 'special', some mothers showed they tried to give the power of naming back to their child when they could. Rather than trying to control or decide for their child, the mothers hoped to leave space for their children to decide some things for themselves.

Social Participation

In this section, the ways in which the respondents in this research understood and considered disability in the context of social participation are illustrated using the examples of educational arrangements and issues related to living in the community.

Educational arrangements

Most of the children in this research went to mainstream schools. As Rehm and Bradley (2005) suggest, going to school is viewed as one kind of normality, and going to a mainstream school was viewed as a type of participation by many mothers in this research. For example, Cathy explained, '*I wanted him to go to the mainstream school and still be part of…everything else that other children do, so, I don't want him to miss out on anything really because of his disability… Ben has his conditions but he still can live his life to the maximum hopefully given guidance and support*'.

The mothers recognised the fact that institutions could influence their child's learning opportunities so they chose the schools carefully. A mainstream school was viewed by Anita as an institutional part of society; she explained, '*I didn't want him to go to a special school because I felt that that was a very false environment because the real*

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world's not like that and I didn't want him to think that it was'. Hence, a school with a number of children with physical disabilities was carefully chosen by Anita, so that her son '*was in the minority, he's not the only one'* in a school where the children were very used to seeing some children with disabilities.

Other mothers expected that the experiences of learning with and learning from non-disabled peers would help their child's development and could provide opportunities for them to practise their social skills for the future as McLaughlin et al. (2008) have also proposed. Lisa disagreed with a suggestion from the education service that her son should be with children of his own level in the special school. Instead Lisa argued, '*I just felt like it was enormously ignorant because I think other children who are able will bring him on, and I don't think he's going to learn from children who are less able. I'm not one to be discriminatory against them...I didn't think he was going to learn more from children who are also delayed in their learning'*.

The decision to send their child to a mainstream school was only the beginning of the process of negotiation. Having a diagnosis or an education statement of special needs did not guarantee appropriate support for their child. It was not always easy to find a school equipped with supportive and understanding staff. The mothers reported their struggles with staff who were not familiar with specific conditions, did not recognise their child's special needs, or were prejudiced owing to their child's previous behaviour before getting a diagnosis. The respondents needed to work with the schools on issues such as how to discuss disability with their child, and to make sure that their child's special needs were recognised and responded to. It was a constant negotiation and not always pleasant.

Some respondents whose children were diagnosed at school age reported more difficulties than other mothers. Those disabilities that were diagnosed later were normally less visible or related to problems of behaviour or emotional development, such as autism and ADHD. Since these schools were not chosen by mothers based on their child's special needs, the schools their child attended were not designed or prepared to provide support for their children. Some mothers found their child was rarely included and more often excluded by the social arrangements, as the social model suggests. Jackie's son was diagnosed with ADHD when he was six years old. Rather than being included, Leon, now fifteen years old, sometimes got 15 day exclusions in a month. Jackie stated,

Education is terrible. Really terrible. And very lacking in understanding of ADHD... My son's school, they don't want to educate themselves, they don't want to understand about it, they don't want to admit that they need to spend more funds to get specialist help in for him...they would rather exclude them.... He's not the only child in this school, he won't be the only child in this school and they're going to have more and more through their doors over the years.

Jackie questioned why school staff did not want to educate themselves so that they would be able to cope with and educate the children better, instead of having the highest exclusion rate in the city. Lisa's son with Down's syndrome was also not welcomed by the head teacher from the beginning:

The head teacher was very clear that she didn't really want him. On the first meeting which was a review of the infant with maybe 10 or 15 people in the room. She sat there and she said to me have I read the behaviour policy? And I said yes, because my other children have it. She said well, if your son kicks any of my staff you have to be prepared, she said, he might be suspended for a week, excluded for a week. And I just felt she'd never seen him, she'd not met him, and her attitude never changed from then really.

Barriers, rather than inclusive support, were set up before Lisa's son went to the school. Despite policy initiatives intended to support children with special needs studying in mainstream schools having been put forward in the last twenty years, as Cole (2005) indicates, the development might be countervailed by other policies. Cole explains, for more than a decade now, in order to improve the standards of education, the idea of a quasi market and parents as consumers has been introduced, and the concepts of competition and parental choices stressed. Schools find it hard to compete with other schools when they have pupils with special needs without extra or enough resources, and this can have a negative influence on the schools' efforts to provide a good quality

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of inclusion (Cole, 2005). As Jackie realised, '*they just want A-stream pupils and they want statistics on their charts*'.

Finding themselves faced with these barriers, some respondents' experiences echoed McKeever and Miller's (2004: p1181) findings that indicate mothers might choose an appeasing, compliant, passive disposition because of 'retributive concerns', by which they mean, 'most mothers acquiesced and played by the rules of the health care game. They recognized the dominant habitus of professionals and hence their powers to set the rules of behaviour. For children's sakes, women modified their behaviours to be consistent with the expected maternal role in the field of paediatric medicine'. In this research, the mothers recalled more difficulties when negotiating over their child's disability and needs in educational settings (Ryan and Runswick-Cole, 2009; Prezant and Marshak, 2006; Neil, 2003).

Unlike medical professionals or social service providers with whom their child did not have to come into frequent contact, the school staff was the ones who took care of their child every day for several hours without their presence. Unlike physical barriers like stairs that might be easily identified as a problem and removed, it was much more difficult to 'remove' the staff or the prejudice or stereotype in their mind. Hence, many mothers chose to work cautiously with school staff. This issue was not mentioned by mothers whose children were in special schools but was raised by mothers whose children were in mainstream schools. Some mothers described their deliberation and hesitation when acting or challenging because they were worried that their child could be picked on by the school staff, a point also made in Prezant and Marshak's (2006) research. Cathy thought, '*I've got good relationships with all, all the people who work with him, because you have to…it's important to keep the relationships going with the teachers, with the education psychologist, people like that because they are people who are going to work with your child for a long time*'.

In other words, the mothers' compliance was in their child's interests. Jackie provided another example involving compliance. Although the paediatrician supported Jackie's request in the reviews, the school still refused to respond to Leon's ADHD. Jackie described how, '*the paediatrician…has actually been in to the school and talked to the school, like the teachers, and they still aren't taking on board what she's told them. You know she is the professional and she said that he won't concentrate…but they just, they don't understand it*'. Without appropriate support, '*he's getting excluded, he's getting*

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put in the seclusion unit and the learning support unit'. Jackie was not happy with Leon being taken away from his peers, but

> *If it's keeping him in school, then I am happy. And also, when he's in the seclusion unit he does a lot more work because he's got one-to-one attention and he's got no distractions. So he's, he gets on with his work and he, you know, work that he's missed, he catches up with and then he gets ahead of the class. So it's not as if he's losing out on his education, he's getting his education, cause he's got the one-to-one.*

The irony is that Leon was not getting the education he needed, one-to-one attention, through an inclusive approach but through an exclusive action, which suggests that inclusion education is not always inclusive enough. In order to keep Leon in school instead of losing out on his education, Leon and Jackie were forced to compromise by accepting his sessions in the seclusion unit and had continued to agree to his 'conditional' participation in his school (Davis and Watson, 2001).

Although the mothers recognised that the greatest obstacles to their child's happiness are the prejudices of society, as the social model suggests, the mothers found it hard to shake the structural system, as previous research has shown (Landsman, 2005; Read, 2002 cited in Ryan and Runswick-Cole, 2008). Since making adjustments for their child seems easier than changing society, some mothers used their tactics to solve the immediate difficulties they faced (Landsman, 2005). After making efforts to work alone with the school for a few years, Lisa was forced to transfer her son to another school because he did not have time to wait until the attitudes and approaches of the school staff towards dealing with his disability had changed for the better.

Although the mothers might not be satisfied with the support they received from the schools, most of them had noticed the differences after the policies of educational inclusion had been implemented. When looking back on the way they themselves had been brought up, many mothers said that they did not really see people with disability around them when they were young. Some admitted that before having their disabled child, they had held negative stereotypical images of disability or felt scared because of their ignorance. Emma recalled,

*When I was younger in schools and anywhere you went, there wasn't
many disabled people or disabled children or anything like that. And I
must admit when I was younger and I come in contact with disabled
children I think you were always a bit scared. I mean, not, I didn't
think badly of them or anything like that, but... you didn't know how
to, really, well act around them.*

However, after occupying their new social position as a mother of a disabled child, the respondents viewed issues around disability differently and illustrated their observations. Most of the mothers stressed the importance and benefit of promoting interaction and understanding between children with or without an impairment. They admired children for being more open-minded and less limited by stereotypes than adults. As illustrated by Mary, '*it amazes me how, how simple it is for kids. They don't deny there's disability or why there is disability, but Siobhan is here, it is the issue.*' Several of the mothers had noticed the difference when a child became one of 'the wise' (Goffman, 1968: 41). Anita compared the different interactions between Patrick and children they met on holidays and between Patrick and his classmates - 'the wise':

*The other children came and, and sort of spoke to Patrick and
realised he was different and then withdrew. They weren't nasty to
him but they obviously didn't know what to do with him so they just
went away... When we came back from the holiday we went to a soft-
play area and happened to bump into a little boy that was in Patrick's
class at school. And it really highlighted the difference because this
other little boy knew Patrick and knew what he could do and what he
couldn't do. He, he came and played with Patrick and he was well
aware of the fact that Patrick couldn't do all of the things but he still
came to play with him, and wanted to be with him. And they, the
children at the school that he's at see Patrick as Patrick, not as the
disabled child.*

Anita's account demonstrates how experience and understanding of disability can reduce the distance between a disabled child and a non-disabled child. It confirms Goffman's (1996 cited in Green, 2003b) argument that if others shift from being 'others' to being the 'wise', they might respect disability more. In this case, when interacting with one of 'the wise', not only Patrick's disability but also his abilities were recognised. Once someone had got to know Patrick as a unique individual, his disability was accepted as part of Patrick. Furthermore, what concerned Anita most was not whether Patrick was viewed as normal by his non-disabled peers, but if he was viewed as a person, known as a person, behind the label.

Mothers acknowledged the benefit of children working with and learning from each other; as Jackie said, '*there's a lot of things they could be doing together. And I think it would, it would work for a better society*'. Mary believed, '*everybody has something to contribute, the more diverse we can be as a society, the better in the end it is. Because the more differences that you are aware of, differences, the more you accept difference. And, um, yes, that' s really tough sometimes. But it is not impossible*'. According to the mothers who took part in this research, it would help in the achievement of an ideal type of participation in a better society if interactions were encouraged between non-disabled and disabled children before the stereotypes took hold, so the number of 'the wise' could increase. This view echoes those of several scholars who have argued for the promotion of a better understanding through interaction (Shakespeare et al., 2009; French, 1988). It might also help to acknowledge the similarities that children can work with and share, while at the same time emphasising a respect for diversity in which everyone's contribution is appreciated. These observations and experiences might be useful for service providers when considering policies related to inclusive education.

Although most of the mothers viewed inclusive education positively, their child did not always stay in mainstream education. One of the reasons for this was the impact of the impairment. Several of the mothers had realised that the gap between their child and his or her non-disabled peers was gradually getting wider. Rather than being included, their child was being more and more excluded. Their child's self-esteem was another reason why mothers considered taking him or her out of a mainstream school. Some mothers were concerned their child was feeling stressed and frustrated about being less able. Maggie considered transferring her daughter to a special school because she wanted Chris to feel adequate: '*I don't want her to feel like 'oh my God, I'm with all these*

children who can manage, and I can't. I don't want her to feel like that… if she's at the stage where she's sort of stopped learning and it's like a plateau, I would rather go to a special needs school then'. Claire chose to let her son with autism go to a special secondary school; she explained, '*I think he'd be daunted, a very big school of teenagers, he wouldn't have been able to cope. So he's better being a big fish in a special school…(rather than) where he would be one of the least able'*. Claire went on to describe the change after her son went to the new school:

> *I think his confidence is growing being in a special school…it's difficult to tell, whether his behaviour is getting better cause obviously he's learning all the time, he's getting older, he's maturing. Or whether he's becoming more confident, and more accepting and things, and he's more comfortable in his own skin, I think it's a combination of both of those things.*

For these mothers, it was not only about disability and ability, they were also concerned about their child's confidence, their sense of competence and their self-esteem, all of which are related to the quality of their child's life and their happiness. Claire's comment suggests that going to a special school might also support a child in developing his or her own identity, or in being '*more comfortable in his own skin'*, as she put it, rather than occupying the category of the less able. Another possible explanation may be because Claire's son found some templates in that environment for him to locate himself that were positive and inclusive rather than feeling different from others all the time. In order to prepare him to participate in society, Wendy also transferred her son Sam, who had multiple disabilities, to a special school because she hoped he would acquire a better understanding of his disability and learn to control it with appropriate support. She stated that she never thought she would be fighting to get her son into a special school. Since she had not seen any inclusion being put into practice in the mainstream school, now she believed sending Sam to a special school was the only way to provide her son with '*an opportunity to participate as an equal'* and '*it's the only way he stands to have any independence as an adult'*.

The other children in this research who were attending special schools had more complicated needs. In contrast to the assumption suggested by Barnes and Mercer (2007)

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that mothers 'hid' their children in such schools out of shame or ignorance, choosing a special school was in fact a carefully considered decision which the mothers made in their child's interests. It also implies that the mothers were flexible about the approach that could help their child to participate at present or develop their ability to participate in society in the future. They did not only rely on dominant discourses to tell them what was better for a disabled person but concentrated on their child's unique potential, abilities and disability. Their child's best interest was the main criterion for deciding on their course of action.

Unlike the suggestion from the social model that one should ignore the effects of impairment, the mothers in this study never denied or ignored the difficulties their child had or the support their child needed. The constantly changing needs of their developing child were the most important factor that influenced the mothers' decisions over their child's educational arrangements. Resisting being limited by the disability, many mothers wanted to give their child similar opportunities to other children. They hoped to help their child participate as much as possible, although needing support. This does not involve a single decision about educational arrangements; it is a process of constant assessment. Although the mothers might not be satisfied by the 'inclusive' education their child experienced, they held positive expectations for a society influenced by that education, however slowly it is changing.

Community--Future and now

Rather than an abstract notion of society, the respondents' experience was on a localised scale. They talked about the places they and their child would go in their daily lives, such as supermarkets, restaurants, soft play areas, and their local communities. These are the places where the mothers' interactions with others took place. In this research, apart from one teenager who lived in his college during the week, all the children lived with their families in their communities. Moreover, the future the mothers imagined for their children was always located in the community, rather than in residential institutions. Hence, in this part I will use the word 'community' to describe the small area of society that the mothers and their children inhabit at present and would like to live in the future.

In disability studies, mothers are often viewed as potential barriers that try to normalise their disabled children or prevent them from living independent lives (Barnes and Mercer, 2007; Finkelstein, 1998). For instance, Finkelstein (1998: p5) states,

> *Parents, however, are already in a 'care' relationship with their*
> *children and, as well-intentioned and responsible adults, want the best*
> *for them. For the vast majority this will mean that they want them to*
> *be like themselves, as 'normal' as possible. Unlike their disabled*
> *children, however, parents actively pursuing the goal of 'assimilation'*
> *into mainstream society are likely to be 'people with abilities', 'shoe-*
> *bound', aurally conversant or visually informed, etc.*

However, I will argue that the efforts made by the mothers in this research were not intended to correct their child's disability or to fit their child into the frame of normality. For example, rather than only focusing on independent living, emphasised by both disabled people and non-disabled people, the mothers made efforts to support and care for their children in participating and being independent on their own terms.

An imagined future that was embedded in the present

The fact that none of the mothers in this research considered the option of putting their child in a residential institution now or in the future could be viewed as a victory for the disability activists' movement. The visions of both the mothers and some of their children concerning the future were all located in the community, and included the options of living at home, living near home, or living with friends with the support of the community.

In the case of some of the more able older children, it was they who had forced their mothers to think about the future. They asked questions and were eager to find out what was available to them. Three sources were referred to by the mothers when portraying these imagined futures. First, the services currently available were used as a reference for an imagined future. In order to ease her son's anxiety about the future, Anita asked a social worker to describe the present services as examples to give Patrick some ideas: '*I know it may not be the same when he is that age, but*

at least he would know that there is some help...the social worker that came was talking about him living independently when he gets older and things like that, so I think he was, he was quite happy about that'.

Second, role models can nurture the imagination. Although some disability activists and scholars such as Barnes and Mercer (2007) are concerned that disabled children living in a community might not have a role model, a few of the mothers in this research suggested that other mothers and their older disabled children were good role models for them because they offered more concrete ideas about the future than the vague medical prognosis. Moreover, in contemporary society, mothers are not limited by geographic communities, such as the 'place community' proposed by Willmott (1986 cited in Crow 2000). Instead, mothers may use tools such as the internet to establish their community, as Cathy explains, *'there isn't a group here in Newcastle that I can attend for Ben's diagnosis, lot of them are a bit further out you know like Morpeth or Durham ... I can't drive so it'd be difficult to get to all those places... I join the support online and I discuss on the forums with other parents so that's been helpful to me'.*

Third, the picture of a future that many mothers and their children portrayed reflected social and cultural norms: for instance, getting married, getting a job, living independently, or having a child. As Claire explained, this was *'because that's what he sees around him'*. This might imply that the role models of these disabled children were not necessarily disabled people but those they interacted with in their daily lives, and that these children did not feel restricted by the disabled label in what they could do or how they should live. If one of the goals of the disability movement is to enable disabled people and disabled children to become whoever they want to become, like anyone else, this also could be viewed as a victory for the disability movement. It also suggests that their disability might not inhibit their ability to imagine something other than the norm.

The circumstances and experiences of the present were important references for the mothers and their children when imagining the future. Also based on the experiences of the present of dealing with social barriers, mothers worry about their child's future. Some of the mothers in this study saw the future as a frightening place, full of uncertainty, which they were powerless to deal with. Since the future was unforeseeable, the mothers in this research could only concentrate on strategies

to help their children to develop their potential and abilities in order to fit in with and participate in their communities.

Independence and dependence

In this part we shall return to the discussion of dependence presented in the previous chapter. Here, I am principally concerned with the respondents' understanding of their child's independence as related to their impairments and their ideas about normality.

Both independence and dependence are identified as important references in contemporary debates about disability. Disability researchers have demonstrated how disability was framed as a burden of dependency following the development of the industrial capitalist society (Finkelstein, 2001; Oliver, 1990; Oliver, 1983). In order to resist this dependent status, one of the main strategies of the disability movement has been to promote independent living in communities (Barnes and Mercer, 2007). Although asserting the importance of independent living, some researchers into disability also admit that no one can be completely independent (French, 1993; Morris, 1991; Oliver, 1990). As Oliver (1990: p.91) clarifies, 'disabled people, however, define independence differently, seeing it as the ability to control and make decisions about their lives, rather than doing things alone or without help'. French (1993) adds that with the support of others, disabled people could spend their time doing things they really like, instead of facing a life of stress and isolation.

Other scholars have indicated how dependency is constructed by contrasting it with the concept of independence in contemporary Western society (Priestley, 2003; Gottlieb, 2002; Kittay, 2002b; Hillyer, 1993). The assumption about independence in the theory of justice has been challenged (Gottlieb, 2002; Kittay, 2002b). Instead of viewing independence and dependence as two separate poles, Hillyer (1993) suggests highlighting the ways in which independence and dependence are interwoven with each other. Kittay (2011:49) further argues that 'human beings are naturally subject to periods of dependency, and people without disabilities are only "temporarily abled"'. As a person who appreciated her independence and self-control, Green (2002) had many worries concerning the possible negative experiences her disabled daughter might face, such as stigma, a poor quality of life (social isolation, rejection, teasing, no friends and no love), and the need to depend on others. Gradually, Green changed her understanding of independence when she saw how her daughter was able to be independent in her

dependency, in ways such as exercising personal control and establishing social contact with others. The respondents interviewed in this research had made similar journeys in rediscovering their views of independence.

