MOTHERHOOD IN THE LIVES OF WOMEN WITH PHYSICAL DISABILITIES

by

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A doctoral dissertation submitted in conformity with the requirements for the degree of Doctor of Education
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ABSTRACT

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This study focuses on the intersection of mothering and physical disability. More specifically, it explores the lives of women with physical disabilities who are either mothers, considering motherhood, or have considered it at some point in their lives. My own life experience as a mother with a physical disability provided the impetus for the research. The purpose of the study is to explore the meaning of motherhood for women with physical disabilities and their mothering-related experiences, issues, and priorities.

Data for the research were gathered via 26 in-depth interviews with 13 participants and 4 focus groups with women who are at different stages in relation to motherhood. Over half of those interviewed are mothers with children at different stages of development; the rest are women who are either in the process of weighing their reproductive options or have already decided to remain childless. All are women who live with a physical disability; namely, a mobility impairment.

In interviews and focus groups, study participants discussed the various messages they have received over the years with respect to sexuality and motherhood. Many had experienced a host of invalidating messages about their ability to attract a sexual partner and to become
mothers. Some grew up in families where their sexuality was either ignored, undermined, or actively discouraged. Parental reticence to acknowledge sexuality was perceived by most as attempts to protect a disabled daughter from sexual rejection and exclusion. Almost all participants who were disabled as children had experienced some level of exclusion by peers in the social and sexual arena.

Also included in the research is the decision-making process of motherhood in the context of a physical disability. Participants elaborated on some of the issues they are presently considering, or have considered in the past, as they contemplate their reproductive options. The study gives a voice to the desire to have children that some have expressed, and to the challenges and barriers that they envision, along with their strong belief that a woman’s happiness and well-being is not contingent upon having children. A number of women talked about the rich and fulfilling lives they lead as women without children and theorized about the importance of separating motherhood from female identity.

Participants with children explored their lives as mothers with physical disabilities. Along with some of the usual joys and tribulations that are part and parcel of parenting, specific disability-related issues were shared and explored. Promoting children’s growth and enhancing their well-being was a major consideration for mothers. Participants discussed the behavioural strategies that they enlist, their attempts to ensure that children’s needs are consistently met, and the types of formal and informal supports that they have. Whereas all participants demonstrated a high level of commitment to their children, they varied in the level of support that is available to them, and in the number and magnitude of stressors that they face. Predictably, the availability of supportive networks is associated with better adjustment for children and families.
The dissertation concludes with a discussion of wellness in light of risk and protective factors encountered by women with physical disabilities. Based on sources of vulnerability and strength I formulate possible recommendations for action at the micro, meso, and macro levels. The recommendations pertain to girls with disabilities, women who are not mothers, and mothers with disabilities and their families.
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INTRODUCTION

I always wanted to be a mother. In my earliest memories I see myself with a doll or two in arms, walking from one area that I designated as the house, to similarly designated playgrounds and grocery stores. I had an old hand-me-down doll carriage in which I ever so carefully placed my precious babies for walks and “errands.” I vividly remember this carriage with the straw coming apart at its worn edges. These days such an item would undoubtedly be classified as antique and considered a worthy collector’s item. I remember daydreaming about the many children that I would one day have; their age difference and order constantly changing. I was delighted when a relative who came back from a visit to “America” brought me a boy doll as a gift, since all the dolls I had ever seen were girl dolls. My interest in dolls continued into middle childhood when most of my other friends were tossing them aside. Playing with dolls became a private activity, hidden from friends who may mock me for such childish pursuits.

As a teenager, babysitting became a wonderful outlet for my interest in babies and young children. For fifty cents an hour I would entertain, feed, and put to bed our neighbours’ four energetic children, one of whom was a baby. Other babysitting opportunities soon followed and I became quite an expert in feeding, changing diapers, and keeping children happy. I took great pleasure and pride in my competence and in the knowledge that I was clearly the favourite babysitter on the block. Even at the young age of thirteen I was cognizant of the magnitude of the responsibility that the job entailed and at my ability to fulfil it.

My love for children and interest in motherhood continued into young adulthood. As an undergraduate student at a religious university in Israel, I saw many of my friends marry and have
children in their early twenties. In that particular milieu, childless and/or unmarried "older" women were viewed with suspicion, pitied, even scorned. Although I enjoyed my studies and the freedom and independence that were part of student life, I knew that my ultimate goal was to be a wife and a mother. I didn't regard these goals as counter-indicated with getting a good education and pursuing a career; however, it was always clear to me that these were secondary to motherhood and family. Coming to Canada as a young married woman, I met peers who were either totally uninterested in motherhood or regarded it as a possible option sometime in the distant future. I worked and continued my studies; motherhood, however, remained a top priority.

My only child, a boy, was born ten years ago when I was 27 years old. Some of my most cherished memories revolve around carrying, delivering, and breast feeding my infant. His first words and other developmental milestones were a major source of pride and joy.

Mothering being so major to my own identity, it is quite befitting that it would constitute the subject of my doctoral dissertation. My gradual embrace of feminism, and a physical disability that began to limit my mobility in adulthood, have had a major impact on the prism through which I view the world. Feminism has helped me understand that my investment in motherhood, while genuine, is not detached from its social construction. Indeed, I am a product of a society that for generations could not perceive of womanhood apart from motherhood. Without undermining the joy and genuineness of my lived experience, I nonetheless recognize that my desire and motivation to mother were impacted by a host of intrinsic and extrinsic factors. The plain truth is that I could not envision my life without children. This was particularly challenging in light of the increasing impact of the disability on my life.

My early parenting experiences were not comparable to those of my friends or any of the
other new mothers I knew at the time. Unlike them, I was not able to take my son on outings by myself, to independently care for him for extended periods of time, or even pick him up after the first few months. I was, as pointed out by Riddington (1989), the only disabled parent in the neighbourhood. Having a supportive partner who was able and willing to carry out child care tasks that I could not, and a mother who was physically and emotionally available, provide the framework for my own positive experiences. Nonetheless, my changing disability continues to be a significant factor in our family life.

This study explores the intersection between motherhood and physical disability. It focuses on the lived experience of women with physical disabilities, those who are mothers as well as those who are not mothers. It attempts to answer some of the following questions: What meaning does motherhood have for women who have physical disabilities? What is it like for them? What messages do they receive about themselves as women, with or without children? What barriers do they foresee and/or come across? How do they see their future in relation to motherhood? Utilizing a combination of in-depth interviews and focus groups, I explored these and other mothering-related issues from the vantage point of disabled women with and without children.

As I indicated above, this research stems from my own lived experience, and as such, it is personally meaningful and significant. However, choosing it as my area of inquiry goes beyond a personal interest and a search for meaning. It is based on my belief that it can contribute to women participating in the research, to other women with physical disabilities, and to knowledge in the areas of disability and motherhood. The intersection of these two entities, motherhood and disability, has received little attention from the academic community. Despite technological advancements and an ethos of diversity, disabled women are rarely thought of as mothers or in
conjunction with motherhood. The rich discourse on motherhood, including that which is explicitly feminist, has rarely included women with disabilities. It is this space that is created between motherhood and disability that I wished to explore; it is the invisibility of these women that I wished to examine and interrupt; it is their (our) stories and dreams that I wished to present. My decision to include women with and without children in the study emanates from my belief that women who do not have children also have issues regarding motherhood, issues that need to be heard and explored. I see this as fundamentally important for women with physical disabilities who live in a society that often regards motherhood as synonymous with womanhood and counter-indicated with disability. In a patriarchal society that defines and values women according to their reproductive capacities, bearing children may also be a way of fighting "otherness."

Although I include women with and without children in the study, I chose to be specific about the types of disabilities that would be represented. The study is thus limited to women with physical disabilities who have varying levels of mobility/limb impairment. Most of the participants are wheelchair users. At least seven different types of disabilities are represented in the study; I refrain from listing them in order to protect the identity of research participants. My reason for limiting the sample to women with physical disabilities is based on my belief that the particular issues and barriers that they face in relation to motherhood may be inherently different from those faced by women with developmental or other disabilities. Whereas some of the experiences and the barriers they face are undoubtedly shared by women with different disabilities, others are more particular and specific in nature. The importance of researching the lives of differently disabled women notwithstanding, I believe that lumping all disabled women together in one research study cannot do justice to either group. Having said that, I recognize that this study can be criticized for
its focus on women with physical disabilities; the very same group that typically participates in research. As Carole Gill has noted, “a lot of research has relied on samples of those of us who are most visible: white heterosexual women with physical disabilities who are functioning in the world and who can speak or write without difficulty” (Gill, 1996, p. 14). I admit that this description applies to my group of participants. It is my hope that other studies will focus on women with other types of disabilities.

Data for the research was gathered via four focus groups and twenty six interviews with women at various stages in relation to mothering. The in-depth interviews with thirteen participants provide the bulk of the data while the focus groups complement the findings. I detail the research process in the methodology chapter, which also includes the theoretical underpinnings guiding this research and the particular methodological problems that I encountered along the way. I present the findings of the research in three data chapters which correspond to different phases of women’s lives: being a girl with a disability, contemplating motherhood, and being a mother with a disability. The final chapter represents my attempts to integrate the findings and explore their significance for research and action. The very first chapter following this introduction is a comprehensive literature review which frames and contextualizes the research.
II

LITERATURE REVIEW

A Historical Perspective on Motherhood and Non-Motherhood

One Hundred Years of Motherhood

Over the past several decades, motherhood as institution and lived experience has been extensively studied and theorized by feminist scholars. Common to all such explorations is the premise that the institution of motherhood has been named and interpreted not by women but by the patriarchal culture in which they live (Achilles, 1990; O’Barr, Pope, & Wyer, 1990). For centuries, womanhood and motherhood were seen as interchangeable, one biologically, inevitably, and unquestionably emanating from the other. To be a woman was to be a mother, and to be a mother was to spend most of one’s adulthood bearing and rearing children. “For patriarchy, femininity is not the core of motherhood, motherhood is the core of femininity” (O’Barr, Pope, & Wyer, 1990, p. 4).

Modern history attests to the idealization of motherhood in the late 19th century and early part of the 20th century, when psychological and cultural differences between men and women were believed to be biologically based. Women’s capacity to reproduce, coupled with their perceived tendency towards sensitivity and nurturance, framed motherhood as a moral and social imperative. In a society which regarded motherhood as women’s highest calling, doctors defined women’s health in terms of the health of their reproductive organs, while denying them knowledge about their own bodies (Lewis, 1990). The physical condition of pregnancy, childbirth and lactation were seen as a basis for societal role division where women did the physical and emotional caretaking, restricted to the private sphere. Their value emanated from their ability to
produce offspring and rear healthy, functioning individuals who would one day become productive, well adjusted workers (Gerson, Alpert, & Richardson, 1990). The pressure to bear children was selectively geared towards upper and middle class white women, whose offspring were considered more desirable and valuable to society.

Despite the romanticizing of the institution of motherhood and its culturally privileged status, individual mothers were consistently undermined and disempowered throughout history, as were women in general. By being restricted to the private sphere and to the never-ending chores of caring, changing, nurturing, and cleaning, women were kept within a safe distance of powerful political and economic institutions in which important decisions about their lives were being made (O'Barr, Pope, & Wyer, 1990). Social policies designed to improve the welfare of mothers and children in the early part of the 20th century were implemented “more out of regard for the national health than out of regard for the welfare of mothers” (Lewis, 1990, p. 7).

The idealization of motherhood of the late 19th century, premised on the separate sphere of women’s activities, has ironically set the stage for the mother blaming which began in the early decades of this century. “Mothers, after all, were responsible for caring for their children. If babies were dying, surely mothers were to blame” (Arnup, 1994, p. 36). Given the high rate of infant mortality at that time, the early decades of this century were marked by a strong emphasis on educating women for motherhood, with films, lectures, radio talks and pamphlets designed for that purpose (Arnup, 1990, 1994). Psychological literature also focused on child rearing practices, with the lived experience of mothers themselves fading into the background (Gerson et. al., 1990). In this exclusively child-centred approach, “motherhood becomes the child’s and not the woman’s experience” (Oakley, 1990, p. 77). Traditional methods of child rearing and the
respect for “motherly intuition” of the late 1800s, gave way to a scientifically based approach of raising children which characterized the early part of this century. “As responsible child rearing became the national duty of the modern mother, the state instructed her to ignore the advice of female friends and relatives and heed instead the precepts of medical and psychological experts on how to mother scientifically” (Pierson, Levesque, & Arnup, 1990, p. xx). Not only were women relegated to the private sphere, they were also disenfranchised and isolated from extended family and from one another.

The history of the institution of motherhood cannot be studied apart from the eugenic ideologies which underlie it. Founded by Francis Galton in the early part of this century, the goal of the eugenics movement was to ensure racial purity and enhance the procreation rate of certain segments of society, while curbing the proliferation rates of those considered less desirable (Franzblau, 1996). Eugenic methods for controlling the birth rate of “inferior” individuals will be discussed later in this review. Relevant to the present discussion is the systematic eugenic effort to influence, cajole and pressure women who were white, middle class, and healthy, to reproduce. In order to advance its goals, the eugenics movement of the early part of the century even attempted to form an unlikely alliance with the feminist movement of the time which protested against unequal pay for women. “For example, Popenoe and Johnston (1922) suggested that the eugenics movement could assist the feminist movement in its protest against unequal pay by simply remunerating women for bearing “quality” children, which would give women freedom of self expression without sacrificing the (white) race” (Franzblau, 1996, p. 55). Eugenicists also suggested that women’s quest for education could be fulfilled by teaching them to appreciate the natural sex differences and the enormously satisfying potential of home life and motherhood
Despite eugenic teachings, the marriage and birth rates in America were declining during the depression of the 1930s, and many women remained childless. Wives and daughters of unemployed men needed jobs in order to support their families and many delayed marriage and childbirth for that reason. In fact, women typically have fewer children during times of distress and economic hardships, such as at the turn of the century and during the depression of the 30s. Not only is this tendency a practical matter of survival, it could also be a form of passive resistance to oppression (Lisle, 1996).

The 1940s and America's entrance into the second world war meant that an unprecedented number of women were entering the work force, as men went out to war and jobs had to be staffed. By 1944, women comprised a third of the nation's civilian labour force. Not surprisingly, thousands of day care centres were abruptly opened as women were needed in the workforce. These same centres were abruptly closed in the post-war years as men returned from war and women were fired to vacate jobs (Franzblau, 1996; Lisle, 1996). Pronatalism was on the rise, reaching an all time high in the 1950s. American families averaged 3.7 children by 1957, and almost without exception, women stayed home to care for their children (Lisle, 1996). Women's move back to the home in the post war years was supported by the influential psychological theories of Bowlby and Winnicott, who described the mother as ever present, selfless and giving, content to be submerged with her child (Mahler Kaplan, 1992). Bowlby was further concerned that various social policies be implemented in accordance with his attachment theory, to ensure the uninterrupted availability of mothers to their infants. He was in favour, for example, to monies being redirected from day care services to housekeeping services so that mothers could focus their
efforts on child care. Not surprisingly, Bowlby’s views were highly endorsed by eugenicists (Franzblau, 1996).

Contrary to the idyllic image of motherhood, many women who had tasted freedom and life in the public sphere during the 1940s were feeling constricted in their homes (Lisle, 1996). Caught between a culture that hailed motherhood on the one hand, and the experience of independence they felt during the war years on the other hand, many women yearned for a greater measure of control over their lives (Ireland, 1992; Lisle, 1996). Mothers were also the targets of a changing but continuous stream of expert advice on how to enhance the physical and psychological well-being of their children. In his well-know book “Baby and Child Care,” Spock was quite blatant about the responsibility that mothers had to bear for the healthy development of their children: “Practically all the children who regularly go on soiling after 2 are those whose mothers have made a big issue about it...” (Spock, 1946, p. 184, in Arnup, 1994). Even in his criticism of rigid feeding schedules, Spock was careful to blame not the doctors who prescribed these schedules, but the mothers who, he suggested, were rigid in implemented them.

Undoubtedly frustrated by proliferating images of motherly bliss coupled with the heavy responsibility of doing it right, these mothers, who wished more out of life, raised daughters who revived American feminism several decades later (Ireland, 1992; Lisle, 1996).

The 1960s and 1970s were years when feminism was on the rise and many challenged the prescription of motherhood for women, something which was taken for granted only several decades earlier (Snitow, 1992). In the USA, contraception for single people was legalized in 1972, allowing for sexual expression and adult privileges without the responsibilities of parenthood (Lisle, 1996). In her 1992 article on feminism and motherhood in America, Ann
Snitow contends that feminists of the 70s were wrongly labelled as anti-mother as they dared to challenge the previously unchallenged — that every woman should become a mother. Snitow discovered that even the harshest critics of motherhood, such as Shulamit Firestone in *The Dialectic of Sex*, were crying out against the inequities inherent in the institution of motherhood rather than attacking mothers themselves (Snitow, 1992). Most agreed that the problem was not children themselves, but the societal context in which their mothers lived.

The most renowned critique of motherhood as institution was forged by Adrienne Rich in her classic book *Of Woman Born: Motherhood as Experience and Institution* (1976). With her own experience of raising three children in the mid 50's as a backdrop, Rich makes an important distinction between the oppressive institution of motherhood and the potentially fulfilling experience of being a mother. Reflecting on her early mothering experiences in America in the mid fifties, Rich wrote twenty years later:

> I had lived through something which is considered central to the lives of women, fulfilling even in its sorrow, a key to the meaning of life...I could remember little except anxiety, physical weariness, anger, self blame, boredom, and division within myself. A division made more acute by the moments of passionate love, delight in my children's spirited bodies and minds, amazement at how they went on loving me in spite of my failures to love them wholly and selflessly. (p. 5)

Indeed, in the decade in which Rich wrote her book, both the joys and the challenges of motherhood were permitted to be explored and expressed within feminism. It was acknowledged that motherhood was not for everyone, was not always fun, and that most women wanted and needed more out of life. It was the institution of motherhood that feminists regarded as oppressive
to women, by placing responsibility for child care almost entirely on their shoulders. The actual experience of mothering was varied, diverse, and influenced by a wide array of social, economic, and political factors.

Feminist explorations of motherhood are no less relevant today than they were in previous decades. In fact, the 1980s saw many women who postponed childbirth in the previous decade, getting pregnant and having children as “the ticking of millions of biological clocks was being heard” (Lisle, 1996, p. 31). The year 1988 was the year in which more children were born to first time mothers in the USA than ever before (Lisle, 1996; Snitow, 1992). And while most mothers today work outside of the home, they continue to do far more than their fair share of house work and child care in what became known as the second shift.

In a recent book titled Mothers’ Images of Motherhood: Case Studies of Twelve Mothers, Mahrer Kaplan (1994) explored the lives of twelve older, well educated mothers of toddlers and how they make meaning of motherhood. Several of Mahrer Kaplan’s conclusions should be of concern to all feminists involved in the discourse on motherhood. For the most part, most of her participants mothered in some isolation, with little reliance on a supportive network or contacts with other mothers. In fact, they regarded other mothers as potentially threatening and intrusive and tended to keep their distance. Of even greater concern is the author’s conclusion that “instead of questioning what has been called the institution of motherhood, these modern women most frequently question other mothers and resist affiliating themselves with women” (Mahrer Kaplan, 1994, p. 202). The participants of this 1994 study tended to frame their occupational decisions in personal terms and were unlikely to engage in social critique or social action.

Present day feminists continue to theorize about the oppressive aspects of the institution
of motherhood. They also emphasize the importance of presenting the lived experience of individual mothers, constrictions and joys included. Rossiter (1987) argues that babies typically are preferentially attached to their mothers due to their bodily connection of birth and breast feeding. Denying this connection and framing it exclusively as a social construction, can result in frustration for both mothers and babies. On the other hand, feminists must be wary of enduring social arrangements which supposedly emanate from this bodily connection.

In addition to disentangling the relationship between biology and the institution of motherhood, feminist work is committed to making room for alternative forms of motherhood, beyond the white, middle class, nuclear family. The authors of a recent article on women in Canadian social policy noted that “the numerous and diverse ways of living-in-relation in which Canadian women participate are for the most part, invisible or unsupported by social policy” (McCannell, McCarthy, & Herringer, 1992, p. 179). These authors explain how particular social policies are detrimental for families of single mothers, contributing to an astounding 60% of single mother families that live under the poverty line. Feminists working towards change in the division of labour within families, in rectifying unjust social policies and in expanding the options available to all women, can contribute to the well being of mothers and their families.

