

4 Pregnant and Disabled 'Body Troubles'?

This chapter continues the theme of pregnancy but provides a different window on maternities, gender, bodies, and space. It examines the experiences of pregnant women with physical disabilities including, but not only, conditions such as arthritis (which can go into remission when women are pregnant), amputations, cerebral palsy, degenerative disk disease, fibromyalgia, congenital conditions, lupus, multiple sclerosis, neuromuscular disorders, spina bifida, and spinal cord injuries. Women with physical disabilities are often as fertile as women without disabilities but disabled women who decide to get pregnant sometimes encounter opposition, discrimination and a great deal of skepticism (Prilleltensky 2003). Some people may be surprised that a disabled woman would contemplate having sex, let alone have a baby.¹

The basic argument mounted in this chapter is that pregnant women with physical disabilities inhabit some of the same emotional, discursive and material spaces as non-disabled pregnant women. They also, however, inhabit some 'different' spaces. The chapter is written from the perspective of a non-disabled woman. Not having walked in the shoes of a disabled woman my understanding is likely to be limited but as researchers it is not always imperative to first live what we study. I did not want to exclude the experiences of disabled pregnant women from the book because it seems that their experiences provide useful insights into the array of different constructions of motherhood. Whereas countless women in many parts of the world experience social pressure to *have* children, disabled women often find they are under pressure *not* to have children (Rogers 2006: 1).

One of the most useful sources of information drawn upon extensively in this chapter is Judith Rogers' (2006) *The Disabled Woman's Guide to Pregnancy and Birth*. Rogers has been disabled since birth. She argues that in recent years there has been greater acceptance of disabled people's sexuality and sexual needs. 'The next step has to be validation of the reproductive capacity of disabled women' (Rogers 2006: xi). When Rogers became pregnant she found there was hardly any literature that addressed her particular needs. There is a vast literature on pregnancy, labour, delivery and

child rearing in general but little of this literature is given over to addressing the specific needs of the disabled.

Rogers collected together academic work and stories from disabled pregnant women in an attempt to further understand their lived experiences. In order to write this chapter I read Rogers' book (it is a weighty 500 pages) and a range of other mainly academic texts (although work in this area appears to be rather limited) on the experiences of disabled pregnant women and mothers, paying careful attention to issues of spatiality. I looked for information regarding the emotional, discursive and material spaces inhabited by physically disabled pregnant women.

The chapter is situated theoretically within the field of feminist disability studies, which

is more than research and scholarship about women with disabilities, just as feminist scholarship extends beyond women to critically analyse the entire gender system. Like feminist studies itself, feminist disability studies is academic cultural work with a sharp political edge and vigorous critical punch. (Garland-Thomson 2005: 1557)

Feminist geographical work on disability also informs this chapter. I aim to build on the work of other feminist, social, cultural and health geographers such as Vera Chouinard and Ali Grant (1995), Ruth Butler and Hester Parr (1999), Joyce Davidson (2001), Isabel Dyck, Nancy Davis Lewis and Sara McLafferty (2001), and Pamela Moss and Isabel Dyck (2002) who have examined women's experiences of illness, impairment and disability. Disabled pregnant women often face 'body troubles' (Dyck 1999) because dominant discourses dictate that their bodies — bodies that are considered unreliable, unsightly and sick — should not reproduce. Over the past few years a literature on disabled parents (and their children who often take care of them) has begun to emerge (see Grue and Tafjord Lærum 2002; McKeever *et al.* 2003; Prilleltensky 2003; Thomas 1997) but still little has been published on disabled pregnant women. This chapter will add to these debates by exploring the 'body troubles' but also the joys and pleasures experienced by physically disabled pregnant women.