For a few of the mothers, being independent was viewed as an essential goal of motherhood reflecting social and cultural norms, as in Anita's wish for her children: '*I think that, what every parent wants, I imagine, is for their children to grow up happy and independent. And I've, that's all I want for my children, I don't care what they do, I don't care who, who their friends are, as long as they are happy and they have a good quality of life*'. However, the mothers' ideas about what constituted a good quality of life and the meaning of being independent had been transformed over time.

Some mothers talked about helping their child to be as normal as possible because they knew how unfriendly their environment could be. However, the notion was not embedded in the context of assimilation as Finkelstein (1998) has indicated. Normalisation was not the mothers' goal. Being aware of the problematic nature of definitions of disability, the mothers also realised they did not have to go along with common assumptions concerning normality. Instead, many of the respondents discussed the topic of normality in the context of ensuring that their child would have similar opportunities to other children, so that their child could develop his or her unique personality, instead of being circumscribed by the label of disability within the frames of normality, a point made in Ryan and Runswick-Cole's (2009) research. What the mothers in this research were pursuing instead was the space for their children to develop their potential even though they were different from others. Rather than assimilation, it is diversity that matters. Therefore, when putting their unique child in the centre, the strategies to support his or her independent living in the future varied.

Helping their child to develop self-help skills was viewed as an important but not the only or main goal by many mothers. Instead, they were concerned with their child's self-esteem, and attempted to help their child to understand their disability/ability, develop their own agency, and learn to make their own decisions. The mothers used diverse strategies to nurture their child in seeking their own independence, although with the support of others. Wendy explained her goal as follows:

> *He's always going to need to have somebody else to help him but I'd like him to have more power over his, over his own life as an adult, and make, be able*

to make independent choices as to who it is who helps him, or how often they come to his house, or you know, I'd like him to be able to get himself in and out of bed by himself or help himself get dressed or feed himself. These are skills that are quite basic and you take for granted but they make a massive difference to his self-esteem…if he's taught how his disability affects him as a person, then he's going to have more control over that.

What the mothers emphasised was the importance of respect for diversity, to see their child as a unique individual. What they tried to obtain for their children was not only 'equal' opportunities to others but also 'suitable' opportunities with the support that their child needed. Rather than denigrating disability or minimising the differences, the mothers in this research embraced their child's disability in their lives and redefined the meanings of normality (McLaughlin, 2006; Rehm and Bradley, 2005). In the context of acknowledging diversity, many of the mothers developed attitudes towards independence that allowed for different levels of independence within their dependence in their child's future. However, they were also concerned with the issue of participation.

Participation and engagement

As their experience and confidence grew, the research participants rethought the relationship between others and their child, redefined their role, and modified their tactics. In this part I shall demonstrate that far from being objects waiting passively to be included by dominant groups, the mothers were active subjects who participated in and engaged with the outside world in order to influence how disability was understood and how institutions worked so that they could eventually promote their child's interests. First I will demonstrate that participation is not an isolated personal action but is related to other institutional arrangements and is embedded in contexts.

Sometimes it is inevitable that one dimension is damaged while pursuing another. Knowing the cost of transgressing social and cultural norms, many mothers tried to help their child develop social awareness and social skills such as being polite. Wendy described their experiences of eating out: '*I'm proud that he's so well-behaved, he understands the sort of manners of being out in a public place, you know, he understands you have to say please you have to say thank you, and you have to, you*

know, things like that, and waiting for his food...He's somebody who I'm never ashamed of when I go anywhere'. The mothers' efforts to try to maximise their child's ability or teach their child to accommodate social or cultural expectations in social settings might be criticised by supporters of the social model as trying to correct/normalise their child (Landsman, 2005); however, they might also be seen as efforts to promote the participation of disabled children and their families. Since research has suggested that mothers might choose to withdraw if they have negative experiences of going out or feel their child will be stigmatised (Ryan, 2005; Green, 2003b), being able to comply with social norms might reduce the risk of being identified as different, and therefore contribute to their willingness to participate socially in their community, as Wendy described.

Going to school had some impact on the mothers and their child's participation in the community, especially in the case of those who did not go to local schools. Lisa described her experience as follows: '*we walked down the road, everybody knew his name, everybody, which they would never have known all my children's names, but everybody in the village knew Boris. Whereas now he's not around as much because we don't walk up and down the road which we would have been, and that's quite sad'*. Because their child did not go to a local school, the mothers reported that he or she did not have local friends and felt lonely, especially during school holidays. The mothers themselves also did not get involved in the maternal social network in the community. As Claire pointed out, '*you don't meet the other parents...they get picked up from your door by transport and taken to school and they get dropped back by transport. You never stand in the school yard like you do with the other children to meet parents...the children (in Robin's class) come from all over Newcastle'*.

In the case of Wendy, for example, who decided to transfer her son to a special school, as mentioned earlier, what concerned her was not only Sam's present inclusion, she further strove to ensure that Sam received appropriate help from a special school that could support his social participation in the future. Since participation is a complicated issue, it is difficult to find a single form of participation that suits everyone's situation in different contexts at different times. Moreover, the respondents in this research revealed multiple dimensions of participation that were taken into account in their considerations. Among the various approaches to participation, the mothers could only choose one, or a few that were viewed as the most important and most suitable for their child, although these might have a negative impact on other aspects of participation (for

example, if they went to an inclusive mainstream school, they would no longer be able to participate in the life of their local community as they had before, or have as many local friends). It would therefore be inappropriate for other people to judge the mothers regarding decisions they had made when they had no understanding of the contexts in which the mothers and their children were embedded.

The mothers were aware of the obstacles to their child's participation, and many used various strategies to create different life experiences for their child to try. Several mothers were concerned about their child's social circle and tried to maintain or enlarge it by getting involved in a variety of activities or keeping in contact with others. For example, Claire tried to create opportunities for Robin to interact with other children by inviting Robin's friends to their house after school or to his birthday party. Mary also made efforts to enlarge Siobhan's circle of friends and invited more people to become involved and included in her daughter's life.

Furthermore, some mothers ensured some space for their children to participate in their own ways. Mary's daughter with multiple impairments sang in a choir and went to Brownies. Mary noted, '*some people might go along and say well, she's not participating but, you know, we know she is. We know that she's learning the different songs…the other important thing for me is the other kids value Siobhan for something she can do. And can see what Siobhan can contribute and not focussing on what she can't do*'.

The older children also tried to find their own identities and to participate in their own ways. Jackie described her son with ADHD as follows: '*he doesn't like being different but he, he, he deals with it by being the class clown…he's always wanting to get people's attention, he's the life and soul of the party. You know, he cheers everybody up and he wants everybody to carry on and laugh with him*'. Anita's son who had cerebral palsy liked to act as umpire for his brothers and his brother's friends' games. Angel was proud of her daughter, because she cared about others in the community (church) and tried to make impact as a member of the community, she described thus: '*she is very sensitive towards everybody, and, not only to disabled people. She's very aware…of elder people as well… She thought particular steps were dangerous so she wants new hand-rails, so she wrote a letter to the church…it wasn't just for her, but she was thinking a lot of elderly people needed it as well*'.

Moreover, as Kittay (2002b: 265) states, 'being a person means having the capacity to be in certain relationships with other persons, to sustain contact with other persons, to shape one's own world and the world of others, and to have a life that another person can conceive of as an imaginative possibility for him - or her'. According to this standard, the respondents' disabled children participated in and made their own contributions to the relationships between themselves and others. The respondents were able to see the contribution made by their disabled child from their participation. Several of the mothers acknowledged that their non-disabled children and their disabled child's peers benefited from interacting with their disabled child and became much more caring persons. For instance, as Maggie illustrated, '*even the three-year-old will say 'mum, no, too many stairs for Chris'* '. Mary was also delighted to find that her daughter '*helped raise the achievement of others in the class*'. Some mothers also reported that their child made them stronger people. Several mothers educated themselves after having their disabled child, as described by some scholars who have claimed that they learned a lot from their disabled child, even though they might not be able to speak (Kittay, 2011; Green, 2002).

It was also found in the current research that the mothers' participation could vary depending on the social position they occupied. In the next chapter, I will show how the role of a mother with a disabled child could influence and engage with her professional career. For example, the way in which the mothers practised their professions and the relationships between the mothers and their clients changed. This could be viewed as a contribution made by their disabled child, who had influenced how the mothers engaged with the world. Several scholars with disabled children have contributed valuable insights from their experiences as mothers that provide different dimensions for their academic disciplines: for example, in the fields of sociology (Runswick-Cole, 2007; Ryan, 2005; Green, 2002; Avery, 1999), feminism (Hillyer, 1993), anthropology (Rapp and Ginsburg, 2001) and philosophy (Kittay, 1999). Accordingly, the experience of disability is not necessarily useless, negative and irrelevant to others, but can make contribution in various ways if we look carefully.

In addition, several respondents experienced different levels of participation in the process of constructing the understanding of disability and designing related services in order to influence the environment their child would participate. Some mothers felt they had participated in the era when inclusive education was developing. They had

witnessed the transformation after the mainstream institutions (schools and nurseries) accepted their child. Maggie recalled,

> *Since they took my, my child in, they didn't used to before, but I think they thought well, maybe we'll try because they knew me and they knew my family and, and they did and they had, got relevant help and equipment. They made big changes in the nursery and then they started taking more in… I'm really pleased cause…you'd crossed a little line there.*

Rather than waiting for things to happen, some respondents tried to exert an influence through their participation. Participation might not only be viewed as their right but also their responsibility, as Hammel et al. (2008) suggest. Some mothers participated in school committees or parents' forums held by the city council and tried to make an impact or raise awareness of the way the institutions worked. Some mothers worked for organisations for disabled people and their families. These mothers focused not only on their child, but tried to support other disabled children in the community. For instance, using her experience of participating in parents' forums, Jackie worked with other parents setting up a group for parents with children with ADHD. Two other mothers tried to establish an organisation for families with children with autism. Mary ran a course for parents of disabled children to empower them in making positive changes in their families' lives and in the life of their local community. She also actively participated in how services were delivered in her town:

> *I'm on the chair of governors of a special school, I've helped the development and the leadership in terms of making sure that that school now is a resource for all the kids. It's not about saying, you know, 'if you look like this then you go to that school', it's about saying 'really, everyone should go to their local school if at all possible. If that's not possible then that's what this special school resource can help'. And now you have teachers from the special school going to nursery school to help them. You have children…*

perhaps children who are at risk of exclusion, not being included but

being helped…it's a resource for the whole of the town.

In other words, not only a disabled child but also other children at risk could benefit from Mary's participation. The parent group Jackie organised was concerned not only with children with ADHD but also with their siblings. Moreover, the contribution Jackie made by participating in the anti-bullying committee at her son's school did not focus solely on disabled children, but every child in her son's school benefited. Accordingly, the respondents not only realised that it was possible for them to become involved in the construction of understanding of disability in interpersonal relationships, some of them further recognised that it was possible for them to influence how institutions worked in their communities. Through participation, they could and did experience a process of empowerment. They focused not only on their disabled child, but also on the community of disabled children and other children in the community.

Sometimes, trying to get involved in the system also gives you another perspective from which to understand things. According to Jackie, after participating in a parents' forum held by the city council, she had the opportunity to get to know professionals and the system on a friendly basis. Instead of being just an angry mother fighting all the time, she found that '*you see how difficult things are for services to run and to provide, I think you start to understand that things aren't going to change next week or next month. It is going to take a year or more for things to change*'. Gaining this insight into the limitations of the service system did not mean that Jackie then passively accepted it for what it was. Instead, she realised that every step was hard work, so she was keen to contribute her effort and make changes.

Conclusion

The respondents' experiences showed that the meaning of disability is not only about biological impairment, nor is it only about social barriers. The mothers in this study did not deny the impact of impairment and even encouraged their children to accept their disabilities as part of them. Most mothers did not try to shape a normal identity or a disabled identity for their child but made efforts to resist the limitations imposed by the label of disability. Rather than being concerned with normalisation or assimilation, the

mothers endeavoured to ensure opportunities and services in order to support their children in developing their potential and unique personality. At the same time, because of the uncertainty in the future, they made efforts in the present to develop their child's abilities in order to prepare them for their future. Therefore, how the mothers in this research understood disability was not a linear process with a specific direction guided by professionals or existing models. Instead, the respondents learned from their daily experiences, both from their positive experiences and from their mistakes. They modified their strategies based on their child's needs and their personal circumstances.

It was also found that the mothers embraced the uncertainty in which their hope and their child's potential were embedded. Because of this uncertainty, the mothers came to realise that the meanings of disability are negotiable. The mothers also demonstrated diverse approaches to understanding, interpreting and presenting disability. Rather than being passive receivers of welfare, the mothers showed they had great ability to develop their own understanding of disability for themselves and others through adapting flexible and changeable strategies in order to ensure their child's interests. Accordingly, unlike the label of 'unrealistic' that is often attached to such mothers, I argue that these mothers are practical social actors. Their every decision in their daily lives has required careful consideration and management based on their updated understanding of their growing and changing child, including the current boundary between disability/ability, the support/resources available, and the future/goals they hoped to achieve. While appreciating mothers' efforts, as Scully (2010) argues, it is important to recognise the power inequality that means mothers have to make great hidden efforts to manage these issues.

The respondents were concerned about issues involving inclusion, and many mothers took active steps to make it possible for their children to participate on their own terms (Hammel et al., 2008). If we examine the diverse forms and levels of participation these children are able to achieve, as shown in this research, we might be able to rethink the issues of dependence, burden and independence. Therefore, I argue that it is important that we appreciate the diverse forms of engagement by these disabled children and make efforts to allow space for them to participate in their own ways, which is precisely what their mothers have devoted themselves to achieving.

Additionally, several respondents also extended their unselfish and unconditional care to other children and made efforts to support other families. What they were endeavouring to do was to make a better world for their children, their grandchildren

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and other children, as Jackie asserted: '*obviously we're not going to be able to change things for our children, but grandchildren, other people's children*'. These mothers demonstrated how their experiences and reflections would connect with and benefit other members in the community, such as children in need or at risk. Therefore, I would like to argue that mothers' experiences and approaches can provide us with alternative perspectives from which to consider issues not only involving disability, but also motherhood, childhood, and how to create a better society.

Chapter Six

Transformations between and across social positions -

Mothers with professional backgrounds

The occupations of ten of the sixteen mothers interviewed for this research were related to services for disabled people (see Appendix 6-1: mothers' previous and current occupations). Five were related to education or social services, and five mothers worked in health care. Two of the respondents had just completed counselling courses and planned to work for charities for disabled people and their families. Therefore, excluding the latter two, these ten mothers had various levels of experience of medicine, illness and disability before having their disabled child.

The occupations and experience of these ten mothers were diverse in many ways. Some were professionals with qualifications; others were not. Some mothers worked with children with disability, others worked with disabled adults. Some had experience of helping children with the same disability as their child; the experience of others was less direct. Although some of them might not have met the criteria for professionals suggested by scholars (Friedson, 2008; Williams, 1993), many of these mothers identified themselves as professionals on their own terms and viewed themselves as different from other mothers.

The first two chapters analysed the sample as a whole because having a professional is only one of mothers' various roles, it did not show significant differences between the women. However, this chapter will make a distinction because the area of this chapter will be important to only focus on the ten mothers with professional backgrounds. In this research the phrase 'mothers with professional backgrounds' has been chosen to describe these mothers, for four reasons. Since this research is based on the mothers' perspectives and since they did occupy the positions of service providers for disabled people and their families, I decided to accept the mothers' self-definition as professionals. Second, in their research, Klein and McCabe (2007) also use the word 'professionals' to describe mothers who were employed by an American early intervention programme because of their expertise as mothers of disabled children, although a degree was not required. Third, the mothers' professional positions and the resources associated with these positions were viewed as important aspects of their

background that influenced how they managed their role as a mother. Finally, in many cases, the mothers' professional knowledge was relegated to the background and overlooked by service providers.

The view that knowledge is socially situated and that an individual's knowledge is embedded in his/her social position has been increasingly accepted in sociology since the efforts made by feminists and postmodernists (Mann, 2000; Harding, 1993). For example, the knowledge the knower possesses is not just his/her own knowledge, instead it is knowledge influenced by his/her social position, including aspects such as race, age, class and gender, that 'enable[s] and set[s] limits on what one can know' (Harding, 1993: 54-55). The knowledge individuals acquire is derived from their social worlds. However, scholars also emphasise the fact that individuals can exercise their agency. Giddens (1991:52) states,

> The 'identity' of the self, in contrast to the self as a generic
> phenomenon, presumes reflexive awareness. It is what the individual
> is conscious 'of' in the term 'self-consciousness'. Self-identity, in
> other words, is not something that is just given, as a result of the
> continuities of the individual's action system, but something that has
> to be routinely created and sustained in the reflexive activities of the
> individual.

Skeggs (1997) is also concerned with how knowers know. She argues,

> Subject positions are based on structural organizations such as class,
> race and gender which circumscribe and access movement into certain
> subject positions. These structurally organized social positions enable
> and limit our access to cultural, economic, social and symbolic capital
> and thus the ability to recognize ourselves as the subject positions we
> occupy. (Dis)identifications from/with and (dis)simulation of these
> social and subject positions are the means by which identities come to
> appear as coherent (1997: 12-13).

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Hence, based on their previous biography, that is, what they already know of themselves, individuals ensure their subjective positions, develop their identities and recast their relationships with others (Jenkins., 2004; Skeggs, 1997; Giddens, 1991). This section will demonstrate how the mothers used their professional backgrounds and associated resources to manage their new social position as a mother with a disabled child. It will also be shown how, as time went on, the mothers continuously adjusted their subjective positions as mothers and their positions in their relationships with others.

Moreover, professionals and mothers are normally viewed as separate social actors who may possess a different understanding of and expectations concerning the child's impairment (Graungaard and Skov, 2007; McLaughlin, 2006; Landsman, 2005; Green, 2003; Green, 2001; Kearney and Griffin, 2001; Landsman, 1998). Since their professional backgrounds meant that these mothers crossed the boundary between professionals and mothers, I will present the diverse knowledge the mothers acquired from their two different social positions. By examining these mothers' accounts of their experiences, this chapter will show what they had learned from their social positions as both professionals and mothers with disabled children; the reasons why mothers' expertise is important will also be examined, and the reasons why cooperation between mothers and professionals is essential for the welfare of disabled children.

The discussions will draw principally on the experiences and reflections of the ten mothers who had worked as service providers before having their disabled child. In the first section it will be demonstrated how the mothers' professional backgrounds helped them in their situation as mothers with disabled children. In the second section the limitations of their professional backgrounds will be discussed. The third section will explore how the mothers' experiences of raising their disabled children have influenced their careers and their professional practice.

From a professional to a mother

In this section I will examine how the mothers' professional backgrounds, including their experience or knowledge related to disability, influenced their strategies of managing issues surrounding disability.

A good foundation to start from

Most of the mothers who had acquired experience or knowledge of disability from their occupations stated that they had begun their journey from a position different from that of mothers who had no experience or knowledge, as Mary claimed: '*I didn't come in to this with no knowledge*'. Instead of being given a medical diagnosis, Wendy, Lisa and Anita had noticed their child's syndromes from their experience, before a medical professional had detected them. Both Lisa and Wendy even explicitly identified their sons' impairments - cerebral palsy and Down's syndrome. Because of their self-diagnoses, they did not have to go through the long process of searching for an answer that other parents may go through. They also avoided having to go through the negative experiences caused by the unfeeling approach to delivering a diagnosis adopted by some professionals, as research has suggested (McLaughlin, 2006; Green, 2001). Their children obtained a definite diagnosis and follow-on support that focused on their children's needs more quickly than others in the early stage.