**One Hundred Years of Non-Motherhood**

The cultural glorification of motherhood throughout history has been particularly oppressive for women who are not mothers. Nullipara and nulligravida, the medical terms for a woman without a child and for one who has never been pregnant, respectively, come from the Latin word empty, void (Lisle, 1996). These terms reinforce the popular cultural assumption that motherhood is intrinsic to adult female identity, an assumption that necessarily implies an absence
for any woman who is not a mother (Ireland, 1992). As far back as biblical times, women's barrenness was seen as a sign of God's displeasure, notwithstanding the recognition of such prominent women without children as Miriam the prophet and Deborah the judge (Lisle, 1996). For the most part, barren women in the bible and in folk tale are portrayed as frustrated and bitter, tirelessly pursuing their quest for a biological child. This portrayal is probably an accurate one, given that for generations, the social status of women was inextricably bound with bearing sons. In the less ancient past, the childless wives of King Henry the VIII were beheaded or divorced, and the Catholic church allowed childless marriages to be annulled (Lisle, 1996).

Although childlessness as a chosen lifestyle was not really possible before the time of effective birth control and abortions, there were women throughout history who have attempted to gain control of their reproductive lives. Chaste marriages were initiated by some women as a way of preventing pregnancies while others decided to forgo marriage altogether in order to gain an education or become involved in political life (Lisle, 1996; Sandelowski, 1990). The fertility rate declined sharply towards the end of the 19th Century as women began to assert their right to education, careers, and political power. Alarmed by declining birth rates and by the expanding presence of women beyond the home, the state reinforced the cult of motherhood along with an active intimidation of childless women (Lisle, 1996; Sandelowski, 1992).

In her article on female agency and fertility in a historical perspective, Sandelowski (1990) emphasizes the role that physicians played in endorsing procreation and perpetuating the negative image of childless women. Ambitious women who sought an education were viewed as perverting their biological destiny by diverting energy from their reproductive organs to their brains. This set the stage for the enduring belief that infertility is often nothing more than a failure
of volition. A paper read at an Ob/Gyn section of the American Medical Association at the turn of the century framed the causes of infertility almost exclusively in volitional terms. Similar claims were made in 1931 by Childs, a physician and author of *Sterility and Conception*, “in a particularly vitriolic attack against American women, including ‘fat women’, ‘academicians’, ‘public women’, ‘detached women’ and ‘social corsairs’” (Sandelowski, 1990, p. 48). The more women expanded their roles and influence beyond their homes, the more popular explanations of volition in sterility became. This trend continued in the post war years when many women left their jobs and “returned home.”

Statistics point to a mere 3% of married women in America who did not have children during the 1950s. These women were considered deviant and socially aberrant, with studies using terms such as ‘introverted’ and ‘maladjusted’ to describe them (Lisle, 1996). Although more subtle than in earlier decades, female agency was again implicated in fertility, with the increasing interest in psychoanalysis and psychosomatic medicine. Psychoanalytical theory explained infertility in terms of a woman’s unconscious fear of femininity and refusal to assume an appropriate gender role. Many physicians readily embraced this explanation, as it provided them with an etiology in cases of medically unexplained infertility. In some cases, even repeated miscarriages were explained as an unconscious refusal to bear a child (Ireland, 1992; Lisle, 1996; Sandelowski, 1990).

Being involuntarily childless in the 40s and 50s was a particularly harsh and painful experience for women, given the stigma and scorn associated with it. “Living in an intensely pronatalist period characterized by a special cultural ‘aversion’ to childlessness, these women constituted a ‘discarded group of blighted women’, ashamed to reveal their situation and suffer
the severe opprobrium that was then attached to childlessness” (Sandelowski, 1990, p. 55). In addition to the iatrogenic impact on women of having a lack of desire implicated in infertility, many childless women faced barriers in their attempts to seek medical solutions. A eugenic ideology was prevalent in medical circles, resulting in infertility treatment being extended only to those deemed sufficiently wealthy, stable, and competent to become parents (Sandelowski, 1990).

Those who write about childless women highlight the 60s and 70s as a period when many women were able to forge a female identity apart from motherhood. The 1971 addition of Our Bodies/Ourselves goes to great lengths to reassure women that they can be whole without having children and that there are multiple routes to happiness and fulfilment (Lisle, 1996; Snitow, 1992). Feminism on the whole questioned the inevitability of motherhood for women and several (albeit short lived) organizations were formed by and for people without children. This period of relative freedom was not to be for long, however, as the “New Right was mounting a massive offensive against all efforts to separate women and mothering” (Snitow, 1992, p. 39). Stay-at-home mothers were once again glorified in the culture and in the media, motherhood was portrayed on television, movies and magazines as a panacea for loneliness, whereas choosing to remain childless was considered shallow and self-indulgent (Lisle, 1996). Those who were childless by default rather than by choice, were again implicated in their infertility as sexual freedom and delayed childbirth were indicated as major contributing factors to fertility problems. Reflecting on her own experience as a childless woman in the 80s, Lisle writes: “I sometimes felt the blast of pronatalism as debilitating, and I found myself avoiding the confession that I had no child, uneasy once again about my lack of conformity to 1950s ideals, now revived with a vengeance” (Lisle, 1996, p. 30).
As we head towards the end of the twentieth century, women who are not mothers continue to struggle with issues of female identity apart from motherhood. Ireland (1992) studied the lives and meaning-making of women who are not mothers. She conducted focused interviews with over 100 women whose childless status was due to either choice (transformative women), infertility (traditional women), or ambivalence that led to delay (transitional women). Of the three groups, those who actively chose a child-free lifestyle tended to be most content with their careers and relationships and least conflicted with their identities as women without children. The traditional women, on the other hand, had expected to fulfil their identities through motherhood and were at a greater risk for seeing themselves as defective and incomplete as women without children. Those who coped successfully were those who, after mourning their loss, re-oriented themselves towards work or some other meaningful endeavour. Expanding their social network to include other women without children was also a protective factor.

In her conclusions, Ireland (1992) criticizes the implicit societal assumption that motherhood is an intrinsic part of female identity, an assumption that has been reinforced by many psychological theories and insufficiently challenged in feminist analysis. Similar assertions are made by Snitow (1992), who embarked on her analysis of feminism and motherhood following her own experience of infertility. She is concerned that the pervasiveness of pronatalism in society has also been incorporated into feminism; “in the long run we were better able to attend to mothers’ voices than we were able to imagine a full and deeply meaningful life without motherhood, without children” (p. 33). Both Ireland (1992) and Snitow (1992) emphasize the need to expand existing female images and role models to include the lives and experiences of women without children.
Approaching this topic from a different angle, Sandelowski (1990) poses another challenge for feminist theorizing on childlessness. She contends that many feminists who highlight the oppressive elements of New Reproductive Technologies, fail to give credence to infertile women who have a strong desire to become mothers. This desire can too readily be theorized as socially constructed, as yet another manifestation of oppression, rather than construed as an authentically experienced desire for children (Sandelowski, 1990). This dismissive approach is arguably more detrimental to women than patriarchal prescriptions as it is coming from within the feminist movement itself.

A final caveat will conclude this section on motherhood and non-motherhood. The well being of women, be they mothers or not, cannot be advanced by presenting ambitions and personal aspirations as incompatible with motherhood, thereby further polarizing women with and without children. Discussing women who chose to remain childless, Ireland writes: “for transformative women, there is an internal expectation of excellence that makes it impossible for them to pursue both creative non-maternal work and mothering” (Ireland, 1992, p. 76). The logical implication of this quote is that mothers do not have this same “internal expectation of excellence,” an implication that should not be made by feminist theorists. Instead, feminists need to work collectively towards the “reproductive rights of women to define and determine their own sexuality, whether to have or not have children, and the economic conditions needed to care for these children” (Franzblau, 1996, p. 69).

**Women with Disabilities and Motherhood**

Whereas healthy, wealthy white women have traditionally been encouraged to bear children, women with disabilities, along with poor women, immigrant women, and women of
colour, have been historically discouraged from procreation. In this section I review existing literature on women with disabilities in relation to motherhood. I begin by exploring the many barriers that women with disabilities faced and are often continuing to face, in relation to sexuality and motherhood. I then review the existing literature on the impact of parental disability on children's well-being. Finally, I focus on the lived experience of mothers with disabilities through published narratives and the handful of studies on this topic. As I indicated in the introduction, my particular focus is women who have a musculoskeletal type of physical disability which typically results in impaired mobility. Although I attempted to focus on literature which is most relevant to mobility impaired women, a lot of the existing literature on women with disabilities adopts a cross-disability approach where the distinction between types of disabilities is underemphasized. This is not due to negligence or oversight; rather, it is embedded in the philosophy that many of the oppressive elements in disability are socially constructed. As such, the similarities between women with different disabilities, as far as oppressive attitudes and discriminatory practices are concerned, are regarded as more telling and noteworthy than their differences.

Sexuality and Reproduction

But what if you’re considered a smashed pie? In a current article on the health experiences of women with disabilities, Carol Gill, a disabled psychologist, researcher, and disability rights activist, tells the following story. In a recent seminar at a health centre for women with disabilities, a psychologist addressed the topic of self-esteem. Several women with disabilities in the audience related the difficulties associated with developing positive relationships and having a good self-esteem when they experience so much social rejection. The psychologist's response was that “different” does not mean “inferior”; in a restaurant, some customers will choose the
lemon meringue pie while others will prefer the banana cream pie. Just because one pie is chosen over the other, that does not make the unchosen one inferior. Like pies, women too, are different. “A hand shot up in the back of the room. A middle-age African American woman with a visible physical disability quickly brought the discussion back to basics. She asked, ‘But what if you are considered a smashed pie?’” (Gill, 1996a, p. 5).

This powerful story poignantly illustrates the social, psychological, and sexual barriers faced by many women with physical disabilities. It is hardly surprising, given society’s obsession with fitness and youth, and the dominant values regarding the centrality of beauty and physical appearance to a woman’s self worth (Lonsdale, 1990; Wendell, 1989). These values are further perpetuated by television and other media images where sexual behaviour is almost exclusively associated with young, attractive women. In contrast, people with disabilities are typically depicted as objects of sympathy and pity, usually for fund-raising purposes (Linton & Rousso, 1988). Women and men with disabilities have traditionally been stereotyped as child-like, dependent and asexual, often regarded by others as incapable of fulfilling adult social roles (Asch & Fine, 1988; Lonsdale, 1990).

Many stories have been told by women with physical disabilities about the deleterious impact of being treated like a gender-free being. These women have often been regarded by their families and the wider community as incapable of attracting a mate, being a sexual partner, or even having a need for intimacy and sexual expression (Asch & Fine, 1988; Begum, 1992; Nosek, 1996a, 1996b). In the words of one participant in a study on sexuality and disability: “I always felt like a neuter sex. It’s like I’m not a woman, not a man, I don’t know what I am because I was never approached like a woman” (Nosek, 1996a, p. 166).
Women with pre-adolescent disabilities were often socialized as girls to regard themselves as asexual. Accepting a child's sexuality is often difficult for parents of non-disabled children. For parents of girls with disabilities, this is often compounded with concerns that their growing daughters will not be successful in the sexual arena and should be spared the heartache of sexual and social rejection. Such parental beliefs may result in conveying messages, explicit or implicit, that sexual intimacy should not be expected or sought by the girl with a disability. (Begum, 1992; Kocher, 1994; Rousso, 1996). Studies on the sexual development of girls with physical disabilities suggest that they are significantly more limited in their sexual and social involvement than girls without disabilities (Rousso, 1996). In a retrospective study on the impact of parental attitudes on social success for girls with disabilities, 43 women with physical disabilities were interviewed. Thirty one women had pre-adolescent disabilities while the remaining 12 had acquired their disabilities after adolescence and served as a control group. Compared to the control group, women with pre-adolescent disabilities reported limited opportunities for heterosexual activities during childhood and adolescence. General parental attitudes and expectations did not differ significantly between the two groups. However, in comparison to the control group, parents of girls with pre-adolescent disabilities had lower expectations of their daughters in the social and sexual arena and higher expectations in the educational and vocational arena. The mothers of these daughters were also less likely to have conversations with their growing daughters on such topics as dating, marriage and children, topics that are frequently discussed between mothers and daughters (Rousso, 1988, 1996).

The conclusions of this study point to the negative consequences of having one's sexuality denied or ignored, and being excluded from social and sexual encounters during adolescence.
Those who write about sexuality and disability often implicate physicians and the medical model for perpetuating the asexual stereotype of people with disabilities. Stories abound in the literature of pre-adolescent women with disabilities being poked, prodded, and made to walk undressed in front of doctors and medical students (Begum, 1992; Gill, 1996b). Even more common than these stark sexual violations is the medical objectification of disabled body parts and the concomitant reference to "good" (non-disabled) and "bad" (disabled) limbs and body parts (Finger, 1990, 1993). Many women with physical disabilities have been subjected to this functional limitation approach inherent in the medical model and embraced by many physicians and health care professionals (Hansen, 1992; Nosek, 1996b). Children needing assistance with personal care may also experience exposure and objectification of their body and a lack of privacy for sexual exploration. Unclear boundaries with respect to touching and handling the body may interfere with a child's ability to distinguish between appropriate and inappropriate touch and thus render her more vulnerable to sexual abuse (Cole, 1988; Cole & Cole, 1993; Saxton, 1984). This is but one explanation for the alarmingly high rate of sexual abuse perpetrated against women and girls with disabilities.

Past research on the lives of adult women with disabilities suggests that their social and sexual rejection is not limited to the adolescent years. They are less likely to be partnered than either non-disabled women or disabled men and, if they acquire their disability in adulthood, are more likely to be left by their partner (Asch & Fine, 1985, 1988; Ferguson-Matthews, 1983). The disadvantage that women with disabilities face in the relationship sphere can be explained in terms of aesthetics and function (Gill, 1996b). The aesthetics explanation refers to stereotypical standards of feminine beauty, according to which women with visible disabilities may be perceived
as flawed or defective. The functional explanation refers to patriarchal notions of women's roles as caretakers and nurturers, in conjunction with distorted assumptions about the inability of women with disabilities to care for and nurture others. Unfortunately, men with disabilities can also be implicated in judging and devaluing women according to these standards, as many of them eliminate women with disabilities as potential partners (Asch & Fine, 1988). Much like the intraracial romantic rejection reported by some dark-skinned African American women, disabled women may be rejected by disabled men who seek “a majority culture partner to offset rather than mirror their own socially devalued status” (Gill, 1996b, p. 185).

In a current follow-up research of special education students, young women with disabilities were found to have the same marriage rates and even higher parenting rates than non-disabled women, 3 to 5 years after leaving school (Wagner, 1992, in Rousso, 1996). This may lead us to believe that most barriers to social and sexual inclusion have been successfully removed for women with disabilities. A closer look at the data, however, reveals that this pattern applies to women with learning, emotional and speech disabilities, but not to women with physical disabilities, who were a lot less likely to be married, live with a partner, or have children (Rousso, 1996). Notwithstanding the fact that many young women with physical disabilities may choose to remain single and without children, these results suggest that “for those young women whose bodies diverge from the cultural norm of beauty and attractiveness because of physical disability, the barriers to social success remain formidable” (Rousso, 1996, p. 113).

Eugenics - a thing of the past, or alive and well in the present? In an article on the reproductive issues of women with disabilities, Waxman (1994) argues that “beneath the asexual stereotype lurks the belief that disabled women’s reproductive capacity is a biological, moral, and
economic danger” (p. 155). Waxman is among a growing number of disability rights activists who expose and condemn the restriction of full reproductive freedom that many women with disabilities have experienced and reported over the years. Restriction of reproductive freedom can take many forms. Stories of coerced abortions (Gill, 1996a) and pressure to undergo tubal ligations and hysterectomies (Ridington, 1989; Rogers, 1991, 1996) can be found in the literature on women with physical disabilities and were probably more prevalent in the past. While such extreme measures of control and coercion appear to be the exception rather than the rule, other, more subtle pressures to refrain from reproducing are more commonly reported.

Historically, medical and professional literature was virtually silent on issues pertaining to the sexual functioning and reproductive health of women with disabilities, while in private offices physicians tended to discourage these women from having children. Consequently, there exists an astounding disparity in knowledge about the reproductive health of disabled versus non-disabled women; almost nothing is known about the number of disabled women of childbearing age, or their rates of fertility, pregnancy, birth and abortions (Nosek, 1996b; Waxman, 1994, 1996; Saxton, 1994). This state of affairs should come as no surprise: “If research pursuits reflect social values, it makes sense that a society that has long ignored the gender role of women with disabilities has invested little effort in understanding their potential for love, partnership, and motherhood” (Gill, 1996b, p. 189). In the Boston-based project “Women and Disability Think Tank”, all ten participants had similar stories of being actively discouraged from considering pregnancy by health practitioners or family members (Saxton, 1994).

Women with disabilities have been discouraged from having children for a variety of reasons, ranging from fears that they will produce “defective” children, to scepticism about their
ability to look after their offspring, to concerns about the psychological well being of children who have a disabled parent. Some of these reasons will be further explicated later in this review. For the purpose of the present discussion, this proscription of motherhood for women with disabilities cannot be divorced from the prescription of motherhood for women deemed "good reproductive material" which I discussed earlier. According to Francis Galton, the founder of the eugenics movement, "(its) first object is to check the birth rate of the Unfit, instead of allowing them to come into being...the second object is the improvement of the race by furthering the productivity of the Fit by early marriages, and healthful rearing of their children" (Galton, 1908, in Franzblau, 1996, p. 53). Whereas women considered fit have been targeted by positive eugenics, those considered unfit, women with disabilities included, have been the targets of negative eugenics.

Eugenics -- rooted in the Greek meaning of "good birth"-- the word itself is enough to send shivers up one's spine as it conjures images of Nazi atrocities. However, merely several generations prior to the second world war, "America led the world in eugenic studies, action, and propaganda, following England's lead and soon passing it" (Shaw, 1994, p. 23). In western Europe and in the USA, sterilizations of institutionalized individuals labelled "feeble-minded" were commonly performed. Twenty four states in America had sterilization laws by the end of the 1920s with some 30,000 sterilizations being performed by the mid 1930s. Marie Stopes, known as the pioneering advocate of birth control, was an ardent supporter of eugenics and attempted to prevent her son from marrying a woman with glasses on the grounds that it would be a crime against his country (Campion, 1995; Shaw, 1994). Eugenics was also popular in Canada, with the province of Alberta enacting a sterilization act in 1928 which lasted 44 years. British Columbia
also had such a law which was revoked as recently as 1973 (Globe and Mail, 1996, in entourage, 1996, p. 9). Although the dangers of eugenics became crystal clear after World War II, it continued to be practiced in many institutions for mentally retarded residents.

Today, we can safely say that involuntary sterilization has been made illegal in most of the western world. However, disability rights activists and other proponents of human rights have raised their voices against another variation of the eugenic ideology, one that has specific implications for people with disabilities. Great advancements have been made in recent years in New Reproductive Technologies in general, and in the detection of fetal abnormalities in particular. Increasingly, women are choosing (or more accurately are chosen) to undergo prenatal tests that will detect the presence of disability in the fetus and will, euphemistically speaking, “expand their reproductive choices.” In other words, women who carry a disabled fetus can (and most often do) choose to terminate the “defective” pregnancy; there is an estimated 80% rate of abortion of fetuses diagnosed as having a condition that could result in a significant disability (Blumberg, 1994a, b).

The screening for fetal abnormalities, which has become an integral part of prenatal services, is of concern to disability rights activists in general, and to women and men with disabilities in particular. More than vehemently opposing all prenatal screening, activists emphasize the importance of problematizing these procedures rather than embracing them wholeheartedly as has been done by most of the medical community. They speak out against the anti-disability bias that undergirds much prenatal testing and selective abortions, where disability is regarded with horror and alarm and the assumption is made that no life at all is better than a life with a disability. For the last several decades, people with disabilities and the disability rights
movement have been advancing the notion that the most troubling aspects of living with a disability are socially constructed. The disabling condition itself may actually pale in comparison to the oppressive attitudes and discrimination that often accompany it. Removing physical and attitudinal barriers would do much to improve the quality of life of people with disabilities and would significantly decrease its impact on their lives. This view of disability is all but lost in prenatal testing, where disability is regarded solely in bio-medical terms. (Asch, 1994; Blumberg, 1994a, 1994b). As Marcia Rioux, the executive director of the Roeher Institute points out, more than 90% of infant disability is due to social rather than genetic factors and 85% of adult disability is incurred after the age of 13 (Rioux, 1996).