Numerous disability activists and scholars have over the past decade questioned the assumption that disability is a lack, an excess, or a failing of some sort (see Gleeson 1999; also see Chapter 8 this volume on constructions of subjects as lacking). Instead disability has come to be understood in broadly social rather than medical terms (Irmie 1996; Oliver 1990). Geographers have stressed the importance of understanding not only the intersections between impairment and sociality, but also space. Dyck (1995: 308) explains:

Close attention to the body in material context provides the potential for exploring the involvement of dominant discourses and power rela-

tions in the social construction of ideas about the body and identities, including that of the 'disabled body' and the implications of the experience of place.

A complex relationship exists between place, maternity and disability and much work remains to be done in this area. My contribution is limited to examining concepts of body and space in an attempt to better understand the daily lives of a few women who are pregnant and physically disabled.

Rogers' (2006) book has been invaluable in helping with this task. She has gathered together 'the stories of 90 women with disabilities who chose to have children and who were willing to share their experiences of pregnancy through the postpartum period' (Rogers 2006: 1). Rogers also provides an appendix that contains these 90 women's detailed pregnancy histories. Issues of space and place, however, are not mentioned in all these histories.

In short, the chapter attempts to offer insights on the embodied experiences of some pregnant physically disabled women and the emotional, discursive and material spaces that they shape and are shaped by. It begins with a discussion of the emotional spaces and how disabled pregnant women often feel both affirmed and disapproved of for becoming pregnant. Second, the chapter examines the ways in which the eugenics movement created an oppressive discursive space for disabled women and their offspring that constructed them as lacking. The sentiments of eugenics have not disappeared entirely today even if the science has been discredited. However, disabled women have resisted the societal quest for bodily perfection and instead taken up their rights to become mothers. Finally, the chapter looks at some of the difficulties faced by disabled pregnant women and mothers in relation to mobility and the disabling effects of some material environments. Negotiating the material spaces often associated with motherhood such as homes, clinics, birthing wards, and shopping areas can sometimes be a challenge for disabled pregnant women and mothers.

EMOTIONAL GEOGRAPHIES: NEGOTIATING NEW SUBJECTIVITIES

Over the past few years geographers have begun to pay more attention to 'emotional geographies' (see Davidson, Bondi and Smith 2005, and the special issue on emotional geographies in *Social and Cultural Geography* 2004, Vol. 5, No. 4). In the editorial to this special issue of *Social and Cultural Geography* Joyce Davidson and Christine Milligan (2004: 523–524) claim:

Our emotional relations and interactions weave through and help form the fabric of our unique personal geographies. We live in worlds of

pain or of pleasure; emotional environs that we sense can expand or contract in response to our experience of events ...

This is especially evident in some of the geographical research on disability. For example, Ruth Butler and Hester Parr's edited collection *Mind and Body Spaces* (1999) contains a number of contributions that focus on the emotional highs and lows that go along with continual efforts to negotiate (dis)abling social and material spaces. Contributions such as Gill Valentine's (1999) on 'what it means to be a man,' Isabel Dyck's (1999) on 'women, the workplace and negotiations of a disabled identity,' and Hester Parr's (1999) on 'different geographies of mental health' are testimony to the emotional geographies of those who live with illness, impairment and disability.

The emotional geographies of pregnant physically disabled women illustrate that at times these women feel excluded from the mainstream on account of their disability. At other times they feel accepted as part of a new community of mothers. Examining pregnant physically disabled women's pains and pleasures as experienced across a range of sites and scales reveals a complex geography of continual (re)negotiation with self, loved ones, family, friends, co-workers, and strangers. It quickly became apparent when examining the narratives of pregnant physically disabled women that their experiences and emotional geographies vary enormously — a point that is borne out in the narratives that follow.

Deborah Kent is blind. From a young age she had always dreamed of becoming a mother but her blindness marked her as 'different'. She felt she had no role models to follow. When Kent finally became pregnant she was thrilled.

I loved being pregnant. Unlike those Victorian ladies who went into confinement, disappearing behind whispers and closed doors the moment their 'delicate condition' became apparent, I wanted the world to take notice of my bulging belly. I seized every opportunity to walk the streets, to ride the city buses, to present myself in public. I revelled in the anticipation of motherhood, and somewhere too, I felt an exhilarating sense of defiance. (Kent 2002: 81)

When Kent became pregnant she felt healthy and happy, and received affirmations from supportive parents and friends for fulfilling the role of mother. However, she also suffered prejudice, self-doubt and anxiety about her ability to be mother, and a fear of others considering her to be an inadequate parent on account of the fact she is blind.