Mothers with disabled children are normally expected to learn about various aspects of their child's disability, including treatment and medicine, after receiving the diagnosis. However, several of the mothers with professional backgrounds interviewed in this study reported that they already knew about their child's disability or even had some experience related to the disability. Libby, who used to be a teacher, described the difference between herself and other parents as follows: '*because they just had no experience at all, not like, I'd worked with children like Carl for twenty-five years, so it's, it's no surprise, there are lots of surprises but it's not, it's not a total surprise*'. Even if the mothers' professions were not directly related to their child's disability, they acknowledged that their backgrounds gave them a good foundation on which to establish an understanding. The mothers described themselves as fast learners, mastering information efficiently when dealing with problems. As an immigrant (Asian background), Lily reported that she had benefited from her knowledge of pharmaceutical science that helped her to understand the medical aspect of her daughter's autism quickly and which enabled her to communicate with professionals despite the language barrier.

Advantages as an insider

Following the diagnosis, the mothers started to interact with various professionals; as Mary illustrated, there were about twenty-eight different professionals dealing with her daughter. Angel, who used to be a nursing auxiliary, described the situation as follows: '*all of a sudden, you've got these people coming in… For some people it must be quite frightening, daunting, having these people. They've never dealt with people, you know, professional people before*'. While other mothers struggled with getting to know the various kinds of professionals, the experiences of working with other professionals in their places of work helped these mothers to skip the confusion stage, since they already possessed a general understanding of the roles and responsibilities of different professionals.

Moreover, these mothers were more aware that professionals did not exist in isolation but that they had to work alongside other professionals in the service systems. They were embedded in and influenced by institutions, bureaucracy and related policies. For instance, Lisa acknowledged her understanding of the limitations of the National Health Service (NHS) from her work experience, which gave her more practical or realistic expectations of the service system. Their general awareness of how the community, institution or system worked further enabled these mothers to exert their influence over the process of assessing or designing services for their child. In the following paragraphs the ways in which the respondents managed issues involved in both accessing and manipulating information will be used to illustrate the influence of their professional backgrounds.

Obtaining a diagnosis does not guarantee getting suitable services. Mothers without professional backgrounds reported more difficulties than those who had professional backgrounds when attempting to access information, and this reflects the findings of previous research (Clavering, 2007; Green, 2001; Beresford, 1994). Cathy, who did not have a professional background, found that the service providers did not inform people or make information readily available. Sometimes she found something out purely '*by accident*'. As she argued, '*how would you go about asking for something that you don't know exists?*' In contrast, many of the mothers who had professional backgrounds stated they already had some idea of where and how to obtain resources and support, not only within but also outside their professional fields.

The mothers further used their professional knowledge to influence how their child's disability was assessed because they knew how to present, indicate or interpret information in order to get the support they needed. For example, as a nurse, Anita knew how to 'present' her son's syndromes to fit medical professionals' concerns, for instance by highlighting his chewing problems, so that her son could get the speech therapy that she really wanted. Claire, a GP, confirmed this strategy of manipulating information when she said,

> *We (my husband and I, both doctors) know…how to mobilise services, so to deal with health visitors or social workers or you know, benefits agencies or schools, like you know producing reports, asking for services…I think it's very difficult for people who can't write reports…Because we write professional letters and reports all the time, although it's slightly odd doing it for your own son. You know what people would be looking for, what they're asking for, and how to put forward a strong argument for something.*

Mothers with professional backgrounds were more familiar with formal approaches to dealing with information and acting upon it when involved in discussions with other professionals. As in Claire's example of writing a report with a strong argument, the negotiations several of the mothers engaged in were less personal and private than simply arguing verbally in person. Moreover, the ways in which these mothers accessed and processed information were also related to how they had been trained. Especially in the case of mothers with medical backgrounds, they tended to use the existing medical understanding concerning their child's disability to explain or have expectations of their child, as in developmental milestones. Many of these mothers referred to conferences, workshops, courses and research as being their sources of information. Some illustrated how they used more academic ways to process the information, as in the following comment by Claire,

> *We (she and her husband) can access information. We can read things. We can process the information. We get about it, if new*

information comes in, then we can process that in perhaps a more
scientific way rather than an emotional way. We tend not to hang on
to sorts of ideas like diets or injections…but actually look at the
scientific, what is the evidence behind this and you know what needed
to be considered.

Claire refers to her ability to process information in a 'scientific' way. She also implies that she prioritised a scientific, rational or academic approach based on medical evidence over an emotional approach, and rather than opting for complementary/alternative medicine, which was the approach adopted by the parents who participated in Prussing et al.'s (2005) study.

Furthermore, most of the mothers with professional backgrounds tended to use public or abstract discourses to legitimise their child's needs and interpret their circumstances. Some mothers used the concept of 'discrimination' in the context of 'law' to frame the barriers they encountered (p105). They highlighted their child's 'rights' when fighting for the services to which their child was 'entitled' (p174). Mary refused to adopt 'the medical model', noting, '*the thing I struggle with, it's just the, the clinical stuff, I guess, the medical model of disability that Siobhan is, you know, she, she's not, she doesn't have bits to be fixed*'. The stress on the notion of rights, the resistance of discrimination and 'the medical model' shows the positive influences of the debates in disability studies. Due to the contribution of the debates of disability studies, it is important to recast mothers in disability studies rather than viewing them merely the potential barriers as presented in chapter two.

When carefully examining the mothers' accounts, it becomes evident that it was not only the theoretical knowledge they had acquired from training or textbooks that helped them, but the resources associated with their occupations were also very useful. Bourdieu's theory of capital which highlights how elites use their network assets to produce, maintain, reproduce their capital and transfer this capital to their offspring (Field, 2003) is a useful frame for demonstrating how the mothers with professional backgrounds used their network assets to deal with their problems. Bourdieu (1986: 243) proposes,

Capital can present itself in three fundamental guises: as economic
capital, which is immediately and directly convertible into money and

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*may be institutionalized in the forms of property rights; as cultural
capital, which is convertible, on certain conditions, into economic
capital and may be institutionalized in the forms of educational
qualifications; and as social capital, made up of social obligations
('connections'), which is convertible, in certain conditions, into
economic capital and may be institutionalized in the forms of a title of
nobility'.*

Bourdieu further suggests various forms of capital which are relevant here. In particular he identified symbolic capital as how an individual is perceived and recognised as legitimate and then acquires power, for instance through role, legitimacy, authority or prestige (McKeever and Miller, 2004). Wacquant (2008) suggests, for Bourdieu, capital is viewed as resources that enable individuals to gain certain profits through participation and competition with others. My discussion will only focus on how mothers use the capital attached to their social position as a professional in order to make an impact on their relationships with other professionals. It will also illustrate the diversity among mothers with professional backgrounds due to the different amount and form of capital they possessed.

The way that economic capital can affect various experiences of disability has been discussed in the literature (Vernon and Swain, 2002; Fawcett, 2000). In this research, several mothers, especially those with medical backgrounds, seemed to have better financial security. Two of the mothers were able to purchase the support they needed, such as a nanny, a personal assistant, or a lawyer if they needed to go to a tribunal. Although because of her son's autism they did less than they would like to do, Claire stated that they were still able to maintain their family lifestyle, which included things like going on foreign holidays and horse-riding.

The status and power of professionals is not only assured by their knowledge and skills, but is also supported by various types of institutional recognition, such as educational qualifications. This 'cultural capital' might put more credit in the mothers' accounts. Using the example presented earlier of the three mothers who identified their child's impairments before the professionals detected them, none of them said they were questioned about their self-diagnosis. It is reasonable to suggest their professional background as a nurse, a physiotherapist, and a teacher of adults with learning

difficulties provided some credibility to their speculations, unlike experiences of other mothers without professional backgrounds, Cathy was viewed as imagining things, and Sherry suggested that she was worried to be viewed as paranoid when sharing their observation or perspectives with professionals.

Their professional knowledge and skills were used as tools to handle their difficulties. Since these mothers were willing to adopt a more academic approach to managing things, for instance by reading research studies or going to conferences, they might also be more familiar with certain types of professional language used by other professionals, such as jargon. Or like Claire's example (p169) about the academic approach to process information. Rather than receiving only one-way guidance, this might improve the quality of the communication and discussions between these mothers and professionals. Moreover, their cultural capital also increased their confidence. As Claire stated, '*I think we probably fight Robin's corner better because we are well educated and have the ability to do that… The whole process of getting him through an education statement is huge. And I think that's not as daunting for us as it could be for some people*'. Identifying herself as someone in the social position of being 'well educated' and having ability supported Claire's confidence in going through the complicated process of obtaining a special needs statement.

The mothers also gave various examples of how they used their 'social capital', which was generated through social relationships: for instance, since they knew the professionals personally within their existing social network, they knew which person they wanted to be referred to, or which person they needed to argue with. Based on their experiences of working with other professionals, they were acquainted with the roles, responsibilities and concerns of different occupations, and knew how to interact with them. They were not only mothers but also the colleagues of professionals. Hence most of them asserted they were less nervous when interacting, negotiating or arguing with other professionals.

Symbolic capital refers to first being perceived and recognised as legitimate and then obtaining power. The most prominent example of this in this research was Claire. Being a doctor not only gave her the cultural capital of a qualification, but she also acknowledged that the social meanings and symbolic capital attached to the occupation legitimated her efforts on her son's behalf in the eyes of other professionals:

I have to say I use that (being a doctor). I mean I make that quite

clear… I haven't got any pride…but it does mean, I know what I'm

talking about, that I'm confident about what I am talking about and

don't give me nonsense. You know, this isn't good enough, it's not the

standard that I expect…this is the deadline…I think if I come over as

'I'm a doctor', and then a mother, that carries more weight than me

just being Robin's mother.

Knowing that being a doctor was more useful and gave her more power than being a mother, both socially and culturally, Claire chose to acknowledge it. Since doctors are generally recognised as a higher authority in the hierarchy of professions, they have more chance of crossing the boundaries between professionals and even of making demands. McLaughlin and Goodley (2008) obtained similar findings concerning a mother in their research who successfully resisted the treatments for her son because she was also a paediatrician, an authority on medicine.

Furthermore, Bourdieu (1986) indicates the transformable feature between different types of capital and especially identified economic capital as the root of other forms of capital. Reay (2001) also suggests, these different types of capital cannot be understood in isolation, through intertwining with each other they construct individuals' advantage and disadvantage in society. In this research, mothers' cultural capital might contribute to professionals' economic and symbolic capital. There can be a close relationship between economic and social capital. In the case of Claire, being a doctor gave her economic capital (not hesitating to hire a lawyer for going to the tribunal), cultural capital (qualified and licensed), social capital (knew how to negotiate with professionals) and symbolic capital (was a legitimated authority with more power). Being a doctor, as Claire suggested, meant she knew and was confident about what she was talking about and that it was not nonsense (or she claimed that she was correct). Owing to the influence of her combined capital, Claire was the most significant example of a mother who benefited from her professional role. It could be argued that it was because Claire possessed more types of capital than others. However, not every mother with similar types of capital gained power like Claire. Claire's example might imply that it was not only about how much capital one had, but also how the various types of capital were weighted by others within the power relationship. For example, being a doctor did occupy the highest social status within the medical hierarchy, so

Claire had more power that allowed her to exercise her capital freely and efficiently. It also suggested the category of 'professional background' could have different social meanings since it is composed by various service providers. Moreover, it also suggested the influences of how others positioned mothers' professional backgrounds. For example, some mothers' professional backgrounds sometimes were not viewed as relevant though they might have various types of capital, like the example illustrated by Lisa (p145). Therefore, how individuals exercise their capital is a dynamic negotiation within interpersonal relationships and is influenced by external social structures that assume and rank the social position individuals occupy.

The respondents' experiences showed that being a mother was not their only identity. Previous research has shown that background aspects such as being middle class might reduce the impact of disability (Vernon and Swain, 2002; Fawcett, 2000); similarly, in the current research the respondents demonstrated that the influence of the capital they possessed by virtue of their roles as professionals was significant and worked in diverse ways. It might help to explain the variations in the mothers' experiences, despite the fact that they all occupied the same category of mother. Mothers with a professional background were aware of a status, power and resources that other parents may not possess (Fox et al., 2009; Klitzman, 2006). As Claire admitted,

> *I am very aware that other people don't, and Robin may well end up having resources that other children also should have, you know, I, I don't, I, you know, that they should all be entitled to the same thing but because I am able to fight harder, Robin may do better which is not…and, I, I have felt guilty about that, but…the doctor in hospital said my duty is to get the best thing I can for Robin. At the end of the day I'm his mother and I should, you know, I have to put that first. But that's difficult.*

Unlike other research, in which it was found that the mothers worried about not doing enough (Prussing et al., 2005; Leiter, 2004; Gottlieb, 2002; Beresford, 1994), the mothers with professional backgrounds who took part in this research did not mention this issue. It is possible that they were confident about what they had done for their children. They 'knew' they had fought as well as they could for their child. They were

aware that they might get better support from the limited resources available because they knew how to access them as a result of their professional backgrounds.

Accordingly, the combination of their understanding of the system and their medical knowledge equipped these mothers with a better chance of getting the results they wanted. This applied not only to needs related to their child's impairment, but their knowledge was used when negotiating with other professionals. This suggests that taking care of their child was not the only difficulty the mothers had, as the social model suggests. This reflects the point highlighted by the other respondents, that apart from knowledge about their child's impairment, they also needed to learn and exercise social skills in order to manage issues related to their child's disability, especially in their interactions with professionals. Furthermore, the differences found in this research between those mothers who did and those who did not have professional backgrounds confirms Clavering's (2007) suggestion that the social inequalities caused by social hierarchies should be highlighted because they can have a negative impact on support for marginal families.

In what ways were their professional backgrounds not helpful?

Although the mothers stated that their professional backgrounds helped, this did not mean these mothers had no problems. They reported various difficulties and nearly all of them agreed that their knowledge was insufficient when handling issues surrounding their disabled child. This section will also illustrate how professional boundaries became barriers even for them.

Limitations of their professional backgrounds

The respondents offered various reasons to explain why their experiences and knowledge were inadequate. Although most of these mothers described themselves as professionals, they did not identify themselves as specialists in their child's disability. Some mothers explained that they did not have direct experience of their child's specific disability. They worked with other kinds of disability or disabled people of different age groups. Hence, their experience could not really help.

Having had direct practical experience of their child's specific disability at a similar age, Libby and Lisa still stated that taking care of their child was much more difficult

than they thought it would be. Libby used all of the skills she had acquired from her twenty-five years' experience as a teacher for children like her son, but she still found it difficult to manage. One of the reasons for this was that they could not simply apply their professional knowledge and skills to their child but needed to modify them. These mothers were aware of the limitations of their general knowledge in the face of the diversity that exists among people sharing the same diagnosis, as Anita illustrated: '*cerebral palsy wasn't, I, I knew of it, I knew what it was, I knew what the causes of it were, and I knew that it affected different people in different ways*'. Moreover, although these mothers were professionals, they were only one of the various kinds of professional their child needed. They still needed support from other professionals. Hence, even though they were specialists, their professional knowledge was not enough. Similar difficulties when interacting with professionals to those reported by those mothers who did not have professional backgrounds were also reported by these mothers.

In addition, maintaining social distance from their clients is viewed as an essential tactic of professionals for ensuring that the boundaries remain intact (Turner, 1995; Williams, 1993); as Weber (1987: 27 cited in Fournier, 2000) states, 'the professional sought to *isolate* in order to control'. As described in the literature review, strategies such as emphasising abstract esoteric knowledge, accreditation, and their autonomy or self-containment are employed by professionals in order to ensure that only the possessors of such things are allowed to occupy the social position of professionals (Fournier, 2000; Turner, 1995; Williams, 1993). Fournier (2000) suggests that professionals not only occupy the field through exclusion, but also make the field a place where professionals' knowledge and interventions are legitimated. Professionals distinguish themselves not only from lay persons but also from other professionals, as Turner (1995: 134) suggests: 'professionalism is a special type of occupational control within the market place rather than merely a list of attributes which define some fixed essence of a particular occupation'. These discussions concerning the boundaries professionals intend to maintain or highlight are useful to explain the difficulties the mothers with professional backgrounds experienced.

Several of the mothers found that their professional backgrounds were not always appreciated or recognised as a positive thing from other professionals' perspectives. In the example of Lisa's negotiations with Boris's head teacher (see p145), the head teacher claimed superior power and status within her own jurisdiction. Lisa had no

standpoint as a physiotherapist and was simply a mother within the scope of the head teacher's jurisdiction. Lisa's professional background was not viewed as valid by education professionals. Her capital was not useful in this case. For service providers, these mothers might be professionals, but they were not in the same discipline as the service providers, in whose eyes they were only 'licensed non-experts' (Prior, 2003: 49). Hence, being a professional did not always give these mothers an advantage because their area of expertise might not be recognised as relevant.

Even for mothers who were members of the same profession as those they were interacting with, in their relationships with professionals they themselves were not in the position of a professional but occupied the social position of mother. From the professionals' perspectives, mothers were just mothers, with or without professional backgrounds. Therefore, it was not about who had more knowledge, it was about who occupied the professional field and who wielded the legitimate power attached to the social position. It was about professionals trying to erect boundaries (Fournier, 2000).

Accordingly, like the other mothers, most of the mothers with professional backgrounds agreed that their job was more complicated than simply taking care of their child (Runswick-Cole, 2007; Todd and Jones, 2003), not because these mothers did not have the same professional knowledge the professionals possessed: it was the social barriers, such as the boundaries established by the professionals and their social position as the mother of a disabled child, that denigrated the expertise of these mothers and made it difficult for them to manage challenges.

Problems related to their professional backgrounds

This part will present two types of problem related to these mothers' professional backgrounds. The first involves their relationships with others; the second concerns their professional frames. Sometimes, their role as a professional was not useful in their families. Anita's explanation based on her medical knowledge was not always accepted by her son because he thought Anita was biased as his mother: '*I did, a long time ago, train in child psychiatry but it's different when it's your own child and I, I think Patrick…to some extent needs an outsider to come in, to discuss things with him because I think that he thinks that I'll just not tell him that he's going to die then, because I don't want to upset him*'. This implies that Anita's role as a health professional had been weakened because of the role boundaries of being a mother. The

knowledge or skills she had acquired from books were not necessarily useful when applied to her son when she was also his mother. Anita provided another example of the limitations of her professional role in her family life:

> *We (my husband and I) were invited to do a course on communicating with disabled children which was very beneficial. When Patrick was younger, particularly for my husband, I think for me it was more of a revision type of thing, but I think it's quite difficult sometimes for me to tell my husband what to do. It's easier if somebody else tells him. Because sometimes if I say something he takes it as a criticism – that I'm telling him he's not doing something the right way whereas in that sort of situation, it was we both went along to learn how to do something more effectively. And he took that on board far better from them than he did from me.*

Outside their families, their professional background could also cause barriers that kept the mothers from accessing informal resources. When interacting with other mothers, mothers with medical backgrounds seemed to be more aware of their professional roles and seldom sought support from or exchanged information with other parents. Milly recalled that at first she always had her '*professional hat*' on when interacting with other parents. After she broke down at a meeting, she started to receive support from other families. Moreover, professional mothers can be stigmatised. Claire was aware that she was often viewed as a doctor by other parents. She once went to a self-help group that discussed a conspiracy theory about the immunisation that doctors were giving and how it might damage children. She found herself targeted because she was seen as a doctor, not a mother, which made her feel very much an outsider, therefore she decided not to go again. Deverell and Sharma (2000) obtained similar findings that for some marginal groups, such as gay people, professionals might be viewed as people who criminalise and pathologise them, so professionals are not welcomed by these groups. In addition, Claire found that it was not a two-way street; she said that as a doctor she was expected to support others but thought that others were not able to support her. The impact of this is that this group of mothers could be isolated from

informal social support networks. This offers an additional explanation for the isolated type of motherhood presented earlier in chapter four.