There is a glaring and ironic disparity between the billions of dollars funnelled for genetic screening and the meagre funds allocated towards improved nutrition, social support and other low cost measures that could enhance well-being and minimize the incidence and impact of illness and disability (Rioux, 1996; Blumberg, 1994b). "Ironically, the society in which we live is devoting more and more resources towards preventing people with disabilities at the same time it is doing less and less to prevent people from having disabilities" (Blumberg, 1994b, p. 150). The ubiquitous and unquestioned promotion of prenatal testing also runs the danger of limiting rather than expanding women's reproductive choices. The growing sophistication of prenatal tests, coupled with societal disdain for imperfection, translates into increased pressure on women to ensure the infallibility of their offspring. Women choosing to forego prenatal testing often have to contend with the clear disapproval of their doctors (Stewart, 1996) and potentially, may even run the risk of losing their medical insurance if they choose to bring to term rather than abort the "flawed" (and expensive) fetus (Blumberg, 1994a, 1994b; Rioux, 1996; Saxton, 1994).
Carole Gill (1996a) writes about her encounter with her gynaecologist who remarked on how incredible she must be to be happy despite her severe disability. The gynaecologist disagreed when Gill indicated that happiness is more closely related to one’s ability to meet goals and have fulfilling relationships than on the extent of the disability. Gill later found out that this gynaecologist was the medical director of genetic services at the clinic and, in that capacity, counsels parents about their possibility of having a child with a disability. “I shudder to think about what this Ob/Gyn is telling her patients about bringing people like me into their lives” (Gill, 1996a, p. 11). Indeed, genetic counsellors typically have minimal knowledge about life with a disability and tend to focus on the limitations associated with it rather than see it as just one facet of the individual. Consequently, life with a disability may be described to prospective parents with an exclusive focus on limitations and difficulties, while potential contributions and accomplishments are underemphasized (Asch, 1994; Blumberg, 1994a, 1994b; Gill, 1996a). Provisions are rarely made for parents to meet adults with disabilities in the community who lead productive and fulfilling lives, in order to gain a more balanced perspective.

How are women with physical disabilities affected by the increased popularity of prenatal testing? For one thing, the societal pursuit of perfect babies suggests that people living with disabilities are really a tragic mistake of nature, “defective faulty machines that should have been recalled” (Blumberg, 1994b, p. 139). In addition to the questioning of their very existence, women with disabilities are more likely than their non-disabled counterparts to be perceived as being at risk for producing children with disabilities. The hereditary nature of some disabilities may call into question the right of disabled parents to produce a baby that may carry their genetic code, disability included. The author of an article published as recently as 1984 in *Journal of Legal*
**Medicine** proposed reproductive quarantine for people who may have disabled children and charges of fetal abuse to be made against those who refuse to abort a disabled fetus (Shaw, 1984, in Blumberg, 1994a, 1994b). In 1991, a talk show host in California invited listeners to comment on the pregnancy of Bree Walker, a Los Angeles television news presenter with a hereditary condition which results in the fusing of fingers and toes. The talk show host questioned the appropriateness of Walker’s decision to produce a child who is likely to inherit her condition. People phoning in criticized Walker’s decision, with comments such as ‘I would rather not be alive than have a disease like that when it’s a 50-50 chance’ (Campion, 1995, p. 136). Outraged by this invasion of her privacy and the lack of opportunity to respond on the radio show, Bree Walker filed a complaint, still pending. She was also interviewed by Barbara Walters on 20/20, providing her with an opportunity to dispel some of the negative stereotypes of life in the context of disability (Campion, 1995; Saxton, 1994).

The reader should not be left with the impression that most disabilities are inheritable (most in fact are not); or that women with disabilities are unified in their opposition to prenatal testing. Some may actually avail themselves of these very tests that may have prevented their own existence, were they available several decades earlier. Saxton (1984) shares this difficult dilemma in an article on reproductive technologies and people with disabilities. “Could I choose to abort a baby with my own disability, end the life of someone somehow an even closer kin to me than my own child?” (p. 301). She ultimately decided that she would not terminate such a pregnancy; another woman may come to a different decision. In a recent article on this subject, Barbara Waxman (1994) asks “Are disabled women using this technology? If so, are they somehow responding to society’s ultimatum that will allow them to enter the boundaries of reproduction?”
Undoubtedly, the subject of prenatal screening is highly sensitive and fraught with ethical dilemmas. Recently, the science section of the Globe and Mail dealt with this very topic under the heading “Abortion: A troubling ‘cure’ for hereditary diseases” (December 21, 1996, D6). This sensitivity probably accounts for the reticence of the disability rights movement to adopt a clear position on this issue. In two comprehensive and compelling articles on the subject, Blumberg (1994a, 1994b) suggests some concrete position that the movement should take in order to combat eugenics, while carefully sidestepping the abortion debate. Women’s right to choose an abortion, regardless of the health status of their fetus, should not be negated by disability rights activists; rather, the movement should strongly oppose a geneticist’s call for mandatory prenatal testing or any legal or social policy that would limit medical coverage for “preventable” babies.

A review on the sexuality and reproduction of women with physical disabilities must include the historical tension between the feminist movement and women with disabilities with respect to these issues. In recent years, disabled feminists have criticized the movement for failing to give a voice to women with disabilities and include their concerns within the feminist agenda (Keith, 1992; Lloyd, 1992; Morris, 1992). This exclusion appeared to be most apparent in matters pertaining to sexuality and reproduction, where disabled and non-disabled women often found themselves on opposite sides of the same issue. The feminist movement has been united in its outrage with the sexual objectification of women, which they consider a concern for all women. For women with physical disabilities, the flip side of this concern is the deleterious impact that asexual objectification has had on their lives (Asch & Fine, 1988; Lonsdale, 1990). Lisi (1993) reminds us that “not all of us take being a sex object for granted. For someone who does not expect to be viewed as attractive, a wolf whistle from a passing truck can be a great experience.”
(p. 202). In a similar vein, the feminist struggle for reproductive freedom was defined only in terms of women’s right to terminate unwanted pregnancies. This narrow definition was exclusionary and thus invalidating of women with disabilities who often framed their own struggle as the right to have children. Women with disabilities have also contested the fact that some pro-choice activists have used birth defects to support their argument for free and safe abortions.

The outcry against the feminist exclusion of women with disabilities has not gone unheeded, according to the very recent literature on this subject. In the last few years alone, increasing numbers of women with disabilities have been invited to contribute to women’s anthologies, conferences, and women’s programs (Gill, 1996a). In addition to bringing their issues and experiences into the mainstream, women with disabilities are also gaining greater visibility in health services and are asserting their right to control their bodies and their lives (Krotoski, Nosek, & Turk, 1996). Not only are they more vocal and prominent as consumers of health services, they are also participating in the community as researchers and clinicians, thereby having a much needed input into what is funded and researched. Consequently, some of the recent research on sexuality and disability has been conducted by women researchers with disabilities. In addition to outlining existing barriers, these researchers are also pointing out some encouraging trends that may directly impact women and girls with disabilities. For example, Rousso (1996) found that while they continue to face social rejection, “many young women with disabilities have become tougher and more creative in their strategies of resistance to negative assumptions about their social potential” (p. 114). Another study also attested to the importance of positive parental attitudes to the development of a positive sexual self-concept among girls with physical disabilities (Nosek, 1996a). This study also outlined characteristics that are common among women with
disabilities who have a positive sexual self-concept, thereby providing a blueprint for enhancing
the sexual self-concept and overall well-being of women with disabilities

Parental Disability, Family Life, and Children’s Well Being in Professional and Research
Literature

In her recent book titled Who’s Fit to Be a Parent?, Campion (1995) asserts that “today,
the focus of assessment for parental fitness has shifted away from whether people can produce the
right quality of genetic offspring to whether they are up to the actual task of child-rearing” (p.
132). Campion then proceeds to describe several groups of “parents on the edge;” those whose
fitness to rear children has been traditionally questioned. People with physical disabilities are the
first group described, followed by mentally handicapped parents, gay parents, teenage mothers
and drug addicts. As indicated earlier in this review, the discouragement of motherhood for
women with disabilities can only be partially explained by societal fears that they will produce
disabled children. Another commonly held belief, and one which has been supported by some of
the literature, is that children’s physical and psychological well-being is at stake when they have a
disabled parent. In this section I review some of the research studies and professional literature on
the relationship between parental disability and the well being of children and families.

Of the research and professional literature covered for this section of the review, the most
damaging depiction of parents with disabilities was found in a 1979 article titled Counselling the
Children of Handicapped Parents (Kennedy & Bush, 1979). In the very first sentence, counselling
is recommended for children of disabled parents in order “to facilitate their adjustment to
deficiencies in parenting behaviour and family structure that may have resulted from the parent’s
disability” (p. 267). In case the reader is not yet convinced as to the importance of counselling for
these kids, the authors go on to claim that “handicapped parents, because of their frustration, may make their children scapegoats and assign them additional responsibilities” (p. 267). The article is replete with such terms as “afflicted”, “stricken”, “bed-ridden” and “physically defective” in its description of disabled parents and concludes by portraying these parents as frustrated individuals who “become increasingly disagreeable” (p. 270). Published less than twenty years ago in a respected counselling journal, this article was undoubtedly read by many professionals who came in contact with children of parents with disabilities. Its potentially iatrogenic impact is clear.

Whereas the negative biases of the authors are crystal clear in the above mentioned article, they can be more insidious and therefore escape detection in other publications. One such Canadian study (Peters & Esses, 1985) investigated the effect of parental chronic illness (Multiple Sclerosis) on family functioning. Thirty three research participants and the same number of controls aged 12-18 years and matched for sex, age and socioeconomic status, were administered the Family Environment Scale. This scale is a 90 item paper and pencil test that assesses the perception of family environment on the dimensions of family relationships, personal growth, and system maintenance. The results of the study point to significant differences between the two groups with research participants obtaining higher scores than controls on the conflict subscale and lower scores on the subscales of cohesion, organization, intellectual-cultural orientation, and moral-religious emphasis. The authors conclude that this study supports the contention that children who have a disabled parent perceive their families significantly differently than those who do not have a disabled parent. More specifically, they regard their families as having more conflict, being less organized and less involved in cultural activities and intellectual pursuits, and as placing less emphasis on moral and religious issues.
The grim results of this study and its implication for disabled parents must be considered in light of what I consider to be a major methodological drawback which receives no more than lip service by the authors. While the research “subjects” were recruited through the local MS society, all of the controls were students at a local religiously affiliated school (Mennonite Brethren). The authors give no other information about the school other than its religious affiliation. Nowhere in the article is it mentioned, for example, that this is a private school rather than a publicly funded one. The reader would not have this information unless they, like me, lived in the city where the study was conducted and worked in its school system. Would we not expect some differences between families whose children attend private schools and those who attend public schools? The authors only mention the religious affiliation of the school, refer to it very briefly as a methodological drawback, then minimize its impact by arguing that most of the control group scores were “reasonably similar” (p. 307) to standardized scores. These methodological drawbacks cannot be considered minimal given the possible ramifications of the results.

In the same year that the above mentioned study was published, an edited book on this topic also hit bookstores and libraries. Titled *Children of Handicapped Parents: Research and Clinical Perspectives* (Thurman, 1985), this book criticized some of the methodological flaws of previous work, emphasized the need for high quality studies, and cautioned against unnecessary infringement on disabled people’s parental rights (Thurman, Whaley, & Weinraub, 1985). These caveats notwithstanding, negative biases can also be detected in this book, along with a disregard for societal factors and a complete division between people with disabilities as research “subjects” or clients and the non-disabled professional community of researchers and clinicians. For example,
one article asserts that since more and more people with disabilities are becoming parents, more emphasis should be placed on studies which examine the impact of parental disability on children. This would prevent unnecessary denial of disabled people’s parental rights while ensuring that children’s well being is not compromised. The authors further suggest that “reaching this goal requires the cooperation of legal, medical, rehabilitation, and family service professionals. To be successful they need up to date information that will help them decide whether a particular disabled parent in a particular set of circumstances places a given child at a developmental risk” (Thurman, Whaley, & Weinraub, 1985, p. 3). The notion of such an extrapolation where research can potentially be used to curb parental rights is a dangerous one. It also flies in the face of a rudimentary research tenet; that research findings based on a sample cannot be applied to any one individual with any degree of precision. Furthermore, this description of collaboration of professionals from diverse areas of expertise (legal, medical, rehabilitation, family services) for the purpose of assessing risk, corroborates the claim of many parents with disabilities that they are closely scrutinized as parents.

Another point of contention is these authors’ perception of researcher bias and their suggestions for its amelioration. “One area of concern for all us researchers, clinicians and scholars is our own biases and perceptions. In order to study this population and render required services to them, it is important to develop our theories and practices with as few a priori assumptions as possible” (p. 7, italics added). Some of their suggestions for reducing attitudinal biases include learning as much as possible about the etiology of disability, exploring the correlation between parental style variables and outcome, and examining of one’s own (researcher and professional) feelings about disability. Nowhere is it suggested that parents with disabilities
themselves may have valuable knowledge in this area, or that some of them may also be researchers and professionals. The suggestion that theories and practices can be developed free of biases is also a naive notion that has been refuted by many reputable researchers.

Having described three articles that focus on the detrimental impact of parental disability, I find it important to emphasize that not all of the research and professional literature is negative in this respect. In the same edited book described above, Greer (1985), a physically disabled father, describes a study he conducted in 1965 on the adjustment of 69 adults with Cerebral Palsy. His findings suggest that of those participants who were parents, 90% were well adjusted individuals. Buch (1981, 1982) explored the relationship between paternal disability (Spinal Cord Injury) and the subsequent adjustment pattern of adult children. In this study, 45 adult children of Spinal Cord injured fathers and a matched control group were compared on various psychological and attitudinal measures reported in the literature to be influenced by parental disability. While some differences were found between the two groups, paternal disability was not correlated with any adverse effects on the children's well being. Adult children were found to be well adjusted, emotionally stable, and having positive recollections of family life with a disabled father (1981a). Furthermore, a very small scale comparison between children of quadriplegic and paraplegic fathers suggests that the severity of paternal disability does not affect child outcome (1981b). In a more recent study, the interaction patterns between mothers with Multiple Sclerosis and their 8-12 year old daughters was compared with non-disabled mother-daughter dyads (Crist, 1993). Interactions between mothers and daughters during a work task and a play task were videotaped and scored. Statistical analysis revealed no significant differences in the interaction patterns of the research (mothers with MS and their daughters) versus the control group (non-disabled mothers
and daughters). This is despite the greater number of single mothers in the research group and their lower socioeconomic status.

What conclusions can be drawn from the research literature on parental disability and children’s well being? Several recent publications on the subject denoted the limited use of previous studies due to small sample sizes, lack of regard for gender, and indifferetiation between disability situations, just to mention a few (Roy, 1990, in Campion, 1995; Kirshbaum, 1996; Olsen, 1996). Along with critiquing flawed research, researchers who align themselves with disabled parents emphasize the importance of the overall family constellation as well as sources of risks and protective factors external to the parental disability. The family’s level of isolation versus support, the impact of poverty and disincentives for gainful employment, and inaccessible environments faced by many parents with disabilities are being raised as important contributing factors that should be considered in research (Kirshbaum, 1996). In a recent article, Olsen (1996) critiques the current literature that has sprung up on young carers, children who care for ill or disabled relatives, typically parents. He asserts that in conjunction with the portrayal of young carers as victims who have been robbed of their childhood, existing literature pays no more than lip service to the support that disabled people need to empower them as parents. Furthermore, the debate about young carers which appears to be a “hot topic” in the UK, “has taken place without basic, high quality research into who young carers are, what they do, how their caring restricts or enables different activities, and, perhaps most importantly, how their experience differs from those we might call ‘non-caring’ children” (p. 41).

The critiques presented above notwithstanding, my own conclusion to this body of literature is to question the very premise of conducting large scale studies which compare children
of disabled parents to peers of non-disabled parents. Within physical disabilities alone, conditions vary in terms of chronicity, severity, and stability versus progression. Is it really feasible to create such distinct categories of disabilities as Kirshbaum (1996) suggests? More importantly, what would we gain by having methodologically sound studies which compare the well being of children of disabled parents to controls? Would it result in more enlightened policy, or in knowledge that could be directly beneficial to these families? I believe that it is fair to say that parental disability can constitute a potential risk factor for children, just as growing up poor, experiencing parental divorce, or having parents who are highly involved with challenging careers, can be risk factors.

The large body of literature on risks and protective factors has long demonstrated the inadequacy of inferring negative outcome based solely on the presence of a risk factor. For example, women who lost their mothers before the age of eleven but received adequate care following the loss, were less likely to experience depression later in life than those whose care was not adequate following the mother’s death (Brown et al., 1986; in Nelson, Prilleltensky, & Peters, in press). In other words, the overall context in which the risk factor is embedded is more relevant to the outcome than the risk factor itself. The difference in outcome between girls who received adequate care following maternal loss and those who did not has important implications for practice.

The same logic can be applied to the subject of parental disability and children’s well being. A current article on this topic describes a very large scale research study which analyzed data from the 1988 U.S. National Health Interview Survey on Child Health. (NHIS-CH). Approximately 47,000 households containing about 122,000 persons, filled out a survey which
provided extensive information on the health of family members residing in the home as well as on the health, emotional well-being, and educational performance of one randomly selected child per family. Information on the child was gathered from the parent (typically the mother) via a 28 item index which inquired whether the child exhibited particular types of behaviours sometimes, often, or not at all, in the last 3 months. A sample of 11,248 surveys on children were analyzed for the present study. Disability was very broadly defined as “a restriction due to an impairment, on the ability to perform activities that are normal for persons of the same age” (LeClere, Marsteller, & Kowalewski, 1994, p. 459). The results of this study indicate that the mean number of severe and common behavioural problems were significantly increased by the presence of a disabled family member. After controlling for covariates (income, education of the responsible adult, family structure, marital status of mother), children living with a disabled parent or with more than one disabled relative were found to be the most affected. The authors conclude that the magnitude of these effects should not be understated and that more attention should be paid to the families of disabled individuals.

This large scale study clearly demonstrates that parental disability constitutes a risk factor for children. However, the very broad definition of disability seems too inclusive to provide us with useful information as far as physical disabilities are concerned. In the absence of any information on types of impairments, parents who are limited in their functioning due to mental illness or alcoholism, for example, could also fall under this rubric, while the problems they face in their parenting may be qualitatively different. Furthermore, this type of a study sheds no light on the mechanisms by which parental disability impacts family life and children’s well-being, a limitation noted by the authors. Also left untouched is the exploration of differential outcome for
families of disabled parents.

What helps some families cope well despite the presence of risk factors and what can be learned from their ability to function healthily in the presence of illness and disability? A study which explored the family’s functioning with the mother’s chronic illness can enhance our understanding of these issues. The study sample comprised 125 families in which the mother had chronic illness (non-metastasized breast cancer, diabetes, or fibrocystic breast disease). The families were followed over an 18-month period, with each family being interviewed five times in order to determine the impact of the mother’s chronic illness on the family. Fathers also filled out self-administered questionnaires measuring their level of depression, marital adjustment, and perception of the adjustment of their children. The results of the quantitative study suggest that the mother’s chronic illness and its demands on the family, positively and significantly correlates with depression in her spouse and in marital dissatisfaction. However, frequent use of familial introspection, defined as the ability to reflect on the family performance and make adjustments in the face of illness demands, was associated with positive outcome for the family, including better adjusted marriages and better parent-child relationships (Hough, Lewis, & Woods, 1991; Lewis, Woods, Hough, & Bensley, 1989).