Kent's narrative relays some of the highs and lows, the joys and sorrows, of embarking upon motherhood. Her story of becoming pregnant is useful because she identifies a number of issues that arose in many disabled women's accounts of pregnancy. Kent reflects:

No one ever told me point-blank that 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. Nearly all of the women I knew were mothers, but not one of those mothers was blind. It was always a sighted mom who pushed the stroller, ran the Scout troop, or called to her kids over the backyard fences. Throngs of sighted mothers filled the auditorium for music programs at school. I knew only two adult blind women, and both of them were childless. In my young mind, this sample translated to a global truth. Sighted women were mothers; blind women were not. (Kent 2002: 81)

Although words of prohibition were never uttered, Kent from an early age felt excluded from the spaces of motherhood. Fortunately this did not deter her and at age 34 she became pregnant and took pleasure in joining a new community of mothers. Kent (2002: 83) says:

No longer was my blindness the primary focus of attention when I met someone for the first time. Now, instead of my disability, people talked about pregnancy and parenting. These things they understood, valued, and celebrated. My blindness receded into the background. I was no longer an outsider; I was one of the initiate at last. (Kent 2002: 83)

Others with physical disabilities report similar experiences. Grue and Tafjord Lærum (2002) claim that a theme that emerged from their interviews with 30 mothers with physical disabilities in Norway was that disabled women become accustomed to their bodies receiving a great deal of medical attention, focusing on what is wrong with them, and what might enable their bodies to function better. The mothers in their study commented that when they became pregnant their bodies were made into something of 'great value, something capable of producing new life' (Grue and Tafjord Lærum 2002: 676). These mothers also reported that for those who had been physically disabled since childhood, becoming a mother meant that 'for the first time in their life they experienced being looked upon and being met by other people as an adult person and not just as a disabled person. Becoming a mother made them achieve womanhood' (Grue and Tafjord Lærum 2002: 676).²

Ora Prilleltensky (2003) conducted interviews with 13 women and four focus groups with a total of 25 physically disabled Canadian women. Eight of the 13 interviewees were mothers with children of different ages. The other five women were without children. Similarly, two of the four focus groups were attended by mothers, the other two by women without children. Most of the participants had mobility/limb impairments and used a wheelchair. Prilleltensky is herself a mother with a physical disability (muscular dystrophy). Amongst other things, participants described reactions to their pregnancy — their own reactions, and the reactions of others.

Some of Prilleltensky's participants were delighted to discover they were pregnant. 'One woman who was told for years by her family that she would not become a mother, described a sense of elation that stayed with her throughout her pregnancy' (Prilleltensky 2003: 26). She said that when she learned that she could become a mother and the gynecologist said to her 'you know, you're normal' she started to cry (tears of joy) because she'd always been told that she wasn't 'normal'. Another participant told Prilleltensky (2003: 26) 'I do conceive really easily ... that's the one part of my body that seems to work ... my eyes and my uterus ... I always figure, everything else is going to disappoint me, nothing else is completely reliable, but these two work well ... it feels great.'

One of the most poignant articles I read on the topic of disability and pregnancy was Ann Neville-Jan's (2004) autoethnography of her quest for a child. Neville-Jan is an academic with spina bifida who lives in the United States. She writes 'For me, giving birth to a child became the ultimate life project that would demonstrate I could achieve the same goals as normal people' (Neville-Jan 2004: 117). Neville-Jan's first pregnancy came to a tragic end when, due to complications associated with amniocentesis, her baby daughter was born at 20 weeks gestation. She did, however, become pregnant a second time and gave birth to a healthy son. At a similar time, Neville-Jan and her husband adopted a daughter from China. What makes Neville-Jan's article so powerful is that she writes as both a researcher and research participant noting that she 'became aware that a gap of representation existed in the scholarly storyline of pain, the voice of the person in pain' (Neville-Jan 2004: 114). Neville-Jan speaks frankly about her pain and her sexuality but also about her success in her quest for a child.