Moreover, although they might know how to fight efficiently, these mothers reported that they were more likely to be refused when applying for formal support because they had done well, because they were rich, or because they had good family networks. Professional mothers often have their children late and as a result often have better financial security; however, this does not mean they have fewer difficulties, as other people sometimes assume. As Milly illustrated, '*you don't get any help, because you're rich, apparently…because I was 38 before I had Joseph. So, I had, I'm lucky that I had my own home and I don't have a mortgage. So I can live on that money. But if I didn't have my own home, I would be below the poverty line*'. Anita also argued that it was unfair:

> *I'm very much aware of the fact that there are other children out there whose family get a lot more support than we do… if I was a single parent and less financially secure and didn't look after the children very well, that there would be so much more support coming in, but because we try our hardest every day people just think that you're coping.*

No matter how well their families functioned or how many resources the family had, help was still appreciated. After Claire had demonstrated her good parenting skills and shown what a nice family unit they made, the social worker decided that they were doing so well, they did not need any help. However, Claire argued that they would not do as well if the support (respite care) were taken away. Her reaction to losing their respite care is a good example of how a happy family can be influenced and sent '*tumbling down*'. She recalled that one night she could not sleep and got up to write a letter on the computer, like the '*ramblings of a, some demented, mad woman, a complete lunatic*'. The way she described herself that night was completely different from the way she normally saw herself: well-educated, always planning and managing things in a scientific way. This reminds us of the discussion on dependence in chapter four. A family may be unable to function well when taking care of their child becomes the responsibility of the family alone, even a family like Claire's that was assumed to have more resources than others.

It was not easy for some of the mothers with professional backgrounds to admit their limitations in front of others and ask for help. Three mothers with health professional backgrounds described their efforts to hide their feelings about having a disabled child from people outside their families. This kind of experience is not unusual for mothers with a disabled child, but the mothers with professional backgrounds in this research seemed to have more issues with presenting or pretending they were coping well. One of the possible reasons for this is that because they were professionals they were expected to be able to handle things better, either by others or by themselves. The higher in their hierarchy they were, the more they were believed and assumed to have resources they might not actually have.

It was only when mothers like Milly and Claire took off their professional hat, or their make-up, or abandoned their professional identities and allowed their weaknesses or deficiencies to show, that they were able to get support, and they resented having to do this. Rather than being independent and autonomous professionals, these mothers had to admit they were not coping and needed help, and this could put them in a weak position within their relationship with other professionals. It might explain why the mothers with professional backgrounds employed their knowledge and social capital in order to regain some sense of control but still felt disempowered and frustrated, as Wendy expressed: '*you do have to spend a lot of your time relying on others*'.

This frustration could have been exacerbated by the mothers' transformation from being autonomous service providers who judged, made decisions, assessed and gave instructions, to being mothers who had to depend on the decisions of others and who now themselves were being judged, assessed and expected to comply, a dynamic other research has revealed (Fox et al., 2009; Friedson, 2008; Kay et al., 2008; Klitzman, 2006; Fournier, 2000). In other words, simply because they were occupying the weak social position of being mothers, these women lost the autonomy and power they possessed in their positions as professionals. These mothers' experiences provided further evidence of the unbalanced power relationship between mothers and professionals.

In addition, for some of these mothers, the frame they adopted as a professional could become problematic. Two mothers with health professional backgrounds appeared to be located at the opposite ends of a broad spectrum in terms of their acceptance of their child's disability. Lisa, a physiotherapist, accepted her son without any reservations, noting, '*when he was first born, I would say, um, we (my husband and I) both felt*

absolutely fine about it. I don't think either of us went through any grieving process in the way that I think other parents do. Um, probably because we both had experience of knowing people with Down's syndrome'.

On the other hand, Milly was located at the opposite end of the spectrum. She used to be an occupational therapist and chose several negative phrases to describe her son and her life, including *'permanently grieving'*, *'got penalised'*, and *'devastation'*; she stated, *'I'm very honest. I say to my friends, my friends know it, I know it, I hate it. If I could, if I could flick a switch, I would make Joseph normal… it's a very hard life to be disabled. It's a very hard life. And it's a life sentence for me as well'*.

Milly's health professional background could be one of the most influential factors that contributed to this perspective. According to Milly, since she got the diagnosis, she had never been free of worry. She used the phrase *'ignorance is bliss'* to illustrate the difference between her and other mothers: *'if you don't know something you're better off because you don't know it anyway. It's better not to know. In fact I find some of the mothers are in this situation. Because they don't want more… Sometimes they just kind of blinker their eyes and don't think to the future… I worry about the future'*. This suggests that, being a medical professional, Milly identified herself as knowing things that allowed her to 'know' or predict the future better than other mothers (Ingstad and Christie, 2001). However, there is a risk in having this knowledge. The findings of Ingstad and Christie's (2001: 201) research into doctors being ill suggest that 'while a patient is more or less free to construct his/her own explanatory model or particular *illness* experience, a doctor is bound by the knowledge of *disease'*. In other words, the knowledge professionals possess not only enables but also restrains how they make sense of what they encounter. This echoes the discussions in chapter four and five about mothers' struggles with professionals about their restricted focus on deficits caused by impairments rather than leaving space for their child's potential and mothers' hope.

Milly seemed to frame things in a negative way that focused on deficiencies, which is one of the reasons why the medical perspective has been criticised. Milly identified Joseph's disability as the cause of her subsequent difficulties, such as her divorce and the end of her career. When she nearly had a breakdown, she went to the doctor and had some counselling. She commented *'there's nothing going to get better, because Joseph isn't going to get better'*. In this context, her profession was no help because it could not make Joseph better; it could not make the impairment disappear.

While other mothers challenged health professionals when they set limitations for their disabled child, Milly frequently used expressions like 'never', 'could not' to describe her son: for instance, '*I will never be free of the worry about Joseph. Cause he'll never grow up, you know. He'll never be able to look after his own money, he'll never be able to…he'll never be able to live on his own. He'll always need somebody to look after him*'. Although Joseph had multiple disabilities, he had proved the medical prognoses wrong and was able to see, walk, talk, write, was lovely, and planned to get married to his girl friend; however, Milly still adopted a quite negative perspective on Joseph's development. She explained, '*I always felt that it was sad because of each milestone…when he did take a few steps, or when he did, I was, I wasn't proud, I was relieved. Cause I felt 'oh thank God for that'. You know, cause I thought, you know, he was never going to*'. Milly's accounts illustrate how individuals can be influenced by the prevailing discourses, and how the medical perspective can have a negative effect on how people understand impairment. However, it also points out that the impact of impairment is significant and can never be ignored from mothers' perspective, a position that is different from what the social model suggests.

Claire's medical knowledge also did not help her easily to accept her son's autism. After getting the diagnosis, Claire recalled, '*I think I was just crying every day for weeks afterwards, I can just remember thinking I've never ever thought of autism and now it's my life, every day, probably for the rest of my life*'. As Ingstad and Christie's (2001: 20) discussion about doctors who become patients states, 'what previously took place outside the body as part of a professional career has now become part of one's own body - it has been embodied'. The distance Claire used to maintain between herself and illness had been taken away.

In addition to influencing their acceptance of their child's impairment, mothers with health backgrounds tended to use their medical knowledge as an important frame when making sense of, interpreting and dealing with other issues surrounding disability. When Anita's son with CP asked about his friends' illnesses, or when her son was aware of his own disability, her answers were always based on medical knowledge and fact. Various medical terms and explanations were also adopted to describe and interpret their situation, her son's needs and her own feelings during the interview.

The experiences referred to above show that how and what professionals understand can be profoundly influenced by how they have been trained. After becoming a mother with a disabled child, the respondents started to realise the limitations of their

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knowledge and started to reconsider the frames they had been trained to use. For example, at first Lisa had derived her expectations regarding her son's development from the medical prognosis, which was based on existing medical knowledge about Down's syndrome, and from research articles she had read. She explained how she modified her expectation, '*I suppose it's a constant re-adjustment, expecting him to be like other children with Down's syndrome of his age and then finding he's not and then realising we, we're expecting too much, you know. If we keep going at his pace rather than, that's, I think that's been quite important for us to do*'. When generalised knowledge could not provide suitable guidance, other types of information became important references for mothers to access for their situation in order to develop their tactics and goals.

As Landsman (2005) suggests, mothers may encounter the medical model first and then the social model later. Social barriers were recognised by all the respondents within this group. For example, Lisa used the phrase '*let down by the system*' to describe the situation of disabled children. Therefore, as well as the medical aspects, social barriers were also taken into account by the mothers with medical backgrounds.

In contrast, Wendy, who was a manager in further education who supported disabled students in a college, also pointed out that some aspects of her professional training had caused her to overlook the overall impact of impairment. She explained,

> *I think you kind of see the disability straight away as a separate thing,*
> *and we've, you know, as professionals you're told to see people as an*
> *individual and not to, not to sort of view them as a disability with a*
> *person sort of attached and all of this, but I don't think you really,*
> *fully appreciate how intertwined everything is and you can't separate*
> *the disability from the individual because the disability affects how*
> *you are as a human being in every way because it affects how you can*
> *access things, it affects how you can interact with things, it affects*
> *how you see things and your perception of how you're seen by other*
> *people and, oh, it's just impossible to detach the two things and I think*
> *the, my empathy levels for other parents obviously have increased*
> *massively.*

It is probably the social model, which tends to sideline the impact of impairment, which influenced the professional frame through which Wendy had learned to view disability. It is generally accepted that this is a politically motivated strategy designed to emphasise the barriers facing disabled people that are caused by inadequate social arrangements (Thomas, 2008; Shakespeare, 2006; Hughes and Paterson, 1997). However, Wendy's reflection shows a risk that non-disabled service providers might not be able to meet disabled people's needs owing to their incomplete comprehension of disability that ignores the impact of impairment, an important part of disabled people's lives as highlighted by Shakespeare (2006) and Crow (1996). Although the social model reverses the causal relationships of impairment and disability proposed by medicine and argues it is the social barriers that disable disabled people, it has been criticised for becoming another master narrative. For disabled people, since the social model mainly concentrates on a specific area of the difficulties disabled people face, mainly the social barriers, there is a gap between it and the real lives of disabled people, as discussed in chapter two. For non-disabled people, as Wendy's notion suggested, the over emphasis on inappropriate social arrangements leaves the impact of impairment aside; this can be another form of distortion that leads to misunderstanding and can not help others to know disabled people's real lives better. It does also lead to insensitive services, a concern raised by Connors and Stalker (2007). They argue that 'inclusive policies' that do not acknowledge differences but place an emphasis on being 'the same' can be dangerous; this is because the rules and procedures are designed for the majority and may not suit the minority or take disabled children's special needs into consideration.

Unlike those mothers who did not have professional backgrounds, who began from their individual subjective understanding of disability through taking care of their child, and who only later acquired more general knowledge about disability, these mothers started from a general understanding of disability learned from their work, and then examined the knowledge they had acquired from their daily lives. Although influenced by their professional medical frame (for example, a speech therapist may concentrate on the speech aspect rather than seeing her child as a whole), these respondents did not view their child's impairment through this frame alone, but valued their child as a unique, complete individual. The respondents also realised that theoretical abstract knowledge was not the 'only' or always useful guideline because it might not be

applicable to their children. They found that professional knowledge and academic discussions could not provide them with correct answers or direct solutions but only with a general comprehension of their child's impairment; hence they became a reference point only. Instead, their understanding of their child's needs, personality and personal history were chosen by the respondents as the most important considerations when managing challenges.

In addition, the respondents also showed the danger of attempting to understand mothers from only one perspective, such as categorising their experiences within the discourse of personal tragedy when they expressed their sorrow. The reality was much more complicated. Although Milly seemed to be profoundly influenced by the medical perspective, she still had a close bond with her son. She enjoyed being Joseph's mother and possessed a '*tempered proudness*', as in the 'paradox' suggested by Larson (1998) and Landsman (1998). She did not ignore the barriers presented by the outside world and believed that the prejudices against disability were other people's problems, and not disabled people's fault. She fought for Joseph's rights and helped other parents to fight for their children. She argued that it was the services that created '*difficult parents*'. The mothers' comprehension of disability was constantly changing, and their approaches could be viewed, as Ryan (2008:738) suggests, as 'a hybrid of social and medical models'.

The transformation of their social position from that of a professional to that of a mother enabled these mothers to reconstitute their knowledge and resist or question the social forces around them from both social positions. Instead of sticking to a single professional frame as they had previously, the mothers became more open-minded. Their recognition of the shortfalls in their knowledge made space for other types of knowledge, such as their personal reflections and other parents' experiences. They began to search the available discourses and modified the framework through which they viewed disability through their experiences of raising their disabled child as a mother. They also started to learn a new language, culture and strategies to manage issues surrounding disability. As Hahn (1995: 257, cited in Ingstad and Christie, 2001: 202) suggests, when the boundary between patients and professionals becomes blurred, mothers might negotiate between 'two cultures, two languages, two societies'. However, this integration is not always a smooth process; the balance can shift over time and the two aspects can sometimes conflict.

It may thus be concluded that, although the mothers discussed so far in this chapter benefited from their professional backgrounds, these backgrounds did not help them to manage every difficulty in their lives. The mothers' professional backgrounds not only gave them certain advantages, but could also have a negative impact on their relationships with others, on the support they could get and on how they made sense of disability. Their new social position as mothers made their professional background invisible or irrelevant. Their experiences of losing their autonomous and independent status on assuming the social position of a mother also provide additional evidence of the unbalanced relationship between mothers and professionals. Moreover, their recognition of the fact that they possessed capital that others might not have highlighted the social inequalities and the diversity among mothers. Gradually, these mothers learned to be more flexible when choosing their strategies. They chose how to present themselves to suit the particular time and place. Sometimes, they made use of their professional role; sometimes they chose to stay in the maternal role.

Although their professional backgrounds were useful that enabled them to have a better idea about the service system, understand the medical facts of the impairment, negotiate with service providers, resist or fight certain barriers, and be more confident, these mothers did not show significant differences with relation to other issues discussed in previous chapters. These mothers experienced similar problems to the other mothers related to their interaction with family members, friends and unknown others. Like other mothers, the segregation from their existing social network was also experienced. Since these mothers with professional backgrounds reported receiving less formal and informal support as presented in previous sections of this chapter, rather than useful, their professional backgrounds might instead contribute to their isolation.

When managing issues around disability, these mothers were enabled and restricted by their professional knowledge and roles that influenced how they interacted with others. Apart from some of their negotiations with professionals as presented in earlier sections, mothers did not really benefit from their professional background when interacting with their family members, as Anita illustrated previously (p177-178). Moreover, mothers' backgrounds were also invisible when they were interacting with unknown others; as Ryan (2008) suggests, the past and future of a particular individual is not taken into consideration by unknown people in public places: instead, people judge solely on the basis of what is happening in the present. One of the possible reasons for this is that being a professional was only one role in their lives that had a limited influence on the

other parts of their lives. This is also indicative of the complicated nature of people's lives that cannot be simply reduced to a collection of medical problems, and that the problems people encounter cannot be solved purely by means of the knowledge and skills offered by professionals.

Reflecting on mothers' careers

This section will demonstrate how these mothers' experiences of raising a disabled child had affected their careers and their professional practice. I will argue that mothers' expertise and professional knowledge are not incompatible. Instead, disabled children can benefit from the interaction and cooperation between their mothers and professionals.

The way professionals should be?

In this section, the mothers' experiences and reflections on being at the same time a professional and a mother with a disabled child are used to examine some of the assumptions concerning professionals and the relationship between professionals and mothers. A corpus of research that investigated the experiences of doctors who had become patients will be used as a reference, since these doctors had crossed the boundary between being a doctor and a patient.

The mothers were impressed by the knowledge they had acquired from raising their child. As Anita indicated, you cannot have this knowledge '*until you actually live with somebody with something like that. Nothing really can prepare you for that*'. Klitzman's (2006: 452) research into doctors who became patients also found that 'illness taught them what books failed to'. No longer concentrating solely on what they had learned from books, these doctors started to gain insights from their experiences as a patient. In my research, most mothers reported that their experiences of raising their disabled child had made an impact on their work and most of them stated that they had a better comprehension of experiences related to disability. Having had sixteen years' experience of working with people with learning difficulties, Wendy said,

I don't think you can ever fully appreciate how it affects you as a family until, um, it happens to you really. I think you, as a professional, I used to think I was really in tune with what was happening in people's lives and what was happening in their families and I think I used to think 'oh I know it all, I know it all', but you just don't know the start of it, as a professional you really don't know how it affects people's energy levels, you don't know how it affects their self-esteem, you don't know how it affects their sort of general well-being, you don't know their health and, um, ability to sort of cope with, um, stress and pressure, and things, and how people are going to react in different situations because you don't really fully appreciate how invasive it is, into every part of your life.

Mackenzie and Scully (2007: 335) argue that the risk involved in imagining others' situations or 'putting ourselves in the place of others' is that we may simply project our own perspective onto theirs, or further miss the opportunity of engaging with others on the basis of both the similarities and differences between us. As Mackenzie and Scully (2007) suggest, 'being/having a specific form of embodiment places real constraints on our capacities both to imagine ourselves otherwise and to imaginatively put ourselves in the place of others', when disability was embodied in Wendy's daily life, she started to learn the situated knowledge attached to the unique social position occupied by a mother. Rather than singling out impairment as an isolated thing, the impact of impairment was located within contexts, within daily lives. It was not only a biological deficit, but could affect various aspects of life practically and influence an individual's self-esteem and well-being. Lisa, a physiotherapist, no longer only focused on those goals her clients did not achieve but put their motherhood in the contexts she now had more comprehension of due to her experiences of being a mother with a disabled child. She reflected,

I think I've learnt an enormous amount from having Boris, which has benefited my work. Because I'm just much more realistic. Um, I think I probably used to judge people in, you know, if, if, particularly I think where mothers are, maybe give in to their children a lot more, um,

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and you'd want the mothers to be firmer, and I, I'm as guilty of that as anybody. Because I'm a mother and I can see that now and I don't feel like I judge people. You know, I think you listen to your child as opposed to thinking, and, you know, sometimes it's, it's a weakness, not being able to be firmer, or whatever but I, I think I'm less hard on myself now that, and less hard on other people, from that point of view.

In line with the findings of other research (Leiter, 2004; Gottlieb, 2002), some mothers in this research complained that their circumstances and responsibilities in their daily lives, such as taking care of another child, were not taken into account by professionals, as Angel argued: '*can you tell me when I should be doing this and how I fit everything else in?*' The mothers with professional backgrounds had come to recognise the diversity of their clients' circumstances that they used to neglect. Libby, who used to be a teacher of children with special needs, reflected that she now understood how much effort needed to be made before parents used the services they provided as reflected by Cole (2005). The small things that professionals ignored might be the essential factors that had an impact on mothers' decisions. After having Boris, Lisa became aware of the conflict between families' diverse situations and the narrow focus of the professionals' specialised fields that only concentrated on children's development. Hence she stated, '*I like to be holistic. I don't like to think, well, I'm just concerned with this part of the child and the family and nothing else*'.

