School of Sociology and Social Policy
The University of Leeds

"Being Brave" : Disabled Women and Motherhood

Victoria Radcliffe

Submitted for the Degree of Masters of Arts in Disability and Gender

Date of Submission: 1st September 2008

Acknowledgements

I wish to sincerely thank everyone that has made this dissertation possible. Particular heartfelt thanks are due to:

The research participants who willingly shared their thoughts and experiences with me. I have really valued the insight, enthusiasm and time they have contributed to this project.

Angharad Beckett whose continual encouragement, support and advice have been invaluable. I have really appreciated it.

The Isle of Man government for their financial assistance.

And finally my mother and Thomas for their encouragement and unwavering support.

Abstract

This dissertation seeks to explore the reasons why motherhood and women with impairments remains an uneasy association in Western society. Firstly an in depth literature study examines the feminist movement, disability activism and the place of women with impairments within both in order to explain how women with impairments are viewed in society. The focus then shifts to look at stereotypes and commonly held assumptions surrounding women with impairments such as their perceived asexuality, dependence and incompetence and how this "creates" negative attitudes towards, and enforces the taboo of, women with impairments as mothers. The influence and impact of eugenic theories will also be reviewed in relation to this subject.

A commitment to the social model of disability provides the basis for an inductive approach to the research in this study. A small research group of seven women with impairments make up the empirical research dimension of this dissertation through questionnaires and telephone interviews. Parallels are drawn between current literature regarding this topic and the lived experience of participants to examine if mothers with impairments are discriminated against and if so the extent to which this affects their lives.

This study cannot draw conclusions representative of society as a whole; however, it is evident that of participants studied all encountered attitudes that made them feel uncomfortable about their pregnancies and their abilities to become "effective" mothers. Their "situations" were compounded by additional structural barriers they encountered. This small study has raised issues for further study surrounding the correlation between negative societal attitudes towards mothers with impairments and the every day structural barriers mothers with impairments encounter. The continued influence of such attitudes pervades society and has disabling effects.

Table of Contents

"Being Brave" : Disabled Women and Motherhood

Acknowledgments

Abstract

Contents

Chapter One   Introduction

The UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) came into force in September 1981. The convention protects women against all forms of discrimination and states that organizations and authorities must ensure that all women are treated on an equal basis with men (CEDAW). Section E of Article 16 proclaims that women have the right to decide how many children they wish to bear and to the necessary information and education to assist them in exercising their rights as potential mothers. Twenty-six years later the UN Convention on the Rights of Persons with Disabilities was opened for signature. The Convention asserts disabled people's right to become parents. It declares that information on reproduction and family planning are to be provided to disabled individuals together with the means required to exercise this right (CRPWD). Broadly speaking this Convention declares persons with disabilities' right to life: the most basic of all human rights (Clements & Read, 2008).

Defining how an individual leads a full and enriching life is a complex issue. Priestley believes an individual's ability to parent is a key cultural and social marker of adult status in Western Society (Priestley, 2003). Similarly Wates believes the social role of parent eases individuals into mainstream adult life (Wates, 1997). While child rearing can be considered an integral element of adult life and a Human Right, disabled parents and more specifically disabled mothers, have until relatively recently remained invisible in parenting literature, in disability activism issues and feminist writings (Campion, 1995; Mintz, 2007; Morris, 1996; Olsen & Clarke, 2003; Prilleltensky, 2003; Wates, 1997).

This dissertation seeks to explore whether disabled women face attitudinal and structural barriers as they contemplate motherhood, throughout their pregnancy and during the post partum period. This study includes an empirical aspect which aims to examine the voices of a small number of women with impairments regarding their experiences of motherhood and pregnancy. The aim of this research is to compare participants experiences with the issues covered in disability and feminist literature, and, to explore the reasons why motherhood among women with

impairments has historically been a taboo subject and if it indeed remains so today in Western society. The main objectives of the research are to:

- ➢ Examine the historical reasons for the attitudinal barriers which women with impairments and mothers with impairments face and the disabling effects of such.
- ➢ Highlight the lived experiences of a small group of mothers with impairments and compare it to existing literature that discusses this topic.
- ➢ Explore if, in a social climate that promotes human rights and equality, women with impairments are still assumed incapable of motherhood, and if so, why is this the case?

Defining Disability

It is necessary to define the difference between disability and impairment and the definitions used throughout this study. Focusing on impairment and "what the body cannot do" defines disability through one's pathology. This "medical model" of disability advocates a "cure or care" philosophy which is individualistic, attributing disability to the

body's inability to function in a "normal" way. Medical theories and practices are thus applied to "treat" disability. Patronizing notions of tragedy and sympathy are used to explain living one's life as a disabled person. As Barnes states,

> 'In short, disability amounts to a "personal tragedy" and a social problem or a "burden" for the rest of society.' (Barnes & Mercer, 2003, pp. 1)

The social model of disability however, defines the disadvantage and exclusion experienced by individuals with impairments as a result of a segregating society which does not account for individuals with impairments and thus excludes them from the "mainstream"; it is a social issue (UPIAS, 1976 cited in Barnes & Mercer, 2003). Thus,

> 'Disability is the restriction imposed on top of our impairments by the way our society is formed' (Sheldon, 2004, pp. 69)

Impairment refers to the functional limitations individuals experience (Barnes & Mercer, 2003). This dissertation is written from a social model perspective where disability is defined in social terms and impairment as a functional limitation.

Setting the Scene

Historically the role of women has been to bear children. Woman's ability to create life justified her purpose on earth; her reproductive rights however, were controlled by men (Sullerot, 1971). In the ancient world women's sexuality was controlled by men. Promiscuity and adultery were punishable by death (Sullerot, 1971). Myths and beliefs were also used to explain female sexuality and reproduction, assigning certain character traits to women on account of biological difference such as, woman as overly emotional, fragile and irrational. Women were subject to the unpredictable and mysterious womb leaving them hysterical, weak, vulnerable and incapable of controlling their own lives (Greer, 2006). As women were irrational and uncontrollable, patriarchal rule was justified and necessary to maintain social order.

Traditionally understood as a negative trait, feminism now celebrates woman's connection with nature and her ability to use emotion to understand the world. Notions of woman as "dependant" and "weak" have been challenged through feminism, and the concept of motherhood has been reclaimed through exploring the miraculous ability a woman has to nurture life.

Feminism has however, come under increasing scrutiny for its initial categorization of women as one homogeneous group. Ethnicity, sexuality, class and impairment were not originally differentiated within feminism. Some women were thus marginalized within the women's movement itself. As women with impairments were still perceived as weak and dependant they were largely excluded from feminist literature. Their "difference" also disrupts the notion that all women are united and wish for liberation in the same way. This tension within the feminist movement continues to be confronted by women with impairments writing about their own experiences.

The Impact of a Stereotype

Notions of difference create stereotypes. The disabling consequences of attitudes towards individuals with

impairments as "different", "lacking" and "without" has a long history. Traditionally myths and superstitions have identified individuals with impairments as sinister and pathetic (Barnes, 1991). Impairment has been portrayed through the media as evil, sinister, the result of sin and association with the devil (Barnes, 1992). Individuals with impairments are often subject to violence, victimization and are the subject of ridicule (Barnes, 1992). There is an extensive list of such stereotypes. In relation to women with impairments some are perhaps more relevant than others.

Impaired bodies are seen as deficient and unable to function "properly" (Barnes & Mercer, 2003). This perceived physical "malfunction" influences societal perceptions of the emotional capacity of individuals with impairments to form physical relationships. The rare association of sexuality and "disability" is often related to men who fall prey to two stereotypes: assumed impotence, or, sexually starved and degenerate (Barnes, 1992; Sanders, 2007). In contrast women with impairments are often depicted as asexual; without sexual drives or desires. The assumption is made that women with impairments will not and do not experience sex.

As individuals with impairments are seen as incompetent and "burdensome" it is understood that they will not form intimate relationships. This is perpetuated through charity advertising and telethons that focus on the "doom and despair" of impairment (Barnes, 1992). Thus, impairment becomes synonymous with dependency, a trait that does not sit well with "would be" mothers.

In contrast however, individuals with impairments can also be portrayed as exceptional or "super human". Achievements become over achievements and are met with excessive amounts of praise (Barnes, 1992). "Overcoming one's disability" is used to "celebrate" the ability of individuals with impairments but actually perpetuates the stereotype of difference. "Disabled mothers" can fall prey to the "super cripple" stereotype when they bear children "against all odds."

It is attitudes such as these that have their origins in history but continue to linger today creating further disabling consequences for individuals with impairments.

Impairment Equals Incompetence

Although there is much written on the social model of disability, the medical model continues to influence literature

and societal attitudes. Historically the small amount of

literature surrounding mothers with impairments has centered

on individual impairment and the assumed negative impact,

and risk this has on children (Olsen & Clarke, 2003). Much

focus is given to the early stages of a child's life and the need

for practical and physical care from "competent" mothers.

The ability to perform tasks unaided such as nappy changing,

lifting and feeding become the bench mark of a successful

mother. The perceived inability of mothers with impairments

to fulfill such tasks independently provides the basis for their

scrutiny by professionals. Thus, women with impairments

have historically been discouraged from contemplating

motherhood, advised to abort babies or encouraged to be

sterilized (Asch & Fine, 1998). The labeling of individuals

with impairments as incompetent and dependant creates a

category of "other" where individuals who deviate from

society's "norms" are grouped together at the margins of

"acceptable society".

The Influence of Eugenic Principles

It is not only the "fear" that mothers with impairments

are unable to cope with the demands of motherhood that

places them on the societal margin. The notion that babies with impairments are born from women with impairments influences attempts to deter them from bearing children. This view echoes theories of eugenics where the fittest and strongest individuals are encouraged to reproduce a healthy and strong nation. Individuals perceived as weak and dependant become exempt from this process. In this, individual parenting desires are disregarded by concern for the greater public good (Shakespeare, 2008).

The fear of reproducing impairment is one aspect of the eugenic debate, pre-natal screening and professional intervention provides another. When fetuses are screened and abortions considered where impairment is present, aspersions are cast over the value society places on the lives of individuals with impairments. The wider implications for advocating pre-natal screening and "necessary" abortions of "unacceptable" babies are serious, they echo the notion that living with an impairment is a "life not worth living" (Morris, 1991); this influences societal perceptions of impairment.

The Double Bind

This chapter has explained that women already occupy the societal periphery on account of their oppression by a patriarchal society. The marginal position of individuals with impairments merely adds to the oppression that women with impairments face. Reviewing the historical context explains why individuals with impairments have been subject to oppression. Women with impairments are therefore dually oppressed as they are considered weak on account of their biological make up as women, and as abnormal on account of their impairment (Oliver, 1990). The idea that women with impairments can assume their traditional mothering role when they are viewed as inferior on two separate levels reveals in some part why this notion is often met with negative attitudes. Feminism has however, reclaimed motherhood, and disability has been redefined as a social construction by the disability movement, which presents the quandary; why does the idea of mothers with impairments remain an uneasy topic?

The Structure of this Study

This dissertation is split into five chapters plus four appendices. Chapter one introduces the dissertation topic and my research questions as well as giving an overview of

the key themes to be discussed in the following chapter.