Many of the participants in Rogers' (2006) study also talked about their successes in their quest for a child or children and about feeling affirmed when they became pregnant. She reports:

Julie [said, I] 'loved being pregnant because for once my body worked right.' Arlene said, 'Having a baby made me less handicapped because I was able to fulfill one of the female roles in society and I was really rewarded for it.' Heather felt that she was 'proving I was as independent and as self-reliant as anyone.' Noelle 'loved being associated with the non-disabled population. It was my only chance,' adding that the shared interests and concerns of parenthood offered a basis for friendships with non-disabled people. (Rogers 2006: 37)

Grue and Tafjord Lærum's (2002: 676) research reveals that for many women, depending on when they had become physically impaired, having a child meant either 'capturing' a gender, or 'recapturing' a lost gender. Some of the participants reported having found it difficult during adolescence and early adulthood to stage convincing gendered performances as

women. One particular participant in Grue and Tafjord Lærum's (2002) study, Kari, puts it like this:

I instantly felt more like a woman when my son was born. During my whole life I had felt like a person without a gender. The process I went through during pregnancy and afterwards made me more conscious of my identity and my worth as a human being. My child made it possible for me to say both to myself and in relation to other women — see, I am the same as you. (Grue and Tafjord Lærum 2002: 676)

Despite these positive reports from physically disabled women who felt a strong sense of affirmation — a shift in identity from a disabled person to a mother — their decisions to become mothers were in some instances extremely complex and difficult to make. Rogers (2006: 33) points out that most books that aim to help people decide whether or not to become parents do not address the concerns of women with disabilities. Also, social disapproval and disabled women's own fears of becoming a parent tend to work against many disabled women in their decision to have children. From the outset then, pregnancy, birth and motherhood can be difficult terrain to embark upon for disabled women. There is a long history of disabled women feeling under pressure to, and even worse, being forced to, be sterilized or abort their unborn babies.³

DISCURSIVE GEOGRAPHIES: POWER AND RESISTANCE

Prilleltensky's (2003: 22) research reveals that not all physically disabled women feel affirmed when they embark upon motherhood. Some face opposition, skepticism and even hostility.

As a group, women with disabilities have been traditionally discouraged or even denied the opportunity to bear and rear children. Whereas other women experienced societal pressure to have children as oppressive, women with disabilities were perceived as child-like, dependent and asexual and were excluded from fulfilling traditional female roles. (Prilleltensky 2003: 22)

A number of authors have now documented stories of disabled women feeling incredible pressure to refrain from reproducing, or to have abortions, hysterectomies, or tubal ligations (e.g. Gill 1996; Rogers 2006). Prilleltensky (2003) tells the story of a participant in her research who was single and unexpectedly found herself pregnant. The woman was initially upset but soon formed a strong connection with her unborn baby and decided not to terminate the pregnancy even though many tried to persuade her to take this path.

A number of people said that to me ... I was having nurses coming in and out because I was having my blood taken ... it would be like ... say you have a cough, 'maybe you should have cough medicine' ... that's how casually they were saying it, 'maybe you should have an abortion, maybe it would be for the best' ... they thought his life wasn't important. (participant quoted in Prilleltensky 2003: 27)

Prilleltensky (2003: 27) argues, and I agree wholeheartedly, that the demands put on this single disabled woman to abort her possibly disabled fetus need be understood within the context of eugenic ideology.

Eugenics or 'racial hygiene' — the term used in Nazi Germany — questions the value of caring for the 'weak' (Pritchard 2005). If the weak survive they may reproduce, thereby passing on their weakness. The aim of eugenics is to actively manage human reproduction to encourage the fittest to reproduce and discourage the least fit from reproducing (Pritchard 2005: 82). Women with disabilities are more likely than non-disabled women to be considered as being at risk of producing children with disabilities.