Some mothers, like Lisa, further examined the differences between what they were trained to think of as 'correct' approaches and what they knew in reality as a mother with a disabled child. As a professional, Lisa knew what was 'right' based on her professional knowledge. However, what was right according to professional definitions was not necessarily 'suitable' for mothers and their children. Shifting from the professional's perspective that demanded that mothers be firmer and not give in to their children, Lisa now understood why mothers did not always do what they were expected to do. The strategy that focused on developmental goals was called into question; instead, their clients' priorities in life were acknowledged. For example, as a mother, Lisa realised the importance of listening to and respecting her child's perspective. She explained,

> *Their child is a human being who's got their likes and dislikes and*
> *their home-life and things they want to do and that we need to develop*
> *their confidence more than anything and enjoying those things rather*
> *than spending our time being therapists and educators and all of those*
> *things, I suppose… I think probably parents do that, and it's*
> *professionals who need to learn that really. That life's not all about*
> *improving, and perfecting.*

When Angel came to feel that giving her daughter a cuddle was waste of time, she realised how the focus on rehabilitation could erode her relationship with her daughter, and hence decided to change her priority. Thus, both the subjectivity and will of the disabled child and the relationships between the mothers and their children were accorded more weight and importance than meeting the professionals' expectations. Lisa' reflections concerning being more realistic, respecting more of the diversity and the weakness of humanity, and allowing more flexibility for others and herself when working were echoed by other mothers with professional backgrounds in this research.

As a result, having learned from their own experiences of recasting the priorities in their family life and their circumstances, and from the contexts in which they were embedded, the mothers began to respect their clients' choices more. Most of the respondents claimed they were less judgemental in their jobs. This reflection echoes Leiter's (2000: 843) call for the adoption of a 'family choices' philosophy that would 'allow mothers to decide what kind of role they wanted to play in their children's therapeutic care, rather than having professionals impose norms upon them'.

The mothers who participated in this research had recognised their ignorance before becoming the mother of a disabled child. This was not necessarily their personal fault, since the perspectives of mothers with disabled children are normally absent, not valued in professional training and work, and located in the private domain. One of the factors highlighted by the mothers' experiences was the professionals' efforts to distinguish themselves from lay persons in order to maintain boundaries (Williams, 1993; Deverell and Sharma, 2000; Fourier, 2000). Rather than being included, the experiences of the mothers with professional backgrounds demonstrate how their perspectives were excluded when these boundaries were emphasised in their relationships with

professionals, in the same way as those of the mothers who did not have professional backgrounds.

Apart from the professional boundaries, scholars have suggested another reason why these mothers' practical expertise is not respected, namely, the influence of gender (McLaughlin and Goodley, 2008; Callery, 1997). Skeggs's (1997) research into why and how women in the North-west of England learned to understand and position themselves through the caring courses at a local further education college suggests that women's caring role is a socially, culturally and economically constructed historical legacy that is influenced by gender and class. Rather than being viewed as experts, women, especially those who are also working class, who take care of others might be viewed as morally dangerous, needing to be guided and regulated, especially by professionals (Skeggs, 1997; Hays, 1996). After becoming mothers, the respondents in this study recognised that the understanding acquired from being a mother was normally regarded as a personal, emotional, subjective, private and practical and less important than objective and rational professional knowledge, - the core of the professionals' claim to authority: abstract, public and scientific and legitimate. Other writers have also highlighted how different forms of knowledge and expertise are placed within professional hierarchies (McLaughlin, 2003; Lowton, 2001; Fournier, 2000; Callery, 1997; Turner, 1995). Even caring professions like nursing are easily viewed as an extension of a woman's 'innate female nurturing qualities' because they sometimes involve emotion management, therefore occupying a lower level in the professional hierarchy (Bolton, 2000: 220). However, gradually, the mothers with professional backgrounds questioned the distinction between the two types of knowledge.

As Fournier (2000: 71) indicates, 'at the core of the professional project is the constitution of disciplinary knowledge representing or mirroring a "naturally" isolated and self-contained reference object in the world'. However, when contexts, circumstances and priorities were considered, the claim that knowledge could be fixed, isolated and pure, and that reality could be objectively reflected from their professional knowledge was viewed as less reasonable by the respondents. Instead, the respondents realised that their reality was multiple, diverse, negotiable, changing and highly complex (Fawcett, 2000; Mann, 2000), so they learned to allow space for discontinuity, uncertainty and ambivalence that in turn allowed for more possibilities as McLaughlin and Goodley (2008) suggest.

Additionally, the mothers also reconsidered the boundaries between professionals and their clients that required detachment from personal feelings. Professionals are required to be detached from personal values and opinions so that they can remain rational and avoid bias, as McLaughlin (2003: 286) indicates: 'group and individual professional identity is closely linked to an apparently clear and fixed boundary between the professional and personal self; to act professionally is to act rationally with no reference to personal feelings or connections'. For instance, the perspective of a qualified doctor in Callery's (1997) research was discounted because her position as a mother was assumed to undermine her claims to being objective and detached. Although issues such as partnership, empathy sensitivity and respect for clients' choices are now given more emphasis in both professional discourse and policy guidelines, professionals still insist that losing the boundaries between professionals and others may damage the professionals' focus on the public good and their altruism (Fournier, 2000). However, the mothers in this research had different experiences regarding the risk of crossing the boundaries. Here, I will use the issue of self-disclosure as an example to examine the assumptions that knowledge should be objective and that the relationship between mothers and professionals should be detached or their clients' interests will be damaged.

Self-disclosure remains a problematic ethical issue in professional practice (Fox et al., 2009; Malterud et al., 2009). The strategy of self-disclosure is normally questioned on the grounds of its potential cost, such as abusing patients' trust or distracting from the focus on patients (Fox et al., 2009). Generally, self-disclosure is not recommended among professionals; instead, detachment is valued in order to ensure neutrality and objectivity. For example, a doctor in Ingstad and Christie's (2001) research decided to stop opening up and to be more 'professional' after criticisms by her colleagues, even though her clients had responded positively when she shared her experiences of being a patient. Self-disclosure is only viewed as appropriate when contextual factors have been carefully examined and when it could add value to the consultation (Fox et al., 2009). The experiences of the mothers in the current study demonstrate what it means to 'add value'.

Most of the respondents in this research did not conceal their roles as mothers. Known as mothers of disabled children, they found that they were given more credit by other parents of disabled children. Although an assistant to physiotherapists, occupational therapists and speech and language therapists does not have great power or authority within the medical hierarchy, Debbie stated that parents tended to give more weight to

her opinions and listened to her more. She suggested this was because she was one of them: '*all the children that I work with, their parents all know I have a child with special needs, and I see, I don't know whether it's just me, sort of seeing things that aren't there, but certainly I think they're more likely to listen to me*'. Being an insider enabled Debbie to pick up on things that outsiders would not notice, this finding confirms the findings of other research concerning the privilege of insiders to access marginalised groups (Almack, 2008; French, 1988). As the outreach workers in Deverell and Sharma's (2000: 28) research note, 'being gay is our expertise'. These insiders do not have to practise feeling sympathy artificially, they did not have to put themselves in others' shoes, because they are 'in the same boat' (Malterud et al., 2009: 86).

Several mothers claimed they felt empathy with other parents. As Wendy put it, '*Since I've had Sam and I can tell them that I'm a parent of a disabled child myself and then you've got that bond and the empathy and all of that*'. Moreover, this increased empathy contributed to the mothers' commitment to their work. Understanding parents' struggles, they worked harder than before. As Wendy explained, '*when you're reacting to other people who've got disabilities, realising their potential, and, thinking that would be my son, you know, and, would I want him to be treated like that? Would I want him to have you know that barrier put in his way, and, and makes you more conscientious I think, you do try harder*'. Hence, her emotional involvement did not harm Wendy's clients but may have benefited them, as a result of the bonded relationship built between Wendy and her clients and of her commitment.

Instead of using a rigid approach that demanded their clients' compliance or engaging in a one-way process of transmission of knowledge from a professional to a lay person (Williams, 1993), the respondents allowed more interactions between their clients and themselves. A more open-minded approach to communication was adopted by several mothers. For example, Mary acknowledged that her experiences of trying to communicate with her daughter made her a better teacher who was more patient, was better at picking up non-verbal communication, and was willing to try different ways to communicate with her students. These changes reflect findings of previous research: that doctors who have been patients themselves give their patients more opportunities to ask questions, supply more information, and listen to their patients' opinions more (Fox et al., 2009; Klitzman, 2006). Klein and McCabe (2007) found that listening and sharing experiences is beneficial to both professional mothers and their clients. Moreover, by

adopting a more realistic, practical or non-judgemental attitude, the mothers could establish a more equal or reciprocal relationship with their clients, as other research has revealed (Klein and McCabe, 2007; French, 1988).

Unlike the objective and neutral actors that professionals claim to be, Malterud et al. (2009) instead suggests patients might prefer a sympathetic doctor who is not afraid to apologise for his/her faults. Malterud and Hollnagel (2005, cited in Malterud et al., 2009) further suggest that 'a better balance between emotions and rationality can prevent humiliations in the consultation'. That a professional is still only a human being was a well known fact for the mothers in the current research, even though professionals are concealed behind boundaries and are not keen to admit this. The mothers found that the emotional, subjective, practical element did not damage their professional status. Instead, the knowledge they acquired from being an insider enabled them to be better professionals. I am not suggesting that only insiders can provide better support for their clients, rather I would like to propose that if professionals can be more flexible about what they 'should' be, they may be able to see things outside their professional frames; this could contribute to their understanding of their clients' needs and enable them to offer appropriate solutions that suit their clients' circumstances.

Boundaries between mothers and professionals

The mothers' responses demonstrate that it was not always advantageous to cross the boundary between their role as a professional and their role as a mother, and reveal why it was sometimes essential to maintain these boundaries. The respondents found that integrating their experiences as a mother with a disabled child into their careers could also create problems. Lisa found herself no longer only belonging to the professionals' group but wanting to stand alongside her patients.

> *I got very, very stressed. And I think my biggest stress is what to do*
> *with being in very similar situations that I have been in, but with my*
> *patients. So I would maybe be in a meeting around a table with lots of,*
> *with some very…prejudiced schools or people in education, and with*
> *a parent who I felt I understood where they were coming from, and I*
> *used to feel very angry, and I think I felt more angry than I would*

have done if I didn't have Boris… And I had to sort of take a bit of a
back seat in that. Because, knowing that I'm just a physiotherapist
and I can't solve everything, and everybody's problems…I think I
have to, you know, not get too actively involved, cause it used to stop
me sleeping…and put myself in the role of that parent and get, just get
very emotionally affected by it. So, from that point of view, it's not
always been a positive thing but I think I'm learning to separate the
two more.

Lisa's account illustrates how social positions can influence individual perspectives. Instead of seeing things from the service provider's perspective alone, Lisa now also looked from the parents' perspective. She felt angry because it was not just a case, but a family she understood and empathised with. Although professionals assert that they employ ethical codes and the requirement of detachment in order to reduce such problems, in reality it does not always work like this, as the professionals' prejudices Lisa observed in the meeting.

Because of the emotional effect on her, Lisa found she needed to find a balance between her role of a professional and that of a mother. As insiders, the outreach workers in Deverell and Sharma's (2000) research also find it important for them to maintain a professional boundary in their relationships with their clients, other professionals and their personal life. However, for mothers in this research, it was not about trying to maintain the authority of being a professional as Fournier (2000) indicates, but because of conflicts that arose when the two roles overlapped. It also was not that Lisa's clients' interests were affected, as professionals assume will happen when the boundaries between professionals and their clients are blurred, but that her personal standpoint was influenced.

Another reason to maintain the boundary between their role as a mother and their role as a professional was that the respondents believed their child could benefit from such a boundary. Although the mothers described themselves as professionals, most of them did not emphasise their professional backgrounds when interacting with other professionals, with the exception of Claire. Apart from the fact that these mothers did not view themselves as specialists in their child's impairment, another reason for this was they did not want to be viewed as professionals but to stay in their role as mothers,

this was what their child needed. The question Jaye and Wilson (2003: 213) put forward regarding 'where the collegial relationship ended and the consultation began' was also an issue for these mothers. When interacting with other professionals, some of the respondents preferred to be treated as clients, not colleagues, as Ingstad and Christie (2001) also found in their research. For example, knowing Lisa was a physiotherapist, her son's portage teacher talked to her about the problems of the education system, but Lisa said, '*I didn't want to hear that, I just wanted her to focus on Boris as my son and give me some advice on what to do with him rather than telling me her problems*'.

The different types of knowledge professionals and mothers posses are normally viewed as significant elements that construct the boundary between professionals and mothers. Professionals call into question the expertise of lay persons on the grounds that this expertise has been derived from their personal experience and thus must be partial and limited (Prior, 2003). However, objective, generalisable knowledge was not what these mothers were seeking, firmly believing this to be the realm of the professionals. They expected the professionals to provide the knowledge and advise them on what to do. What they themselves were interested in was how to care for their own particular child. Moreover, the mothers knew their knowledge was partial and restricted. They knew they could not meet their child's needs by themselves, so they needed the help of other professionals to ensure their child's welfare like parents in Fitzgerald's (2008) research also found. What the respondents asked was that they be allowed to participate and contribute their incomparable expertise gained from looking after their child, a unique individual. Wendy stated,

> *Look, we understand it's difficult for you, we understand you've got limited budgets and we understand that, you know, if you order something we've got to wait for it, that's all well and good, but what we're looking for is, for them to appreciate that we know Sam, and we know what he needs, and we're not stupid. We're not you know, imagining things you know, we do know what he needs cause we're with him, and, you know we know if the chair's not supporting him properly, and we know if something's uncomfortable, and it's hurting him, and we know there are lots of things we don't know.*

The respondents were aware of the boundaries between professionals and them. Like professionals, they recognised the different types of knowledge they possessed. The boundary was viewed by the respondents as essential so that both professionals and mothers could play the role their child needed. However, what mothers further highlighted was the cooperation between professionals and mothers. According to these respondents' reflections, the understanding they had obtained of their child's disability from books and work experiences were not enough, even though they were senior professionals themselves. Instead they acknowledged the significance of the knowledge they had acquired as mothers. They highlighted the importance of listening to and working with mothers. They argued that if their perspective, derived from taking care of their child, was neglected, their child's needs could not be fully considered. If professionals could not really understand the difficulties and problems mothers and their disabled children encountered, these professionals would never be able to provide suitable support or give them any useful advice.

The transformation of mothers' careers: Calling

Having a disabled child has been described as a form of what Bury (1982) calls 'biographical disruption'. The experiences of raising their disabled child had greatly influenced some mothers' professional career directions in two ways. First, previous research has found that mothers tend to give up their jobs or choose a flexible part-time job to suit their care responsibility (Clavering, 2007; McKeever and Miller, 2004; Taanila et al., 2002; Dowling and Dolan, 2001), and many of the respondents in this study also reported that their responsibility for taking care of their disabled child had had a negative impact on their careers. Traustadóttir (1991) suggests that the inequality between the salaries of women and men forces disabled children's mothers, rather than their fathers, to change their style of work. Other researchers, on the other hand, suggest it is a result of the gendered norms that assume women should take the responsibility for care (Chodorow, 1978). Hence disability may restrict a mother to a more traditional gendered caring role regardless of her educational and financial background as previous research suggests (Leiter et al., 2004; Gray, 2003).

However, among the sixteen mothers interviewed for this study, four of those who had professional backgrounds (Mary, Claire, Lisa and Debbie) claimed that they had a more equal partnership in parenting. For example, Mary stated that, '*me and Adam…have a*

very much, an equal partnership in bringing up both the kids. So it's not necessarily about my motherhood or his fatherhood. We tend to work as a unit anyway'. One similarity among these four mothers was that their husbands were also service providers for disabled people and their families (see Appendix 6-1). These fathers with professional backgrounds were described by their wives as having a good understanding of their child's impairment and as always being involved in parenting. Although O'Brien (2007) suggests that fathers tend to give more 'help' to their partners/wives when the mothers are the main carers of their disabled children, however, of the sixteen mothers who took part in this research only these four stressed their husbands' involvement and support. O'Brien's (2007) other suggestion that white middle class fathers may participate more in parenting since they have more capital might be useful to explain these professional families' parenting style. This could also be seen as another example of the positive influence of 'the wise' proposed by Goffman (1968): since these fathers were members of this group, they were able to share in more of the parenting duties.

As their trajectories and life plans gradually lost importance in their minds or became less and less possible to pursue, the parents in McLaughlin and Goodley's (2008) research found that they were released from the normal narratives of the 'good family', and that the way they were beginning to develop as a result opened up possibilities and opportunities they had never thought of before. They also reassessed values that had been taken for granted and tried to find new patterns of family life. In this part, I will illustrate how these new patterns relate to disability, the second type of career changing, which is less discussed in research into mothers' experiences.

Klein and McCabe's (2007) research into mothers working in the field of early intervention after having children with disabilities in Florida, America, is a rare piece of research that focuses on this topic in disability studies. These mothers were employed in the organisation solely because of their expertise as mothers. They used the term 'calling' to describe this career, which has had an impact on their identity, satisfaction and confidence. They stated that this career had changed their whole outlook and had made having a disabled child meaningful and purposeful because they had become useful and had something to give instead of only receiving. They also started to benefit from being professionals, as the first section of this chapter suggests. They reported having more equal relationships with other professionals, having the knowledge necessary to access resources, having social capital to make use of, and having a better

sense of control. Ryan and Runswick-Cole's (2009) research based in the U.K. also found that a few mothers in their research changed their career paths and also became involved in services for disabled children, which is similar to the findings of this research.

In this research, the mothers not only tried to integrate their role as a mother of a disabled child into their existing roles, some of them also decided to pursue a new career based on their experiences of being a mother. Many of the mothers in this research moved to jobs which had closer or more direct links with disability. For example, Debbie, who had previously been a residential childcare officer, now worked as an assistant to physiotherapists, occupational therapists and speech and language therapists. Angel no longer worked for the elderly, but in a playgroup recommended for disabled children. Lily had given up her PhD studies in pharmaceutical science and was hoping to do bio-medical science research into autism in the future. Lily also worked with other parents and was trying to set up an organisation for other parents. Mary was grateful to have this opportunity to contribute her abilities and support to other parents of disabled children. She used to be an accounting teacher and taught tourism; one of the courses she ran examined accessibility for students with learning disabilities in a college. Now she ran courses for disabled children's parents. Her husband was a manager of a charity for carers. She explained,

> *If Siobhan hadn't been born, we (my husband and I) wouldn't have been in the same work, so it's strange. I like it because…I'm helping other families and other people. It fits in with my political beliefs and values and things like that. And it means I can I suppose use some of those to good effect…I like what I do…it gives you a lot of satisfaction.*

Sherry and Suzy went on to do a course in counselling after having their disabled children and planned to work for disabled people and their families. The reason they chose this career was profoundly influenced by their experiences and role as a mother with a disabled child. They were keen to use their insider knowledge that was strengthened or authorised by their positions as service providers in helping other parents to get the sort of support they themselves had not had, a desire found amongst

parents in Ryan and Runswick-Cole's (2009) research. Sherry explained, '*My aim when I started was to help other parents…to help them understand themselves, cause that's what I needed*'. The commitment they showed was strong and they intended to make the experience they had gained from mothering their disabled child more valuable. They not only promoted their child's benefit, but also endeavoured to enhance the welfare of other disabled children and their families.