In addition to the quantitative study, a sub-sample of 11 families was selected for case analysis, 5 well adjusted families (low depression, high marital satisfaction based on scales) and 5 poorly adjusted families who were at the opposite extremes on depression and marital satisfaction. The type of illness or physical symptoms in the mother did not distinguish the two types of families. Rather, in comparison with poorly adjusted family, well adjusted families had fewer number of stressors in their lives which taxed the family. Furthermore, social support was an
important distinguishing factor between the two types of families. All of the well adjusted families relayed positive experiences of being supported by family and friends and, in turn, were able to reciprocate and offer support to others. In contrast, insufficient social support was mentioned by all the poorly adjusted families. Interestingly, the quantitative analysis of the data in the larger study described above did not reveal a significant effect of social support as measured by size of social network. However, the perception of support emerged as a consistent and important factor in the qualitative study. Both quantitative and qualitative analysis found that an emotionally satisfying and secure spousal relationship is paramount to successful familial adaptation to mother's chronic illness.

Another study of parents with Multiple Sclerosis also identified specific coping mechanisms that were utilized by well adjusted versus poorly adjusted families (Power, 1985). Specifically, initial denial or minimization of the impact of the disability was found to be adaptive as it cushioned the initial shock. Other positive coping mechanisms were open communication within the family and with health care professionals, flexibility in roles and a willingness to share responsibility, outward-directed activities, and continued involvement of the disabled parent in family activities and engagement as a competent decision maker. Poorly adjusted families were characterised by poor communication, insufficient knowledge about the illness and its implication, and a tendency to unnecessarily exempt the disabled parent from daily responsibilities. Another interesting finding is that of the 18 families where the mother had MS, 15 were among the well-adjusted families. Furthermore, 7 families initially labelled as “uncooperative” by the service agency, had demonstrated good adjustment patterns in the study.

These types of studies are helpful as they advance our knowledge about specific coping
strategies associated with positive outcome. They have clear implications for practice that can be used by professionals and are potentially empowering to people with disabilities who are either parents or are considering parenthood. An encouraging trend among some researchers and service providers, is one of approaching disabled parents with the purpose of identifying strengths. One such example of focusing on strengths is Talking it Out in the Family, a video portraying real life situations of parental disability where the actors are the people living the experience (Blackford, 1990). Research currently under way at Through the Looking Glass in California includes several projects that focus on strengths: An in-depth study of families with at least one significantly disabled parent, where the parents perceive themselves as having positive parenting experiences; a longitudinal study of children of parents with physical disabilities which explores factors that promote positive child outcomes as well as those that increase risk; and research consisting of both a qualitative and quantitative components exploring the impact of assistive technology on the transition to parenthood (Kirshbaum, 1996). Research and professional literature which accentuates the strengths of parents with disabilities and their families tends to be more descriptive in nature and to focus on the lived experience of these families. Next, I review existing literature on the experience of motherhood in the context of physical disability.

Mothering in the Context of a Physical Disability: Exploring the Experience, Enhancing Well-Being

Many of the articles reviewed in the previous section criticised the dearth of published studies on the relationship between parental disability and the well-being of children and families. My own review of the literature brings me to conclude that as sparse as they may be, these studies still outnumber ones that explore the experience from the point of view of the disabled
parent. The lived experience of mothers in general has traditionally received little attention from the research community in comparison to the multitude of studies on child development. The experience of motherhood in the context of disability is no exception to this; if anything, the depiction of women with disabilities as dependent, asexual and requiring care, has resulted in a paucity of research on their mothering experiences.

Regardless of the amount of research on the subject, the phenomenon of motherhood in the context of disability has always existed and is clearly on the rise, due to improved health and medical care, the establishment and proliferation of the disability rights movement, and the general trend of de-institutionalization. Consequently, many publications have surged in recent years that describe the lives of mothers with disabilities and their families. Most of these are narrative accounts published in feminist and nursing journals, in books and journals for disabled consumers, as well as in the UK based Disability, Pregnancy, and Parenting International, a magazine specifically geared for parents with disabilities. In this final section of the literature review I explore the experience of motherhood in the context of physical disability based on existing research and consumer-based literature.

Negative attitudes and scepticism encountered by many women with disabilities who choose to become mothers is quite prevalent in this literature. Earlier in this review I discussed the lack of professional knowledge on the reproductive health of women with disabilities and the opposition they have traditionally faced from doctors, family members, and others. In a recent survey in the UK on disabled mothers’ experiences of maternity, a third of the 199 respondents had been advised against having children, mainly by a relative other than their partner, but also by physicians and geneticists (Goodman, 1994). Formidable hurdles may therefore be experienced
even before the transition to motherhood as women attempt to get information on the intersection of pregnancy and disability. Barriers have also been reported by women attempting to adopt a child (Kopala, 1989; White & White, 1993); obtain custody following a divorce or separation (Mathews, 1992; Campion, 1995), or even take their infant home from the hospital (Campbell-Earl, 1993; Mathews, 1992; Kocher, 1994). In one case which has received wide publicity, a young mother with Cerebral Palsy in California lost both of her infants who were apprehended at birth and eventually adopted out of state (Mathews, 1992). Although such horror stories are the exception rather than the rule, many women with physical disabilities describe having to demonstrate their competency and parental fitness. In one such case, a doctor brought her own eight month old infant to see if her spinal cord injured patient could carry out child care duties. A group of physicians and health professionals then tried to convince the mother to either give her baby up for adoption, or put her in foster care for several years. Both offers were declined by this mother, who went on to successfully raise four children (Pischke, 1993).

Several Canadian studies conducted in Vancouver in the mid 1980s focused on the inadequacy of the health care system in meeting the needs of women with disabilities during pregnancy and childbirth. In one study, 24 women with Rheumatoid Arthritis were compared with controls with respect to the information and services they received during pregnancy. While shortcomings in childbirth education were identified by both groups, disabled women were less likely than controls to receive adequate information and more likely to experience inappropriate referrals and a lack of coordination of services. Most of the disabled women interviewed (20/24) indicated that the education and services they received did not meet their needs, versus only a small number (4/24) of the non-disabled women. A survey of 20 agencies offering childbirth
education classes in greater Vancouver also point to similar results; most of these agencies referred women with physical disabilities elsewhere for services, usually without ascertaining the appropriateness of the referral. Staff at the agencies felt they were not equipped or sufficiently informed to serve this population, nor that it was their function to do so (Conine, Carty, & Wood-Johnson, 1986, 1987; McEwan, Carty, Conine, & Hall, 1990).

Narrative accounts and the handful of studies on this topic indicate that difficulties with the health care system are not limited to the perinatal period. In one study of 16 chronically ill mothers, participants experienced the health care system as ill equipped to meet their needs as both chronically ill women and mothers. They were either given medical recommendations that were highly incongruous with their roles as mothers, or, when parenting was addressed, the implications of the chronic illness were ignored. Furthermore, participants found that they had to look and act sick in order to secure the health care services they need in order to function in their parenting capacity. Emphasizing the illness and its implication, however, was counter-indicated with their like-wise important need to present themselves as competent mothers, capable of looking after themselves and their children (Thorne, 1991). “Thus, the predicament for these women was that the more they tried to take responsibility for their lives, the more they jeopardized the support and services they needed to succeed in raising their children” (p. 217).

This study underscores a common misconception which many mothers with disabilities see as germane to their experience of oppression and devaluation. Rooted in both patriarchy and able-ism is the supposedly clear-cut division between dependence and independence, between those who care and those who are cared for. This division was virtually unquestioned in the past and has contributed to the depiction of people with disabilities as residing exclusively on the receiving end
of care and support. Highly derogatory in and of itself, this stereotype is especially lethal in conjunction with the social imperative for women to be nurturers. In growing numbers, disability rights activists are denouncing this form of devaluation while emphasizing the multitude of roles people with disabilities fulfil (Keith, 1992; Morris, 1992). Nonetheless, this stereotype may explain the incongruence experienced by many mothers with disabilities as they try to accommodate both their disability and their family into their lives. This incongruence is manifested in such barriers as inaccessible daycare centres and toddler play groups on the one hand, and supposedly accessible housing on the other, where only one bedroom can be reached with a wheelchair since the possibility that the disabled inhabitant is also a caregiver was not even considered (Blackford, 1993; Dunn, 1988; Ridington, 1989; Morris, 1993).

Lack of physical accessibility of the kind described above is but one of many socially constructed barriers reported by mothers with disabilities. Having to keep their earnings artificially low in order to retain eligibility for medical coverage precludes meaningful participation in the work force for some disabled mothers (Hillyer, 1993; Kocher, 1994). The financial disincentives in the USA for marriage in the context of disability can also unnecessarily tax the family system (Gill, 1996b; Reinelt & Fried, 1993; Waxman, 1994). According to this policy, people with extensive disabilities who marry or live with a partner, may lose some of their government funding for equipment and health coverage, given the increased earning of the family unit. This may be a contributing factor to the proportionally higher number of disabled mothers who are also single mothers.

By far the most discriminatory and problematic policy, and one which directly affects mothers with disabilities, is their limited or nonexistent access to funded assistance with child
care. Unlike traditional child care which is typically provided in the parents’ absence, some mothers with physical disabilities need ongoing physical assistance in order to care for their children. This point was underscored in a highly publicized court case which dealt with the potential removal of a non-disabled infant from her physically disabled parents. Both parents were severely disabled and received regular attendant care. However, state laws prevented their attendants from providing any care to their infant daughter. Instead, they were warned that they were being closely watched by social services (Bergman, 1993). This is but one example of a commonly reported policy whereby personal care attendants are prohibited from assisting disabled parents with child care (Reinelt & Fried, 1993). Here in Ontario, one trailblazing mother led the way in securing funding to assist her in caring for her infant (Odell, 1988). However, as it currently stands, this policy is only available to parents who are disabled enough to require attendant care themselves; it renders ineligible those who can look after themselves unassisted, but require help in order to care for their children. As Blackford (1993) notes in her critique of Canadian policy, “a mandate for accommodation of difference in law is little better than a symbol unless policies, funding and bureaucratic practices are in place to ensure accommodation of difference in the everyday lives of mothers with disabilities” (p. 284)

Social isolation is a common theme in the life stories of mothers with disabilities. A survey of physically disabled mothers in the UK found feelings of isolation to be quite prevalent amongst the 101 women who responded to the survey (Goodman, 1994). This point was further underscored in a recent conference report on parenting and disability, titled I Thought I Was the Only One (Shackle, 1993), as well as in a Canadian survey titled The Only Parent in the Neighbourhood: Mothering and Women with Disabilities (Ridington, 1989). Physical constraints
on getting out and about may require some mothers with disabilities to spend more time at home than they would like, thereby contributing to their social isolation (Goodman, 1993). In a Canadian study on the social adjustment of mothers with Multiple Sclerosis, all eight participants reported significant changes in their social relationships following their diagnosis. “Energy was seen as a scarce resource preserved primarily for child care, work, and home maintenance, next for the husband and family activities, and lastly, for friends” (Lyons & Meade, 1993, p. 36). The presence of social support facilitated coping with the illness and was associated with emotional well-being for the mothers. More importantly, being perceived as a valuable, competent individual who is fun to be with and is capable of contributing to the well-being of others, was central to emotional well-being.

Mothers who have illnesses that are progressive or result in fluctuating health may worry about the impact of the illness on their children and families. In one study of 16 chronically ill mothers, participants shared their concerns regarding their hampered ability to carry out some parental duties and to be consistently available to their children during times of hospitalizations or increased illness demands (Thorne, 1991). Similar concerns are expressed in the following narrative account of a mother with Systemic Lupus: “‘Mommy hurts, mommy no feel good’, my two and a half year old daughter, Jennifer, says as my husband comes home from work. It always upsets me to see her so confused and upset over my ongoing battle with systemic lupus” (Lindner, 1993). I chose to present this quote for its bold description of a hardship directly related to the mother’s illness. The presence of such concerns notwithstanding, they are far less commonly reported in this literature than some of the socially constructed barriers described earlier. This is compatible with the popular and widely reported assertion that environments can be more
handicapping than the disability itself (Kocher, 1994).

In growing numbers and with increasing clamour, mothers with disabilities are speaking out. Through the stories they tell they defy stereotypes, name their oppression, and assert their right to bear and rear their young. Along with explicating the barriers they face, mothers with disabilities are telling heartwarming tales of fulfilment of a dream (Goodman, 1993; Killoran, 1994; Kopala, 1989), loving relationships and positive communication (Blackford, 1990; Reinelt & Fried, 1993; Rogers & Matsumara, 1990), and pride in children who are well-adjusted, caring, and appreciative of human diversity (Goodman, 1993; Ridington, 1989). Motherhood may be particularly cherished by those who had to struggle in order to attain it. Acknowledging both the challenges and the joys of motherhood, Killoran (1994) makes the point that while it may be hard for any woman to care for a child, “for me and for the other disabled mothers I know, it is particularly hard and maybe particularly wonderful” (p. 121). The joy and fulfilment that their children bring to them is consistently found in this literature, even in the presence of multiple barriers.

Through their life stories these mothers challenge the assumption that the well being of children is compromised by a parental disability. There are both personal accounts and observational studies of babies lying perfectly still for diaper changes and otherwise facilitating their care by their disabled parent (Kirshbaum, 1996). The suggestion has even been made that the slower pace dictated by many disabilities may be more harmonious with the slower pace of babies (Mathews, 1992; Shackle, 1993). It is also important to keep in mind that the intensity associated with caring for an infant is a relatively short-lived phase in the life-long relationship between mother and child (Campion, 1995).
As children get older, their self-esteem and sense of competence may be enhanced by carrying out certain duties and responsibilities. Of course, “there is a fine line to walk between asking too much of a child and helping them to be self-sufficient and self-confident” (Reinelt & Fried, 1993, p. 199). There is nothing in this literature which suggests that mothers with disabilities abdicate their parental role or overburden their children with chores and responsibilities. If anything, the inability to participate in certain activities with children may be compensated by an increased emphasis on emotional presence and availability (Kocher, 1994). Contrary to some of the literature on the adverse impact of parental illness, most mothers with disabilities describe their children as both independent and self-sufficient on the one hand, and as having a heightened capacity for caring and compassion on the other (Kopala, 1989; Therman, 1990). As Killoran points out, “the ability to be a good mother does not reside in the ability to chase around after a toddler, nor in the ability to teach your child how to ride a bike. Being a good mother has to do with making sure your child has a strong sense of self-worth, and an appreciation of the wonders and abundance of life” (122).

Although they do not hesitate to point out insensitive attitudes and unjust policies, mothers with disabilities also pay tribute to the many allies who have helped them along the way. As a group, nurses and midwives are especially noteworthy for their attempts to facilitate the well-being of mothers with disabilities. There are various stories of nurses asking how they can be of help (Kopala, 1989); physicians who facilitate and support disabled women’s reproductive rights (Goodman, 1993); and social workers who go out of their way to obtain resources and supports that could facilitate motherhood (Morris, 1993). One particularly poignant quote attests to the impact that a supportive professional can have: “After talking to the physiotherapist and the social
worker, I stopped feeling guilty about my children suffering deprivation because of my disability. I realized that children do not have any more right to a perfect parent, that is, one who is not handicapped, than a parent does to a perfectly formed child” (Belohorec & Kikuchi, 1985, p. 33).

Positive and affirming attitudes towards parenting with a disability can also be found in some of the professional literature on this topic. Publications in nursing journals emphasize the importance of focusing on strengths rather than on deficits (Asrael, 1982; Hanna & Edwards, 1988), and of asking disabled parents what nursing supports they require, rather than providing assistance which is not perceived as helpful (Kopala & Heine Egenes, 1984). Perhaps even more significant is the apparent shift in attitude amongst medical and rehabilitation researchers and practitioners, a group that has traditionally been highly invested in the medical model and therefore less likely to approach this subject from a disability rights perspective. This attitudinal shift is exemplified in the following quote from a current book on reproductive issues for people with physical disabilities: “Studying reproductive issues and developing techniques and strategies that enable people with physical disabilities to become parents is a powerful affirmation of the commitment of the rehabilitation research and training community to the empowerment of individuals with physical disabilities” (Graves, 1993, p. 336). Even more recently, a conference titled “The health of women with physical disabilities: Setting a research agenda for the 90s” was sponsored by the National Centre for Medical Rehabilitation Research (NCMRR). Sexuality and reproduction was one of the major areas covered in this conference whose audience and presenters included women with physical disabilities, practitioners, and researchers, some of whom are themselves disabled women. This conference, which also provided the material for a recently published book, (Krotoski, Nosek, & Turk, 1996), has undoubtedly expanded the
knowledge base on the health and well-being of women with physical disabilities, with sexuality and reproduction identified as a major component.

A shift in attitude is not limited to the medical and rehabilitation community. Most recently in Canada, there seems to be a surge of media interest on this topic, with an article published in the Globe and Mail and three television documentaries, all within the last year. On Saturday, May 11, 1996, the front page of the Globe and Mail depicted a woman in a wheelchair holding an infant. The accompanying article noted that “...in doctors’ offices and on the street, the politics surrounding disabled parenthood is changing...there’s an awareness on the part of disabled women that it’s possible to become a parent, and an awareness on the part of health professionals not to discourage them” (Philip, 1996, p. A12). The importance of a more positive portrayal of parenting with a disability notwithstanding, it has yet to translate into more equitable policies and increased resources for mothers with disabilities. The uplifting comment about shifting perspectives is tempered in the Globe and Mail article by the following reminder of the status quo: “While more disabled people are taking the plunge into parenthood, most are left to cope with the huge challenge of caring for a baby and coping with daunting physical limitations on their own” (Philip, 1996, p. A12). As we rejoice that “attitudes, they are a changin,” we are best to remind ourselves that a positive outlook is but one step towards enhancing the well-being of mothers with physical disabilities and their families.
III

METHODOLOGY

Harding (1987) has made the distinction between method -- the specific technique utilized for data collection, and methodology -- the philosophical and theoretical grounding on which the data is based. This distinction notwithstanding, a close relationship exists between underlying assumptions about knowledge and specific techniques of data collection. As Morgan and Smirchin (1980) remind us, “the virtues of techniques and methods cannot be determined and categorized in the abstract because their precise nature and significance is shaped within the context of the assumptions on which the social scientist acts (p. 499).

In this chapter I explicate the underlying assumptions which guide my research and the specific techniques used to gather, analyze, and interpret the data. Beginning with the former, I discuss the theoretical underpinnings which frame my research as one which is qualitative, feminist, and informed by a disability rights perspective. I then move to an elaboration of the research process and to the various phases of data collection, analysis, and interpretation. With the theoretical underpinnings as backdrop, I conclude the chapter by outlining the major methodological issues that I came across in the process of the research and my attempts to deal with them along the way. While I do not purport to have resolved or even fully recognize all pertinent methodological issues, I attempt to give as clear an account as possible, allowing the readers to come to their own conclusions.

Research Paradigm

Guba and Lincoln (1994) define paradigm as the “basic belief system or worldview that guides the investigator, not only in choice of method but also in ontologically and
epistemologically fundamental ways” (p. 105). They further emphasize its centrality by their assertion that questions of method are secondary to those of paradigm. My own world view guiding this research is couched within a qualitative, feminist, and disability rights perspective. Like a paradigm, qualitative research is an approach to knowledge rather than merely a set of techniques. Broadly speaking, qualitative approaches to research are based on the belief that methods used to investigate the physical world are inappropriate for the investigation of human lives. Unlike the physical world which is predictable and largely unaffected by the act of investigation, the social world is forever shifting and evolving, constructed and reconstructed by people's values, goals, and particular contexts. Whereas the overall purpose of quantitative research is to explain and predict, qualitative research seeks to understand people's lives and the multiple meaning they give to their lives as they negotiate their existence. The process of investigation cannot be separated from what is being investigated and from who is doing the investigating. Researchers are part of the world they research and their own experiences, beliefs and value systems impact every aspect of the research process (Denzin & Lincoln, 1994; Howe, 1992; Hunt, 1992; Morgan & Smircich, 1980; Smith, 1983).

Feminist research is also classified as an approach rather than a particular method of data collection (Maynard, 1994; Maynard & Purvis, 1994; Reinharz, 1992). At the core of this approach is a commitment to the production of knowledge that is useful and empowering to women and can contribute to their growth and well-being (Edwards, 1993; Fine, 1992; Maynard, 1994). Of prime importance is the openly ideological, value-laden nature of feminist research which focuses on the oppressive factors in women's lives and on the inter-relation between gender and other social constructs such as race, poverty, and disability (Fine, 1992; Lather, 1986; 1991;
Maynard, 1994). The centrality of the political and ideological nature of feminist research is evident in every phase of the research process with more and more emphasis being placed on research which is transformative, empowering and action-oriented (Acker, Barry, & Esseveld, 1991; Fine, 1992; Kelly, Burton, & Regan, 1994).