The heredity nature of some (but not most) disabilities may call into question the right of disabled parents to produce a baby that may carry their genetic code, disability included ... Certain drug treatments can also increase the risk of fetal abnormality. (Prilleltensky 2003: 23)

Megan Pritchard (2005: 81) poses the question 'can there be such a thing as a "wrongful" birth?' She is interested in the development of pre-natal testing for impairment and the increase in courts 'around the world' hearing cases of 'wrongful birth'. To explore this Pritchard examines the eugenics movement. Drawing on the work of Pilnick (2002), Pritchard argues that although eugenics had little impact on policy in the United Kingdom, in the United States it led to the development of the Immigration Restriction Act and involuntary sterilization laws. Hubbard (1997) estimates that by 1935, 20,000 people had been involuntarily sterilized in an attempt to prevent what the state saw as 'wrongful births' (Pritchard 2005: 82).

There were also institutional arrangements in New Zealand from the late 1800s that segregated and controlled the 'physically anomalous body' (Sullivan 1995). Martin Sullivan (1995: 12, italics in original) explains:

In 1903 W.A. Chapple, a New Zealand born and bred politician and surgeon, published *The Fertility of the Unfit*. In it, Chapple advocated negative eugenics as a panacea for the colony's ills. ... The solution lay in ... encouraging the *fit* to have more children and by sterilizing the *unfit*.

The 'unfit' included those with 'physical defects' such as the 'deaf, dumb, blind, epileptics, paralytics, cripples, debilitated, and deformed' (Chapple 1903: xii cited in Sullivan 1995: 12). Chapple recommended that such peo-

ple undergo compulsory sterilization. Physically disabled women of child bearing age, and the wives of disabled men, according to Chapple, ought to have tuba ligation. Chapple's book was widely read and supported (Sullivan 1995).

The Eugenics Education Society of New Zealand was founded in 1910. Amongst its members were some influential and well-resourced people including politicians, academics, and F. Truby King who was Medical Superintendent of Seacliff Mental Hospital. King 'frequently voiced concern at the country's declining birth rate and the physical and moral degeneration of Empire and country' (Sullivan 1995: 13). In August 1913 King gave an address at the National Congress in London entitled 'The New Zealand Scheme for Promoting the Health of Women and Children'. King (1913: 3) stated that the first aim of the Society was:

To uphold the sacredness of the body and the duty of health; to inculcate a lofty view of the responsibilities of maternity and the duty of every mother to fit herself for the perfect fulfillment of the natural calls of motherhood, both before and after childbirth, and especially to advocate and promote the breastfeeding of infants.⁴

In 1915 His Majesty the King conferred on the Society the honour of being titled 'The Royal New Zealand Society for the Health of Women and Children'. From around 1925 the Royal New Zealand Society for the Health of Women and Children (Inc.) became more commonly known as the Plunket Society.⁵ The Plunket Society aimed at producing 'healthy' children and making infant mortality in New Zealand one of the lowest in the world. Deem and Fitzgibbon (1953: foreword) in *Modern Mothercraft* the official handbook of the Plunket Society claims: 'The work of the Plunket Society has had a profound effect in laying the foundations for a healthy nation, and there is growing evidence, too, that other countries are finding the system of great help and value.' Sullivan (1995: 13) argues convincingly that although the stated goal of the Plunket Society was to reduce maternal and infant mortality, King believed that disciplined and highly regulated bodies created moral and normalized citizens. The objective was, therefore, to

Reduce moral degeneracy by producing fit, healthy, whole, complete, working Truby King babies by training the nation's mothers in techniques of mothercraft. Mothercraft consisted of prescriptive norms of mothering, body technique, corporeality and character structure which constitute and coalesce in a new national icon — the *Truby King baby*. (Sullivan 1995: 13–14, italics in original)

Over the years it has been widely stated that millions of New Zealanders 'owe a debt of gratitude to Sir Truby King' (Snowden and Deem 1951: 8). Yet King's regime did much to put women under surveillance and con-

structed a cultural hegemony around ‘perfecting’ mothers and babies that had not existed in the same way prior to his interventions.