Conclusion

Normally, mothers with a disabled child and professionals are viewed as being in separate or even competitive categories. The experiences of the mothers examined in this chapter bridged the perspectives of these two groups and provided valuable insights based on both of their social positions. The transformation from professional to mother led these mothers to become aware of the limitations of their previous frame and knowledge for solving the complex issues involved in bringing up a disabled child. Since taking care of their child was not the only challenge the mothers encountered, their professional knowledge was insufficient to manage the difficulties as Barnes and Mercer (2007) argue; since generalised knowledge cannot explain and provide solutions for all the unique children, it is not helpful to expect mothers simply to follow the suggestions of professionals. Instead, it is essential for a diversity of types of support to be provided.

The understanding they gained from recognising their clients' contexts, priorities, choices and emotions was demonstrated by the respondents as being important and beneficial in carrying out their jobs. Rather than adhering rigidly to the 'right' way they had learned from their training, their experiences as mothers had taught them that it was more important to find and adopt a 'suitable' approach in order to meet the different needs of disabled children and their families.

The respondents' experiences clearly demonstrate that the meanings of disability are not fixed, but can be negotiated through the diverse ways of presenting or interpreting information concerning disability. This calls into question the rationality and objectivity professionals claim for their assessments. It explains why mothers with or without professional backgrounds believe their fighting can make a difference. Their experiences also challenged the assumption that professionals must be objective, rational, neutral and independent in order to ensure their clients' welfare. The mothers

learned that, although they were professionals, they did not know everything, hence they were more willing to embrace a much less clear cut, diverse and flexible reality that allowed space for negotiations, possibilities and other sources of knowledge.

Therefore, these mothers' experiences add a unique perspective to the debates concerning the limitations of professional knowledge and to the question of why mothers' perspectives and expertise are important from their position as professionals. They demonstrated how the diverse knowledge they had acquired as a mother could contribute to revising our understanding of knowledge, professionals, and the relationship between professionals and their clients.

Although the experiences of the mothers in the current study demonstrate the benefits of recognising their clients' needs and of allowing their clients to participate, this does not mean that these mothers intended to break through the boundaries between professionals and mothers. Their experiences challenged the necessity for the professionals' defensive attitude in maintaining their boundaries when interacting with their clients, since these mothers had no desire to replace the professionals but preferred the existing division of labour so that they could just be mothers. However, the mothers believed that their child's welfare could only be achieved when the perspectives of both they and their children were respected and appreciated. The experience the mothers had acquired from both their social positions implies that professional knowledge and lay expertise are not incompatible. Accordingly, I suggest that it would be highly beneficial to appreciate and include mothers' practical experiences of applying knowledge into the chain of the production of knowledge. If professionals can be more open-minded, accept that they do not know everything, and start to listen to and respect what mothers have learned, this could pave the way for a better cooperative partnership with mothers. The more dialogue takes place between professionals and mothers, the more we will be able to understand disability and provide more suitable services for disabled children and their families.

The respondents' reflections indicate the importance of acknowledging the influences from external structural factors. The ways in which they perceived, interpreted and evaluated problems were shaped by how they had been trained. They knew that professionals were embedded in and influenced by institutions, bureaucracy and policies. Both professional assumptions and the institutions themselves became barriers when they attempted to access informal or formal support. The mothers with professional backgrounds interviewed in this study provided evidence of the various types of power

attached to different social positions in the unbalanced relationship between mothers and professionals that could exclude mothers' perspectives.

The mothers' experiences demonstrated how a transformation of social position could help them to solve problems, but at the same time could also set limitations on how they made sense of and managed their challenges, confirming the argument that knowledge is socially embedded as suggested by various scholars (Mann, 2000; Harding, 1993). Since different social positions can contribute their own unique perspectives and experiences, I would like to suggest that it is essential to acknowledge the knowledge mothers obtain from their daily lives. If our goal is to acquire a deeper understanding of disability, it would be dangerous to allow our thinking to be dominated by the knowledge produced by particular groups, whilst excluding the perspectives of mothers and their children. In other words, it is important to facilitate the partnership between professionals and mothers. Moreover, the mothers also came to realise that they could not solve problems all by themselves but had to rely on teamwork to ensure the welfare of their child and their clients, which again brings us to the importance of interdependence, as discussed in previous chapters.

Chapter Seven

Conclusion

The importance of the parental role and parental perspectives in the care of disabled children has been emphasised in several recent pieces of U.K. legislation and policies: for example, 'Aiming High for Disabled Children: better support for families', published in 2007, and The 'SEN Green Paper, Support and aspiration: A new approach to special educational needs and disability - A consultation', published in March 2011 (DfES, 2011). Parental participation has been viewed as a useful approach to engaging with parents' experiences and perspectives. Although various strategies have been introduced to facilitate parents' participation, the findings of this research confirm those of previous research which have indicated that mothers still feel their perspectives are ignored or excluded (McLaughlin and Goodley, 2008; Runswick-Cole, 2007; McLaughlin, 2006; Swain et al., 2003; Brett, 2002; Dowling and Dolan, 2001).

After having their disabled child, the respondents in this study were expected to assume the traditional maternal role and became the main carer. They found themselves excluded by family and friends and experienced an isolated type of motherhood. Many respondents identified themselves as different from both professionals and other mothers with disabled children, so they maintained a flexible and changing distance between themselves and others over time. As research has illustrated, mothers have been often portrayed as deviations, being seen either as unrealistic or difficult by professionals (Larson, 1998; McKeever & Miller, 2004; Runswick-Cole, 2007) or sometimes as overprotective by disabled adults (Finkelstein, 2001; Campbell & Oliver, 1996). Hence, their experiences related to disability were still not paid the attention they deserved.

The experiences of the mothers in this research demonstrate that there are several premises that need to be acknowledged and put into practice before full parental participation can be realised. Based on the findings of this research, I not only want to highlight the importance of taking into account mothers' expertise, but also to argue the importance of relocating mothers within their social network and context; this will enable us to understand the dynamic, changing and diverse character of the mothers' expertise that is generated from the relationship between the mothers themselves and

other members of our society. The limitations of the study are also discussed in this chapter and suggestions are put forward for future research.

Reposition mothers

This section will discuss how, rather than seeing mothers of disabled children as a special category, separate from the rest of society, it would be beneficial both to them and to society as a whole to reposition them within their relationships with others, and in relation to prevailing discourses and expectations. Issues related to social position, the diversity among mothers, and the importance of public support will be acknowledged.

Social position

The respondents provided evidence that knowledge is situated and can be influenced by the social position individuals occupy. After moving from being a non-disabled person to being the mother of a disabled child, the respondents revised their priorities and values and viewed things through a different lens, as Debbie described: '*the world's just on a different level*'. They modified their motherhood, their understanding of disability, and their professional practice and career paths. From this new social position as mothers with disabled children, the respondents gained knowledge and developed their expertise. These experiences not only influenced their relationships with others, but also affected how they saw themselves.

Since being a mother was not their only role, the resources and capital associated with their other existing positions could influence how they managed their difficulties. For instance, the reflections of the mothers with professional backgrounds clearly reveal how their social positions as a professional and a mother could both enable and limit their strategies and credibility (McLaughlin and Goodley, 2008; Callery, 1997; Harding, 1993). Additionally, their other roles could also affect how the mothers were viewed. Many respondents gave examples of how their perspectives were assumed to be emotional or paranoid simply because they were mothers/women.

At the same time, the mothers with professional backgrounds experienced disempowerment as mothers, which was different from their experiences as professionals. Even though they were based on their professional knowledge, their

claims could be weakened by their social position as mothers. Their reflections highlighted the unbalanced relationship between social positions, professionals and mothers that made the mothers' accounts either less valued or often completely excluded from consideration. It will be difficult for people who perform caring roles/tasks to gain an equal position when interacting with professionals. If these structural factors are not considered, if women's expertise and knowledge continues to be devalued, it will be unrealistic to expect mothers to have an equal partnership with professionals.

By contrast, the experiences of the mothers with professional backgrounds demonstrated why mothers' expertise was important. Although their professional backgrounds helped in several ways, at the same time they had become aware of the limitations of their professional knowledge, which had become a point of reference only when handling difficulties. Instead, they acknowledged the expertise and insights they had gained as mothers of their unique child. Rather than their narrow focus as professionals, their experiences as mothers had enabled them to understand disability from other perspectives that revealed the complicated aspects of experiences related to disability, aspects which they had not been conscious of as professionals.

In addition, the respondents also indicated the differences when another person shifted his or her position from being one of the 'others' to being one of 'the wise' (Goffman, 1968). They praised the policy of inclusive education, especially when they witnessed how children with experience of interacting with their disabled child could work with him or her. Six grandparents also demonstrated their better understanding of disabled children and their mothers' circumstances as a result of their own experiences of being ill, being disabled or their experiences as carers or friends of disabled people. Four fathers with professional backgrounds in particular were described by their wives as sharing a more equal parenthood with them. These examples illustrate how understanding and support can be increased when 'others' enter the category of 'the wise'. Hence, how to increase the size of the category of 'the wise' will be a useful consideration to be included in policies and service programmes.

Although this research highlights the knowledge and expertise generated from the respondents' unique marginalised social position as mothers, the intention is not to assert that the mothers' perspective is necessarily the most important. What these respondents showed was that, based on their experiences, they had gradually come to understand their place as a mother. The respondents knew that what they believed was

based on their role as a mother; their considerations and arrangements for their child were not exactly what their child needed or wanted, so they made efforts to discuss related issues with their child and gave them opportunities to make decisions when they could. They knew they were not disabled people, so they were careful when discussing the impairment with their child. Nor did most of the mothers in this research try to dominate in their relationships with professionals. Instead, they insisted on maintaining the boundary between themselves and the professionals so that they could stay in their role of mother. They were not interested in invading the professionals' field but expected the professionals to do their job, generalise their partial experiences and provide useful knowledge and strategies to help disabled children and their families. The mothers knew that teamwork was necessary to ensure their child's welfare. They were always prepared to cooperate with professionals as a mother.

Furthermore, the findings of this research show that the mothers knew they could only make choices based on contemporary discourses, an understanding or knowledge of their child, and the resources available. Hence, their expertise or knowledge concerning disability and what their child needed was constantly developing and shifting. The mothers were aware that they might be right on some points but that they could also be wrong, so they were open to learning from their mistakes. Hence, they never claimed that their perspectives were the only true perspectives but were keen to learn from the experiences of others. What they asked was that their perspectives on and intimate expertise involving their child, this specific child, should be included, so that their child's welfare could be truly achieved.

Since knowledge is situated, it is unrealistic to ask professionals fully to understand their clients' needs and circumstances (Mackenzie and Scully, 2007; Scully, 2005). Continuing to present and dialogue with different perspectives and experiences could help to give us a deeper understanding of disability and the mothering experience. Moreover, the experiences shared by mothers with professional backgrounds in this research indicated the positive influences when they adopted strategies such as being open-minded, allowing their clients to participate and cooperating with their clients. These experiences could be useful references while considering tactics for establishing a better partnership between professionals and their clients.

Accordingly, the findings of this research confirmed the valuable knowledge generated from the specific social position, a mother with a disabled child, as various scholars have argued from different perspectives. As feminist standpoints perspectives, rather

than being distorted by dominating groups, the voices of this marginalised group can provide accurate knowledge attached to their social positions. Alternatively, as postmodernists propose, these accounts could be viewed as only some stories among many other possible stories when acknowledging the diversity among mothers. They are not objective, but can provide us with insights and reflections from these mothers' perspectives based on their unique social position. For scholars such as Lindemann Nelson (2001) and Scully (2008), these kinds of narratives have their potential to become counterstories for filling the gap between the master narratives and individuals' subjective experiences, correct and repair the dominating groups' misunderstanding and challenge inappropriate assumptions about the group with damaged identities. It can also provide individuals with a damaged identity with another perspective to make sense of their own experiences and further support them to exercise their moral agency. Therefore, this research suggests continuing to pay more attention to mothers' experiences.

Diversity

Although some mothers noted that they were more comfortable interacting with other mothers with disabled children because they could understand each other, this did not mean that they shared a homogeneous understanding and homogeneous attitudes towards or experiences of disability with other mothers of disabled children. Both similarities and differences were recognised by the mothers. Many of the respondents stated that they were not like other mothers because they knew they were influenced by aspects of their own backgrounds such as class, ethnicity or professional frames, hence had their own subjective interpretations of disability and their own ideas about being a mother. The findings of this research support the call of Crow (1996) to recognise the multi-dimensionality of lives disabled people and their families. They also reinforce Shakespeare's (2006) suggestion that the meanings of disability are not fixed but highly complex, and fluctuate within interpersonal relationships in diverse contexts. Accordingly, the experiences of the mothers in this research lead us to question the supposition that mothers are a homogeneous category and the assumptions attached to it.

The mothers with professional backgrounds who took part in the study provided further evidence of the inequalities among mothers with disabled children. The mothers with

professional backgrounds were aware that their privileged social position as professionals provided them with more resources than other mothers and helped them fight in more efficient ways. They therefore were concerned about the inequality among families which meant that some families had fewer resources available to them to help them manage their challenges. As Claire argued '*they (disabled children) should all be entitled to the same thing*'; however, in reality this is not the case.

The experiences of the mothers with professional backgrounds in particular demonstrated that professional knowledge could not solve all their difficulties. This implies that it was not enough for mothers simply to follow the professionals' suggestions. Instead of finding 'one' good service strategy, such as parental participation, and thus concentrating on 'one' specific professional focus, it would be more useful to learn from the mothers' reflections and to acknowledge the contexts in which mothers and their children are embedded and the diverse types of support they need.

Moreover, it is unrealistic to expect to find 'one' approach that could serve every family's needs (Hammel et al., 2008). For example, although there are good intentions behind encouraging parents' participation, it might not be an easy thing for every family to do. It might also not be what all families want or are able to do. As Kirk (2000) indicates, parental participation is normally taken as common sense, it is viewed as the parents' unquestionable responsibility no matter what their situations. However, the mothers in this research demonstrated a wide variety of approaches to this issue, not only because of the diversity among them, but also as a result of their changing circumstances. It is therefore unfair and not useful simply to judge mothers on the basis of rigid and narrowly-focused professional standards. The mothers who had professional backgrounds had also learned to acknowledge and respect their clients' 'choices' and 'priorities' based on their changing situations.

Hence, I would like to argue that parents should be allowed to make choices about how they want to participate. They should be able to have a say concerning the boundaries between themselves and professionals/the state instead of having expectations and responsibilities imposed on them, with all participation being seen as their entire responsibility, or even being blamed if they cannot meet others' expectations. Since the situations and challenges the mothers face are in a state of constant flux, the choices mothers make when they need to effect changes should be respected.

Active agents within social networks

In addition to recognising mothers' social position and diversity, I suggest repositioning mothers within social networks, since, as the findings of this research indicate, the ways in which the respondents practised their motherhood and managed issues surrounding disability were embedded in social encounters (Shakespeare, 2006). After having a disabled child, the respondents recognised that their motherhood and what their child's impairment meant were not a private domain, but were influenced or monitored by other social actors, such as how they themselves were raised by their mothers, and their interactions with their disabled child, their family members, unknown others, professionals and other mothers with disabled children. They were affected by social expectations, such as discourses on motherhood and disability, feminism, the medical perspectives, their child's rights, the disability movement, and the expectation that children will become good citizens in the future. The public services, including service programmes, policies, institutions such as hospitals and schools, and organisations for disabled people and their families also played an important role in influencing their maternal practices and management of disability. The boundaries set by assumptions of what 'should be' or of what constitutes 'normality', that they might not have noticed before, were now recognised in their interactions with others.

From their experiences of interacting with these social actors, discourses and institutions, the mothers gradually came to realise the limitations of prevailing discourses and knowledge. The assumption of normality, the medical prognosis, the social expectations of motherhood, the stereotypes they used to share with others, and the general professional knowledge they possessed were not always right. The mothers in this study knew that there were numerous things that fell outside the boundaries drawn by these existing understandings. For example, the medical prognosis was sometimes proved wrong by their child's development. Although the medical and social models are useful when discussing issues surrounding disability, they cannot fully explain the mothers' experiences of disability. The respondents simultaneously emphasised diversity and uncertainty. They resisted certain assumptions as pointed out by other research : for instance, they asserted their child's unique personality and potential when the professionals failed to see past the diagnosis to appreciate these things (Clavering, 2007; McLaughlin, 2006; Green, 2001; Larson, 1998). They maintained and cherished the space of uncertainty in which their child's unique

personality and potential could be embedded, as McLaughlin and Goodley (2008) suggest.

Furthermore, when moving from one social position to another, as from non-disabled person to mother with a disabled child, or when simultaneously occupying two different positions, such as that of professional and that of mother, and when negotiating the meanings of disability with others, the mothers realised that the meanings of disability were not fixed but changeable. The respondents identified a gap between what 'should be', according to general assumptions, and what was actually the case. This gave the mothers the message that it was not only possible but that it also might be necessary for them to get involved in the process of constructing understanding of their disabled children in order to ensure their child's welfare. Therefore, they put their child in the centre and started to make efforts to mediate through flexible strategies.

Therefore, the respondents repositioned their role. Their previous experiences and comprehension were used as a foundation on which to make sense of the new expectations, assumptions and related discourses attached to their new role as a mother. Through constant reflexive construction and modification, the mothers relocated their self-identity as a mother with a disabled child and their relationships with others so that new challenges could be integrated into the continuity and consistency of their identities (Jenkins., 2004; Giddens, 1991). With their increasing experience and knowledge, their confidence grew, and this supported them in their negotiations with others and in making their own decisions. These mothers not only were the main carers of their disabled children, they were the key persons who negotiated with the relevant social actors and interacted with external social forces. They chose the role that suited the specific situations they encountered: for instance, the role of educator, fighter, advocate, protector, carer or just that of a mother. Rather than being passive receivers, the respondents showed that they could be active social actors when interacting with the other social actors, discourses and institutions.

Through managing information, for instance by presenting, interpreting and updating information about their child within these interpersonal relationships, the respondents made bridges between what their child needed and the support their child could receive as McLaughlin (2006) also suggests. They were the pivot who managed the diverse information and advice suggested by various professionals. They evaluated their circumstances and decided whether they wanted to make the boundary visible through revealing their child's impairment, or what kind of information they wanted to select

and present in order to help others to understand and interact with their child. Although many mothers decided to stop explaining to others, they never reduced their efforts to preserve their child's relationships with family members and friends because they wanted their children to be surrounded by people who cared about them when pursuing their independent lives.

Regarding the criticism put forward by disability activists that mothers try to assimilate their disabled children, the findings of this research reveal the complexity of this issue. Although the mothers seemed to socialise their children to conform to dominant social and cultural norms, this was viewed by the mothers as helping their children to participate, a similar goal to that of the disability movement. What I saw in the mothers' practices was they did not try to fit their children into a box shaped by social and cultural norms. Instead, they appreciated their child's unique personality, abilities and disabilities while at the same time employing strategies designed to help them participate, such as teaching them to be polite. The respondents also illustrated the diverse strategies they employed to remove barriers, and to protect their child in the context of an unfriendly society which is changing only very slowly. Apart from helping their children to be independent in the future, the respondents placed a great deal of weight on how to help their children to develop their self-esteem, acquire a better understanding of their abilities and disability, and ensure suitable help was available so that their disabled children could participate in their own ways, and contribute on their terms.

It was found that those mothers who had professional backgrounds had modified their professional framework and their interactions with their clients since having their disabled child. Their reflections on the relationship between mothers and professionals also suggested that it was not necessarily harmful if professionals allowed their clients to participate and get involved. They reported that they now respected their clients' perspectives more, appreciated the diverse situations and contexts their clients found themselves in, respected their clients' choices and priorities more, judged less and worked harder in their jobs. These mothers had also thought more deeply about the insistence on professionals being objective, rational and abstract in their thinking and had become more open to learning from their practical, subjective and emotional understanding.