Chapter two builds on the key themes, exploring existing literature and setting the context of my research questions. Specifically, the literature review will explore the following: feminist dilemmas and the relationship between women with impairments and feminism; the formation of stereotypes and their disabling consequences; the importance of the "competency" debate with regard to women with impairments and the role of their children and; how the issue of competency contributes to the notion of eugenics when applied to impaired fetuses and pre-natal screening. Having identified the key themes within this debate chapter three will discuss various research methods, theoretical considerations and my epistemological position as well as explaining the empirical research dimension of this study. Chapter four discusses my research findings in relation to the attitudinal and structural barriers research participants have encountered. My concluding chapter will relate the research findings to current literature to identify similarities between the claims made through academic literature and the individual experiences of my small research group. The aim is to explore whether attitudinal barriers create the structural

barriers that disable mothers and prospective mothers with

impairments.

Chapter 2   Disabled Mothers In Context

This chapter seeks to contextualize the research objectives. Firstly, the development of the feminist movement and how this has traditionally dismissed the experience of women with impairments will be discussed. Feminist and disability activist attitudes towards motherhood will then be examined. Following this, the wider societal attitudes and stereotypes that disable women with impairments in relation to their sexuality and ability to mother will be explored. Finally, the contribution principles of eugenics add to the debate about whether women with impairments have the right to become mothers will be examined. The purpose of this detailed exploration is to define the social context of my research participants, the influence of which will be discussed in chapter four.

The Difference Debate

Both feminist and disability rights movements have been criticised for categorizing all women and individuals with impairments into two homogeneous groups (Crosby, 1992;

Fawcett, 2000; Shakespeare, 1998). The identity of "woman" and "disabled" initially represented all women and individuals with impairments everywhere. This presents a dilemma for women with impairments who identify as both, thus falling between the two movements. For rights movements to be effective they must be unified there is however, the danger that unity comes at the cost of difference. Second wave feminism has tackled the issue of difference through debates surrounding "race", class and gender. Women with impairments have also engaged in discussions of difference within the disability movement through writing their stories. There remains the assertion, however, that for the most part women with impairments are overlooked in the feminist movement as a whole (Blackwell-Stratton et al., 1998; Fine & Asch, 1998; Morris, 1991; Thomas, 1999).

Barkley Brown believes including the notion of difference in feminist theory is essential to the effectiveness of the movement (Brown, 1995). Moreover she attests that difference alone is not enough, but must be understood in relational terms (Brown, 1995). For example:

'It is important to recognise that middle-class women live the lives they do precisely because working-class women live the lives they do.'

(Brown, 1995, pp. 275)

Thus difference is relational. Women without impairments need to communicate with women with impairments in order to break down attitudinal barriers that continue to keep women's experience of disability absent in feminist literature.

Difference becomes problematic however, when a particular difference is rated as inferior to other differences. Feminists without impairments have disassociated themselves from women with impairments as they seek powerful and independent role models (Fine & Asch, 1998). Fine and Asch describe a discussion which took place between the co-author of their book who does not have an impairment and a feminist academic who inquired:

'Why study women with disabilities? They reinforce traditional stereotypes of women being dependent, passive and needy.'

(Fine & Asch, 1998, pp. 4)

Blackwell-Stratton et al. argue there is much to be gained from a coalition between the women's and disability movements. Women with impairments make up a significant portion of society and through their inclusion they are contributing to the political agenda of the feminist movement which aims to represent *all* women (Blackwell-Stratton et al., 1998). Similarly the disability movement benefits from forming a strong alliance with the feminist movement whose voice is politically strong in striving for equal participation for every individual in society (Blackwell-Stratton et al., 1998). Despite the publication of literature written by women with impairments the issue remains, however, and the debate continues surrounding whether or not feminism makes room for disability.

Feminists Can be Mothers Too

While feminist discussions may overlook impairment, there has been much to say on the topic of motherhood. Early radical feminism confronted the notion that sexism is perpetuated through motherhood because gender roles are defined and sexist attitudes reinforced as children are raised

in Western society (Hooks, 2000). Feminist discussions about motherhood assert the claim that for women child bearing is a duty where one's identity becomes lost (Greer, 2006; Oakley, 1979). Women are thus defined by their body's ability to have children and their role in society as producers of human beings (Oakley, 1979; 1980).

As such motherhood becomes a life event which changes a woman's status, her physical state and medicalizes her life (Oakley, 1980; 1986). Oakley highlights that for some women bearing a child invokes feelings of loss as well as gain: a child is gained, but, in the process there are losses such as leaving a job, control over one's own life, or a change in one's relationship with a partner (Oakley, 1980). The life event of motherhood however, marks the entry into a complete adult feminine role; it epitomizes culturally constructed gender roles and identity (Oakley, 1980).

> 'Without a child to call her own a woman in our culture falls short of cultural expectation. She has not achieved the standard that is set for all biologically female persons.'
> (Oakley, 1980, pp. 183)

Motherhood can be viewed as a duty and expectation which is another form of oppression for those that "achieve" it and for those that wish for it, but cannot obtain it. Moreover because women's ability to reproduce has a social impact, i.e. that of reproducing the human race, motherhood becomes a societal issue (Oakley, 1980). For this reason motherhood in Oakley's opinion are idealized. Women are expected to reproduce and this, it is assumed, will bring them joy.

Oakley contests, however, that for some women, entry into motherhood actually produces feelings of low self-worth and depression (Oakley, 1979). Romantic notions surrounding motherhood are culturally created through patriarchal expectations and "professional" domination to associate motherhood with all that is pure, caring and loving which equates to passivity, sub-ordination and compliance (Oakley, 1980; 1986).

Thus, early feminism claimed that motherhood is a further way women are oppressed by patriarchy and dominated by the medical profession (Oakley, 1979). Differences of opinion have, however, come to the fore within

the feminist movement and there is now a move to re-claim, celebrate and defend the role of mother. Traditionally linked with all things natural feminists have fought to,

'Insist more and more confidently upon seeing pregnancy and childbirth as part of a sphere of significant action as meaningful and civilized as any of the accomplishments of men.'
(Stanworth, 1990, pp. 299)

Hooks asserts that the feminist movement is pro-family, and, oppression and unhappiness occurs where patriarchal domination is present (Hooks, 2000). Thus, current feminist debates are centred on acknowledging that motherhood is not an expected role for women in society, but it is a choice that is fulfilling, demanding, rewarding and deserving of recognition, and, freedom from patriarchal intervention, and, rule by medical professionals.

There is, therefore, an ideological divide between motherhood as 'bad' - subject to medical intervention and patriarchal power: and as 'good' - a positive and emancipatory experience (Stanworth, 1990). In the following

section I would now like to briefly touch on the position of women within the disability movement because they too face oppression by medical professionals and societal attitudes as they consider motherhood.

Women in the Disability Movement

As has already been discussed women with impairments are side-lined by their non-impaired sisters in feminist discussions. It has also been argued that women with impairments have been overlooked and thus disabled by the patriarchal system which dominates the disability movement. Oliver would argue that the disability movement has been slow to recognise women and the impact that gender has upon disability (Oliver, 1990). Barnes, however, would argue against the assertion that the disability movement excludes women (Barnes, 1996). Moreover Barnes states that the disability movement is dominated by women (Barnes, 1996). He affirms:

> 'It is not true to suggest that the experience of disabled women is absent from the literature on disability.'
> (Barnes, 1996, pp. 28)

Indeed many women have contributed to ongoing debates within the disability movement which challenges the assertion that they remain under represented (Morris, 1989; 1991; Sheldon, 2004; Thomas, 1999).

Nevertheless, given the focus upon equal representation of all women within feminism and all individuals within the disability movement, it is perhaps not surprising that motherhood and parenting has remained a topic of at best secondary importance to both movements. The disability movement, however, *is* now beginning to voice the experiences and opinions on parenting and motherhood through the written accounts of mothers with impairments.

Motherhood First, Impairment Second

As feminism addresses women's struggle to break free from the oppression of marriage and motherhood, Mintz argues that for some women with impairments they struggle to break *into* that domain (Mintz, 2007). Gillespie-Sells et al. explain that in their opinion disability can cancel the mothering role (Gillespie-Sells et al. 1998). Mintz continues stating:

'Many disabled women voice an urgent desire to claim

those very qualities deemed stereotypical and

delimiting by feminism.nurturance and even a

maternal extinct.'

(Mintz, 2007, pp. 140)

Such characteristics reflect what is deemed "normal" in Western society; indeed notions of normalcy pervade family life (Olsen & Clarke, 2003). Campion suggests that women with impairments that have children take part in the process of "becoming normal" in a society that views impairment as "abnormal" (Campion, 1995).

Women with impairments are now beginning to dispute the "abnormal" label. New insights and experiences are shared through their writings, enriching the disability movement. Jo Campling provides such insights. Her frank approach shares practical advice and realistic situations women with impairments may encounter (Campling, 1979).

'A disabled mother may run into difficulties if she has

not taken into consideration her own limitations and the

extent of help she is able to rely on from her partner, family, friends and social services.'

(Campling, 1979, pp. 21)

Although the tone of this article appears somewhat sombre and cynical, Campling discusses the potentially disabling experiences and barriers to motherhood those with impairments may face. Her voice is reflective of other mothers with impairments, creating a feeling of solidarity and raising awareness about an issue that she explains there are,

'Many misunderstandings and taboos ….A major issue for many disabled women is the right to have children.'

(Campling, 1979, pp. 20)

Thus many women with impairments have discussed their right and ability to raise children. Indeed many mothers with impairments have described the positive contributions they make through the "mothering role". Many women with impairments feel they are able to spend more time with and provide strong emotional support to their children (Parker, 1993; Wates, 1997). Accounts have also included the non-

judgemental, caring and thoughtful attitudes children have developed throughout childhood as a result of living in a home where impairment is part of everyday life (Campion, 1995). Indeed much focus is given on the dependence women with impairments have on personal assistance, however Kate, a research participant in Wates' study explains,

'I'm a much more resourceful person. The more you're encouraged to do the more you can do.'
(Wates, 1997, pp. 67)

Indeed Jenny Morris states regarding women with spinal cord injuries,

'Many of us find that even while lying flat on our backs in hospital, we are the ones who organise to keep the family together and cared for.'
(Morris, 1989, pp. 127)

Thus while an impairment may prevent a woman from physically doing something it does not prevent her from finding a solution.

New discussions thus, seek to emphasize the unique and positive aspects mothers with impairments possess. The new literature provides a stark contrast to traditional discussions surrounding negative associations that are made with impairment. Such associations, and stereotypes, linger in our society ensuring mothers with impairments are still not fully accepted. In the following section I now wish to discuss the origins and the disabling effects of such negative associations.

Women with Impairments as Asexual

John Tomlinson, a specialist in sexual health explains that certain impairments do not affect women's reproductive systems but the psychological effects of impairment can alter ovulation (Tomlinson, 2005). As a medical professional Tomlinson's approach is individualistic defining impairment as the reason women with impairments encounter opposition when considering motherhood. The psychological effects are linked to the tragedy theory of impairment rather then

exploring other possible reasons why mothers with
impairments are in the minority.