Some mothers in New Zealand in the 1950s experienced The Plunket Society’s regimes as rigid and harsh (but see Bryder 2003 on New Zealand mothers displaying more agency than might be expected in relation to the Plunket Society). There was little allowance made for women’s social, cultural, or embodied differences. For example, all women were told to breastfeed no matter what. I recall my mother saying that the Plunket nurse told her she had to breastfeed my sister (for various reasons my mother wasn’t keen on this) unless she had a letter from her doctor. My mother refused and so eventually the nurse bottle fed her. The nurse, though, was angry with my mother and so wouldn’t bring the baby to her for feeding. My mother also told me a story about my aunt. She had not wanted to breastfeed because her nipples were extremely sore, but the nurse made her. The baby was forced to drink milk and blood.

Not only was breastfeeding (or natural feeding as it was often called) heralded as ideal for *all* mothers and babies but also there were very strict instructions as to how and when feeding should take place (see Deem and Fitzgibbon 1953: 52–71). The suggested ‘Routine Day for the Nursing Mother and her Baby’ as outlined below in the Official Handbook of the Plunket Society (Deem and Fitzgibbon 1953: 63) is testimony to this regimentation — the social inscriptions — that mothers (and babies) in New Zealand faced during this era.⁶ The aim was to create physically healthy and fit [read: not disabled] mothers and babies.

‘A discourse involving the norms of corporeality, technique, measurement and judgement quickly grew up around King’s notion of the physically fit infant’ (Sullivan 1995: 14–16; also see Ettorre 2000 on ‘reproductive genetics, gender and the body’). A wide-ranging infrastructure of surveillance emerged which subjected the mothers and babies to constant scrutiny. One of the forms that this scrutiny and policing took was the issuing of a *Plunket Book* to all mothers from 1924 onwards (Sullivan 1995: 14). These books are still issued to all mothers and infants today. Plunket Books contain a weight chart, room for mother to record baby’s progress or lack of progress, and space for the Plunket nurse to record her observations and suggestions about feeding and care. It can be nerve-racking for mothers waiting for the Plunket nurse to visit; waiting for her to measure and weigh the baby, wondering what she will enter into the book — an entry that will be recorded for posterity.⁷ When I was visited by a Plunket nurse in June 1995 she wrote in the Plunket Book: ‘You have a healthy boy fully breastfed on demand. Mum — have three good meals a day; lots to drink; rest when you can!’ Along with this written advice she told me that I *should* put a toy in the basinet for the baby to look at. The Plunket Book and visits by Plunket nurses can be sources of support for women who are caring for babies but they can also function to survey and normalise the corporeal and emotional behaviours of mothers and babies.

Currently, not only is a record kept of the baby's progress after birth, but also a record is kept of pregnant women's health, well being and 'growth'. It is common during antenatal visits for pregnant women to have their urine analysed for the presence of sugar and albumen (protein) and their blood pressure measured. Then, the fundus (top of the uterus) is measured, the fetal heart is checked and the abdomen is palpitated in an attempt to determine the baby's position. Women used to be weighed but this is less common today. This information is noted by the General Practitioner or Midwife in their records. It is also entered on a card, referred to as a 'co-operation card' in the United States, which pregnant women themselves keep (Kitzinger 1989: 48–49). Women bring this card with them each time they have an antenatal check-up. This record functions in a very similar way to the Plunket Book. The record can be seen as a surveillance tool which works to regulate and normalise the bodies of pregnant women. For physically disabled women whose bodies do not fit the norm this kind of regimentation and record-keeping could be a continual reminder of their embodied 'difference'.