Several respondents had made efforts to influence how institutions worked through their participation, in order to ensure the welfare of their own child and that of other

disabled children. They had learned about the power of collective actions, as in breaking down barriers by going out together, organising their own groups, helping other parents to participate, or taking part in committees or parents' forums in order to make an impact on how policies were put into practice. These mothers not only paid attention to their own child but endeavoured to support other children, both in the present or even for the future, not only children in the U.K. but also in Taiwan. The mothers' narratives also show their resistance to social expectations and prevailing discourses. Their recognition of their power to make an impact and bring about changes, which went beyond the frame of tragedy or failure, might also be viewed as part of the process of empowering these mothers.

In contrast to labels such as 'unrealistic', 'overprotective' or criticisms of trying to 'correct' their disabled child, the respondents showed that they were realistic and experienced practitioners who examined the various pieces of advice offered by related social actors and carefully accessed, exercised, and managed their strategies to respond to various circumstances. Their maternal practices and their understanding of disability interlaced with each other in complex ways within these social encounters in the public sphere. Their comprehension was constantly changing as a result of their experiences and learning. They continually struck a balance between the professionals' knowledge and their expertise as a mother. They were active agents within social networks.

According to the respondents' experiences, their health care and education professional backgrounds played an important role while they manage their challenges. It may imply that these professional backgrounds were useful because they had a close relationship with services for disabled people and their families, thus these mothers were privileged from other professional backgrounds. Although I agree the benefit brought by the professional backgrounds involved in health and education services for disabled people and their families, I do not suggest that only these types of professional backgrounds are useful. Instead, my experiences as a social worker in Taiwan further taught me that the resources and experiences of parents can contribute to welfare of disabled people and their families in various ways. For example, Mary's experiences as a trade unionist (p110) facilitated her ability to challenge the authorities and make efforts to guide other parents to organise themselves in their own communities. One father I worked with in Taiwan provided work opportunities for disabled people in his factory after teaching them related skills, another mother used her academic skills to study social policies for their organisation's campaign. The resources and experiences mothers have their

diverse strength and can contribute in their own way if we look at carefully, provide them space, and support them to do so. How mothers' backgrounds or other social role can influence their motherhood and manage issues around disability can be another research topic in the future.

Public support

The public support in this section refers to two things. One is public services disabled children and their families need; another is public support for providing services for disabled children and their families. Although the respondents demonstrated their efforts and resources in managing their difficulties, this did not mean that they could handle the situation all on their own. On the contrary, the respondents had learned that they could never achieve their child's best interests by themselves but would need the support of others.

The reason that this research has emphasised the mothers' strengths and portrayed them as the important social actors on behalf of their disabled child's welfare that they in fact are has been in an effort to counteract previous negative images of and assumptions regarding mothers' experiences. I have not attempted to romanticise these mothers or to suggest that support from professionals and the state are not important. By contrast, including even the more privileged families in this research, the mothers claimed that they would not be able to function well without support. If the mothers/families were supported, their child might be able to have a better quality of life. On the other hand, if the mothers/families were exhausted owing to a lack of support, it would be their child who suffered. Although the welfare cuts and other reforms planned by Conservative/Liberal Democrat government seems hard to avoid and will influence various aspects of lives of disabled people and their families (BBC, 2010), I would still like to suggest that the state and professionals should not retreat from their responsibility of providing care and support for disabled children and their families.

The discourse on rights, the responsibility of the state, and the boundaries between mothers and state/professionals were flagged up in several of the mothers' accounts. Many mothers realised that rights were not simply given but had to be claimed, by filling in application forms, negotiating or fighting with service providers, or getting involved. Although the mothers fought on the basis of the discourse of rights in order to remove social barriers for their children, this did not reduce their feeling of stigma when

asking for help. When taking care of their disabled child was viewed as mothers' individual responsibility, it is reasonable to suggest that their asking for support can still be viewed as failure and dependence by other members of society. When their disabled child was viewed as unable to become a productive and independent citizen of the future, the mothers' care for their child was devalued. The frame of burden and dependence can marginalise both mothers and their children. Accordingly, the emphasis on the notion of rights does not successfully detach the stigma of dependency.

By contrast, scholars' appeal to rethink the value of care, interdependence, connectedness, and the over-emphasis on independence could be a useful approach to reverse the negative assumptions about dependency (Fine and Glendinning, 2005; Gottlieb, 2002; Kittay, 1999; Hillyer, 1993). When non-disabled people are viewed as 'temporarily abled' in their life courses (Kittay, 2011:49); when interdependency, trust, bonding and connection are valued more than segregation, exclusion and distinction; and when contribution can be appreciated from various aspects rather than only focusing on economic productive perspectives, then care may be able to be delivered with dignity within interdependent and cooperative social networks. Relocating the needs of disabled children and their families in the context of interdependence rather than that of need, dependence or burden might reduce the stigma related to dependency.

Although the debates between the medical model and the social model have expanded our understanding surrounding disability, most non-disabled people are still not familiar with these ideas or view disability as irrelevant. One of the possible reasons is that these discussions take place among 'the own' and 'the wise' groups (Goffman, 1968), and are thus not included in prevailing discourses. According to the respondents, ignorance and a limited understanding of disability are among the possible reasons for the reactions of shock and fear when people encounter illness and disability, or for their hesitancy when disabled people are present. According to the mothers' experiences and scholars' arguments presented above, it is important to help 'the others' to see their connections, interdependency and relationships with disabled people and their families, who are simply occupying different positions in the continuum (Ryan and Runswick-Cole, 2009); this would help to give other people a better comprehension of and empathy with disabled children and their families, and thus make it more likely that they would be willing to back up the policies that support them. Furthermore, the huge gap between stereotypes and reality does not necessarily need to exist (McLaughlin, 2006). If mothers' experiences - a branch of human knowledge related to disability - could be

included more in prevailing discourses, they might be able to help others when facing illness and disability. Therefore, I would like to highlight the importance of raising awareness and increasing others' comprehension of disability so that we may be able to widen the category of 'the wise'. Rather than expecting mothers to educate others in the private domain, I suggest that the subject should be discussed and executed on a larger scale in the public sphere: for instance, through social policies.

The wise

Since Goffman (1990) defined the categories of 'the own', and two types of 'the wise', most literature just accepted these categories. Although there are a lot of debates within disability studies in Britain about professionals' power, the limitation of professional knowledge, and the potential problems of parents' dominating voices, connections are seldom made to Goffman's categories of the other, the wise, and the own. As presented in chapter two, one of the reasons for this is the subjective individual experiences within interaction that Goffman analyses are not the main concerns of the supporters of the social model. However, the findings of this research provide an opportunity to rethink the category of 'the wise'. Although professionals and mothers are both named as 'the wise', I will first argue that there are various differences between the two types of 'the wise' and within each type of 'the wise'. Second, I will question how wise is 'the wise'. Next, I will question if 'the wise' automatically become 'the wise' simply because of their social relationships with 'the own'? Last, I want to highlight the gap between what 'the wise' think and what 'the own' want and need.

The experiences of the respondents in this research have demonstrated in what ways they were different from professionals. Although both professionals and mothers are named as 'the wise' by Goffman because of their close relationships with people with spoiled identity, the disabled people, the affect of associating with disabled people is different. Professionals may earn praise and respect from helping or treating disabled people, but mothers may be stigmatised or blamed as mothers with a disabled child.

Within the relationship between professionals and mothers, the power they possess is hierarchically different. Professionals' knowledge is authorised and supported by their training, and licences that legitimates professionals' power while mothers are viewed as lay people gaining their comprehension through subjective experiences. These two sources of knowledge are given different social meanings and weight with professional

knowledge surpassing mothers' experiences. According to the respondents with professional backgrounds, possessing knowledge is not the only reason that gives professionals power, it is the social position individuals occupy that matters. Although the respondents with professional backgrounds had their professional knowledge and experiences, it is not recognised or appreciated because they are mothers, not occupying the position as a professional. Normally, professionals are the ones who have the power to categorise others as disabled, and judge or monitor mothers' efforts in taking care of their disabled child. Therefore, the relationship between professionals and mothers is unbalanced.

Moreover, the way professionals and mothers view their knowledge is different. According to mothers with a professional background, one of the differences between these two types of 'the wise' is, professionals might overvalue their evidence-based scientific, generalised, and objective knowledge when the respondents always bore their unique child in mind. When the professionals ask others to obey their 'correct' approach to solve the problems, the respondents, including mothers with professional background, admitted that they did not know everything hence were willing to learn and cooperate with others.

Furthermore, the diversity within the category is worthy of more attention. Among those who are viewed as 'the wise' because they are family members or friends, other social roles such as their gender, class, race, or occupations, will influence how their perspectives are accounted for. For instance, as a woman, mothers also encountered gendered barriers where their expertise may be devalued. In this research, mothers' occupations play an essential role. Mothers with professional backgrounds have illustrated how their professional backgrounds affected how they viewed themselves and facilitated their strategies for dealing with issues they encountered. Therefore, it will be essential to recognise the diversity or even the inequality among the category, 'the wise' composed of by family members and friends. In addition, diversity also exists in another type of 'the wise', and that is the professionals. Professionals may hold different comprehension about disability or they may have various approaches although under the umbrella of medicine, as Scully (2008) points out. The respondents in this research also reported that the professionals' suggestions sometimes conflicted with each other because they viewed their clients from their professional focuses. Since different professionals may have different perspectives about the disabled child, whose wise is wiser?

The next question I want to raise is how wise is 'the wise', what do they actually know? Mothers in this research echoed findings of previous research that the professionals may have their professional generalised knowledge about the illness/disability, but they did not know their specific child, and sadly, they did not always make great efforts to do so. Gradually, mothers in this research did not interpret the professionals they encountered as 'wise' as presented in chapter four. The ways in which the mothers talk about actively managing their interaction with professionals in chapter five also suggested that mothers realised the so called generalised, objective, scientific knowledge was not necessarily right or suitable for them. Therefore, they made efforts to influence the process of evaluation and interpretation about their child's impairment. They make sure space for their child's potential to develop. They avoided the unnecessarily limitation proposed by medical prognosis but appreciate the knowledge they generated as a mother. Furthermore, in chapter six, one lesson mothers with professional backgrounds learnt was even though they worked hard and believed they were in tune with their clients based on years of working experiences, they still found a huge gap between what they knew as a professional and a mother with a disabled child. Another reflection mothers with professional backgrounds indicated was the differences between the narrow professional focus and the need to view their child as a whole. These mothers suggested that the professionals might know the narrow area based on their professional knowledge but it was only one part of their child's life. Therefore, they are only wise in some aspects

Similar doubt can be put on mothers' claims that they had better ideas about their child's best interests. Although stating mothers knew best, several respondents also admitted that their perspectives about their child's best interests were not necessarily what their child wanted or needed. Moreover, even though the respondents claimed that they knew their child, they knew they could only make decisions grounded on the situations and resources they had at the moment and their child's current abilities. They were not always confident in their decisions but continued to modify based on updated understanding about their child's development and needs. They did not know what would happen in the future. They admitted they were not always wise and they did not have control due to the uncertainty of their situation.

Although two groups of 'the wise' have their own approaches to being wise, the next point I want to make is that they are not necessarily 'the wise'. Some scholars suggest that the status of 'the wise' is not automatically given but has to be accepted, recognised or even authorised by 'the own'. Being a professional or a relative is not necessarily

viewed as the wise immediately. Larsen (2009) suggests that the professionals have to prove themselves as wise so that their status can be validated and accepted by individuals with chronic illness. Additionally, Veinot (2009) indicates, some people with AIDS do not let their family know their situations; they chose who can be the members of the group of 'the wise'. Therefore, occupying a social role in a category of 'the wise' does not mean you are 'the wise'. This leads to another question, who can decide who is 'the wise'.

Since knowledge is situated, we might only be able to say 'the wise' knows some aspects of the disabled people from their perspectives. However, it is only one perspective among others. Moreover, as these mothers had learned that they did not know everything, it is important for 'the wise' to recognise that they will never really be able to understand 'the own', owing to the situated nature of knowledge and the diversity among 'the own' (Mackenzie and Scully, 2007; Scully, 2005). Since it is difficult to imagine others' situations and needs by simply trying to putting on others' shoes, how can 'the wise' know what 'the own' really need? Or based on what foundation are thy able to claim they know what is the 'best interests' of 'the own'? If 'the wise' never listen to 'the own', how can they claim they 'know'. How can it be 'wise' from 'the own's' perspective?

Furthermore, is it a wanted 'wise'? This challenge can be found in disability studies especially when professionals and parents are viewed as people who oppress disabled people. For example, disabled people might be expected or socialised by the professionals' expectations about being a disabled person. As what Scott argues in his book, 'the making of blind men' (1969 cited in Barnes and Mercer 2007) argues, people with a visual impairment are expected to fit in to professionals' assumptions of being a person with visual impairment. If they do not meet professionals' expectations, they may be labelled as blocking or resisting. Scott also finds the expectations towards people with visual impairment can be different in different countries and cultural contexts. Therefore, how to be a person with a visual impairment is socially constructed, and professionals play important roles in it (Boswell and Wingrove, 1974), since they have more power to define how disabled people should live or impose their values on disabled people. Parents are also criticised as trying to normalise or assimilate their disabled child based on their knowledge as a non-disabled person (Finkelstein, 1998). Therefore, both professionals and parents are viewed as problematic in debates in disability studies.

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Rather than arguing who is right, or who has the right or wisdom to speak, I instead appreciate the voices from different angles and would like to consider how to make these related parties work together for the welfare of 'the own'. First, it will be useful to acknowledge perspectives especially from the marginalised position that used to be ignored before. Not only the perspectives of disabled people, as activists and scholars in the disability movement have advocated, the findings of this research show that experiences of mothers with disabled children are also normally ignored although they are in fact quite important. However, it is essential to acknowledge that what mothers believe or prefer is not necessarily what disabled children want or need.

The counterstories provided by the respondents in this research have shown many aspects that were not considered, such as the reflections of mothers with professional backgrounds. These mothers think differently from our contemporary assumptions of mothers of disabled children. The findings of this research highlight the importance of creating space for new and marginalised counterstories to emerge. It can be problematic if 'the wise' truly believe that they are the 'wise' and refuse or stop listening and including others' diverse voices as activists and scholars have argued in disability studies. Openness is essential to understand others so that the differences can be appreciated and respected, so that suitable support and care can be delivered, and so that 'the own' can participate and contribute on their own terms (Hodge and Runswick-Cole, 2008).

Although it is important to highlight the differences between 'the own' and 'the wise', I do not believe they are necessarily opposite each other. Mothers with professional backgrounds illustrated how these two types of knowledge could be compatible and utilised when they are dealing with difficulties. Mothers used their professional backgrounds to support their motherhood, they also used what they learnt as a mother to facilitate being a better professional who engaged with and listened to their clients. Rather than being harmful to the relationship between professionals and their clients, these mothers instead showed that the engagement contributes to positive relationships. These valuable experiences may help professionals to work 'wiser' when working with mothers and disabled people (Leasure et al., 1995).

Based on these recognitions, we may be able to have better ideas about how to establish an improved partnership between 'the wise' and 'the own', and between the two types of 'the wise'. Rather than categorising people into hierarchical groups that possess different value of experiences and knowledge, the arguments of ethics of care may offer

another perspective to recast the relationships between these groups. Rather than emphasising the differences that separate groups or viewing other groups as abnormal deviations, it may be helpful to view these groups as merely occupying different positions within the continuum and every group is connected with each other in one way or another.

Last, do we have to abandon the terms of 'the wise' and 'the own'? In my opinion, since it is used for several decades, and it is only a name of the category, it might not necessarily have to be changed. However, it is important to know the limitations and issues among the categories. What is more important is to supplement comprehension about the terms and connect them to the existing and developing debates and give them new life.

Limitations

The subject of this research was a small group of mothers in North-east England. Since many of the mothers who took part in this research had experience of working as service providers, these mothers might have had clearer ideas about participating in research or about what research could do, hence they might have been more confident when talking about their private experiences with a stranger than mothers who had not had this sort of experience. This might also explain why the respondents showed a high level of participation in various forms. It also implies that the self-selection recruitment method might have limitations, in that less privileged groups are not as likely to volunteer (Ryan and Runswick-Cole, 2009). Therefore, it is not appropriate to generalise the findings to all mothers of disabled children; the research can, however, be viewed as a contribution from their perspectives.

One of the most important lessons I learned from conducting this study was to recognise my standpoint and to acknowledge the limitations of my situated knowledge. When I started this project, my standpoint was vague. However, it still influenced how I conducted this research. My position as an outsider: as a non-disabled person, a mother without a disabled child and a foreigner, had affected my comprehension, analysis and interpretation of the data. Moreover, because of my personal situation, it took seven years to finish this thesis, but owing to limitations of time and money, it is not possible to interview the respondents again and update their perspectives. On the long journey of

this project, my standpoint shifted a few times. Through these different lenses, I learned to understand things from different perspectives.

These challenges also gave me valuable opportunities to explore issues outside my previous knowledge and in new and unexpected fields. For example, although my limited understanding of the cultural and social context might have weakened the validity of the analysis, however, my position as an outsider also enabled me to see the mothers' experiences from another perspective. Because of deficiencies in my English language ability, these generous mothers spent more time explaining their experiences to me. My maternity leave gave me an opportunity to catch up with what the mothers had taught me and modified my areas of interest, which led to my obtaining richer and more fruitful data. This was not a strictly structured piece of research; however, the absence of a rigid and limiting structure allowed space for the respondents to provide even richer data. This research is a result of realising the limitations, pushing the limitations, learning from the limitations, and recognising new limitations. Accordingly, these limitations became an important part of this research.

If given another chance to do this research again or do another similar project in the future, I would like to approach it differently in several ways. When looking back, I realised my focus on literature related to disability and parents' experiences of raising their disabled child was not enough although it was practical due to my English limitations. Theoretically, the various sociology theories provided me with wider and diverse frameworks to analyse the mothers' experiences. I would choose to conduct a project that is much more structured by theoretical frameworks in the future. Moreover, because of the limitation of English, I was not always confident to discuss my research with others. If I could do the research again, I would like to expose it and discuss it with other scholars when I can.

Practically, it also suggests that disability is only a part of the lives of mothers with disabled children and disabled people as pointed out by other scholars (Scully, 2010; Shakespeare and Watson, 2002). When disability is the only focus when analysing mothers' experiences, other aspects may be dismissed or ignored, as Wendy (p97) argued, the similarities with others were left aside when only differences were highlighted. It also implies that mothers are viewed as a separate category that can be a form of segregation that distinguishes mothers from others. As a result, the connections between mothers and others may be neglected. Moreover, the mothers with professional backgrounds also showed me that being a mother was only one of their social roles and

identities. Therefore, it is not enough to understand their experiences solely on the theories generated in disability studies. A framework that is concerned with interaction, interconnection, and independence will be adopted next time when exploring mothers' experiences and the care they provide.

There are some themes that I did not explore enough in the current research. I would like to pay more attention to the issues related to class which is not recognised as important in Taiwan but is essential when doing research in Britain. Moreover, instead of solely focusing on their maternal role, mothers' other social roles will be a theme that I would like to explore more, such as focusing on mothers with professional backgrounds, or comparing the differences between mothers with or without professional backgrounds. Additionally, the impact of cultural context is much more complicated than I previously assumed. It may be small but can be very influential changing the whole meaning of the action. For example, 'getting on with it' was mentioned by many respondents. After I put it into the context respondents' offered, I was able to appreciate their strength of confronting the difficulties they encountered rather than passively accepting their situations. However, my internal examiner, Dr. Jackie Leach Scully, told me that when women with North-East background said these words, it showed that they were 'proud' of what they have done. Therefore, based on the awareness and observations generated within these years in the UK, I will be more sensitive about the cultural meanings. If possible, I would like to make some comparison between Taiwan and the U.K. If doing a research in Taiwan, I will be more sensitive about the influences of cultural, historic, and social contexts and be careful when using theories and frameworks generated from the western culture.