Linking sexuality and impairment creates a taboo
subject as it contradicts "the ordinary" within society
(Sanders, 2007; Longhurst, 2008). Kath Gillespie-Sells et al.
completed a research project in 1998 which examined
women with impairment's sexuality. The findings from one
hundred and fifty participants revealed that many of the
women did not receive sufficient sex education at school and
as a result entered adulthood with a basic understanding of
puberty and reproduction (Gillespie-Sells et. al, 1998). Some
of the women attributed the lack of education in this specific
area to a common stereotype; women with impairments are
asexual and therefore will not need knowledge about sex
(Gillespie-Sells et. al, 1998). Mothers with impairments can
often encounter surprised reactions and confusion regarding
their ability and decision to bear children as this contradicts
commonly held assumptions that women with impairments do
not have sex.

In sharing her personal experience Alessia Di Virgilio
explained that she experienced low self esteem and felt she
never "belonged" due to her impairment because society puts

31

so much emphasis on sex (Virgilio, 2005). Similarly Christina Johnson detailed how she never felt attractive or "eligible" for a sexual relationship because of her impairment and thus sought to make herself as asexual as possible (Johnson, 2005). In a society that creates norms surrounding body image, beauty and desirability, the right to experience sexual drives and desires are negated where impairment is present (Sanders, 2007). The reasons why women with impairments are labelled asexual are two fold: firstly, theories about what makes a woman desirable and therefore capable of forming a relationship: secondly, the notion that individuals with impairments will not wish to, nor should they, reproduce.

The notion that women with impairments are unable to bear children is connected to their impairment itself, as well as a misplaced understanding that women with impairments are perpetual children (Prilleltensky, 2003) and therefore unable to enter the "adult sphere" of motherhood. It is for this reason that women with impairments are also seen as dependant.

Impairment Equals Dependency

There is the belief that individuals with impairments need caring for and cannot therefore be the provider of care. Tomlinson states,

'The lower pregnancy rates reported in women [with impairments] are probably the result of conception being avoided because of patient's concerns over their ability to raise a family and manage their impairment.' (Tomlinson 2005, pp. 55)

Bodies that require assistance and mechanical aids to fulfil certain tasks contradict maternal myths that promote the 'soft "naturalness"' of breasts, arms and laps' (Mintz, 2007 pp. 137). Emphasis is placed on the attractiveness of women's ability to nurture and care for others; women must thus be capable of providing physical and emotional support to offspring (Fine & Asch, 1998). Many new mothers often seek support and assistance from health care workers and family members as they adjust to caring for their new born child. The issue here lies in the assumption that a woman without impairments can cope with her children but may need some support, while a woman with impairments will consistently

need support to care for her children. Requiring assistance however, does not mean a woman with impairments will become a "bad" mother.

Assumptions, however, must exist in our society concerning what qualities and abilities constitute "good mothering" for unease to exist around the subject of women with impairments becoming mothers. The attitude that it is inappropriate and even irresponsible for women with impairments to bear children (Wates, 1997) can cause them to experience feelings of guilt and inadequacy (Olsen & Clarke, 2003). Deborah Kent a research participant in Robyn Longhurst's study stated;

'No one ever told me point-blank I couldn't have children. Nobody had to say it in words. From childhood on, I heard the message in a subtext of denials and omissions.'
(Longhurst, 2008, pp. 57)

As women with impairments continue to be portrayed as unreliable, in need, helpless and sick (Longhurst, 2008; Prilleltensky, 2004) the notion that impairment equals

dependency is reinforced. For this reason "non-disabled"

feminists have traditionally ignored impairment in their

literature because women with impairments,

> 'Reinforce traditional stereotypes of women being
>
> dependent, passive and needy.'
>
> (Fine & Ash, 1998, pp 4)

In this light independence is defined by one's ability to take

care of one self, thus persons who require personal

assistance must be, by default, dependent. Prilleltensky

would however dispute this assumption.

> 'Independence is more about the freedom to make
>
> important life decisions and have control over daily
>
> routines. It is also about the right to decide what
>
> assistance is needed, how and when it will be delivered
>
> and by whom.'
>
> (Prilleltensky, 2004, pp. 16)

Thus, it is a woman with impairment's ability to have control over her own and her child's life that marks her independence.

Newman believes too much emphasis is placed on parents who are "sick" and how they impact upon "healthy" children (Newman, 2003). Assistance is viewed negatively if "sick" mothers require it. Thus quality of parenting is often assessed in physical terms rather than exploring the spectrum of support parents with impairments can provide to each child (Newman, 2003). Prilleltensky states,

'The inability to carry out some of the physical tasks associated with parenting has little to do with one's ability to be a competent parent.'
(Prilleltensky, 2003, pp 24)

Thus much emphasis is placed on a woman's ability to physically care for her child unaided. Where assistance is required incompetence is assumed. This notion is also connected with the belief that the children of women with impairments will automatically have to care for their mothers which will now be discussed.

The Role Reversal Debate

As has been discussed mothers with impairments are often judged by their inability to fulfil "normal" physical tasks, however,

'Parenting is a lifelong relationship of which baby care is an important but very short lived stage.'
(Campion, 1995, pp 148)

There exists a contentious debate around the idea that the children of mothers with impairments will assume the role of carer, thus reversing the traditional role of the care giver and the cared for. The idea, however, that children should fulfil certain domestic duties, is problematic in Western culture (Campion, 1995). In other cultures children are expected to make contributions to the domestic sphere and to care for those who require assistance (Campion, 1995). For Western children, however, it is claimed that fulfilling caring and domestic duties is a negative experience and consequentially parents become burdens on their children (Campion, 1995; Olsen & Wates, 2003). This then creates an "abnormal"

family where traditional and "appropriate" familial roles become blurred to "cater for the impairment" (Stables & Smith, 1999).

To children of mothers with impairments labels are given such as "brave little soldiers" and "poor innocent victims" (Stables & Smith, 1999, pp. 256) on the assumption that the impairment creates hardship for them. Stables and Smith (1999) examine the impact the media has had on this debate naming films which have negative connotations "Cinderella stories". Little attention is usually given to the positive aspects of this "alternative" family,

> 'The messages delivered…are of the tragic child, the heroic child, and the helpless, dependent, self centred adult…[they] draw on the victim/villain allegory – a tried and tested plot, whose codes and conventions are recognised.'
> (Stables & Smith, 1999, pp. 260)

The young carer debate blames the mother or her impairment for providing "negative" childhood experiences; it echoes the personal tragedy theory (Stables & Smith, 1999). "Negative"

experiences can be apparent where a child is given responsibility rather than experiencing the archetypal "carefree" childhood (Stables & Smith, 1999). Most children however, enjoy being giving responsibilities and as Olsen and Clarke highlight the label "young carer" has been created by adults and professionals and does not necessarily reflect the way the children see themselves or their role within the family (Oslen & Clarke, 2003).

The backlash against this debate discounts the notion of an enforced Cinderella role but highlights the need for greater support for women with impairments whose children take on additional responsibilities. Olsen and Clarke acknowledge that at times children do have to provide a particular amount of care, indeed within policy there is a framework of support for "young carers", however, the focus in this situation should be on the failings in support provided for adults (Olsen & Clarke, 2003). Interestingly they continue to discuss "parentification" as not applicable to children who provide care on the basis that there is a difference between parenting tasks and the parenting role (Olsen & Clarke, 2003). Indeed some children may take on parenting tasks, but the parenting role which provides love, support and

protection is another matter quite different to the daily domestic tasks of bed making, dish washing, etc. (Olsen & Clarke, 2003).

There is, however, another dimension to the young carer discussion. It is argued that for some children the role of carer overrides the child's ability to receive care. (Newman, 2003). The child may become too attached to the parent affecting his/her ability to develop relationships in adulthood as well as experiencing anxiety and worry in their childhood (Newman, 2003; Parker, 1993). It is argued that this can expose the child to exploitation and vulnerability. Newman states,

> 'Damage is believed to occur when the process of "giving" by the child becomes internalized to such an extent, that meeting the demands of others becomes an intrinsic part of the child's personality and is carried forward into adult life.'
> (Newman, 2003, pp. 60)

This claim, however, fails to consider the parents awareness of their circumstances and the emotional relationship and

support between parent and child. Again, emphasis is placed on the personal tragedy angle and the resultant inner emotional turmoil this causes the child as a result. As has been discussed, notions of dependency, incompetence and child carers seek to undermine the ability women with impairments have to become mothers. This negative association links into theories of eugenics which reflect the opinion that impairment should be avoided and manufactured out of society to "ease the burden" of living with such. In the following section I wish to discuss the link between women with impairments and eugenic theories.

The Impact of Eugenics

It has long been believed that individuals with impairments hinder the success in the growth of societies through their potential to bear babies with impairments. The ancient Greeks practised infanticide if a child was born with an impairment as he/she was seen as weak and unable to contribute to the welfare and growth of Greek society (Barnes, 1996a). The Romans also practiced infanticide to eradicate "sickly persons" from society (Barnes, 1996a). Charles Darwin's theory of natural selection permeated

attitudes in Victorian and Edwardian society creating a moral

panic that improvements in sanitation, reform and

government would afford individuals formally viewed as

"weak" the opportunity to reproduce (Shakespeare, 2008).

The eugenics movement in Britain and America in the early

twentieth century followed on from earlier ideas about social

control through sterilization and birth control. Major Leonard

Darwin discussing eugenics stated,

> '[There] is a highly beneficial result to be expected from
>
> the prevention of parenthood amongst defective
>
> persons…. Many…maladies could undoubtedly be
>
> stamped out in time if the persons so afflicted would
>
> make the noble sacrifice of refraining from parenthood.'
>
> (Darwin, 1928, pp. 30 – 31)

Perhaps the most commonly known example of applied

eugenics is the mass sterilization program undertaken by the

Nazi regime which sterilized approximately 375,000

individuals with impairments over six years (Shakespeare,

2008). Although principles of eugenics were evident in

countries such as America and Britain before the rise of

Nazism, Nazi attitudes towards individuals with impairments and their subsequent treatment of such has, however, undoubtedly left a legacy that remains influential in societal attitudes today.

Attitudes that reflect eugenic principles have an impact on societal expectations of mothers with impairments. Talking from a feminist perspective Oakley discusses the capturing of women's wombs through patriarchal domination and medicalization (Oakley, 1986). One could suggest that the wombs of women with impairments are also subject to such, as well as, societal attitudes regarding the reproduction of "normal" beautiful bodies. Indeed much of the impetus behind pro sterilization discussions for mothers with impairments is based on the misinformed belief that all impairments are hereditary and can therefore be reproduced (Prilleltensky, 2003; Campling, 1979).