Māori women were also continually reminded of their embodied 'difference'. Linda Bryer (2003) in her history of the Plunket Society 1907–2000 argues that the relationship between Plunket and Māori is complex. The Plunket Society, for many years, had a monocultural image. The New Zealand Health Department and Plunket came to an agreement early on that Department rather than Plunket nurses would address and manage Māori infant health. Māori women were permitted to use Plunket's services but few did so. Groups such as the Women's Health League, although not as well resourced as Plunket, were more popular with Māori. After the Second World War, however, Māori urbanization gained momentum and the segregated services could not be maintained. Plunket has had to work at combating its racist image. These days not only does it have to prove that it offers a credible service to Māori but also for a range of other ethnic groups residing in an increasingly multicultural New Zealand (Bryer 2003).

To return to the issue of disability, over the years the influence of eugenics and the discursive space it occupies has waned (Pritchard 2005: 82) although certainly not disappeared (see Pilnick 2002 on how developments in genetics in recent years have revived this discourse). Many still do not expect disabled women to give birth and to become mothers. One of the major themes that emerged in Prilleltensky's (2003) interviews was that the health-care system in Canada was unable to deal effectively with the dual factors of pregnancy and disability. It is common for women without disabilities to feel a loss of control of their bodies when dealing with health and medical professionals. Women with disabilities are likely to have more frequent contacts with the health-care system over the course of their pregnancy, a system which has long tended to label them as abnormal. Prilleltensky (2003: 29) notes:

while the medical system has a long history of managing illness and disability, it is literally in its infancy when it comes to dealing with the reproductive issues of women with disabilities. Consequently, women with disabilities are often 'groping in the dark' as they attempt to gain information about pregnancy in the context of disability.

Many physically disabled women though are no longer prepared to accept the assumption that their disability is a defect. There is greater acceptance that disability is a social construction rather than a medical condition and in many instances there is no reason why a woman with a physical disability ought not have a baby. Some physically disabled women are now beginning to share their stories about pregnancy and motherhood in an attempt to encourage other disabled women to have children (Rogers 2006). A strong focus in these stories is the physical and mobility challenges presented by various material environments for disabled pregnant women and mothers.

MATERIAL SPACES AND MOBILITY

While able-bodied women sometimes find the final few months of their pregnancy challenging in relation to feeling heavier, clumsier, less mobile, and more likely to topple off-balance this tends to be accentuated for pregnant women who have a physical disability. Often they face mobility challenges earlier in their pregnancy (see Butler and Bowlby 1997 on disabled people's experiences of public space). These mobility challenges occur not just in public spaces but also at home (see Dyck 1995 on disabled women's 'hidden geographies').

One participant in Rogers' (2006: 205) study, Sally, who has a spinal cord injury, found that she was unable to stay as upright in her chair. She kept sliding down. Others experienced more difficulty transferring or being lifted from one space to another. For example, Nadine, who has limb-girdle dystrophy, had problems with her balance because of her larger pregnant stomach. She found it difficult transferring from being seated to standing, and getting in and out of bed and the bathtub. In the third trimester she stopped driving. Natasha, who also has limb-girdle dystrophy, comments that pregnancy exacerbated the difficulty that she has getting up from chairs and couches. In short, a number of the 90 respondents in Rogers' study noted increased mobility difficulties during pregnancy. It is vital, therefore, that these women receive the assistance and the necessary equipment they require whether it be a trapeze lift, step stool, bathtub seat, power wheelchair, walker, or 'reacher' to make adaptation to pregnancy as easy as possible.

Sometimes even maternity wards are not equipped to cope with disabled women's needs (see Chouinard 1997 on ableism). Grue and Tafjord Lærum

(2002), referring to their study of 30 physically disabled mothers in Norway, explain 'several women told us that the maternity ward had no toilet accessible for wheelchair users or other facilities that made it possible for them to nurse their newborn child. This fact may reflect the view that disabled women are not *expected* to be mothers' (Grue and Tafjord Lærum 2002: 673). Within medical discourse disabled women are still often perceived as patients rather than as women capable of giving birth.