There are many similarities and parallels between what the feminist movement has attempted to do for women and what the disability rights movement has attempted to do for people with disabilities. Both have emphasized the role of oppressive contexts and have advocated for macro level changes in the social structure and for a more equitable distribution of resources. Researchers such as Oliver, (1990, 1992), Fine and Asch (1988), and Zarb (1992), to mention a few, have documented and exposed the anti-disability bias that undergirds a lot of the mainstream research on disability. More often than not, people with disabilities have been depicted as unfortunate individuals who are forever trying to come to terms with their tragic reality. In this kind of research, problems encountered by people with disabilities are seen as inherent in the physical condition itself, rather than mediated by environmental, social and political factors.

Having provided a synopsis of qualitative, feminist, and disability rights research paradigms, I now present some of the fundamental principles associated with these approaches. I choose to focus on refuting positivism, importance of context, centrality of the research relationship, participant and researcher voice, and research from an openly ideological perspective. These principles are not mutually exclusive and exhaustive, nor are they afforded equal weight in the paradigms under discussion. I believe, however, that their presentation can facilitate an understanding of some of the more intricate issues involved in research conducted from these three perspectives.
Refuting Positivism

The main tenet of positivism is the existence of a single reality or truth that can be studied and apprehended in an objective, value-free manner. Unearthing truth and reality through research is contingent upon the scientist’s ability to remain neutral and value free in relation to the object under investigation. Internal validity, external validity, reliability and objectivity are the four criteria used by positivists to evaluate their research. Applying these criteria, especially that of objectivity, ensures that investigator and investigated “object” remain independent and uninfluenced by one another and that the ensuing data is uncontaminated. “Inquiry takes place as though through a one-way mirror. Values and biases are prevented from influencing outcome, so long as the prescribed procedures are rigorously followed. Replicable findings are, in fact, ‘true’” (Guba & Lincoln, 1994, p. 110).

Over the course of the century, positivism has been transformed by post-positivism, which contends that reality can only be approximated and not fully apprehended. Using multiple methods to capture as much of reality as possible, post-positivists remain highly traditional in their emphasis on the discovery and verification of theories and in the evaluation criteria they utilize. For both positivism and post-positivism, the aim of inquiry is to explain, predict and control phenomena, be it physical or human (Denzin & Lincoln, 1994; Guba & Lincoln, 1994; Oliver, 1992).

Positivism and post-positivism have been fiercely attacked by those who believe that all research is conducted within a particular social context, that it cannot be value free, and that it should cast a wider net in terms of the goals of inquiry. Although some qualitative researchers operate from within the post-positivist paradigm, others situate themselves within a constructivist
and/or critical perspective. It is beyond the scope of this short review to outline the differences between critical theorists and constructivist researchers. Suffice it to say that both camps denounce positivistic researchers for producing "only a certain kind of science, a science that silences too many voices" (Denzin & Lincoln, 1994, p. 5). Their focus is the understanding of people's lives and the multiple meaning they give to their lives. In addition to studying contextualized lives enhanced and constricted by a host of factors, some researchers emphasize the transformative potential of research with advocacy and activism being key concepts.

Like most other social research, "the history of research on disability is undoubtedly one that has been dominated by the positivist research paradigm both in terms of the research undertaken and the assumptions underpinning it" (Oliver, 1992, p. 107). Oliver (1992) identifies two main pernicious outcomes stemming from the dominance of positivism over disability research. The first relates to the portrayal of disability as residing solely within the individual and emanating directly from a medical condition. This supposedly value-free portrayal of "reality" served to obscure any relationship between socio-political conditions and the individual experience of disability. The second detrimental impact of positivism has to do with its naive assumption that a non-problematic relationship exists between research findings and policy change. Lest we cast these flaws as residing in a decadent, positivistic past, a recent article titled "Disability and the myth of the independent researcher" suggests that this is a persistent problem (Barnes, 1996).

Positivism has been refuted by feminist researchers on similar grounds. Feminist researchers share the belief that their values and life experiences impact every stage of the research process - from deciding what to investigate, to the formulation of research questions, to
conducting and analysing the research. They object to notions of neutral, value-free research which culminates in objective knowledge that is not contaminated by the researcher's subjectivity. Rather than asking whether values, beliefs and experiences influence the research, the question becomes one of clarifying those values and beliefs and explicating the particular lenses through which the research is conducted. Given that the researcher is part of the social world that she is investigating, her own presence in the research is acknowledged rather than neutralized (Edwards, 1993; Fine, 1992; Lather, 1986, 1991; Maynard, 1994).

The more recent feminist research literature takes issue with previous claims that only qualitative research can be considered feminist due to its focus on multiple meanings and personal constructions of reality. This argument was more characteristic of second wave feminism where quantification was seen as distorting women's experience as it ignores aspects of their lives that cannot be pre-known and pre-defined. While it had some bearing in the early stages when women's experiences were still invisible as far as research is concerned, it is hard to justify this orthodoxy today. The more recent feminist literature seems to be in agreement that qualitative, quantitative, or a combination of the two are perfectly legitimate tools to be used by feminist researchers (Jayaratne & Stewart, 1991; Kelly et al., 1994; Maynard, 1994; Reinhartz, 1992). In some cases, quantification can serve an important social purpose which may not be possible to achieve with qualitative techniques. For example, statistics on the intensity and severity of violence against women, on equity issues in pay, or on the feminization of poverty, can be instrumental in fighting oppression (Maynard, 1994). As Mary Maynard (1994) asserts, it is the doctrine of positivism, rather than the use of empirical procedures, that should be contested.
The Importance of Context

The importance of context is emphasized by many qualitative researchers. As Denzin and Lincoln (1994) claim, "there is no clear window to the inner life of an individual. Any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity. There are no objective observations, only observations socially situated in the worlds of the observer and the observed" (p. 12). The wide range of qualitative methodologies vary, among other things, on the degree to which they focus on context as an important organizing principle.

Phenomenological research which focuses on participants' experience of meaning attempts to actually strip away at context in order to come to the essence of meaning. Although context is not negated or ignored, a distinction is made between what exists inside, which is the focus of phenomenological research, and what exists outside, which is of little interest (Moustakas, 1994; Polkinghorne, 1989; Van Manen, 1990). Context is also afforded a limited role in Heuristic research as described by Moustakas: "Only the co-researchers' experience with a phenomenon are considered, not how history, art, politics, or other human enterprises account for and explain the meaning of the experience....the depiction is complete in itself. Interpretation not only adds nothing to heuristic knowledge but removes the aliveness and vitality from the nature, roots, meanings, and essences of experience" (Moustakas, 1994, p. 19).

As researcher, I situate myself within the contextualized, constructivist approaches to qualitative inquiry. From the narrative approach, I resonate with the notion of people leading storied lives and telling stories about the lives they lead (Clandinin & Connelly, 1994). The telling of life stories is an interpretive process that has a formative impact on one's identity (Ochberg, 1994). As stories are told, new meanings and interpretations come to the forefront, shaping not
only the story but also the life on which it is based (Widdershoven, 1993). With life story as its starting point, life history research is "a way of understanding life as lived in the present and influenced by personal, institutional, and social histories" (Cole & Knowles, in press, p. 18). Its purpose is to understand people's lives and meaning making through a reconstruction of past events and within particular personal, social and political contexts (Cole, 1991, 1994). While context is also considered in the narrative approach, it is more prominent in life history research which often considers other sources of data in addition to life stories. At times, the externally-gathered information is conflicted with or contradictory to the personal story that unfolds and may require challenging on the part of the researcher. As a result, researcher and participant engage in a jointly negotiated co-construction of knowledge (Cole & Knowles, in press; Cole, 1991, 1994; Goodson, 1992; Measor, 1985).

Goodson (1992) discusses the danger of studying subjective experience apart from its restrictive or facilitative context. He underscores the importance of researching lives within the constraints imposed on them by broader social forces such as race, gender, and ethnicity. Having the privilege of the "bigger picture," this knowledge can be shared with participants, thereby facilitating their understanding and meaning-making. Similar assertions are made by Bertaux (1981), who feels it is the responsibility of the researcher "to put together bits of knowledge that might be found everywhere...and to draw a picture of the whole and its movements" (p.40).

I consider the social, political, and historical context central to life history research, as imperative in the study of women with disabilities and mothering. Neither motherhood nor disability is located solely in biology; both emanate from a complex interaction of physical, personal, and social factors. I share Goodson's "concern for telling the story with an equal
concern to provide a broader context for the location, understanding, and grounding of those stories” (Goodson, 1992; p. 243).

The importance of attending to context is also emphasized in feminist approaches to research (Acker, Barry, & Esseveld, 1991; Fine, 1992; Holland & Ramazonoglou, 1994). “Although we view people as active agents in their own lives and as such constructors of their social worlds, we do not see that activity as isolated....Rather, we locate individual experience in society and history, embedded within a set of social relations which produce both the possibilities and limitations of that experience” (Acker, Barry, & Esseveld, 1991, p. 135). Gender is seen as a major organizing principle in women’s lives and the social construction of gender is at the heart of feminist inquiry (Lather, 1991).

In more recent feminist work, it has become increasingly apparent that to study the oppressive factors emanating from the social construction of gender, without its relation to other social attributes such as race, class, and disability, is to add insult to injury to marginalized women. Consequently, a lot of the more recent feminist inquiry has focused its efforts on studying the particular ways in which gender braids with other social constructs (Edwards, 1993; Fine, 1992; Lather, 1991; Maynard, 1994; Phoenix, 1994). Much feminist research has begun to focus on women who have been most invisible and under-studied in order to bring their experiences and realities into the mainstream, as the following quote indicates: “Much feminist research claims to name new topics, to examine the invisible, to study the unstudied, and to ask why it has been ignored...we have demonstrated how certain people are ignored, their words discounted, and their place in history overlooked. We have shown how certain things are not studied and other things are not even named” (Reinharz, 1992, p. 248).
This trend has wide implications for women with disabilities who have been critical in the past of both the disability rights movement and the feminist movement for neglecting their needs. While the former did not value their particular concerns as women, the latter neglected their specific circumstances as disabled (Lloyd, 1992; Oliver, 1990). For example, early research on disability focused exclusively on the experiences and needs of disabled men; disabled women were rendered invisible. As to the second charge, disability and feminist theorists like Jenny Morris (1992) and Lois Keith (1992) demonstrated how women with disabilities have been left out of the feminist agenda, as if their issues and concerns are of no importance to feminists. In a compelling article titled *Who cares wins?*, Keith (1992) is highly critical of the apparent insensitivity to women with disabilities demonstrated in feminist research and in debates on community care. In their advocacy of women-centred issues of care, most feminists have totally aligned themselves with women as care providers (for it is usually women who do the care giving), and have failed to identify with the recipients of care, many of whom are disabled women. In fact, those on the receiving end of care have often been categorized simply as dependent people of no specific age or gender. Taking context into consideration entails, among other things, the inclusion of both disability and gender as important organizing principles. The growing body of literature on women with disabilities in recent years suggests that these criticisms have not gone unheeded. This research study will hopefully contribute to this body of knowledge.

**The Centrality of the Research Relationship**

Whereas traditional research seeks to separate researchers from those being researched (Kincheloe & McLaren, 1994), this separation is counter-indicated in qualitative studies. Qualitative researchers and theorists place a major emphasis on the relationship with study
participants. "When we enter into a research relationship with participants and ask them to share their stories with us, there is the potential to shape their lived, told, relived and retold stories as well as our own. These intensive relationships require serious consideration of who we are as researchers in the stories of participants, for when we become characters in their stories we change their stories" (Clandinin & Connelly, 1994, p. 422). Recognizing that research can have either a negative or a positive transformative impact, researchers acknowledge the care that has to be taken when personal experience methods are used. The importance of upholding the dignity, respect and well-being of participants is consistently emphasized in this literature, as is the need to consider issues of reciprocity and to search for ways in which the research can have a positive impact on participants.

Enunciating a commitment to participant well-being without acknowledging the many barriers to its attainment is at best naive and at worse outright dangerous. Far from remaining at the level of ethical platitudes, descriptions of specific ethical dilemmas abound in the qualitative research literature. Burgess (1989) refers to these subtle predicaments as the ethical grey areas of qualitative research. Riddell (1989), among others, discusses the "ethics of raising highly charged issues and then walking out leaving them unresolved and offering no solutions" (p. 90). Despite the potential benefit to participants of telling their story to an attentive listener and having an opportunity to explore experiences and meaning making, the risk of "opening up" potentially charged and painful issues must be considered.

Another closely related issue is the ethical limit of probing for further information. Seidman (1991) discusses his own preference for the word "explore" rather than "probe" which conjures images of an intrusive medical procedure. Whichever word one chooses to use,
attempting to elicit further information from participants can be an intrusive and potentially risky endeavour. Despite the natural tendency to learn as much as possible, the need to respect the boundaries of research participants is emphasized (Cole, 1991, 1994; Glesne & Peshkin, 1992; Measor, 1985; Yow, 1994). Qualitative researchers would agree that, when in conflict, participant well-being always comes before the wish to obtain a rich and thick account. However, whether one stops probing “before you get ordered out” (Yow, 1994, p. 72) or much sooner than that, is still left to the individual researcher.

Control over the process and product of the research is also discussed in this research literature. In traditional methodologies there is little question as to the separate, and very distinct roles of the researcher and the researched. Other than the right to withdraw at any time, participants don’t have much control over the research process. Their role is one of being a source of data for the research and ends once the data have been collected. Participants play a much more substantial role in personal experience methods where they are often interviewed several times, may be asked to review transcripts for any mistakes or misunderstandings, and may even provide input at the level of analysis and interpretation. Cole (1994) discusses the importance of giving participants a measure of control over the research process. She reflects on her role as “the researched” in a project she undertook with a graduate student with the explicit intent of experiencing life history research as a participant. Despite her status and the care with which the research was conducted, she describes moments of self doubt, hesitation about the relevance of her stories, and concerns over the accuracy of the accounts. Having the opportunity to add to stories and clarify meanings did much to enhance her feelings of having control over the unfolding of her story.
Similar issues can be found in the feminist research literature, both in terms of the commitment to participant well-being and in terms of the ethical dilemmas that arise. This overlap is to be expected, given that many if not most feminist studies utilize qualitative methodologies. In addition to some of the issues already raised, many feminist researchers emphasize their attempts to minimize the distance and power differential between themselves and their participants. Feminist studies often entail a greater sense of connection between researcher and participant and possibly some sharing of her own experiences by the researcher. In her much quoted article about her research on motherhood, Ann Oakley (1981) discusses her departure from conventional, male-oriented interviewing ethics by establishing a non-hierarchial relationship and investing herself in the research process. Other feminist researchers also discuss the benefits -- both to participants and to the research process -- of being less formal and more forthcoming with research participants (Reinharz, 1992; Skeggs, 1994; Webb, 1984). This may include some sharing/disclosure by the researcher and may even culminate in the development of friendships. In the introduction to their edited book on feminist methodology, Fonow and Cook (1991) write that “some authors in this collection discuss the difficult yet rewarding transition to friendship that occurs with informants” (p. 10). Reinharz (1992) also notes that “blurring of the distinction between formal and personal relations...is a characteristic of much, although not all, feminist research” (p. 263).

It is important to indicate that despite attempts to form a more equitable research relationship, most feminist researchers acknowledge that it is naive to assume that power differentials can be altogether eliminated in feminist research (Maynard, 1994; Skeggs, 1994). Moreover, several recent publications have challenged the notion that the reduced distance which
typically marks feminist research relationships are in fact beneficial to participants. Several feminist writers have pointed out the potential for exploitation that exists when women “let down their guard” more than they otherwise would have done, given the reduced distance and the sense of intimacy that develops. This is particularly so when the researcher uses shared experience (as a mother, worker, patient) to facilitate rapport (Holland & Ramzanoglu, 1994; Reinharz, 1992; Riddell, 1989). Riddell (1989) wonders whether her tendency to share certain things about her private life prior to interviews with women and girls can be considered a manipulative strategy to get more information. She asserts that “if this strategy was manipulative, it was not consciously so, but the dilemma remains” (p. 85). Another group of researchers who formed friendships with many of the women they interviewed discuss their somewhat painful realization of “unarticulated tension between friendship and the goals of research. The researcher’s goal is always to gather information; thus the danger always exists for manipulating friendships towards that end” (Acker et al., 1991, p. 141).

Before concluding this section I find it important to indicate that issues pertaining to the research relationship have also been raised by disability rights theorists and researchers. The negative experiences that many people with disabilities have had as research subjects and the ensuing feelings of distrust and suspicion towards researchers is demonstrated by the following quote: “Few of us have escaped the researchers’ scrutiny of their seemingly pathological fixation on the limitations and negative aspects of disability. We have been portrayed as sick, helpless, and incompetent; incapable of living independently” (Woodill, 1992, preface). Those who critique research from a disability rights perspective advance similar arguments raised by feminists regarding the traditionally powerless and passive role of research participants. Oliver (1992)
contends that most research on disability has contributed to the problems faced by disabled people by reinforcing the dominant idea that disability is an individual problem. This does not only characterize traditional approaches to research. Oliver (1992) provides a scathing critique of any research on disability which is not emancipatory and is not under the full control of consumers.

In recent years, a gradual paradigm shift has taken place in research and action with people with disabilities. This shift includes efforts to change environments rather than “fix” people with disabilities, an emphasis on strengths rather than deficits, and a shift in the balance of power from professional control to consumer control. This paradigm shift has led to many research partnerships between researchers and people with disabilities (Nelson & Lord, 1996).

**Voice of Participant, Voice of Researcher**

Participant voice is a central concept in qualitative research. Unlike positivistic research whose large scale designs all but drown out individual voices, these same voices are often front and centre of qualitative studies. Giving room for participants to tell their stories, their version of life events and their priorities for action, can be validating and empowering experiences and ones which may facilitate change. As Yow suggests, “this validation is especially important to people our society devalues” (Yow, 1994, p. 117). Both women and people with disabilities have traditionally suffered from devalued social status. Good social research is one way of bringing their issues and priorities to the forefront.

Participant voice is a major concept in both feminist and disability studies. Feminist researchers emphasize the importance of amplifying women’s voices in research. After decades of having men speak for them and interpret their experiences, women tell their own stories and reflect on the multiple meanings of those stories. Reinharz (1992) asserts that feminist researchers
favour interviewing as a research tool as it "offers researchers access to people's ideas, thoughts and memories in their own words rather than in the words of the researcher. This asset is particularly important for the study of women because in this way learning from women is an antidote to centuries of ignoring women's ideas altogether or having men speak for women" (p. 19).

Similar arguments have been advanced by disability rights theorists and researchers. Early research on disability focused more on non-disabled people's reaction to disability than on the subjective experience of living with a disability. While this type of research can enhance our understanding of prejudice and stereotypes, it tells us nothing about the personal experience of living with a disability in a disablist society (Asch, 1984; in Fine & Asch, 1988). The subjective experience of disability, rendered in the first person, can give insight into its socio-political embeddedness. It should also, according to Morris (1992), make room for all aspects of living with a disability, including experiences of frailty or ill health. In an article on life history research with people who have learning difficulties, Goodley (1996) argues for the significance of amplifying the voices of cognitively impaired individuals. "Reinforcing the insiders' subjective understanding of their own position prompts readers to challenge their own (often generalized) understandings of the teller. In short, our own 'truths' are quickly changed by the account" (p. 335).

While the importance of representing the voices of participants is an uncontested terrain in research conducted from the aforementioned paradigms, this cannot and should not replace the voice of the researcher. Like participants, researchers too are situated within a host of attributes such as class, race, age, gender, and health. Situating participants advances our understanding of
their experiences and the meaning they attribute to those experiences. By the same token, not situating ourselves as researchers presumes an objective, non-contaminated account of these lives. "Researchers must first accept their own personhood, their co-participation in the human venture they seek to understand. The failure to acknowledge this is probably the largest single reason for the failure of social science research to influence practice" (Hunt, 1992). These warnings may sound like "old hat" and elicit a response of "been there, done that." However, the fact that they continue to resound in the most current literature suggests that researchers continue to omit their own signatures from their work.