Indeed of the mothers studied by Gillespie-Sells et al. the general opinion was held that pressure is applied to women with impairments not to reproduce themselves, unless of course they can bear an "able-bodied" child (Gillespie-Sells et al., 1998). Anne Finger describes her experience at a women's conference where she discussed

her distressing time in hospital as a young child with polio. A lady present in response to her story stated,

> 'If you had been my child, I would have killed you before I let that happen. I would have killed myself too.'
> (Finger, 1990, pp. 33)

Not only does this reflect the lady's discriminatory attitude towards individuals with impairment, it by default lays blame on Anne Finger's mother for bearing a child that acquired an impairment. Finger later states,

> 'I wanted something perfect to come out of my body.'
> (Finger, 1990, pp. 172)

This is reflective of eugenic influenced attitudes. It is possible that due to the discrimination Finger has experienced, she desires to bear a non impaired "healthy" baby. In this Finger displays how she has "internalised" attitudes that exist within society.

Preoccupation with "designer babies" has heightened discussions about pre-natal screening now offered to every

pregnant woman. While the basic principle behind this procedure is to inform the woman about the health of her baby, it can also be argued that it is influenced by the principles of eugenics. If impairment is present in the foetus the woman can be offered an abortion (Bailey, 1996). The rationale behind this notion is that of relieving suffering; suffering of the mother: the family and the child itself. As this procedure is posited from a philanthropic angle it becomes an "acceptable" practice in society. In reality, however, it is about preventing impairment, it is founded on the medical model of disability where once again impairment is assumed to bring with it a lower quality of life and psychological problems (Bailey, 1996).

If this idea exists about the life of a baby with an impairment, it is fair to assume that the same attitudes exist about an adult with an impairment i.e. a disabled life is a life that is not worth living (Bailey, 1996; Morris, 1991). Shakespeare states that screening foetuses offers solutions to what becomes by default a "problem" (Shakespeare, 1998). He also highlights that genetic screening does not consider the many people that acquire impairments in later life, thus its objective to remove impairment from the gene

pool will never be reached (Shakespeare, 1998). The basic notion of "checking for problems" and offering the solution of abortion instils within individuals the idea that impairment is a curse and can be avoided. It is for this reason individuals that have an impairment are seen as cursed and tragic. Similarly mothering by women who have impairments is viewed as running the risk of perpetuating the "tragedy" of impairment.

Conclusions

This chapter has explored how feminism has failed to include women with impairments in its discussions on oppression, difference and motherhood. It has discussed the necessity of motherhood to fulfil societal expectations as well as being something to be celebrated within women. For this reason women with impairments have started to discuss their experiences of motherhood with the focus on: what makes them good mothers, what assistance they require, and, what in society prevents them from fulfilling this role. The negative impacts of stereotypes and attitudes women with impairments face when contemplating motherhood have also been examined. The misconception that children of mothers with

impairments will inevitably care for their mothers is linked in

with the belief that women with impairments are incompetent.

Further, the belief that eugenic principles of sterilization and

pre-natal screening medicalize the motherhood experience of

women in society and especially those that have

impairments.

Chapter 3   Research Explained

This chapter will define emancipatory and participatory research and the extent to which this dissertation incorporates these research methods. The importance of theoretical research will then be discussed together with the author's ontological position and objectivity. Epistemology and the production of knowledge will then be discussed followed by the practical aspects of the research process such as empirical structure, ethics and limitations.

Emancipatory Research

Mike Bury discusses the claims that disability research is sometimes oppressive for individuals with impairments. It is predominantly performed by "able-bodied" researchers and has a negative impact on individuals with impairments (Bury, 1996). Mike Oliver calls for a different research approach to that which explains disability in individual terms defined by impairment (Oliver, 1990). Sally French states that at times

individuals with impairments are not included in the research process itself (French, 1994).

An emancipatory research paradigm however, seeks to empower and liberate individuals from social oppression as its fundamental principle lies in the social model of disability (French & Swain, 2000). Zarb believes that emancipatory research has to be empowering, that empowerment must be taken and not given (Zarb, 1992 in French, 1994). Thus, individuals with impairments must determine and control the research process and work with researchers (Zarb, 1992 in French, 1994). Oliver suggests,

'Researchers have to learn how to put their knowledge and skills at the disposal of their research subjects.' (Oliver, 1992 cited in Bury, 1996, pp. 35)

Emancipatory research seeks full involvement from research participants and must seek to benefit both researcher and the researched (Oliver, 1992 in Bury, 1996). Stone and Priestley believe in six core principles research must encompass to be emancipatory,

> research must be founded in the social model of
> disability

> there must be a clear political commitment to achieving
> individuals with impairments self-emancipation through
> the surrendering of claims to objectivity

> the outcome of the research must benefit and empower
> individuals with impairments and/or remove disabling
> barriers

> research must be produced under the control of
> individuals with impairments and their organizations

> personal voices are to be politicized as well as a drive
> to acknowledge the political similarities of individual
> experiences

> The differing needs of people with impairments must be
> accommodated through utilizing a variety of research
> methods

> (Stone & Priestley, 1996, pp. 10).

This dissertation cannot claim to adhere to all of the above

principles. While participants were free to express additional

thoughts and opinions, it could be argued they were restricted

by the content of the research. In this respect research was

controlled by the researcher and the politicization of participants voices were somewhat muffled. There is some difficulty in formulating truly emancipatory research as part of a Masters program as opposed to a funded research project where facilities and funding are available to implement the research findings in such ways as to make a difference to the lives of individuals with impairments. This presents a difficulty to the researcher in regards to dissemination. The researcher, however, wishes to submit this study to the internet based Disability Archive UK for general public viewing as well as addressing the Leeds based organisation "Women's Health Matters" interest in this study by sending a copy.

This dissertation claims a participatory approach to the research. Research is conducted *with*, rather than *on*, people (Reason & Heron, 1986 in French & Swain, 2000).

> 'Participatory methodologies have arisen from qualitative research approaches that aim to reflect, explore and disseminate the views, concerns, feelings and experiences of research participants from their own perspectives.'

(French & Swain, 2000, pp.38).

This form of research enables participants to create knowledge about themselves (Reason & Heron, 1986, in French & Swain, 2000) and challenges hierarchical divisions of power within the research process. Participants are given the opportunity to develop and contribute their strengths to create rounded and fair research representative of all who are involved (French, 1994). Participants in this study were encouraged to express thoughts and opinions and were given the freedom to elaborate or "verge off the beaten track" throughout communications. Traditional forms of research were challenged, such as research that is performed *by* an "expert possessor of knowledge" carried out *on* participants. This research however acknowledges that participants in this study are the experts on motherhood and the disabling barriers in society and the researcher is the collator of information. For this reason the researcher believes the research can justifiably claim to be participatory.

Theoretical Underpinnings to the Research

In order to investigate the subject fully detailed theoretical research has been conducted. Literature and a documentary entitled "Mum's The Word" were used as secondary data. This theoretical element was imperative to the formulation of the empirical dimension. Theoretical perspectives on the social model of disability informed the research process which is reflective of my own personal biography and commitment to the social model. My interest in this subject has been shaped by my experience of my Aunt who had Multiple Sclerosis. I can recall family members expressing relief that there were no children involved in my Aunt's life due to her impairment. I have often reflected on this statement. I am somewhat ashamed to admit that at times I too genuinely thought my Aunt's life was more manageable without children. Reflecting on how my Aunt doted on her nieces however, I believe children would have enriched her life greatly. It is from this ontological position, expressing the belief that prejudice does exist in society against mothers with impairments, that I express my belief, that every woman has the right to be a mother.

Jenny Morris explains her decision to use the voices of eight women with impairments in her study,

'My intention is to make our personal experience political, using an exploration of our subjective reality to assert the validity of our accounts as opposed to the way that non-disabled people view our lives.'

(Morris, 1991, pp. 11)

This research is structured with the same intention. I acknowledge that as a woman without an impairment this may sit oddly with the reader. A political commitment however, on the part of the researcher to the eradication of the oppression that disables individuals, together with a firm belief that discrimination against, or coercion to avoid, women with impairments becoming mothers is an issue that is inherently wrong in our society, enables the researcher to investigate this subject from a stand point.

The question of objectivity is thus raised. Hunt believes there is no middle way in research; the researcher is either committed to serving the interests of an oppressed group or committed to serving the interests of the oppressors (Hunt, 1981 in Sheldon, 2001). Bias and personal experience however, influence one's knowledge, highlighting the

impossibility of being completely objective about things that relate to the human world and our "creations". Popper discusses what he calls "the world of objective knowledge" where he disputes that epistemology provides the base for knowledge production (Popper, 1972 in Lazar, 2004). Rather, knowledge is produced independently all around us and is interpreted and understood by different individuals at different times which continues to raise new problems (Popper, 1972 in Lazar, 2004). Only in this circumstance does Popper believe objectivity is possible (Popper, 1972 in Lazar, 2004). Hunt however, believes that individuals cannot be objective if they take a detached stance (Hunt, 1981 in Sheldon, 2001). Detachment does not guarantee objectivity. Rather an attachment to represent "disabled persons" and "non-disabled persons" fairly affirms for the researcher that her stand point has not hindered her ability to be objective about this subject.

Epistemology

Epistemology is concerned with the theory of "how one knows what one knows". Stanley and Wise believe that epistemological privilege cannot be granted to specific groups

with assumed superior knowledge as the notion of a 'truer' reality does not exist (Stanley & Wise, 1993). Rather they state,

> 'Knowledge…is situated, specific and local to the conditions of its production and thus to the social location and being of its producers.'
> (Stanley & Wise, 1993, pp. 228)

Thus, knowledge is formed by multiple factors such as experience, language, resistance and social situations. It follows then that an epistemology of disability must be based on the lived experiences of individuals with impairments and must endeavour to provide a platform from which their voices can be heard.

It is for this reason that this study utilizes an inductive research approach. Inductive research is largely qualitative and involves the collection of data to generate general conclusions in explaining patterns and regularities in social life (Blaikie, 2000). Blaikie explains that inductive approaches address the "what" questions (Blaikie, 2000). Inductive research however can be criticized as qualitative

methods are inevitably based on the researcher's perspective and what Spicer calls "hunches" or "pre-formulated" theories (Spicer, 2004). It would be difficult to approach research with no form of bias. Thus, while much of the literature that was consulted claimed that women with impairments are oppressed and marginalized, the researcher wished to investigate if this is in fact accurate, and did not merely assume that it is so and thus structure the research on the premise that oppression is inevitable.

The researcher was mindful that her own "standpoint" position may influence the structure and content of the research. The research tool of open ended questions was selected to allow participants freedom to expand upon their answers. As individual experiences interested the researcher in providing understanding to her research objectives a quantative approach was not deemed necessary. This is not to say that the research is therefore not valid. Seale defines validity as:

'The truth-value of a research project: can we say whether the reported results are true?'

(Seale, 2004, pp. 72)

Truth and knowledge are closely linked with the former traditionally defined by experts and professionals. Truth however, is an ever changing concept; it is reinforced by collective experience. Experience can question commonly held "truths", for this reason, the qualitative aspect of this study seeks to challenge or consolidate commonly held "truths" present in society. The researcher believes that the value of research can be found in:

'Whether it promotes insight, understanding or dialogue...whether it gives voice to particular social groups whose perspective has been hidden from public view.'
(Seale, 2004, pp. 72)

The researcher feels these objectives have been met in this study, the research is therefore valid.