Regarding the research design, I would like to consider more about the recruitment criteria depending on the research aim. If the research intends to concentrate more on a specific group, the types of the child's impairment and the age of the child will be considered more in order to explore mothers' situated experiences and knowledge since I've learnt about the diversity among mothers. If having enough resources and time, I would like to reach out to mothers who are not as active as the interviewees in this research in order to present their marginalised voice; therefore, a much more wide-ranged strategy should be adopted. If I can carry on doing a research focusing on mothers with professional backgrounds or comparing the differences between mothers with or without professional backgrounds, these criteria about children's conditions will not be stressed. I will try to have a bigger sample to compare the differences between various professional backgrounds, or the impact professional backgrounds make.

Suggestions for future research

Several unexpected and interesting themes arose from the mothers' experiences, but since these were not the main concerns of the original research framework, there were not enough data to investigate them; however, these themes will be worth exploring in the future. First, the mothers with professional backgrounds interviewed for this research provided interesting accounts related to situated knowledge and professionalism. This is an unexplored field in disability studies. Since these mothers are insiders in their roles of both professionals and mothers, they might be able to provide some insights which would contribute towards better partnerships between mothers and professionals; this is therefore a subject worth further exploration in the future.

Although fighting is a common theme in research on mothers with disabled children, the mothers' fight is usually set in the context of the problematic relationship between professionals and mothers. A careful examination of the accounts of the mothers who took part in this study reveals that many of them experienced a process of empowerment, for instance in educating themselves, fighting for their child's rights, and recognising the power of collective actions and participation. Through mothers' experiences we might be able further to examine issues related to care, and women's empowerment and the shared responsibility between families and the state.

Continuing the argument about situated knowledge, I would like to point out that disabled children may have different needs. Probably because all the disabled children in this research were of school age, the mothers reported more difficulties related to educational service providers than to medical professionals, as previous research has found (McLaughlin, 2006; Larson, 1998). The respondents' accounts remind us that these disabled children live in a different era from the forerunners of the social model, and now live with their families, and go to mainstream schools. Hence, it is essential to explore the specific social position occupied by disabled children in contemporary society.

Many mothers in this research were aware of their child's subjectivity, and some of them tried to let go and encouraged their children to speak for themselves. However, protecting their child was still a prevailing discourse in their narratives. Partly because of their child's age or disability, many things were decided mainly by the mothers and their partners either based on resources and the problems at hand or on their imagined

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futures. We might say that the mothers' comprehension of disability was a complex web composed of their subjective interpretations and their responsibility for their child, and will thus be different from the perspectives of the disabled children themselves. On the basis of the mothers' experiences, I disagree with the accusations made by disabled adults that parents are barriers, since I was able to see the mothers' efforts in so many different ways. However, I have to agree with disabled adults that there is a risk that disabled children's voices might be overwhelmed by the voices of their parents. Hence, I would like to highlight the importance of listening to disabled children's voices because they have their own issues that need to be addressed. Moreover, it is not within the scope of this research to determine how this young disabled generation, raised by their non-disabled parents, will influence the culture or identity of disabled people, but this might become a highly interesting field of enquiry in the future.

Although mothers might not be able fully to represent the disabled child's perspectives as some disability activists have claimed, I still believe that the mothers' unique social position as outsiders with a close relationship to disability, or as insiders although not disabled, could offer valuable reflections and experiences that would aid in promoting disabled children's welfare. If mothers are not allowed to speak for young disabled children or people with severe disabilities, this could have a detrimental effect on their welfare (Kittay, 2002b). Moreover, if our goal is to understand disability, mothers should be allowed the opportunity to contribute their perspectives and experiences as individuals.

The findings of this research also highlight the limitations of existing discourses, models and understanding. The diversity among mothers should be acknowledged. Rather than imposing a strict framework, a bottom-up research strategy might be able to provide opportunities to explore more marginalised perspectives and experiences. Moreover, according to the findings of this research, the perspectives of some of those mothers who participated actively in public organisations might become more prevalent in the public sphere. There might be a risk that the perspectives of disadvantaged families will continue being marginalised. Hence, it is essential to consider other strategies designed to recruit the less privileged groups.

While the term 'parents' is normally used in legislation and policies, according to the findings of this research concerning situated knowledge, fathers might have different views and experiences from mothers. It is thus also important that fathers' experiences be addressed in more depth in the future. Accordingly, I suggest that we continue to

study the situated knowledge of mothers, fathers and their children so that we can continue developing our comprehension of the diversity of disability.

Although comparisons between Taiwan and Britain were not the intention of this research, there are some differences I would like to mention for the purposes of future research. Compared with my experiences of working and interviewing parents in Taiwan, the mothers in this research were much calmer. On the basis of the mothers' narratives, I suggest that this is a result of the functioning of the British social welfare system, which provides for their basic needs such as various kinds of allowance. It suggests the importance and function of public support. However, the well-established service system might also make it difficult for mothers in the U.K. to receive suitable flexible support quickly, owing to the complicated and interlaced regulations followed by various professionals. It was also not easy for the mothers to challenge the vast rigid system and ask for more flexible choices that suited their family styles.

By contrast, parents in Taiwan did not receive enough statutory support, and parents fought and advocated together against the government and asked for support. They worked together to create services that had never before existed but were what their child needed. Many foundations founded by parents became important service providers. Parents have been one of the most important social forces in the history of social policies for disabled people and their families in Taiwan. Because parents' knowledge and experience have exceeded those of the government, parents have participated actively in the process of policy making. In some ways, having an unsound system was an advantage because it was easier to break down the badly equipped barriers. However, when parents' perspectives prevail, debates in the U.K. on emphasising disabled people's voices are useful and important.

After studying in the two countries, I was able to recognise the differences derived from various cultural, historical and social conditions. Although their experiences and knowledge were situated, however, there are still some similarities between them, such as that of the experiences of mothers in both the U.K. and in Taiwan not being accorded sufficient attention, although for different reasons. I believe that viewing the interaction between different cultures from different perspectives could inspire new ideas and enrich comprehension about motherhood and disability in the future.

Conclusion

The respondents in this research provided evidence that mothers' expertise is important in understanding issues surrounding caring for a disabled child. They also challenged several assumptions held by professionals, disabled people and others. They demonstrated that they were not unrealistic, not trying to over-protect their child, that they had no intention of keeping their disabled child from independent living, that they were neither 'chosen' nor 'bad' mothers, they were simply their child's mother, and hence possessed important and unique knowledge about their child.

In this research, I learned to look at the difficulties mothers encountered from sociological perspectives. I also learned to see the hidden structural issues behind the scenes. I would like to suggest that social work education in Taiwan increase sociological training for social workers in order to enable them to see the broader contexts in which their clients are embedded.

This project has been a journey of exploration supported by valuable literature, knowledge, and led especially by the mothers' invaluable experiences and reflections. As the respondents demonstrated the differences when individuals shifted from being members of the 'others' to members of 'the wise', I believe it to be the work of scholars to generalise mothers' experiences, and transform their experiences into knowledge so that it can be shared, exchanged, and endured. Through debating, dialoguing and disseminating knowledge, we may help to widen the category of 'the wise'. Hence, what I intend to do in the future is to carry on what the mothers have taught me and put it to good use.

Research questions	Concepts	Themes	Key question	Questions
Motherhood/ disability context	A: within family	Disability does make differences within family and motherhood	1. What are mothers' experiences of raising a disabled child?	1.Would you please tell me about your experiences of raising ☺?
			2. How does disability influence the mother's daily life? (Through motherhood, what kind of figure can we see?)	2.What is it like to be ☺'s mother? (What is the most special part of being ☺'s mother?) Is the mothering of ☺ the same as with your other child?
What do mothers learn?	B: disabled world	There is a disabled world; however, it might not be the same for disabled adults.	For mothers, how does disability influence their family life?	Does disability influence your family life? In what way?
Meanings of disability	B→A	Mothers will construct their own meaning of disability and then build up their own motherhood	What is the meaning of disability?	1. Some mothers have said that they think differently about disability after having their own disabled child; do you share the same experience?
Meanings of disability			What is the meaning of disability?	2. When and how do you perceive disability most clearly (Is there any particular situation that will remind you ☺ is a child with disability)?

Research questions	Concepts	Themes	Key question	Questions
Meanings of disability		Mothers might experience being disabled as well	After having ☺, do you feel it is more difficult to participate in society?	3. After having ☺, do you feel it is more difficult to participate in the society? Do you feel yourself disabled as well?
Meanings of disability/ motherhood context		Meanings of disability are manipulated in the context of motherhood		4. How does ☺ think about his/her disability? How do you deal with problems related to disability? 5. What kind of mother do you think a disabled child needs?
Changes of outside world	C: abled world	Mother's old world might not be the same any more	After having ☺, do you view your old world in the same way?	After having their disabled child, some mothers said their old world changed, such as family relationships, friendship, careers; do you share the same experiences? What changed? Why? How do you feel about it?
Influences from outside world	C→A	Being aware of other's attitudes towards disability would influence their motherhood	Does the understanding of how others think about and treat disability influence your motherhood?	1. Would you please tell me your worries about ☺? 2. Knowing how other people think about and treat disability, some mothers said that influences their motherhood, do you share the same experiences?

Research questions	Concepts	Themes	Key question	Questions
Influences from outside world		Mothers will derive both support and frustration from their old world and their previous life experience	What do you get from your old world?	3. Do you derive support or frustration from your old world? Do you feel your life experience has helped you to be ☺'s mother?
What do mothers learn?	B←→C	Mothers might perceive the differences between the two worlds.	What are the differences between the two worlds?	Some mothers said that they view the world totally differently now, what do you think?
Influences from outside world/ motherhood	A←→B& C	Mothers will learn, modify and develop their own motherhood and attitude towards disability while interacting with others	How do you develop your own motherhood; do you have to defend it?	1. Is it difficult to build or develop your own motherhood? What or who supports you most when developing your own motherhood? Do you have to defend your motherhood to others? Do you care what people think about you? Do you feel judged?
Motherhood vs disability			What kind of person/disabled person do you want ☺ to be?	2. What kind of person/disabled person do you want ☺ to be?
	Ending			Do you feel more confident to be ☺'s mother now? Do you have other advice for other mothers?

Appendix 3-2: Mothers' Information Sheet

Research Project

The experience of mothers with young disabled children

<u>Research Supervisors</u>

Dr. Janice McLaughlin and Dr. Tom Shakespeare, University of Newcastle

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Take time to decide whether or not you wish to take part.

1. **What is the purpose of the study?**

I am a PhD student from Taiwan at the University of Newcastle upon Tyne. As a mother of two young children, I really believe that experiences of mothers with disabled children are extremely important and valuable. I am carrying out a study on the experiences of mothers with disabled children. My overall aim is to focus on your views as a mother. My interest is: what is it like to become a mother with a disabled child? My aims are

- To profile mothers' experiences of becoming and being a mother with a disabled child;
- To explore how mothers with disabled children develop their own motherhood;
- To investigate some of the factors that influence approaches to motherhood.

2. **Who have been invited?**

I am aiming to work with 15 to 20 mothers around Newcastle in total.

3. **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep. You will also be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

4. **What will happen to me if I take part?**

Your involvement, if you decide to join, would involve the following.

Interview of past experiences

I would like to interview you about your experience of becoming and being a mother with a disabled child. I am particularly interested in how you develop your own motherhood. I will also wish to talk about the factors surrounding you that may positively or negatively influence your own approach to motherhood.

I will arrange an interview of about 90 minutes. In some special cases, a second interview might be held with your agreement. I will tape record the interview if you agree. The tape of the interview will be transcribed. You can choose where you would like the interview to be held and can request other people to be present. I can do the interview in your home if this is what you would like.

5. **Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. Your name and address will not be recorded on the interview transcripts. Your interviews will not be discussed with professionals or with other parents. Your name will be changed and we will ensure that you remain anonymous.

6. **What will happen to the results of the research study?**

The material will be presented at academic and professional conferences and in academic journals. Anonymity and confidentiality will still be in place. The findings will also be shared with parents in Taiwan.

7. **Contact for Further Information**

Newcastle University

Dr Janice McLaughlin   Dr. Tom Shakespeare

Tel: 0191 222 7511 (w)

E-mail: janice.mclaughlin@ncl.ac.uk   E-mail: t.w.shakespeare@ncl.ac.uk

Thank you for reading this information sheet and, if it is possible, participating in the study.

Appendix 3-3: Letter for mothers

<div style="text-align:right">

Yi-Ting Shih

Tel: 07840485182

Email: yi-ting.shih@ncl.ac.uk

Dr Janice McLaughlin

Tel: 01912227511

Email:janice.mclaughlin@ncl.ac.uk

</div>

Date

Parent's address

Dear ,

The experience of mothers with young disabled children

This letter invites you to be a part of a research study. Thank you for saying you would like to hear more.

The study is about learning more about what is it like to become a mother with a disabled child. I am seeking to interview mothers like you whose child is now a little bit older in order to reflect back on the process you have gone through. From the experiences you talk through with me, I aim to help other parents including those back in Taiwan who I work with.

The information sheet attached will introduce you to the study and how it will be carried out. I would be very grateful if you would read through the information sheet. The sheet lists the small level of involvement you would have in the study. We can discuss the information and your possible involvement in the study when I call, as arranged, at…

Thank you for reading through the material.

Yours sincerely,

Yi-Ting Shih

Appendix 3-4: Paragraph of advertisement

Research Title

The experience of mothers with young disabled children

Supervisors:

Dr. Janice McLaughlin and Dr. Tom Shakespeare, University of Newcastle

My name is Yi-Ting Shih. I am a PhD student from Taiwan at the University of Newcastle upon Tyne. As a mother of two young children, I really believe that the experiences of mothers with disabled children are extremely important and valuable. Now I am undertaking a piece of research examining what it is like to become a mother with a disabled child and I am seeking to recruit mothers to interview as part of the research. I am interested in speaking to mothers who live around Newcastle. If you would be interested in discussing becoming involved or would just like to know more, you can contact me at: 07840485182 or yi-ting.shih@ncl.ac.uk

Appendix 3-5: Table of interviewees' demographic data and recruitment sources

Name (Mother+ Child)	Child's data					Mother's marital status	Sources of recruitment
	impairment	Age	gen der	position among the siblings	School attended		
Angel+ Cherry	CP (cerebral palsy)	11	F	First child of two	Mainstream	Married	A playgroup I visited
Cathy+ Ben	Visual impairment, learning difficulties, dyspraxia, attention	5	M	The only child	Mainstream	Married	Contact a Family
Libby+ Carl	CP	7.5	M	The only child	Special school	Single Adaption	A participant in a conference
Wendy+ Sam	CP, hearing problem	4	M	First child of two	Mainstream first, then special school	Married	A participant in a conference
Debbie+ Jenny	CP	7	F	The only child	Special school	Married	Snow balling
Maggie+ Chris	CP, Visual impairment	7	F	Third child of four	Mainstream	With partner	A voluntary organisation for visual impairment I visited
Jackie+ Leon	ADHD	15	M	Second child of two	Mainstream	Divorce/ now with partner	Parents' Forum

Name (Mother +Child)	Child's data					Mother's marital status	Sources of recruitment
	impairment	Age	gender	position among the siblings	Schools attended		
Mary+ Siobhan	partial trisomy of the number 8 chromosome with deletions, learning disabilities, mobility problems, can't talk	12	F	First child of two	Mainstream	Married	Contact a Family
Lily+ Cindy	Autistic spectrum	5	F	The only child	Mainstream	Married	Parents' Forum
Milly+ Joseph	congenital dislocating hips, visually impaired, predominantly deaf, physical development was delayed, severely learning disabled	19	M	The only child	Mainstream first, then special school	Divorce / now with partner	Contact a Family
Claire+ Robin	Autistic spectrum	12	M	Second child of three	Mainstream first, then special school	Married	A voluntary organisation for people with autism I contacted
Suzy+ Robert	Autistic spectrum	5	M	First child of two	Mainstream	Single	A voluntary organisation for people with autism I contacted

Name (Mother+ Child)	Child's data					Mother's marital status	Sources of recruitment
	impairment	Age	gender	position among the siblings	School attended		
Emma+ Georgia	Pachygyria-epilepsy(smooth brain)	17	F	First child of two	Mainstream first, then special school	Divorce	Snow balling
Sherry+ Gavin	dyslexic, ADHD	15	M	Second child of two	Mainstream	Divorce	Parents' Forum
Anita+ Patrick	CP	9	M	Second child of two	Mainstream	Married	A mainstream school I visited
Lisa+ Boris	Down's syndrome Autistic spectrum	10	M	Forth child of four	Mainstream	Married	A participant at a conference I attended

Appendix 3-6: Consent Form

Research Project, The experiences of mothers with a young disabled child	
Research supervisors	
Dr. Janice McLaughlin and Dr. Tom Shakespeare, University of Newcastle	
	Please delete as appropriate

Have you read the mother information sheet?	YES / NO
Have you been given a copy to keep?	YES / NO
Have you had an opportunity to ask questions and discuss the study?	YES / NO
Have you received satisfactory answers to all of your questions?	YES / NO
Have you received enough information about the study?	YES / NO

Do you understand that you are free to withdraw from the study:

     ☐   At any time

     ☐   Without having to give a reason for withdrawing

     ☐   Without affecting your future medical care?   YES / NO

Do you agree to take part in the study?   YES / NO

Signed   Date

. . . .

NAME in **BLOCK LETTERS**

. . . .

Signature of Researcher

. . . .

Appendix 6-1 Mothers' occupations

Name	Previous occupation	Current occupation
Claire	A GP (general practitioner)	GP * Her husband is also a doctor.
Lisa	A physiotherapist	A physiotherapist * Her husband is an Inclusion Coordinator**:** advising and training people with communication difficulties.
Mary	An accounting teacher in a college. Was a trade unionist	Works for voluntary agency running courses for parents of disabled children. * Her husband is a manager of a charity for carers
Debbie	1. A residential Child Care Officer in a residential school for children with autism for 3 years. 2. A residential child care officer in a residential special school for 12 years. 3. A classroom assistant at her daughter's school for a year.	An assistant to physiotherapist, occupational therapists and speech and language therapists. * Her husband works in a residential special school as a Senior Child Care Officer.
Anita	Trained in child psychiatry	A paediatric cardiology nurse
Milly	An occupational therapist A volunteer for about 10 years for a charity for disabled people and their families after having her disabled son.	A part-time family worker for a charity.
Lily	A PhD student of pharmaceutical science (new drug development)	Unemployed. Considering working on new drug development for autistic children in the future. She was in the process of organising a charity for families with children with autistic spectrum.

Name	Previous occupation	Current occupation
Angel	A nursing auxiliary (8y) for the elderly	Staff of a playgroup especially recommended for disabled children.
Libby	A teacher in a residential school for 6 years, a teacher to children with special needs in portage service for 19 years	Unemployed
Wendy	A teacher for learning difficult and a manager of further education	A manager in further education (student support for disabled students).
Sherry	Unemployed	Did a course in counselling She planned to work in a charity for disabled people and their families as a counsellor
Suzy	A jewellery designer and then a chef.	Did a course in counselling. She was trying to start a charity for people with autistic children and their families with other parents.

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