Edwards (1993) describes the research process as an interaction of two subjectivities, that of the researcher and that of the researched. Researchers are not merely recording instruments (Edwards, 1993) and the experience of research participants cannot speak for itself (Holland & Ramazanoglu, 1994). Fine (1992) is critical of feminist work that uses the voices of participants to provide a critical social interpretation. Doing so without acknowledging the researcher's own stance is, according to Fine, an exploitation of voices. In a later publication titled "working the hyphens," Fine (1994) further pursues this issue of how researchers account for their interaction with participants and their own presence in their work:

Self and other are knottily entangled. This relationship, as lived between researchers and informants, is typically obscured in social science texts, protecting privilege, securing distance, and laminating the contradictions. Despite denials, qualitative researchers are always implicated at the hyphen. When we opt, as has been the tradition, simply to write about those who have been Othered, we deny the hyphen....we inscribe the Other, strain to white out self, and refuse to engage in the contradictions that litter our texts....When we
opt, instead, to engage in social struggles with those who have been exploited and subjugged, we work the hyphen, revealing far more about ourselves, and far more about the structures of Othering (Fine, 1994, p. 72).

As researchers struggle with “how to be there in the text” and how to inscribe a signature that is neither too thin or too thick (Connelly & Clandinin, 1990), they become increasingly more aware of the indelible mark that they leave on their work. The need to not only acknowledge the researcher’s voice and unique contribution but to also monitor and keep track of biases and subjectivities, is emphasized by a number of qualitative researchers (Glesne & Peshkin, 1992; Holland & Ramazanoglu, 1994; Lather, 1986; Riddell, 1993). Alan Peshkin (1993) writes about his own process of accepting and making the most of his subjectivity which is central to conducting research from a qualitative paradigm. He warns, however, against the possible perils of neglecting to reflect critically on subjectivity. “One’s subjectivity, however, has the capacity to not only enable but also to disable. It is necessary, therefore, to try to see what you are not seeing, to detect what you are making less of than could be made, so that you can temper as necessary that which your subjectivity is pressing you to focus on” (p. 104). By journaling the process of coming to conclusions and continuously attending not only to the emerging understanding but also to gaps, surprises and counter-patterns, subjectivity can become a research asset, rather than a liability.

Researching from an Openly Ideological Perspective

Most qualitative researchers acknowledge the value-laden nature of research and the need to “work the hyphen” between researcher and researched. They vary, however, with respect to the degree to which they use research to advance socio-political ideals. Critical theorists attempt
to use their work as a form of social criticism (Kincheloe & McLaren, 1994). Their aim is "the critique and transformation of the social, political, cultural, economic, ethnic, and gender structures that constrain and exploit humankind, by engaging in confrontation, even conflict. The critique for progress is that over time, restitution and emancipation should occur and persist. Advocacy and activism are key concepts" (Guba & Lincoln, 1994, p. 113). Most qualitative researchers who frame their work within a feminist and/or disability rights perspective would probably align themselves with the criticalist camp.

The centrality of the political and ideological nature of feminist research is evident in every phase of the research process with more and more emphasis being placed on research which is transformative, empowering and action-oriented (Acker et al., 1991; Fine, 1992; Kelly et al., 1994). While acknowledging the importance of starting from women's personal accounts and meaning-making, many feminist researchers indicate the inadequacy of remaining at the level of personal accounts and subjective experiences. They further warn that describing experience as an end in itself can serve to hinder rather than enhance women's well-being (Maynard & Purvis, 1994; Kelly et al., 1994). "To repeat and describe what women have to say, while important, can lead to individuation and fragmentation, instead of analysis. Feminism has an obligation to go beyond citing experience in order to make connections which may not be visible from the purely experiential level alone" (Maynard, 1994; p. 24). By going beyond the personal experience to analyze factors that are oppressive in women's lives and produce a critical socio-political analysis, feminist research can help women understand their experiences in relation to the larger social structure. This may facilitate a re-evaluation of the experience that may, in turn, stimulate action.

Similar calls have been made for situating the experience of disability within a larger socio-
political context (Fine & Asch, 1988; Goodley, 1996; Morris, 1992; Oliver, 1992). Goodley (1996) asserts that “failure to locate stories in social theories of disability may seriously jeopardize informants’ words — leaving them open to interpretations elaborating individual pathology over disabbling environments” (p. 343). This is all the more critical in a study such as Goodley’s, which focused on the experiences of people with learning difficulties who may have less facility with language than most people.

Most disability theorists and researchers would agree that the experience of disability is mediated by a host of socio-political factors. Judging from some of the recent literature, however, there is less concordance over what constitutes good disability research. This debate seems to centre on whether only research which is clearly emancipatory and under the full control of disabled consumers can be considered useful and ethical. Oliver (1992) denounces any research, be it positivist or interpretive, which does not purport to challenge oppressive ideologies and lead to direct policy change. Interpretive research, which attempts to present the meaning of disability from the point of view of disabled people, is not unscathed in Oliver’s critique. He contends that this paradigm, like its positivistic predecessor, has not fundamentally altered the social relations of research production. Nor has it directly led, as Oliver believes research should, to immediate improvements in the lives of people with disabilities. Oliver (1992) condones none other than emancipatory research which focuses on disablism, is under the full control of disabled consumers, and can result in the amelioration of oppressive conditions and ideologies.

My own views on this matter are somewhat less radical than those of Oliver (1992) and those of Barnes (1996), who presents similar arguments in his article “Disability and the myth of the independent researcher.” I agree with arguments for research from an openly ideological
perspective (Lather, 1988, 1990) and with the general thrust towards liberation and emancipation for oppressed groups. Furthermore, disability rights movements have made invaluable contributions to changes in the power structure and control over research. They have successfully pushed for such alternative paradigms as participatory research and research partnerships which involve stakeholders in every phase of the process. These practices ensure that stakeholders can have meaningful input and involvement in publicly funded studies on disability which may result in policy changes. As Oliver (1992) contends, “the very idea that small groups of ‘experts’ can get together and set a research agenda for disability is fundamentally flawed” (p. 102).

Notwithstanding my enthusiasm for stakeholder involvement and increased control over the process of research, I do not believe that instrumentality is the only criterion by which research should be based. I agree with feminist and disability researchers who warn against naive assumptions regarding the degree to which any piece of research can make a real difference in the life of participants. Helping participants reflect on experience in a less self-blaming and oppressive manner and making them aware of existing resources is still a far cry from transforming the conditions of their lives (Kelly et al., 1994; Shakespeare, 1996). Shakespeare (1996), a researcher who describes himself as committed to the disability rights movement, writes the following about emancipatory research:

I have major reservations with the concept of emancipatory research, even while admiring the motivation and commitment of those engaged in it. I am cynical about the possibility of research achieving major change, whether it be radical and emancipatory, or traditional social policy research. Ideas clearly have a role, but actions decide the day, and while it is possible to make the research process more balanced, grandiose claims for its
revolutions potential seem to me to be over-optimistic. (p. 118)

Although I do not share Shakespeare’s pessimism regarding the potential for research to advance progressive social policies, I share some of his scepticism regarding grandiose claims about direct and immediate positive outcomes. I also agree with his right to engage in his current research on sexuality and disability, which, as he states, will unlikely result in policy changes. His hope is that this work will reflect the reality of disabled people and will serve as validation and affirmation for those who read the book. His stated commitment to an ethical research process, in conjunction with a sensitivity to broad-based, contextualized disability issues, can allay concerns regarding harm to participants.

Throughout this review I argued for the importance of attending to context, being clear about the values that undergird the research, and placing a high emphasis on the research relationship. I also framed my worldview and approach to research as influenced by feminist and disability rights principles. Having said that, I also believe that despite its centrality, oppression cannot be the only lens through which research should be viewed. Barnes (1996) argues that since disability research is about researching oppression, “There is no independent haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed” (Barnes, 1996, p. 107). Rather than viewing people as belonging to a distinct category of either oppressors or oppressed, I see them as multifaceted, complex, even messy. I believe that this complexity should be explored rather than reduced to the aforementioned categories.
Method

The Research Story

Clandinin and Connelly (1994) emphasize the importance of presenting not only the stories of participants but also the story of the research project. In this section I tell the story (albeit in a brief and abbreviated fashion) of the research project that served as the pilot for the dissertation research. Some of the data gathered during this pilot project has been incorporated into the dissertation.

My story begins with a session I attended at the American Psychological Association (APA) during my first year of doctoral studies. The topic of the session was women with disabilities. It proved to be a formative event in my life as it marked my first contact with the disability movement or, for that matter, with other women with disabilities. Sitting in a session where the entire panel and most of the audience were comprised of women with disabilities was a moving and empowering experience. I decided that my doctoral research would be on the topic of women with disabilities and began to do a lot of reading in this area. As I immersed myself in the literature, I became increasingly more interested in focusing on motherhood in the context of disability and began to seriously consider it as a possible research topic for my dissertation. Luck would have it that a one day symposium on mothering with a disability was held in Toronto by a women’s health organization. Attending this symposium and connecting with disabled feminists marked the beginning of my working relationship with the DisAbled Women’s Network of Ontario (DAWN Ontario).

The research project that was ultimately conducted was “conceived” at an evening meeting which focused on ways of meeting some of the mothering needs of women with
disabilities in Ontario. At that point, DAWN Ontario was gearing up for a three day symposium on mothering issues as members had identified motherhood as an important area for women with disabilities. We decided that the symposium would be a good opportunity to gather data that would help identify the experiences, issues and priorities that women with disabilities have with regards to mothering. I volunteered to take prime responsibility for developing a needs assessment survey and for running focus groups at the symposium. We thought that the data that would emerge would help inform DAWN's work and may also be beneficial for funding purposes. I regarded it as an opportunity to do community work which could also be beneficial for a future dissertation.

The background to this project is important in that it demonstrates the "bottom up," grass roots approach that was taken. It was a case of a community project turned dissertation, rather than an academically initiated project that enlisted people with disabilities as partners and participants. Although it was very small in scope and was conducted without any financial assistance, this study was commensurate with the paradigm shift in disability research mentioned earlier. It had a community rather than an institutional locus of intervention, focused on the needs and experiences of the target group and, most importantly, was largely controlled by the consumer organization. I took responsibility for developing the needs assessment and focus group guides as well as facilitating the discussions. However, I was accountable to the board and executive of DAWN every step of the way and incorporated the feedback I got from them on an ongoing basis. An example in point is the needs assessment survey which was a lengthy and involved process where input was provided at various stages of its development. After coming up with a version that was satisfactory to DAWN, it was sent out to seven women with disabilities in
the community who agreed to provide feedback and make suggestions. Their input was
incorporated and represented in the final version of the survey.

In terms of outcome, the survey and focus groups were instrumental in identifying the top
barriers and concerns that women with disabilities face either as mothers or as those who are
considering motherhood. It also identified the services and resources they consider to be most
important and their ideas on how the well-being of women with disabilities with and without
children can be enhanced in the community. The results of this study were published as part of the
symposium report and were widely disseminated. Although I had secured permission to utilize the
data for dissertation purposes, I was ultimately a lot more interested in the qualitative component
of the study. Hence, the needs assessment informed this dissertation and was used for
triangulation purposes but does not stand on its own as a quantitative component of the
dissertation.

The abbreviated version of this story does not allow me to expand on the issues that
came up as we worked on this project and on some of the lessons that we learned along the way.
Participation in another APA session, this time as a presenter on a panel, provided the avenue for
describing the research process (O. Prilleltensky & Odette, 1996). For the purpose of the present
discussion I prefer to focus more globally on my experience of doing this work. Having spent my
adult life either working for large school boards or studying in academic institutions, working in
partnership with a grass roots consumer organization provided me with a new perspective on
things. It also served to challenge some of my inflexible notions of how things should be done. I
learned, for example, that relying on the parallel transit system (for people with disabilities)
requires a more flexible attitude to meeting times, as do fluctuating health needs. Interestingly,
this enabled me to be more attentive and respectful of my own health needs and to consider them as a factor in my professional life. This split between the public and private worlds has been discussed by several feminist and disability researchers. As Susan Wendell reminds us, “The public world is the world of strength, the positive (valued) body, performance and production...(whereas) weakness, illness, rest and recovery are generally hidden and often neglected. Coming into the public world with illness, pain or a devalued body, we encounter resistance to mixing the two worlds” (Wendell, 1989, p. 111). I realized, through my work with DAWN, that in my professional capacity in the public world, I myself re-enacted this split. I did so by keeping hidden and private any reference to my own health issues, fully expecting myself to transcend any weakness or fatigue that may interfere with “normal performance”.

The experience of the symposium was most illuminating and rewarding for me, both as a physically-disabled mother and as a student researcher. Surrounded by other women with disabilities, I was delighted and rejuvenated by the atmosphere of warmth, support, and connectedness that marked the symposium. Any early reservations that I had (should I do this research? who would benefit from it? who would be interested?) were put to rest by the support and encouragement I got from the symposium participants. I felt that I was given a mandate to conduct this kind of work. Furthermore, the women I met at the symposium and through my dealings with DAWN readily agreed to participate in in-depth interviews which comprise the main source of data for this dissertation. Consequently, 2/3 of the women I interviewed also participated in the pilot project. Although I bring the “official” section of the research story to an end here, its thread will continue throughout the dissertation.
Research Participants

Data for the research were gathered via 26 in-depth interviews with 13 participants and 4 focus groups with women who are at different stages in relation to motherhood. Over half of those interviewed are mothers with children at different stages of development. The rest are women who are either in the process of weighing their reproductive options or have already decided to remain childless. All are women with physical disabilities who have varying levels of mobility/limb impairment. Most are wheelchair users. Participants are well educated as a group; approximately two thirds of those interviewed hold a university degree. None of them belong to a visible minority group.

The focus groups predated the interviews and were held at the symposium mentioned above. Thirty five women altogether attended the focus groups. The goal of this conference was to meet the mothering-related needs and interests of women with a range of disabilities, physical and otherwise. Consequently, most, but not all of those who partook in the focus groups are women who have a mobility/limb impairment. All those quoted in the study belong to the latter category of mobility impaired women. The interviews took place 18 to 24 months after the focus groups. At the time of the conference, women who were willing to participate in in-depth interviews were asked to provide their names and phone numbers. Consequently, most of those who were interviewed for the study also participated in one of the focus groups. At least ten types of physical disabilities are represented in the study. These conditions are not listed in order to protect the identity of participants.

Data collection

Focus groups. Typically used in market research, focus groups are a way of collecting
information from a group of people on their perceptions and feelings towards a certain issue. It is based on the assumption that people both influence and are influenced by others around them and that this will be reflected in the focus group discussion (Krueger, 1988). As indicated above, data for this research included four focus groups that were held during a weekend symposium on women with disabilities and motherhood. Each group was geared towards a specific group of women with disabilities: women considering motherhood, mothers of young children, mothers of older children, and women who are not mothers. This last group, titled “Not every woman is a mother,” was facilitated by a woman with a disability who does not have children and who is trained as a social worker. I facilitated the other three groups.

The groups were held concurrently with other sessions and workshops to ensure that symposium participants had a choice about participation. Sessions were chosen by participants several weeks before the symposium took place. Those who signed up for the focus groups were informed that it was part of a research project and might be used for dissertation purposes. In addition, a statement was read at the beginning of each session indicating that participation would be voluntary and might be withdrawn at any time. Participants then signed a consent form indicating their willingness to participate in the research. They also consented to my taping of the session and using direct (albeit anonymous) quotes in a research report and/or publication. Unfortunately, one session (for mothers with young children) could not be taped due to a last minute technical problem. Instead, detailed notes were taken by a co-facilitator.

In preparation for the focus groups I developed guides which would tap participants’ experiences, issues and priorities in relation to motherhood (see Appendix III). Although the guides served to provide some parameters, the focus group discussions also centred on the
particular issues and interests presented by participants. Each group had a “life of its own.” All were all characterized by intense, thought-provoking and highly interactive discussions. Stories were shared, advice was sought and offered, and new meanings were in the making. The data that emerged from the focus groups has been integrated with data gathered via in-depth interviews. Together, they are the basis for the three data chapters of the dissertation.

In-depth interviews. Marshall and Rossman (1989) emphasize the importance of choosing a method within qualitative research that is best suited for the question under investigation. The need for consistency between research question and research method notwithstanding, it is also the preference of the particular researcher for certain methods over others that guide the research. Alan Peshkin demonstrates this, as he describes his passion for ethnographic fieldwork: “Rather than pursuing research with questions in search for the ‘right’ methods of data collection, I had a preferred method of data collection in search for the ‘right’ question” (Glesne & Peshkin, 1992, p. 102). In the same vein, interviewing is often appealing to feminist researchers due to its emphasis on avoiding control, connecting with others, and researching women’s lives on their own terms (Edwards, 1993; Oakley, 1981; Reinharz, 1992). I regard the choice of in-depth interviewing as my main source of data collection as both appropriate for the question under investigation and consistent with my preference for a relationship-based, interactive approach.

In developing my particular approach to in-depth interviewing, I drew mainly on the work of Glesne & Peshkin (1992), Seidman (1991), and Yow (1994), as well as on various other feminist and life history researchers. Through in-depth interviews, researchers attempt to understand other people’s contextualized experiences and the meaning that is made of those
Seidman (1991) suggests a series of three open-ended interviews, each having a pre-determined focus. The first interview focuses on the life history in relation to the topic, the second has current details and experiences as its focus, while the third interview is reserved for reflections on the meaning of the experience. He argues for adherence to the particular order of the interviews as it helps maintain a sense of focus and allows for each interview to serve as the building block for the next. If a participant begins to tell a story relating to the present, when past experiences is the focus of the interview, the researcher should refrain from further exploring the story as it can erode the focus of the interview (Seidman, 1991).

After carefully considering this approach, I decided to use some but not all of its components. To begin with, I disagree with the strong emphasis which is placed on the order of the interviews. Rather than linear and consecutive, life experiences and the stories we tell about them are more circular and tangential in nature. I would be less concerned with eroding the focus of the interview than with not following up on a potentially interesting story that the participant chooses to present at any one time. Timing can be an important factor and we cannot assume that what was about to be shared at one time can simply be put on hold for the "proper" interview. I also decided to conduct two rather than three interviews with each participant. Based on the data that emerged from the focus groups, I was interested in maintaining the focus on women with and without children. I also wished to interview mothers of children at various stages of development. Limiting the interviews to two each enabled me to establish that breadth without conducting an unreasonable number of interviews.

I ultimately interviewed thirteen participants (eight with children, five without) and conducted a total of twenty six interviews. Most women were interviewed twice, one was
interviewed only once due to time constraints, while another was interviewed three times due to a combination of mutual interest and faulty taping during the first interview. Nine women also participated in the focus groups a year and a half earlier. The rest were recruited either through some other disability-related work I did in the community or through the snowballing technique in which key informants suggest the names of other potential participants.

Most of the interviews took place in the home of participants, one was conducted at a work setting while two others were carried out at the university. Average length was ninety minutes. Informed by the literature and by the pilot study, I came to the first set of interviews with an interview guide (See Appendix V). As I expected, it was used loosely and flexibly, given the dynamic and interactive nature of in-depth interviewing. Some interviews were completely participant-led. Others required more structure and therefore a greater reliance on the interview guide. The questions were open-ended and phrased and ordered in such a way as to "make words fly" (Glesne & Peshkin, 1992, p. 63). Beginning with questions that are less personal and revealing is likely to increase the participant's comfort level and enhance the quality of the interviewing process (Glesne & Peshkin, 1992; Measer, 1985; Seidman, 1991; Yow, 1994).

Participants signed a consent form indicating their willingness to participate in the interview and to have it audiotaped. They received a copy of the transcripts and were given the opportunity to change and/or clarify information. Together with the transcript of the first interview, participants were mailed a 3-5 page summary. The second interview focused on reflections from the first interview and on a collaborative interpretation of data from the first interview, from the focus groups, and, in some cases, from the survey filled out by the particular participant. Whereas the first interview was more information-driven, the second interview dealt
with the more sensitive issue of exploring possible contradictions and engaging in clarification and collaborative interpretation of the emergent knowledge.