Participants' voices were expressed through questionnaires or telephone interviews. There were practical reasons for such a selection, lack of funding and restraints on time meant that email and telephone communication was the

most feasible option. The questionnaire and telephone interviews followed the same open question approach which the researcher acknowledges is somewhat unusual. Bryman states that self-completion questionnaires ordinarily have few open questions and are short in length to reduce respondents tiring (Bryman, 2008). The researcher, however, believed open questions questionnaires provided a more relaxed approach, enabling participants to complete them in their own time and elaborate as little or as much as they wished. This approach also reduced the possibility of "interviewer effects", where participants' responses are influenced by characteristics of the interviewer (Bryman, 2008). Again the researcher was mindful of influencing participants through her theoretical influenced perspective of their lived experience.

Thus, a research tool that enabled the researcher to take a step back was selected. As Mason highlights, some researchers prefer to remove authorial presence in presenting research findings as the selection process itself can be loaded with bias, rather such researchers prefer to present data and their argument but allow the reader to draw their own conclusions (Mason, 2002). This approach has

also been employed in this discussion. It is now necessary to explore the empirical dimension of this study.

The Empirical Dimension

The empirical research was provided by a small group of women with impairments who are mothers or who were pregnant at the time of writing. A request was posted on two websites; Disabled Parents Network and Disability Pregnancy and Parenthood International as well as a posting on the JISCMAIL mailing list (See Appendix 1). The post requested participation from women who were pregnant or mothers, and have physical or sensory impairments acquired pre pregnancy. Eleven responses were received with seven women committing to take part. All of the women agreed to communicate through emails and complete a questionnaire (See Appendix 2). Where this posed difficulties telephone interviews were conducted. Six completed questionnaires were received and one telephone interview was conducted. Follow up contact was made to expand on information provided in the questionnaire via email for two participants and by telephone for one other participant. Telephone

conversations were recorded with the participant's permission, and transcripts were sent to each party for verification and final consent to be granted (See Appendix 3). A short section at the end of the questionnaire requested personal information such as residency, the nature of each individual's impairment, their age, etc. As there were no major disparities between participants this information was not included in the discussion as the researcher felt it was not relevant. Research was analysed through collating information, noting comparisons and highlighting useful quotes and accounts.

Ethical issues

The researcher was mindful of possible power imbalances in this research and sought to consult with participants regularly reiterating confidentiality and integrity as key principles in the research process. Throughout this process participants were given the opportunity to ask questions and withdraw responses or comments. Each participant received an information sheet and a consent form (See Appendix 4). The British Sociological Association's Ethical Code of Practice was studied to ensure the research

process met its criteria. The names of participants were changed in this dissertation with all information remaining strictly confidential.

Limitations of the research

There are of course limitations to this form of research. The request for participants was limited to those women who had internet access. There is also the danger in internet communication that participants' true identity can never be completely verified. Participation was based on physical or sensory impairment owing to the size of this study. This specification was purely for convenience and the specifics of impairment were not intentionally discussed at any point in the research. The researcher is also aware that the research group comprised of white heterosexual British women and is thus not representative of the "disabled community" as a whole. The research thus aims to explore individual experience and draw general conclusions.

Conclusions

In this chapter emancipatory and participatory research has been discussed in relation to this study. The theoretical

and ontological aspects have also been explored and how

the researcher feels they affect her objectivity. Epistemology

has also been investigated and the impact the researcher's

understanding has had on this study. The practical elements

of this dissertation have also been discussed, explaining the

researcher's empirical approach and adherence to a code of

ethics. Finally, limitations to the research have been

discussed. The following chapter will discuss the empirical

findings of this research.

Chapter 4   Barriers To Motherhood

This chapter will discuss and analyse the empirical research study, contrasting the findings with the theory discussed in chapter two. It will begin by exploring what if any discouragement or negative attitudes participants experienced.   The discussion will then look at what if any structural barriers have been encountered by participants. Finally this chapter will examine if attitudinal barriers are responsible for the creation of structural barriers.

Pregnancy: "Risky" or "Brave"?

A documentary video entitled "Mum's The Word" features a lady named "Ellen" who shares how she believed she would never be a mother due to her visual impairment (Mum's The Word, 1992). The documentary explores the notion that women with impairments challenge a deep seated taboo within society (Mum's The Word, 1992). Of the participants in this dissertation all seven women experienced reactions to their pregnancy that at times made them feel

uncomfortable. Interestingly these reactions can be broadly

split into two categories. Four participants described how

family members and health care professionals reacted with

shock and surprise on the discovery of their pregnancies.

Rebecca: My mum and my sister were unsupportive but

mean well…They said I need to…ask for help, it's hard

work and I wouldn't cope with undressing, changing

and lifting the baby.

Emma: [My family were] paranoid that I couldn't

manage looking after a baby…[There were] some

comments and looks on their faces when I said I was

pregnant…I received looks from some medical staff

when I went for an early scan.

Eileen: I think that people give me negative messages

about being a competent mum all the time really,

strangers, acquaintances and even some relatives.

Orla: Some of my relatives were...saying when I was

getting tired well how are you going to cope

afterwards?...Some of the professionals I was working with…gave me a few looks when I said I was pregnant and raised a few eyebrows.

One of the women interviewed as part of the "Mum's The Word" documentary, "Ellen" similarly relates the reactions she encountered when she announced her pregnancy,

'There was silence, pause, and very nice, how are you going to cope?'
(Ellen, 1992, Mum's The Word).

While some participants stated that they believed family and professional enquiries into their abilities were "done with the best of intention'" they still experienced feelings of unease as third parties consciously or not expressed doubt in participant's well being and mothering abilities. Campion argues this is because,

'Society still objects to disabled parents.'
(Campion, 1995, pp. 134).

There is the belief that women with impairments have acted irresponsibly by becoming pregnant as they will be unable to provide the care necessary to raise children (Campion, 1995; Wates, 1997).

"Cathy" also features in Mum's The Word and relates an encounter she had at hospital when she had an emergency check up. Cathy overheard the nurses discussing how her doctor should never have "let her get into that state", i.e. pregnant. Cathy, on hearing this comment shouted out,

'My doctor didn't have an awful lot to do with it!'
(Cathy, 1992, Mum's The Word)

Like Cathy, most of the research participants in this dissertation felt angry and hurt upon receiving such reactions to the news they were pregnant.

Rebecca: After I listened to mum and my sister my happiness went out of the window…I thought I would be a bad mother…I was so worried about what people thought of me being pregnant or being a mum…I had to

have counselling to overcome my fears…and regain my

self confidence.

Emma: Paranoid that I'm not able to look after my

daughter…asking how I'm coping now my daughter is

bigger and more active…it makes me feel as though

they think I can't manage.

Eileen: Surprised: Yes, Angry: Yes.

Prilleltensky discusses that being under society's magnifying

glass in order to ensure one "measures up" as a mother

leads to stress and anxiety (Prilleltensky, 2003).

The three remaining participants however, experienced

contrasting reactions. Reflective of the tragedy model of

impairment where "disability" requires "super human" strength

to achieve what is "normal" (Barnes, 1992), participants

relayed how news of their pregnancies was met with shock,

followed by commendations for "going against the odds" or,

their impairment did not feature in discussions.

Zoe: Not negative attitudes as such, but a few surprised people, and those with the attitude that I am "brave" etc. One of my mum's friends even described my pregnancy as a miracle! She did mean this in the nicest possible way!!

Diane: More people saying I am "brave". I feel that if anything people have felt it is a taboo to talk about how my disability will affect things. I have openly discussed my concerns and thoughts but people can seem to feel they should not mention it, which makes it seem worse than it is.

Andrea: I actually felt friends and doctors encouraged me too much seeming not to realise the difficulties I would undoubtedly have…It would have been good if I could have got a bit more support and understanding about the physical needs let alone emotionally.

Reactions thus differ between individuals. Michelle Wates, features in the documentary Mum's The Word, explains there is no real marker of who and why some

women experience negativity from the people they interact with (Mum's The Word, 1992). There appears to be an imbalance in, and a lack of, understanding towards: the capabilities of mothers with impairments, and the assistance they require. Many health care workers are unaware how disability affects pregnancy (Lipson & Rogers, 2000) and family members are perhaps unaware of the abilities and resourcefulness of women with impairments (Morris, 1991; Olsen & Clarke, 2003). In this study not all women did experience negativity; the reactions they did encounter however, made them feel uneasy. They explained why they believe this to be the case,

Zoe: [I] did have a feeling [I] may not have children. Not sure where this came from – no one in particular, but it was definitely never presumed I would like my sisters…May…have been self imposed due to a lack of self confidence around my own eligibility.

Andrea: I didn't encounter any negative attitudes while I was pregnant at all but I think it is just in built in me from way back…I have felt on a very deep level …that I

didn't have as much right to children as perhaps other

people and I couldn't really tell you where that comes

from.

Diane: I have found myself worrying that when I go out

looking pregnant with my white stick that people will

judge me although no one has said anything negative

to me.

Olsen and Clarke discuss that women with impairments

may feel guilty for becoming mothers due to negative

attitudes they encounter in childhood and early adulthood

about their future prospects for children (Olsen & Clarke,

2003). One could assume therefore that reactions from

individuals have little to do with the anxiety these women

have felt, rather their doubts could be a result of what

Micheline Mason defines as internalised oppression,

'We harbour inside ourselves the pain and the

memories, the fears and the confusions, the negative

self-images and the low expectations, turning them into

weapons with which to re-injure ourselves, every day of

our lives.'

(Mason, 1990, pp. 1).

However this implies that participants' anxieties are rooted in

the personal tragedy theory. Mason however clarifies internal

oppression as,

'Not the cause of our mistreatment, it is the result of our

mistreatment. It would not exist without the real

external oppression that forms the social climate in

which we exist.'

(Mason, 1990, pp. 1)

Diane describes the reactions she encountered as,

Diane: Perpetuating the idea that disability does not sit

easily with motherhood.

While Zoe muses that she was,

Zoe: Probably influenced by society's attitude to disability in general having an impact on my self confidence.

Thus, while participants experienced negativity or feelings of unease they did not attribute the origins of those feelings to personal issues. Like Mason states, elements of unease in society perpetuate notions of inadequacy.

Defining a "Good Mother"

Stereotypes and misconceptions concerning mothers with impairments have been discussed in chapter two. With that in mind participants were asked if they had concerns about their ability to be good mothers.

Diane: I think problems will arise when I need to get out and about with the pram or need to join in an activity with sighted folk...this is as with the rest of my life i.e. it is often others that cause me problems! I mean in an institutional way, not deliberately.

Emma: I know I am quite capable of looking after my daughter.

Eileen: What mother doesn't from time to time?! I think that's normal. I don't think that because of my blindness I was worried about physically being able to do a mum's job.

Zoe: I do recognize that I (and my husband) may need to do some things outside of the norm, and I am never going to have the energy to be earth mother...I do not think this will make me a bad mother at all. Spent my life doing things slightly differently, so no difference here.