Patricia McKeever *et al.* (2003) investigate the experiences of 11 mothers in a large Canadian city who use wheelchairs and scooters for full-time mobility. They conclude 'mothering with a disability consists of embodied and emplaced practices. Women often felt "out of place" as mothers given the relationship between mothering discourse and mobility devices' (McKeever *et al.* 2003: 179). Women with disabilities are often regarded as incapable of looking after children (Gill 1997; Moss and Dyck 1996). However, not only do these women face disapproval from others, especially if it is thought that their children may have to look after them (Prilleltensky 2004; Stables and Smith 1999) but also it can be problematic finding the equipment required to aid disabled women's mobility. Kent (2002), for example, explains that because she is blind, pushing a baby stroller in front of her was not an option. It was unrealistic to rely on her guide dog to warn her about curbs or obstacles at such a distance. Kent called a number of manufacturers in an attempt to find one that produced a stroller with a reversible handle so that she could pull the stroller behind her instead of pushing in front of her into 'the great unknown'. She eventually found one.

Some community groups have recognized the specific needs of disabled mothers and fathers and set up support systems. For example, 'Disability, Pregnancy and Parenthood *international* (DPPi) is a small UK-based registered charity, controlled by disabled parents, which promotes better awareness and support for disabled people who are considering pregnancy, during pregnancy, and as parents (see Disability, Pregnancy and Parenthood international, 2005, available <<http://www.dppi.org.uk/>>, accessed 27 July 2005). But much more remains to be done. Structural arrangements (by way of government prioritizing disability, policies on disability, social services, support agencies, funded assistance) need to be in place to facilitate mothering for those with physical disabilities. Environments need to be made accessible to all (Gleeson 1999) but this extends beyond just the materiality of environments to also include discursive and emotional environments.

CONCLUSION

Pregnancy and parenting is a time of joy, and sometimes sorrow, for many women but for women with physical disabilities the stakes can be higher. Disabled women can face different sets of issues and may need extra support. In relation to the emotional spaces occupied by physically disabled

pregnant women they are likely to experience both societal approval and disapproval in different spaces at different times, from different people. They are also likely to experience a vast range of emotions as they grapple with the reactions of loved ones, family, friends, acquaintances, and strangers, and with the health-care system, over the course of their pregnancies.

In relation to the discursive space occupied by physically disabled women they are likely to suffer the weight of the heavy historical legacy of eugenics. This movement created an oppressive discursive space for disabled women and their offspring that constructed them as lacking. Eugenics has not entirely disappeared today. There is still a societal pursuit for 'perfect' babies that suggests disabled people are some kind of unfortunate mistake. But not only are disabled women made to question their very own existence, also they are more likely than their able-bodied counterparts to be perceived as being at risk of producing disabled children. 'The hereditary nature of some (but not most) disabilities may call into question the right of disabled parents to produce a baby that may carry their genetic code, disability included' (Prilleltensky 2003: 23). However, disabled women have resisted this societal quest for bodily 'perfection' and instead taken up their rights to become mothers. Like any individual physically disabled women have rights to lead autonomous lives. They also have the right to make important 'life decisions' as they see fit.

Finally, the chapter looked at some of the disabling effects of material environments including homes, clinics, and birthing wards. Some disabled pregnant women and mothers require assistance to carry out many of the physical tasks associated with parenting because all too often spaces and places are constructed in ways that assume people are able-bodied. Hopefully the chapter has provided yet another window on maternal bodies, gender and space. The subjectivities 'disabled woman' and 'mother' don't always sit comfortably together. Emotional, discursive and material spaces and places constitute and in turn are constituted by the bodies that inhabit them. Women's choices and actions are both enabled and constrained by these spaces and places they inhabit. 'New' selves as mothers simultaneously emerge and are quashed as physically disabled women assert their right to get pregnant, bear and rear children.

Too often disabled mothers are (re)presented as 'bad' mothers. The next chapter also discusses (re)presentations of a 'bad' mother, a pregnant woman known in the media as 'Nikki' who wanted the birth of her baby to be filmed for inclusion in a pornographic movie.