Data Analysis and Interpretation

Glesne and Peshkin (1992) refer to data analysis as "the prelude to sensitive, comprehensive outcomes that make connections, identify patterns, and contribute to greater understanding" (p. 146). Along with other qualitative researchers, they emphasize the time consuming and labour intensive nature of the analysis phase, a phase which requires immersion in the data collected. My approach to data analysis has been informed by the work of Glesne and Peshkin (1992), Merriam (1988), and Seidman (1991) and consisted primarily of thematic organization of the data.

My official engagement in data analysis did not begin until most of the interviews had been completed. However, I produced summaries of the first set of interviews as soon as they were transcribed and sent them to participants along with the transcriptions. Without exception, the response to the summary was favourable. A number of participants noted that although they did not get around to reading the full transcript, they enjoyed reading the summary. A few said that it was instrumental in reflecting on past events and even served to trigger new understandings. One woman asked her partner to read it and used it as a stimulus for discussion. For the purpose of the research, the summaries served as a bridge to the next interview and allowed for corrections and clarifications.

When most of the interviews were completed, I entered the next phase of in-depth data analysis. Having constructed the summaries several months prior, I decided to put them aside so as not to preempt my analysis. My first step in this analytical process was to go through each
transcript and label excerpts according to categories. For example, a participant’s account about a recent issue with her child might be labelled in the margins as relationship with child, along with 2-3 words specific to the story. While some categories span several pages, others are no more than several sentences. The next step was to transfer the information from the margin of the transcript into a computer file, noting the page for each category. This process was repeated for each transcript with little concern for repetition of themes and categories. The end result was a list of categories for each participant and for each interview.

The next step was to study what now amounted to a booklet of categories. I spent several days reading and re-reading the categories, looking for connections not only within interviews as I had done before, but also between interviews with different participants. Gradually, this process led to categories being clamped into broader themes and to the emergence of a framework for the data. Further reading, comparing, contrasting, and re-naming of clusters resulted in this framework consolidating into the skeleton of the thesis. When I emerged from this process I had an outline for three data chapters, each one divided into sections and sub-sections. It was time to distance myself from this process and delve into the literature review which was also informed by the data. I returned to my framework after completing the literature review. For each of the three data chapters I went to the transcripts yet again, to see if the headings indeed capture the essence of the data and to look for missed information, connections, and insights. Having been away from the data for a while, this next round of interaction with it unearthed more connections and sparked new ideas. Although further “sitting with the data” would have undoubtedly resulted in more insights, I sensed that the time had come. I was ripe for the writing.

Writing this section after I have completed the three data chapters allows me to reflect on
the process. I think about how I responded to questions from family and friends as to where I am in the thesis journey. Although I referred to the stages as distinct entities of data collection, analysis and writing ("I am now analyzing, soon I'll begin to write"), the process is not nearly as linear as such comments might suggest. In fact, I was amazed at the insights and connections that came about during the writing process, leaving me with a feeling of "thinking through my fingers." These connections are on a higher, more conceptual level than simple analysis and constitute the interpretive comments that I make throughout the document.

Methodological Reflections

In my introductory comments to this chapter I indicated my intention to write about methodological reflections apart from the step by step description of the research. Although this division facilitates the writing process, it is clearly an artificial division given that the entire research process is guided, facilitated, and often impeded by methodological issues and dilemmas. For example, the above description of the analysis and interpretation of the research is incomplete without acknowledging my own voice and signature as the researcher. My own gaze, to use Denzin and Lincoln's term, is filtered through my stance as a mother, a woman with a mobility impairment, and a feminist. In addition to these attributes, I am also white, Jewish, well educated and married to a non-disabled university professor. These latter characteristics are just as important as the former as my experience of disability and motherhood are mediated and filtered through my relatively privileged social standing.

Being a feminist and a disability rights advocate, I am interested in the production of knowledge that aims to contribute to the well-being of women and people with disabilities. My lens is further filtered by my belief that unequal power structures and oppressive ideologies play a
major role in framing the personal experience of womanhood and disability. Unlike Seidman (1991), who states his sensitivity to the impact of attributes such as race, class and gender but does not come looking for them in the research, I approached this research with the explicit intent to study the braiding of gender, disability, and other social constructs. Doing so, however, is not counter-indicated with having an open mind, coming as a learner, and conducting rigorous research. It is simply acknowledging my own role in the research process. In the same vein, I do not apologize for my openly ideological perspective which aims to present the oppressive underpinnings of personal experience on the one hand, and to highlight the strengths of study participants on the other hand. However, I also agree with Lather's claim that an ideological stance must be accompanied by a commitment to conduct rigorous research that can produce credible, trustworthy data. Lather (1986) argues for “the development of data credibility checks to protect our research and theory construction from our enthusiasms” (p. 67).

My own attempts to enhance the rigor of my research prompted me to adopt a very careful and conservative approach to data analysis. Rather than marking passages of interest as Sideman (1991) suggests, I initially marked and categorized almost every transcript excerpt in the fear of leaving out meaningful information. As time consuming and labour-intensive as this process was, I chose to err on the side of over-incorporation and not under-incorporation. Only after everything in each transcript was marked, coded and categorized, did I feel comfortable, the second time around, to be more reductionist and economical in my approach. My other attempts to enhance research rigor include a triangulation of data sources (interviews, focus groups, information from the survey), explicating the process of coming to conclusions, and keeping a running record of hunches, surprises, insights, and dilemmas. My commitment to rigor
notwithstanding, I recognize and acknowledge my role as the elicitor, editor, and interpreter of data and as the weaver of events, life stories, and meaning-making. There are various plausible stories that can be told in any research project (Glesne & Peshkin, 1992) and the particular one I tell is inextricably bound to my own subjectivity and way of being in the world.

Various methodological issues and dilemmas came up for me over the course of the research. Some of these issues had rather simple solutions while others continue to present a source of discomfort. The centrality of the research relationship and the inherent challenges in conducting ethical research are at the heart of these issues and this discussion. Earlier I discussed the centrality of the research relationship and the importance of upholding the dignity, respect and well-being of participants. I also noted the more flexible and permeable research boundaries that are characteristic of feminist methodology. As Reinharz (1992) states, “blurring of the distinction between formal and personal relations...is characteristic of much, although not all, feminist research” (p. 263).

My own approach was to be very informal and forthcoming with participants. I knew some of them on a more personal level before the start of the research and our relationship was enhanced in the process. All participants knew that I am a mother with a disability and most learned more about me over the course of the research. Although I took care to maintain the focus of the interviews on participants’ experiences and meaning-making, I shared some of my own experiences usually in response to direct questions. Mobility impaired mothers are too scarce and difficult to come by for me to withhold information that can be of use. On other occasions, I made spontaneous and brief references to my own family over the course of a discussion. It seemed as though the attributes we shared as women with mobility impairments provided an
immediate connection. Despite my informal approach and the reduced distance that marked the research relationship, I was careful not to exploit this sense of intimacy for research purposes. Participants were invited to share according to their level of comfort and were given the opportunity to delete any information that they wish from the transcript. Furthermore, they had a chance to review and edit the direct quotes that I use in the manuscript. I inserted this additional check-in point in order to provide participants with greater control of the data and provide myself with ethical peace of mind.

The reduced distance that marked my research style contributed to some non-research like interactions with participants. For example, one young mother consulted with me about various child-rearing situations, from letting her baby cry to future decisions about discipline and limit setting. In a sense, I was the perfect candidate for such consultations given my presence in her home, therapeutic background with children and adults, and personal experience as a mobility-impaired mother. My approach was to respond as openly and helpfully as I could while constantly monitoring my role in this relationship. Over the course of three interviews, this participant and I had various opportunities to discuss child-rearing and family issues. I felt that these discussions enhanced the interview process and were also useful for her. Without losing sight of the distinction between research and counselling, I was nonetheless available for questions and discussions. The informal nature of our meetings also included enjoyable time spent holding, feeding, and playing with her baby. The proud mother that she is, she seemed to take great pleasure in my obvious delight with her baby. Despite differences in age, family situation and general circumstances, there was a strong sense of mutual liking. Had this participant not moved away, it is quite likely that my relationship with her would have continued beyond the research.
I have to admit that the reduced distance and more permeable boundaries are not without their challenges. In the focus groups that pre-dated the interviews, the knowledge that emanated from the sharing of lived experience created a very intense emotional climate. My multiple roles of researcher, group facilitator and mother with a disability were challenging to negotiate at times, given my own intense feelings of kinship and validation. I was acutely aware that at times I simply wanted to be one of the group, without the added responsibilities of a moderator and a researcher.

In one group I shared something from my own experience to answer a question that one woman posed to the group and that only I had direct experience with. At the time, I chose to do this as I felt it would be helpful for the woman posing the question. Upon listening to the taped session, I was somewhat concerned about the space that I took to tell my story and wondered if it was not my own need that I was meeting. I had to entertain the possibility that I got carried away by the powerful experience of being surrounded by women who had similar experiences to my own.

Relaxed boundaries can also pose challenges to maintaining the researcher role separate and distinct from roles performed in other contexts. This challenge became apparent to me as I went over one of the interview transcripts. In this case, a mother was telling me about the strained relationship she has with her adolescent daughter. In her efforts to avoid conflict and prevent angry outbursts on the part of the daughter, she typically refrains from posing questions about her daughter’s activities and whereabouts. Without even noticing, I provided input as to how communication can be encouraged in a non-confrontational manner: “I think sometimes parents can find a way of inviting kids to talk about things without pressuring them. So instead of saying ‘why aren’t you with your friends any more’, another way might be ‘you know, it’s really nice to have you around here more. I noticed that you’re not going out so much. I don’t want to
pressure you to talk about it if you don’t want to but…I’m here and I’d like to hear you if you want to talk.” I realized, as I read the transcript, that it was not my place to impart this unsolicited advice. I was there in a research capacity and I clearly outstepped these boundaries in this case. I recognize this as a boundary violation on my part and use this recognition to do a better job of self-monitoring. However, I do not regard this minor transgression as detracting from the overall ethical integrity of the research. Writing about boundary issues in feminist therapy, Brown (1994) states that “feminist ethical principles construe boundary maintenance in therapy as a continuous, rather than dichotomous variable….no therapist is immune from the potential to engage in violations of client boundaries” (p. 215). By recognizing the potential for such violations in their own work, conscientious therapists “can theorize the problem as learning to identify the risk factors for boundary violations, and making a commitment to seek out such risk factors in themselves” (p. 215). Brown’s suggestions can also be applied to feminist research which is also marked by more flexible and permeable boundaries. Being reflective and introspective about our research relationship can go a long way in enhancing its ethical integrity.

Protecting the anonymity of research participants is another methodological issue that presents itself in my work. Maintaining participant anonymity is one of the most basic ethical research requirements. However, this is no simple matter when the population under study is as specific as women with physical disabilities. In studies that draw on more general populations, assigning fictitious names and omitting unique features is often enough to maintain anonymity. The same cannot be assumed for the narrow and specific group under study. The braiding of motherhood and physical disability further heightens the specificity of this group.

I struggled with these issues as I summarized the data from the focus groups for a
research report I prepared for DAWN Ontario. All group participants signed a consent form agreeing to maintain the confidentiality of other participants, to the taping of the session for research purposes, and to the use of direct quotes in a research report or publication. However, after analyzing the data (and despite attempts to disguise personal information), I became concerned that reading their own words may make some of the women feel exposed and vulnerable. After all, it is virtually impossible to truly disguise participants from others who partook in the same group. I ended up sending each of the 35 women who participated in the groups a copy of the report prior to its publication. Along with the report I sent a letter, requesting feedback within a certain time period should anyone find any part of the report uncomfortable or problematic. Unlike individual interviews where changes and omissions can be made relatively easily, this is not the case with focus group discussions where it may be difficult to discern “who said what.” To my relief, no requests were made for deletions or omissions.

I face similar dilemmas with respect to the data I obtained via in-depth interviews. Beyond sharing transcripts with participants and granting them editorial powers, I feel a responsibility to present them with the direct quotes that I ultimately choose for the final manuscript. Interview transcripts are generally lengthy and may not be read in great detail. Furthermore, it is difficult for participants to know what they should edit when it is not clear what will ultimately be used for public consumption. Most importantly, the relatively small and interconnected nature of the disabled community presents particular challenges as far as anonymity is concerned. As researcher, I struggle with the uncomfortable knowledge that “anonymity of individuals and collectives can create tension with the desire to write thick, rich descriptions” (Magolda & Robinson, 1993, p. 12). My commitment to confidentiality and anonymity was a major factor in
my decision not to present complete profiles of participants. Instead, I chose to present quotes in the context of a thematic analysis in the hope of obscuring and protecting the identity of participants. I realized during the writing phase, however, that some of my chosen quotes may indeed make it possible for some women to be identified by others in the community. I also realized that doing away with all such quotes would seriously compromise the quality of the research. I chose to deal with this dilemma by deleting some quotes, changing others, and allowing participants to be the final judges as to what stays in and what is taken out. A number of study participants have shared their experiences in presentations, publications, and documentaries. For some, being identified as research participants is not uncomfortable or problematic. I have therefore decided to concentrate my efforts on ensuring that participants are the final judges over the inclusion of quotes and other potentially identifying information.

It is one thing to give participants control over the editing of material that may make them feel vulnerable; it is quite another thing to involve them in the analysis and interpretation phase of the research. Notwithstanding my commitment to maximizing participant control over the raw data, I struggled with what role they will actually have, if at all, in analyzing and interpreting the research. Seidman (1991) “warns” that to form “such a deeply sharing, mutually intimate interviewing relationship and then claim such one-sided ownership of the material at the conclusion of the interview may be problematic” (Seidman, 1991, p. 76). This may be especially problematic for feminist researchers whose relationship with participants is often informal and more intimate in nature.

After careful consideration of this issue I decided that my commitment to participant well-being and adherence to feminist and disability rights principles are not compromised by my
decision to take sole responsibility for analysis and interpretation. This is not a participatory study and participants were not told at any point that they would have a role in its interpretation. In this regard I part with Oliver (1992) whom I quoted earlier and who is suspicious of any research which is not under the full control of disabled consumers and can result in direct and clear improvements to their lives. I hasten to add, however, that taking ownership over the interpretation of the research also entails my acknowledgement that my way is not the only way that this work can be analyzed, interpreted, and presented.

In this section I shared some general methodological issues that permeate the research. These include reflections on research boundaries, issues pertaining to anonymity, and control over the process and product of the research. The research relationship is the common thread that connects these issues. I have chosen to incorporate more specific methodological issues into the actual data chapters. These are highly contextualized "methodological moments" that occurred as I interacted with the data at various stages. Borrowing Fine's (1994) "hyphen" analogy to symbolize the ever present "relations between" researchers and participants, I attempt to explore and explicate my stance, thereby working the hyphen in relation to participants and to the emergent knowledge. These methodological moments are therefore dubbed "working the hyphen" and can be found as addenda to the data chapters.
ANALYSIS AND PRESENTATION OF DATA:

PART I – GROWING UP AS A GIRL WITH A DISABILITY

Motherhood, the topic of this research, is predominantly an adult female experience. The roots of motherhood however are planted at a much earlier stage as girls form their identities and become aware of their capacity to reproduce. This first data chapter of the dissertation does not deal with the topic of motherhood per se. Rather, it focuses on the early experiences of study participants as girls and young women with disabilities. About two thirds of the women who participated in the in-depth interviews were either disabled from birth or had incurred their disability at a young age. This chapter is based on the stories they shared with me about growing up as girls with disabilities. Although my interview guide did not directly deal with childhood, most participants chose to provide some background and discuss salient childhood experiences in relation to their disability. My fascination with what I was hearing prompted me to ask more background questions in subsequent interviews. I realized that this is highly consistent with the life history nature of my study as it provides a backdrop and a context for present day experiences and dilemmas. It became increasingly clear to me that in addition to providing a context for my research on motherhood, the stories I was hearing about growing up as a girl with a disability need to be presented for their own merit. They provide a glimpse into life on the margins of mainstream girlhood, and as such, can bring the childhood experiences of this group of women into the mainstream and illuminate the socially constructed oppressive factors that have pervaded their lives.

The childhood experiences that were conveyed to me cover family life, school experiences,
and contacts with institutional and medical settings. I begin this section by focusing on expectations both at home and at school for girls with physical disabilities. I then discuss issues pertaining to psycho-sexual development followed by social development and peer relations. I conclude this chapter by highlighting the risks to self-determination that these stories convey as well as the courage and persistence with which it was sought.

It's a Girl...And She Has a Disability: What Does the Future Hold?

Parental Expectations and Family Dynamics

The timeless question "What are you hoping for, a boy or a girl"? is typically met with the equally timeless response "What difference does it make, so long as it's healthy..." It is probably safe to say that most if not all expectant parents wish for a healthy, non-disabled baby. The love they feel for their baby even prior to its birth usually entails dreams and hopes for the future, for what he or she will become. The diagnosis of a disability in a newborn baby unquestionably requires some adjustment on the part of the parents, with shock, sadness, anger, and guilt, commonly reported.

The information parents receive from health-care professionals can have a significant impact on how they perceive their baby. In the present study, two participants reported that their parents were told to expect the early death of their daughters.

My folks didn’t have a lot of support in terms of what to do with me. They were told in the hospital to take me home and that I was going to die...they just said ‘take her home, there is not much hope’...like what a thing for them to have to live with...I think that has always stuck with them, especially my mom...she’s always been very protective of me.

In at least three cases parents were advised to institutionalize their physically disabled daughters,
whereas another set of parents was told that their daughter would always require a special school. This is quite consistent with the prevailing attitude towards people with disabilities some 30-40 years ago when most of the study participants were born and raised. Despite the bleak depiction of life with a disability that these parents were presented with, almost all declined institutionalization and cared for their daughters at home.

Study participants told varied and diverse stories of how their parents regarded their disability and the coping mechanisms that they enlisted. Two described a home environment where their disability was perceived as tragic and severely limiting. This is apparently not related to the extent of the disability as both cases involved girls who were highly mobile and physically independent. One participant noted her mother’s young age and the financial strain that her family was under as important contributing factors. The other participant situated her own devalued status within the cultural context of her family where women in general had limited opportunities and were perceived as inferior to men.

Some of it had to do with the culture...a family of immigrants, not having a really good understanding of the cause of the disability, with religion tied in to that... was this disability the result of a cross, something that somebody had done in the past? And also the protectiveness of the culture where women didn’t get out...and then the disability on top of it. It was just a monster to try and cope.

One participant experienced rejection because of her disability. She recounted the numerous and futile attempts she would make to gain her mother’s love and acceptance.

I remember making efforts to try to make her love me in some way...I remember specifically trying to do things that would sort of make her accept me...I just could never
do anything right... I remember feeling 'I really hate this person' and then I remember other times feeling 'I wish I could just make her love me.'

Rejected by her mother, this participant had a very loving father who provided physical caregiving at a young age and emotional nurturance throughout life. Of the thirteen women interviewed for this study, this was the only indication of clear rejection on the part of a parent. Two other participants noted that while their parents were clearly committed to them as individuals, they fell short of fully accepting their disability. In one family the daughter’s disability was never discussed. The parents provided physical accommodations and consistently followed through with various therapy regimes. However, they never talked with their daughter about her disability and its implication to her life. Lacking any information about her condition, this participant went through a phase where she worried that her disability would get worse, a worry which had no realistic basis in this case.

It (disability) was never discussed and I didn’t want to bring it up... I hated going to camp for children with disabilities because I saw kids with more serious disabilities and worried that my disability would get worse, just like them... at the other end, I thought that if I really really tried, perhaps the disability would get better, go away.

Interestingly, the other participant who felt that her parents did not fully accept the disability was also reluctant to associate with disabled peers. The message that she would walk again and resume pre-injury functioning interfered with her ability to fully integrate her acquired disability into her sense of self.

Contrary to some of the negative and ambivalent messages noted above, several participants emphasized the affirming messages they got from their parents, either explicitly or
implicitly. One noted that her parents’ attitude that one must make the best of every situation has helped her cope in difficult times. Throughout her childhood, this woman perceived her family as affirming and supportive, without stifling her independence. Similarly positive experiences were echoed by another participant:

I always knew that yes, I had a disability but for the most part I could pretty much do and be almost anything I wanted to be...I don’t know if my parents really worked at it or they were just lucky or they had a gift for instilling a very powerful and positive self image.