One would assume that all women have concerns over their ability to be effective mothers, perhaps even more so among women with impairments. The above participants, however, did not have personal concerns about their ability. As Morris discusses, women with impairments are resourceful and capable of raising children (Morris, 1989). Andrea however

raised concerns that her child may "loose out" because of her impairment,

> Andrea: Many physical things that I can't do and feel that he is missing out…Before he was able to stand, I was unable to put him on the floor…we had to play on the bed.

This concern will vary between individuals and is possibly influenced by what Andrea feels is "normal" mother-child behaviour. Andrea feels playing on the bed is not as enjoyable for her child as playing on the floor, where for other individuals playing on the bed is not an issue. This is reflective of Wates' assertion that "normal" equals "acceptable" (Wates, 1997). Zoe an expectant mother at the time of researching however, acknowledged that,

> Zoe: It is all very well being political about it at this stage, but I think I understand the guilt associated with being a mother just while being pregnant, so I can see that some of my self confidence and belief may waver when the baby is actually in my arms.

Interestingly Zoe acknowledges that her experience of being a "disabled mother" will be different to being "disabled". The difference, however, she muses may result in her confidence wavering. It is perhaps presumptive to attribute her wavering confidence to becoming a mother with an impairment and "doing things differently" but, given the examination in this study of stereotypes and attitudes it is perhaps food for thought.   Part of the guilt Zoe mentions could result from what Newman describes as the belief that children of women with impairments are in some way hindered in their emotional development (Newman, 2003). Andrea raised her concern with her son's development,

> Andrea: I don't want him to be so mindful of me that he doesn't develop naturally as any other child would...I don't want him to become so kind and so thoughtful that it is to his detriment where he puts my needs all the time in front of his...I don't want that to become who he is.

There is the thought that children of mothers with impairments will be unable to put their own needs first, rather, choosing to defer to their mothers needs (Newman, 2003). This potential situation could possibly be avoided through "parenting styles" rather than assuming it is the inevitable outcome for children of mothers with impairments. Emma has similarly had an experience where the "normality" of her child's life was questioned,

> Emma: Some comments have been made, not directly to me, that it is wrong to have children to be carers. How can she, meaning me, manage?

This reflects the notion that parenting tasks are equal to the parenting role (Olsen & Clarke, 2003), where little credit is given to the emotional support and authoritative position of a parent, rather, focus is placed on everyday manual tasks of caring for children.

It is notions like this that can be used to explain the fear of incompetence and having one's children removed from the family environment by social services. Orla and Rebecca both felt this concern.

Orla: I was so scared social services would take my

child away because of feeding him on the floor...I was

really scared because I wasn't doing things the normal

way if you like, that they'd take him away.

Rebecca: I was so scared in case social services would

take my baby away.

If the above situation occurs Lipson and Rogers (2000) state

it is more to do with the issue of inadequate support than

inadequate parenting. Indeed, the common association of

social services with child protection fuels concern over social

service intervention (Olsen & Wates, 2003).

Maintaining Control

Most participants referred to the idea of "normality" in

the context of what they felt is expected and accepted by

others. Wates also found in her research study that parents

with impairments were keen to identify as "normal". Wates

states,

'Asserting one's "normality" is linked ultimately with asserting the right to retain control of one's life.'

(Wates, 1997, pp. 14)

The qualifying factors that enable an individual to claim they have complete control over their own life are difficult to define, as they differ from person to person. It was not apparent that any of the participants felt they did not have control over their lives. Participants did, however, acknowledge various structural barriers experienced during pregnancy and motherhood that may have been avoided through a more accessible environment.

> Zoe: Although the hospital has been fine, [the] choice of antenatal classes has been limited as many are held in individual's homes which cannot guarantee to be accessible to my husband and I.

> Diane: Anti-natal classes obviously relied heavily upon visual material although the lady who ran it was very helpful and would describe things to me. All maternity

info…provided was not in an accessible format and this was not offered.

Eileen: Huge problems accessing written material in accessible format, such as Braille or audio.

Emma: Doctor's didn't have a bed that I could get on to be examined at antenatal checks. No accessible shower in the maternity ward. My daughter was in SCBU for six weeks and the staff were wonderful in helping to make things easier for me to manage.

Orla: I was trying to get physio therapy, physically tailored for me to assist me that I would be as strong as possible for the birth...that took until eighteen weeks of pregnancy to kick up and fight to actually get it.

It may be fair to assume that participants were not intentionally excluded by individual personnel from the use of facilities and accessible information. Indeed some participants found that professionals endeavoured to adapt facilities to make them accessible. It appears that

participants were simply not catered for or even overlooked, the problems lying thus, with the "system". Andrea suggested,

> Andrea: It's not in our culture to assist people with disabilities to have children…I don't think we have the culture where that is accepted at all...people don't seem to be aware of that.'

This is of course speculation where Andrea's opinion is shaped by her experience specifically of the difficulty she faced during her stay on the maternity ward. Orla however, had a similar experience during her time on the maternity ward,

> Orla: The manager of the ward was very helpful saying she would try and get me into the room with a disabled shower…but the room was taken…we got the one next to it and that one had a shower cubicle…it had a disabled seat in the shower but it was only the height of my knees…it was too low for me really to use.

This is a complex issue. An accessible environment must be accessible for everyone, but as this research group have demonstrated, needs differ. Andrea highlights,

> Andrea: Even two people with my disability could have different needs so I do realise how difficult it is.

While this is the case, for the most part participants did by and large experience barriers during their pregnancies. Indeed dissatisfaction with the ease and availability of adaptable child care aids was also expressed.

> Andrea: I had to do everything and I was getting quite hopeless really with the people I contacted, there is nothing manufactured for people with disabilities as parents.

> Zoe: It has taken a lot more research to find these products than I would expect it to take non disabled parents to decide what pram/cot to use…our choices are much more limited.

Emma: No prams that would attach to the wheelchair unless bought from America.

Orla, however found,

Orla: A few more contacts to get more adapted equipment…I've now got a hostess trolley that has been turned into a change mat…that's been absolutely fantastic and worth its weight in gold…I also have the four sided cot…made into a three sided cot…so I have a cot side bed…REMAP did that.

As Wates explains there is no gauge that marks how fairly or unfairly women with impairments are treated (Mum's The Word, 1992)

Conclusions

This chapter has explored empirical research undertaken for this dissertation. It has examined the attitudinal barriers and personal impact they have had on participants. Self assessments of participants' ability to be "good mothers" and participant concerns have also been

discussed. Finally, structural barriers and issues of control in maintaining "normality" were reviewed. The following chapter will draw conclusions by relating the empirical findings with the theoretical research.

Chapter Five - Conclusions

The nature of qualitative research makes it difficult to draw conclusions of a generalised significance as data is based upon individual experiences of the social world. This dissertation has sought to examine the link between social perceptions of disability and the "creation" of negative attitudes towards mothers with impairments through communicating with a small research group of mothers with impairments.

The empirical study revealed that four research participants encountered negative attitudes and a questioning of their decision to become mothers. The remaining three participants however, were almost "over encouraged" throughout their pregnancies. Both reactions interestingly created feelings of unease for all participants. This is possibly due to the aforementioned taboo surrounding mothers with impairments. Elements of this taboo were manifest in the lack of information given, and provision made for, participants during pregnancy. Physical and structural

barriers were also apparent through discussions with participants adding emphasis to the notion that women with impairments are largely overlooked in society as potential mothers.

While some participants encountered positive and informative professionals and services it was on an ad hoc basis which, presents the question are all women with impairments necessarily catered for in health care provisions and services for "new mums"? Certainly this is a further research avenue that could be explored.

The writings of women with impairments have heightened awareness of their right and abilities to be effective mothers. Indeed some professionals are more compliant in providing information and support to mothers with impairments, but uniformity across service providers and an understanding of the differing needs of various impairments appears to still be lacking. As Lipson and Rogers (2000) attest it would appear that health care professionals accommodate mothers with impairments as they present themselves rather than striving to eradicate disabling barriers more generally.

With the presence of stereotypes and misperceptions surrounding impairment and the continued influence of medical model understandings of disability it is not surprising that negative attitudes towards mothers with impairments linger in society. This study's findings do in part echo the research work of Olsen and Wates (2003) and Olsen and Clarke (2003) in that experience differs between individuals, and, while some experienced what they interpreted to be negative attitudes during their pregnancies, others did not. All participants did however encounter structural or attitudinal barriers in some form.

It is my assertion that despite living in a society that promotes equal and human rights, theories of disability as: "debilitating" and "tragic" pervade societal attitudes perpetuating the taboo, that, women with impairments are incapable of becoming mothers. This is further emphasised in the lack of provision and aids provided to such women and the structural barriers they encounter. Inevitably this has a disabling effect.

Bibliography

Bailey, R. (1996) 'Prenatal Testing and the Prevention of Impairment: A Woman's Right to Choose?', pp. 143 – 167 in J, Morris (ed.) **Encounters with Strangers: Feminism and Disability**. London: The Women's Press.

Barnes, C. (1991) 'Discrimination: Disabled People and the Media', **The Disability Archive UK**, URL (22/08/07) : http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/Media.pdf

Barnes, C. (1992) 'Disabling Imagery and the Media', **The Disability Archive UK**, URL (22/08/08) : http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/disabling%20imagery.pdf

Barnes, C. (1996) 'The Social Model of Disability: Myths and Misconceptions', **The Disability Archive UK**, URL (22/08/08) : http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/Coaliton.pdf

Barnes, C. (1996a) 'Theories of Disability and the Origins of the Oppression of Disabled People in Western Society', pp. 41 – 60 in L, Barton (ed.) **Disability and Society: Emerging Issues and Insights**. New York: Longman Publishing.

Barnes, C. & Mercer, G. (2003) Disability. Oxford: Polity.

Blackwell-Stratton, M. Breslin, ML. Mayerson, AB. Bailey, S. (1998) 'Smashing Icons: Disabled Women and the Disability and Women's Movements', pp. 306 - 332 in M, Fine & A, Asch (eds.) **Women with Disabilities: Essays in Psychology, Culture and Politics**. Philadelphia: Temple University Press.

Blaikie, N. (2000) **Designing Social Research: The Logic of Anticipation**. Cambridge: Polity Press.

British Sociological Association (2002) 'Statement of Ethical Practice', **Sociology Central**, URL (22/08/08) : http://www.sociology.org.uk/as4bsoce.pdf

Brown, EB. (1995) 'What Has Happened Here? The Politics of Difference in Women's History and Feminist Politics', pp. 272 – 287 in L, Nicholson (ed.) (1997) **The Second Wave: A Reader in Feminist History**. London: Routledge.

Bryman, A. (2008) **Social Research Methods**. Third Edition, Oxford: University Press.

Bury, M. (1996) 'Defining and Researching Disability: Challenges and Responses', pp. 17 – 38 in C, Barnes & G, Mercer (eds.) **Exploring the Divide**. Leeds: The Disability Press.

Campion, MJ. (1995) **Who's Fit to be a Parent?**. London: Routledge.

Campling, J. (1979) 'Better Lives For Disabled Women' **The Disability Archive UK**, URL (22/08/08) : http://www.leeds.ac.uk/disability-studies/archiveuk/Campling/better%20lives.pdf

Clements, L. & Read, J. (eds.) (2008) **Disabled People and the Right to Life: The Protection and Violation of Disabled People's Most Basic Human Rights**. Oxon: Routledge.

Crosby, C. (1992) 'Dealing with Differences', pp. 130 – 143 in J, Butler & J, Scott (eds.) **Feminists Theorize the Political**. London: Routledge.

Darwin, Major L. (1928) **What is Eugenics?**. The Forum Series, No. 9, London: Watts & Co.

Fawcett, B. (2000) **Feminist Perspectives on Disability**. Essex: Pearson Education Limited.

Fine, M. & Asch, A. (eds.) (1998) 'Introduction: Beyond Pedestals', pp. 1 – 37 in **Women with Disabilities: Essays**

in Psychology, Culture and Politics. Philadelphia: Temple University Press.

Finger, A. (1990) **Past Due: A Story of Disability, Pregnancy and Birth**. London: The Women's Press.

French, S. (1994) 'Researching Disability', pp. 136 – 147 in S, French (ed.) **On Equal Terms: Working with Disabled People**. Oxford: Butterworth-Heinemann Ltd.

French, S. & Swain, J. (2000) 'Good Intentions: Reflecting on Researching the Lives and Experiences of Visually Disabled People', pp. 35 - 54 in **Annual Review of Critical Psychology**, Vol. 2

Gillespie-Sells, K; Hill, M & Robbins, B (1998) **She Dances to Different Drums: Research into Disabled Women's Sexuality**. London: King's Fund.

Greer, G. (2006) **The Female** Eunuch. London: Harper Perennial.

Hooks, B. (2000) **Feminism is For Everybody: Passionate Politics**. London: Pluto Press.

Hunt, P. (1981) 'Settling Accounts with the Parasite People: A critique of "A Life Apart" by EJ. Miller & GV. Gwynne', pp. 37 – 50 in **Disability and Challenge**. Vol. 1.

Johnson, C. (2005) 'If Only they Were Disabled, they Wouldn't Complain About Being Ugly', pp. 41 – 45 in C, Kraus (ed.) **Between Myself and Them: Stories of Disability and Difference**. Ontario: Second Story Press.

Keith, L. & Morris, J. (1996) 'Easy Targets: A Disability Rights Perspective on the "Children as Carers" Debate' pp. 89 – 115 in J, Morris (ed.) **Encounters with Strangers: Feminism and Disability**, London: The Women's Press.

Lazar, D. (2004) 'Selected Issues in the Philosophy of Social Science', pp. 7 - 19 in C, Seale (ed.) **Researching Society & Culture**. Second Edition, London: Sage.

Lipson, JG & Rogers, JG (2000) 'Pregnancy, Birth and Disability: Women's Health Care Experiences' pp. 11 – 26 in **Health Care for Women International**, Vol 21, Part 1.

Longhurst, R. (2008) **Maternities: Gender, Bodies & Space**. London: Routledge.

Mason, J. (2002) **Qualitative Researching**. Second Edition, London: Sage Publications.

Mason, M. (1990) 'Internalised Oppression', **The Disability Archive UK**, URL : (22/08/08) : http://www.leeds.ac.uk/disability-studies/archiveuk/Mason,%20Michelene/mason.pdf

Mintz, S. (2007) **Unruly Bodies: Life Writing By Women With Disabilities**. Chapel Hill: University of North Carolina.

Morris, J. (1989) **Able Lives: Women's Experience of Paralysis**. London: The Women's Press.

Morris, J. (1991) **Pride Against Prejudice: A Personal Politics of Disability**. London: The Women's Press.

Morris, J. (1996) 'Introduction', pp. 1 – 16 in J, Morris (ed.) **Encounters with Strangers: Feminism and Disability**. London: The Women's Press.

Mum's The Word (1992) Video Documentory, London: Pal Productions.

Newman, T. (2003) **Children of Disabled Parents: New Thinking About Families Affected by Disability and Illness**. Dorset: Russell House Publishing.

Oakley, A. (1979) **Becoming a Mother**. Oxford: Martin Robertson & Company Ltd.

Oakley, A. (1980) **Women Confined: Towards a Sociology of Childbirth**. Oxford: Martin Robertson & Company Ltd.

Oakley, A. (1986) **The Captured Womb: A History of the Medical Care of Pregnant Women**. Oxford: Basil Blackwell Ltd.

Oliver, M. (1990) **The Politics of Disablement**. London: The Macmillan Press Ltd.

Olsen, R. & Clarke, H. (2003) **Parenting and Disability: Disabled Parents' Experiences of Raising Children**. Bristol: The Polity Press.

Olsen, R. & Wates, M. (2003) **Disabled Parents: Examining Research Assumptions**. Totnes: Research in Practice.

Parker, G. (1993) **With this Body: Caring and Disability in Marriage**. Buckingham: University Press.

Popper, KR. (1972) **Objective Knowledge**. Oxford: The Clarendon Press.

Prilleltensky, O. (2003) 'A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities', pp. 21 – 47 in **Society and Disability**. Vol. 21, No. 21.

Priestley, M. (2003) **Disability: A Life Course Approach**. Cambridge: Polity Press.

Prilleltensky, O. (2004) **Motherhood and Disability: Children and Choices**. Basingstoke: Palgrave Macmillan.

Reason, P. & Heron, J. (1986) 'Research with People: The Paradigm of Co-operation Experiential Enquiry', pp. 456 – 476 in **Person-Centred Review**. Vol. 1, Part 4.

Sanders, T. (2007) 'The Politics of Sexual Citizenship: Commercial Sex and Disability', pp. 439 – 455 in **Disability and Society**. Vol. 22, No. 5.

Shakespeare, T. (1996) 'Disability, Identity and Difference', pp. 94 – 113 in C, Barnes & G, Mercer (eds.) **Exploring the Divide**. Leeds: The Disability Press.

Shakespeare, T. (1998) 'Choices and Rights: Eugenics, Genetics and Disability Equality', pp. 665 - 681 in **Disability and Society**. Vol. 13, No. 5.

Shakespeare, T. (2008) 'Disability, Genetics and Eugenics' pp. 21 – 30 in J, Swain & S, French (eds.) **Disability on Equal Terms**, London: Sage

Sheldon, A. (2001) 'Disabled People and Communication Systems in the Twenty First Century', **The Disability Archive UK**, URL (22/08/08) : http://www.leeds.ac.uk/disability-studies/archiveuk/Sheldon/thesis2viv2.pdf

Sheldon, A. (2004) 'Women and Disability', pp. 69 – 74 in J, Swain; S, French; C, Barnes; C, Thomas (eds.) **Disabling Barriers – Enabling Environments**. Second Edition, London: Sage.

Spicer, N. (2004) 'Combining Qualitative and Quantative Methods', pp. 294 - 303 in C, Seale (ed.) **Researching Society and Culture**. Second Edition, London: Sage.

Stables, J. & Smith, F. (1999) 'Caught in the Cinderella Trap: Narratives of Disabled Parents and Young Carers', pp. 256 - 268 in R, Butler & H, Parr (eds.) **Mind and Body: Geographies of Illness, Impairment and Disability**. London: Routledge.

Stanley, L. & Wise, S. (1993) **Breaking Out Again: Feminist Ontology and Epistemology**. Second Edition, Oxon: Routledge.

Stanworth, M. (1990) 'Birth Pangs: Conceptive Technologies and the Threat to Motherhood', pp. 288 - 304 in M, Hirsch & EF, Keller (eds.) **Conflicts in Feminism**. London: Routledge.

Stone, E. & Priestley, M. (1996) 'Parasites, Pawns and Partners: Disability Research and the Role of Non-Disabled Researchers', pp. 699 - 716 in **British Journal of Sociology**. Vol. 47, Part 4.

Sullerot, E. (1971) **Women, Society and Change**. Translated from the French [MS] by Margaret Scotford Archer, London: Weidenfeld & Nicolson.

Thomas, C. (1999) **Female Forms: Experiencing and Understanding Disability**. Buckingham: Open University Press.

Tomlinson, JM. (ed) (2005) **ABC of Sexual Health**. Second Edition, Malden, Mass: Blackwell.

United Nations (1981) 'Convention on the Elimination of All Forms of Discrimination Against Women' **Division for the Advancement of Women** (21/08/08) : http://www.un.org/womenwatch/daw/cedaw/

United Nations (2006) 'Convention on the Rights to Persons with Disabilities' **Convention on the Rights of Persons with Disabilities** (21/08/08) : http://www.un.org/disabilities/convention/conventionfull.shtml

UPIAS (1976) **Fundamental Principles of Disability.** London: Union of the Physically Impaired Against Segregation.

Virgilio, AD. (2005) 'What Do You Do When You Live In A Shoe?', pp. 29 - 32 in C, Kraus (ed.) **Between Myself and Them: Stories of Disability and Difference**. Ontario: Second Story Press.

Wates, M. (1997) **Disabled Parents: Dispelling the Myths**. Cambridge: National Childbirth Trust Publishing in association with the Radcliffe Medical Press.

Wates, M. & Jade, R. (eds.) (1999) **Bigger than the Sky: Disabled Women on Parenting**. London: The Women's Press.

Zarb, G. (1992) 'On the Road to Damascus: First Steps Towards Changing the Relations of Disability Research Production', pp. 125 - 138 in **Disability, Handicap and Society**. Vol. 7, Part 2.

<u>Appendix 1</u>   <u>Internet Posting</u>

Subject: ***REQUEST: PLEASE HELP WITH RESEARCH

INTO DISABILITY AND PREGNANCY/MOTHERHOOD***

Good Morning,

I am currently a Masters student at Leeds University. I am

based at the Centre for Disability Studies and my degree title

is 'Disability and Gender.' My chosen dissertation topic is to

look at pregnancy among disabled women. Because there is

a limit to the size of project that I am able to undertake, I have

chosen to focus my research on pregnancy among women

with physical impairments, in particular. I am very keen to

talk to any women who may be able to help me.

I am aware this may be a sensitive topic for some women

and will respect the wishes of the women involved if they do

not want to share certain experiences and of course all

respondents will be kept anonymous. I am very flexible

regarding how I can conduct the research, I can send

questionnaires, telephone interviews, use instant messenger,

email and visit individuals providing they are in the UK, this

can be determined by the participants and what they feel comfortable with.

My research will focus on, what if any, attitudinal and structural barriers disabled pregnant women face throughout their pregnancy and after the birth of their child. I would also be interested to discuss the support and reactions women have encountered from the wide range of health and social care professionals involved throughout their pregnancy and again after the baby is born.

If anyone can assist me in this research I would be most grateful and anxious to hear from you, your help and contributions will be treated with respect. Similarly if anyone knows of someone who maybe able to talk to me but is not on this list please could I ask of you to forward this email. For your information my dissertation supervisor is Dr Angharad Beckett (School of Sociology and Social Policy, University of Leeds) and she can be contacted if anyone wishes to clarify my topic or discuss anything whatsoever with her regarding this request. Her email address is: A.E.Beckett@leeds.ac.uk

Many thanks in advance and I look forward to hearing from

you, Victoria Radcliffe

Appendix 2 An Example Questionnaire

Research Questionnaire into Disability, Pregnancy &
Motherhood

Thank you for giving your time in filling in the following questionnaire. If you wish to expand upon any questions beyond the space here please feel free to attach a page at the end or email me your comments. Similarly if there is anything you do not feel comfortable answering please leave the question out. Your participation is greatly appreciated.

1) Did you ever feel discouraged by anyone about the idea of motherhood? Tick all that are relevant

School Teachers

Family X Not so much discouraged than paranoid
        that I couldn't manage looking after a baby.

Doctors

Friends

Others   please provide details

2) Did you/Are you enjoy(ing) your pregnancy?

Yes x No Do you have any further comments?

I had a rough pregnancy but still enjoyed it.

3) Have you encountered any negative attitudes from people you have frequent contact with? If yes I would be most grateful if you could please provide details here, if not, please go to question 5

Yes x No

Some comments, & looks on their faces when I said I was pregnant, by some family members. Looks I received from some medical staff when I went for early scan, due to some bleeding I had at 6 weeks pregnant.

4) If so, how did this make you feel? (Please tick all that are relevant)

Surprised

Angry   X

Hurt   X

Insecure   X

Other   X   please provide details

Paranoid that I'm not able to look after my daughter, even though I know I'm not having problems doing so. Also keep asking how I'm coping now my daughter is getting bigger & more active. Though this could just be curiosity it makes me feel as though they think I can't manage.

5) Have you had concerns yourself, about your ability to be a good mother?

Yes   X   No

If yes and you do not mind doing so, please provide details

I know I am quite capable of looking after my daughter though some comments that have made, not directly to me, that it is wrong to have children to be carers. How can she, meaning me, manage?

6) Have you encountered any 'avoidable' barriers in the preparation for, or day to day care of your child? I am thinking about possible problems with things such as the built environment, transport, design of consumer goods.

	Y/N	Please provide details
Transport	N	
Accessible Buildings	Y	Finding a bungalow that is suitable i.e that I can get in & out of.
Manufacturing of child care aids and products	Y	No prams that would attach to wheelchair unless bought from America. Hospital equipment too high for me to care for daughter in hospital. My daughter was in SCBU for six weeks & the staff were wonderful in helping to make things easier for me to manage. Providing me with low tables to bathe her & anything else I found difficult to do.
Personal Assistance	N	
Other	Y	DRs Didn't have bed I could get on to be examined at antenatal checks. I had to go to the hospital. No accessible shower in maternity ward.

7) Have you ever had any contact/involvement with social services?

No

Yes   X

If yes, how would you describe your experience? For example, supportive and helpful? overly intrusive? Even a very short explanation of your experiences would be very much appreciated.

Nothing to do with pregnancy…

8) If you have had more than one pregnancy has your experience of motherhood, attitudes towards you and support provided differed with each child?

No

Yes   If yes and you do not mind please provide details

Finally, might I ask you a few personal questions?

9) Ethnicity (please circle as appropriate)

A. White
1. British
2. Irish
3. Any Other White background, please write in
_____1_____
B. Mixed
4. White and Black Caribbean
5. White and Black African
6. White and Asian
7. Any Other Mixed background, please write in
_____
C. Asian or Asian British
8. Indian
9. Pakistani
10. Bangladeshi
11. Any Other Asian background, please write in
_____
D. Black or British Black
12. Caribbean
13. African
14. Any Other African background, please write in
_____
E. Chinese or other ethnic group
15. Chinese
16. Any Other, please write in
_____

10) What is the nature of your impairment?

Some of my joints dislocate, I am a fulltime wheelchair user.

11) Where were you resident when you were pregnant?

UK? X   Elsewhere   Please provide

12) Where were you resident when your child/children was/were born?

UK? X   Elsewhere   Please provide

13) At what age did you have your first child?

Under 18   18-24   25-35   Over 35 X

14) When did you have your first child? I would be grateful if you could give me the year(s).

Date Removed

Thank you very much for your time, your views will remain confidential

V: The first thing I had asked had you been discouraged about becoming a mother by anyone like school teachers, of family, or doctors and friends?

O: It was more worry about how I'd be after the birth and my back problems, how I'd actually cope with myself on a day to day basis and then how I'd actually cope with the care of my children, was more worrying and concern really. I had some people in social services that when I said I was thinking about getting pregnant or I just got pregnant would give me a look, other than that its been absolutely fine, maybe in their head they think what's the daft girl up to now? It's not been too bad I just have that sense of erm...

V: Do you think with people that are close to you like family, do you think they have more concern for your welfare rather than anything else where people that don't know you like

people that are maybe in the health care profession or social

services do you think they are more judgemental about it?

O: Yes. They have not come across that many but they've

given the impression, they've actually said mine is a pretty

rare case there haven't been many mums that are disabled

V: Really?

O: Yeah believe it or not and its crazy. I mean I was really

quite shocked about it, she didn't know quite what to do and

where to turn whatever, and ended up getting her line

manager, if you like, involved to help because she wasn't

quite sure what to do

V: I mean I find that kind of crazy, I don't think its unusual

although I have only spoken to a few a small group of ladies

for this but I know one of them said they found there wasn't a

disabled shower in the maternity ward that she was in. I

thought wow that's crazy. Maybe it is quite common but

that's kind of the purpose of me doing a little investigation

O: To be honest with you I think its all a bit different but I was lucky enough in the fact, well, lucky I say, I got an appointment with the ward manager to see what she could do, she was really helpful and she said right we're going to try and get you into this room after you've had him, and when I was in labour, not for very long, they put me in a room that was opposite you know the corridor well across ways, you know what I'm trying to say, to get to the loo

V: So you were pretty close?

O: Yeah, so even though it wasn't a disabled toilet I didn't have to walk very far. They did try and get me to have a shower, they said do you really want the bath? And i said yeah its a treat and i mean having the care available there for me to have one, then when I got moved up to the ward afterwards the manager there was very helpful saying that she would try and get me into a certain room with a disabled shower and all the rest of it but that room was taken unfortunately at the time I was there so we got the one that next to it and that one had a shower cubicle, toilet and that was that but it had a disabled seat in the shower but it was

only the height of my knees, it was one of those you know fold down ones

V: Yeah, was it too low?

O: Yeah exactly, it was too low for me to use really so I made sure that when my husband was visiting I made sure I had a shower then standing up, because just to make sure that if I did slip or fall there was someone there to sort me out really

V: So I guess you could think its like a piecemeal effort sometimes

O: Yep. I mean they did try and get me in that room but it was taken that first night which was a problem really. In my room the sink was in the actual bedroom if you like, it was a single room but the sink was way across the other side of the room so to go and wash my hands I'd have to go right the way across the room

V: I suppose, I mean especially with babies they can't necessarily plan for whose going to come in when but I

suppose that doesn't help from your personal situations with

things being a bit better.

Research Project: Disability, Pregnancy & Motherhood

Researcher: Victoria Radcliffe

Information sheet

I am a student from the University of Leeds and am working on a project that is about disability, pregnancy and motherhood. An important part of this study is to find out what if any, attitudinal and structural barriers disabled pregnant women face throughout their pregnancy and after the birth of their child. The research will also examine the support and reactions participants have encountered from professionals involved in their pregnancy and after the child is born. Finally the research will explore how and if, this experience effects or changes the identity of the participants.

I would very much like to talk to you about these issues and to hear your views.

Respondents will be asked to take part in two questionnaires via email, with the possibility of follow up contact, in the form or telephone interviews or further email correspondence. This can be determined by what participants feel comfortable with.

With your permission, your views will be recorded and I will put your views together with those of other respondents in order to gain a better understanding of disability and pregnancy. No respondent will be named at any point in the writing up of this research and the views of all respondents will be treated confidentially.

If you would like to know more about this research before you reach your decision, please contact me at ss07ver@leeds.ac.uk or on telephone no. 07948 977 355. If you wish to speak to my supervisor Dr Angharad Beckett (School of Sociology and Social Policy, University of Leeds) she can be contacted at A.E.Beckett@leeds.ac.uk

I do hope that you will be willing to take part in this research and thank you in advance for your attention to this matter.

**Please find a consent form attached which I would be most grateful if you would complete and return to Victoria Radcliffe, Flat 609, The Tannery, Cavendish Street, Leeds, LS3 1AG

CONSENT FORM

Research Project: Disability, Pregnancy & Motherhood

Name:………………………………………………………………

Please read the following statements and tick the appropriate boxes.

I have read the information sheet attached
and understand what this project is about

Yes ☐   No ☐

I have been able to ask questions about
the project before reaching my decision.

Yes ☐   No ☐

I understand that I can change my mind
at any point and decline to be involved
in this research.

Yes ☐   No ☐

I understand that the information/opinions
I give during the project will be kept securely
and confidentially and that no respondent
will be named in any research publications.

Yes ☐   No ☐

I consent to taking part in this project.

Yes ☐ No ☐

Your

Signature:……………………………….Date:…………

University of Leeds. Department: School of Sociology and Social Policy. TEF rating: Read full university profile.Â Sociology, social policy and anthropology. The graph shows median earnings of graduates who achieved a degree in this subject area one, three and five years after graduating from here. Â£18k. Â£18k. Since its foundation, the School of Sociology and Social Policy has been a major centre of research and graduate training, and has produced some of the leading academic figures in their fields. The School is home to several distinctive research groups and centres, specialising in the broad areas of: gender, disability studies, racism and ethnicity, family and life course, health technologies and social and political thought. More on Our research and expertise. Our experts. Political Sociology (2). Politics (1). Comparative politics.Â American University of Business and Social Sciences (10) American University, Washington (15) Amity University (16) Amsterdam University of Applied Sciences (AUAS) (1) Anglia Ruskin University ARU (139) Arden University (25) Arts University Bournemouth (12) Ashridge (5) Aston University (94) Audencia Business School (7) Bangor University (195) Beijing Institute of Technology (9) Beijing Normal University (7) Berlin International University of Applied Sciences (2) Berlin. The Sociology team encompasses teaching and research in the areas of sociology and social psychology. You'll discover what you already know, and re-assess what and how you think.Â Chrome users will need to use browser extensions. Animation Policy from Google will help you set your own preferences. Hide GIFS I am Reading lets you turn animated GIFs on when you want them, and off when you donâ€™t want to get distracted. Microsoft Edge. There is currently no way to disable animations within Microsoft Edge.Â Senior Lecturer / Leeds School Of Social Sciences. Dr Natalia Gerodetti. Course Director / Leeds School Of Social Sciences. Dr Tom Goodwin. Senior Lecturer / Leeds School Of Social Sciences. Dr Joseph Ibrahim. Senior Lecturer / Leeds School Of Social Sciences. Our Social Policy and Sociology degree is an interdisciplinary programme which examines the changing nature of social relationships, why social problems and inequalities exist and how the institutions of the state respond to them. Youâ€™ll investigate the dynamics between individuals and wider society and how they impact on one another. Bridging big ideas and practical problems, youâ€™ll study important thinkers and theories in sociology alongside issues like social integration, power and class divisions. At the same time, youâ€™ll explore how poverty, health, housing, education and crime among others have come to be seen as social problems and examine education, housing and urban policies to understand how states provide for peopleâ€™s welfare. English language Test.