Families varied quite a bit in the extent to which they encouraged independence and self-efficacy. One woman, considered highly fragile as an infant, was sheltered and protected throughout her childhood and adolescence. Even when her survival was no longer in question her parents were somewhat reluctant to let her go out with friends; neither did they expect her to partake in any family chores and responsibilities. Antithetically, another participant, also considered fragile, was encouraged to become as independent and self-sufficient as possible.

She (mother) felt that I would have to be tough in order to survive...she would say ‘you have to figure a way to fight back’...she was teaching me to be independent in a way or to fight my own battles and use my smarts...to talk my way out of a fight because I couldn’t do anything about it physically.

Despite the relatively severe nature of her daughter’s disability, this mother had high expectations in behavioural, social, and academic domains. Having a limited education herself and experiencing financial difficulties, she instilled in her daughter that a good education and a good job would be her ticket to independence. Several other participants also noted that their parents were instrumental in enhancing their independence, while one became self-sufficient and independent by
default, as her mother did not participate in her care. For another participant, independence was promoted as far as getting chores done at home; if she could not do something one way, her parents taught her an alternate way. However, expecting that their daughter would always live with them, these parents did little to encourage self-efficacy and independence beyond domestic chores. They were highly opposed to their daughter’s decision to attend university, partially due to a cultural background that did not envision women as professionals.

My family were mainly farmers and everybody had a function in a family...and on a farm you would have to pull your weight and yet you know what could I really do?...I don’t think there were any professional women in my world, in my sphere...so I didn’t have that role model and with being disabled and not being able to pull my weight the question was what actually could I really do?

One other component relating to parental expectations should be mentioned. As children, none of the women I interviewed were encouraged to see themselves in long-term relationships or as mothers to children. Some were explicitly told it was not to be, others got implicit messages to that effect, while others just never remember it being discussed or alluded to. Whereas most girls grow up knowing that they may well become partners and mothers, these girls were either given messages to the contrary, or experienced a total void on this subject. This issue will be further explored later in this chapter.

**Expectations in Educational and Institutional Settings**

Some of the participants obtained at least part of their schooling in segregated settings, either at a school for children with disabilities or in a residential institution. Consistently, they commented on the lack of emphasis placed on academic achievement at these settings and...
poor quality of the education they had received.

There was such an emphasis on students doing things like physiotherapy and so kids would be pulled out of class to go to therapy...the level of the school was not the same as it was in the integrated programs...it was also like this huge playground...there weren’t the expectations that you do your homework or that you have any movement towards adult responsibilities or any kind of responsibilities.

According to participants’ accounts, these settings were largely based on the medical model and targeted physical and medical needs more than academic and educational ones. This was especially so in an institutional setting which focused almost exclusively on physical care. Despite the fact that the institution only admitted children who were of at least average intelligence, academic achievement was blatantly underplayed. One participant, who clearly excelled academically, recounted “fighting tooth and nail to get a study space that was away from the general chaos and mayhem.” Another participant who entered a residential setting in middle childhood found that she was academically advanced in comparison with same-aged peers at the institution, despite the fact that the school she previously attended was also a segregated one.

Everybody my age was in a much lower grade...they were shocked that I was in a grade 5 reader, these kids my age, and they were like in 2 or 3...it was just the way it was there.

The disparity in education became most apparent during the transition to regular school at the end of elementary school; several participants were placed at a lower grade level in the integrated system. One participant indicated the social disadvantage that this created for her.

I remember going to the guidance counsellor once a week and saying ‘I can’t deal with it’...I mean the workload was tough but that’s not what was bothering me...it was the
maturity level of these kids... they were 12, 13, and I was 15... I just felt like I was babysitting a lot of the time.

Set apart by her disability, this student was also set apart due to the significant age discrepancy between herself and her non-disabled peers. Another recounted the catch-up work she had to do in conjunction with her regular work, just to keep up with peers who did not experience the educational disadvantage that she did.

As they reflected on their school experiences, several participants noted the fact that many children who attended segregated settings were not expected to live; some in fact had died throughout the years. The perception that a significant percentage of the student population is not expected to live to adulthood could explain the present-oriented focus of these settings, as well as the emphasis on physical and medical care. The primary function of schools is to enhance children’s development, thereby planting the seeds for adult roles and responsibilities. Teaching students who may not make it to adulthood can generate a great deal of anxiety and ambivalence on the part of educators. Confusion may ensue as to what purpose the school actually serves. Unless these issues are explored and resolved, a school may indeed be turned into a huge playground, compromising the education of many of its students and possibly limiting their options.

**Psychosexual Development: Messages, Perceptions, and Possibilities**

Sexuality is a holistic term which encompasses a wide range of human qualities. Comfort with one’s body and sexual self-acceptance are crucial ingredients to the development of a positive self-esteem (Helminiak, in Mona et al., 1994). For girls with physical disabilities whose bodies do not fit the norm, developing a positive sexual identity may be particularly challenging.
Having their sexuality denied or ignored by others, and being excluded from social and sexual encounters during adolescence, are some of the barriers to a healthy sexuality reported in the literature. In this section I present participants’ accounts pertaining to psych-sexual development and sexual identity.

This Body Belongs to Me

This heading reflects what some of the participants would have liked to say as children to some of their caregivers and health professionals. Several participants recounted instances in which privacy around the body was not respected and which left them feeling objectified. One recalled her experiences as a young child of having to demonstrate her walk to physicians and medical students.

All these medical students were there. I was almost completely naked, walking in front of everyone...I hated that. I never felt comfortable walking, I would become tense and walk ten times worse...and I got the message “you don’t walk right, you’ve got to do better.” When I was home, I could do most things. I got tired, but I could walk...but when I went for a check-up I got the message “there is something defective about you.”

Another participant described similar experiences both at the segregated school she attended and during visits to medical clinics. She was highly critical about the manner in which physiotherapy sessions were organized at the school:

There would be no privacy screens or anything...they’d have us literally running around in our underwear...at ages 9,10,11,12. You know, when you become painfully aware of your body and you’re becoming aware of the opposite sex as well...so you’ve got a number of things impacting on you and they weren’t sensitive at all to how it would make you feel
and how it would impact on you later on...I really see this as a form of systemic abuse in a way.

As a grown woman, this participant can reflect critically on these painful childhood experiences and refer to them as a form of abuse. As a young girl, she felt totally powerless to change things, even though she clearly attributed the frustration and resentment she felt to the manner in which she was treated.

Even if I had verbalized to them what I was feeling it wouldn’t have mattered. They weren’t going to change the way that they were going to do anything anyway.

She would become resistant and uncooperative during treatment sessions and medical exams, even though she knew that this distressed and embarrassed her mother.

My mother couldn’t understand why I would resist so much and why I was so stubborn and headstrong...I didn’t even at that point know why I was doing it...I do realize it now and you know, it’s only been very recently that I’ve begun to realize why I was so resistant...that was my only way of being able to protest.

Two other participants, who also experienced privacy violations as children, described a sense of discomfort without being able to pinpoint its source. Unlike the participant quoted above who could define it for herself but not protest out loud, these participants could not even name it for themselves, “there was no point of reference to say that this isn’t what it should be.” Despite the inability to name the source of the oppression, these experiences have left one child with the impression that she doesn’t really own her body.

Differing levels of privacy violations were noted by half of the participants who had a disability in childhood. These issues did not even come up in some interviews; others described
medical exams that were conducted in a respectful and affirming manner. Regardless of the prevalence of this phenomena, the fact remains that feeling a lack of ownership and control over one's body can pose a significant risk to a healthy sexual identity.

**Being Recognized as a Sexual Being**

Parental attitudes and perceptions about sexuality can have a lasting impact on children's psychosexual development. Girls with physical disabilities are at higher risk than their non-disabled peers for negative parental expectations and messages about sexuality. Conversely, those whose families encourage them to explore and express that aspect of their development are more likely to experience social success and develop a positive sexual self-concept (Nosek, 1996; Rousso, 1996).

Some participants grew up in families where their sexuality was either ignored, undermined, or actively discouraged. One noted that in her family “...there was not an expectation that I was going to date...certainly no expectation that I was going to get married and be in a relationship.” During adolescence her mother steered clear of any conversation about relationships and sexuality. When she shared her frustration at not getting asked to dance at parties, she was told that she has plenty of time and should not concern herself with these matters. Now a grown woman, this participant frames this in the context of her mother not knowing how to respond to the daughter's pain. “I don’t think she knew what to do with that...I think she really struggled with what to do with my pain.” One participant was explicitly discouraged from thinking about relationships and intimacy. Growing up in a culture where women assumed traditional gender roles, her only role model for adult female identity was that of a wife and mother. Although she grew up wanting to assume these roles, she was told that this will not happen in her case.
My family always said ‘you can’t think about boys, you can’t think about relationships, focus on your studies...you’re not going to have any children...this is not for you.’

Exploring these issues some 25 years later, this participant now attributes these messages to her family’s attempts to protect her from the pain of rejection. They could not envision that anyone would find her sexually desirable and wished to spare her the heartache of unrealistic dreams and hopes. Her adult perspective notwithstanding, these messages were devastating and invalidating during adolescence.

Another participant remembers talking with her mother at age 11 about marriage and children. The mother said not to worry; “everybody finds someone and it would take time.” The message was quite different several years later when this woman was no longer a child.

A week after my sister got married we were looking at the wedding pictures...there were some other close friends there at the time and someone said ‘well, that’s one wedding down, one to go’. I was a month short of being 19 at the time and my mother said right in front of me and them and everybody else, ‘well no there won’t be any more weddings in our family’...I remember feeling incredibly devastated.

This insensitive and hurtful remark was made by a mother otherwise described as very caring and supportive. This participant was not treated differently from her non-disabled sister in other domains and was encouraged to become independent and self sufficient. She contextualized her parents’ perceptions about sexuality and disability within the larger societal framework: “a lot of people have biases when it comes to people with disabilities and certainly your own family is not exempt from that.”

Attempts to protect a disabled daughter from sexual rejection and exclusion are common
to all accounts of parental reticence to acknowledge sexuality. In at least two cases, parents were also concerned about safety issues; “my mother’s words to me when I was dating were ‘just remember that you can’t run away.’” Interestingly, this particular participant was not exposed to any negative messages about sexuality. Other than the above warning, her family was generally silent about these issues, a factor she attributes more to their general lack of comfort with discussing sexuality than to any disability-specific factor.

Invalidating messages about sexuality, or ignoring the subject altogether, were not limited to the home front. Several participants noted the absence of any such discussions in the segregated schools or residential facilities they attended as children. The basic information students received on reproduction and the menstrual cycle was not connected to the broader topic of human sexuality.

The head nurse would give you a brochure from the makers of tampax or something that says this is how an egg gets fertilized...but you didn’t have the concept that there were human beings involved. It could have all been in a laboratory the way it was described in the brochures...as far as teenagers going out together, that was highly discouraged...staff were strongly discouraged from having talks with us about sex, and in fact, some staff were fired because they thought it was stupid and if you had a question they would try to answer it.

Another participant noted the open door policy of the residential setting where she was raised: doors had to be left open at all times as staff wanted to monitor adolescents’ behaviour. Some of this changed towards the end of her stay there, with one of the staff members initiating a series of expert-led discussions about sexuality. Despite these reforms, most of the staff remained
suspicious and resistant to any attempts to broach the subject. In the words of one former resident, “you weren’t to be a sexual being and if someone was attracted to you sexually then they must be deviant.” Another participant whose only experience with segregated settings was in a professional capacity, also noted the glaring absence of any discussions about sexuality. She had contact with a number of physically disabled teenagers who lacked the most basic information about sexuality and reproduction.

They would ask me questions and I would bring in books with illustrations because they knew nothing about their bodies, their sexuality, and they wanted to know...most of them were at the age where they just wanted to know about their bodies and the sexual part of it but some also wanted to know about children.

The importance of obtaining relevant information about sexuality was emphasized by another participant, one who acquired her disability as a pre-adolescent. She attributes the dearth of information she had on the subject to her attempts as an adolescent to come across as knowledgeable and self-sufficient in this domain. Consequently, it was not until she was in university that she found out that her disability should not preclude her from expressing her sexuality. She described the excitement she felt after attending an information session about sexuality and disability:

I wasn’t really certain that I could have sex...once I discovered that I could, it was such an eye-opening experience...I was so excited, I felt like I was electric that night.

In an article about girls with disabilities and sexuality, Rousso (1996) notes that “their more limited social and sexual involvement results not from lack of interest, but rather, lack of opportunity” (p. 109). The social development and involvement of study participants will be
discussed in the following section. Pertinent to the present discussion is the experience of sexual rejection during adolescence, a theme common to most of the accounts. Whereas some participants experienced explicit and direct sexual rejection, others were “passed over” or sexually ignored. One participant relayed a particularly painful experience of being mocked for saying that she likes someone:

I remember having this crush on a boy and telling a non-disabled friend about this and it got back to him. Well, that was it, it was the biggest joke...it was very painful because I felt a lot of shame about it...they thought it was totally weird.

Another participant was excluded from a “girl talk” by a non-disabled peer who considered it irrelevant for her.

I remember in elementary school the girls were talking about boyfriends and about getting married...we were guessing who was going to get married first...I was very quiet, I wasn’t making any guesses...and one girl, she just turned to me and said ‘oh well, you won’t ever get married.

These types of encounters are very hurtful and potentially damaging, even when they are experienced as isolated incidents rather than as the defining feature of one’s psycho-sexual adolescent experiences. Furthermore, sexual rejection need not be as explicit and mean-spirited as that described above for it to have an undermining impact and pose a risk to self-esteem. One participant recounted her pain as she watched all her friends being asked to dance while she was left to sit by herself.

There were times when I’d be at a wedding and all the kids would get up and dance, my friends would be asked to dance and I would usually be left sitting by myself. It was
because the fear of the disability in that culture...the fear that maybe I would have children like that...so here I was a teenager with all those hormones and wanting to fit in like the rest of them but not looking the same...and coming home crying.

Interestingly, this particular participant had a disability that did not preclude her from dancing. In this case, the physical disability in and of itself could not begin to account for the handicap of sexual and social exclusion. Rather, it is the inability to conform to a conventional standard of beauty and physical appearance which accounts for the rejection of this girl by her male peers.

This explanation gains further support from another participant’s adolescent experience. Due to the specific nature of her disability, she appeared to be a lot less disabled in adolescence than she actually was. She remembers taking pride in the fact that boys found her attractive and paid attention to her. She was both angry and perplexed, however, at the different treatment afforded to another disabled girl, a friend of hers.

What bothered me was not the way girls treated her but the way guys treated her...they weren’t very nice to her...the sort of looks they were giving her and stuff like that...and they treated me differently than they treated her ...even though she could carry my books, and she could run, and she could sit on the floor, she could do all of the things that I couldn’t do, but it was the way she walked, you know, the CP walk.

The lasting impact that such experiences can have are underscored by another participant’s comment that to this day she finds it difficult to walk in front of a group of kids as it reminds her of her own devaluation by adolescent boys some 25 years ago. Adolescent women in general tend to be alienated from their bodies and judge them through the prism of the male gaze. To the extent that the beauty myth is devaluing to all women, it can be especially detrimental to young
disabled women who may construct their self concepts from these male appraisals (Riger, 1993). The impact that sexual devaluation can have on self-esteem is reflected in several of the accounts. Reflecting on a relationship she had as an adolescent, one woman noted that the best thing about it was that someone found her attractive; she had always considered herself fat and ugly. Another participant indicated the excessive emphasis that she and some of her young disabled friends had placed on being in a relationship. Beyond a longing for intimacy, being in a relationship for these young women was equated with a sense of wholeness and self-worth.

Social Development: Relationships with Disabled and Non-disabled Peers

As a child grows and develops, her initial social circle expands beyond her family to include other children and adults. Adequate peer relations are important for a child’s social and emotional well-being and are also associated with success at school. As young girls, most of the study participants had some contact with neighbourhood children. When they reached school age some joined their non-disabled peers in the regular school system while others attended segregated schools with other children with disabilities. Without exception, all were integrated in junior and senior high school.

Two participants who attended a special school spoke very favourably about the opportunity it afforded them to meet other children with disabilities.

There weren’t any kids with disabilities when I was really really young, I was pretty much on my own...but when I went to (special school), that’s when my world opened up...there was one young girl that we’re still friends, very close...that was the first time when I connected with her, and her mom and my mom got to know each other so I would go over there on weekends and whatever. That was the first time having someone in my life
not in school.

The other participant also emphasized the importance of the social ties that she formed at the segregated school she attended. Amidst criticism of lack of privacy at school and low academic expectations, the social opportunities it afforded were seen as highly favourable. Both participants noted that they formed many lasting friendships that carried them over the years and are still important to them today.

I got a lot out of that. I didn’t get anything academic, that’s for sure, but I got some incredible friendships...I still have a lot of these friendships and I think that that was really important for me in terms of having a solid base of friends with disabilities who I could relate to in ways that I maybe couldn’t relate with non-disabled peers.

Although segregated settings by their very nature provided opportunities to meet other children with disabilities, many of their practices were actually counter-productive to healthy socialization. Commenting on her experience at a residential facility, one participant noted the unnecessary adherence to the medical model where routines like daily temperature taking accommodated staff schedules rather than children’s social activities. Describing many of these practices as unnecessary, this participant indicated that at the very least they could have been scheduled with the children’s needs in mind.

As I indicated earlier, all of the participants had experienced regular school settings either for their entire schooling or following elementary school. One participant had predominantly positive social interactions:

I was in a regular school...if there was a fire drill, the two biggest boys made a fireman’s lift and carried me out...there was no fear of insurance claims at that time...Kids knew I
had a disability, I knew I had a disability, but it was put in perspective. It was part of who

I was.

This participant, as well as another one who only attended a regular school, experienced some
disability-related adjustments when they made the transition from elementary to junior high
school. One found herself having to explain her disability to peers, something she had never
encountered in elementary school where everyone knew her as disabled. She described going
through a phase when she wished she didn’t have to answer such questions as why is she limping
and why does she have a key to the school elevator. The participant quoted above had similar
concerns, although the transition she ultimately experienced was a smooth one. She described the
doubts she had when she began attending a different high school than her neighbourhood friends
due to accessibility issues:

I only knew one person who was going to that school, another girl, and we didn’t
particularly like each other...so it was a case of being in a new school situation, making a
whole new group of friends...so for that brief time I had a little bit of self doubt...I realized
that all the neighbourhood kids and the ones I had gone to school with, they always knew
me for who I was and yes, they knew I had a disability but that was just part of the
package...and here’s a whole new group of people who I don’t know who don’t know
me...they don’t know that I’m O.K.

Both participants were integrated throughout their schooling; their peers in elementary and junior
high school were familiar with their disabilities. The transition to a new situation and to peers who
were not familiar with them precipitated some degree of concern and discomfort. A positive
adjustment had ultimately been made in both cases.
A number of participants described more difficult transitions, usually from a segregated elementary school to an integrated junior high school. Most reportedly went through a stage where they did not want to be associated or "lumped together" with other students with disabilities.

We had our own home room. We were called OH students, Ontario Handicapped or something like that, I don't know. But we were labelled...in the lunch room they had a special table for us, and I didn't want that. I didn't want to be segregated. Some resisted any kind of special treatment which clearly set them apart from their non-disabled peers. One noted how one of her teachers in junior high school would exempt her from a detention that the rest of the class got. Another recounted her discomfort when she was called to a meeting over the school's PA system along with other students with disabilities.

Various students in the school had disabilities and I guess in their mind (the administration) they were thinking: 'what can we do to make it easier for them, we'll call a meeting for all students with disabilities'. Well, that's fine when I think about it as an adult, but when you're in high school you don't like to be singled out...and that's exactly what they did when they called us over the PA system...it was so clear, so and so is in a wheelchair, and so and so uses crutches, and so and so well, she limps...they're calling all the crippled kids...it just bothered me that I had to be a part of that group.

Along with resisting an association with other students with disabilities, several participants recounted their attempts to make friends with non-disabled peers and some of the barriers that they came across. Some had to overcome personal barriers such as extreme shyness or a lack of exposure to a non-segregated environment.
It was a bit harder for me to make friends at high school because there was such a huge gulf in my cultural experience compared to theirs. I was removed from the community... for 6 years I hadn't really had interactions with non-disabled kids...in the institution a volunteer would come up to you and say ‘do you want to do this and do you want to do that’, so in high school I sort of thought well, if a kid wants to hang out with me they’ll approach me...but they didn’t because they were just as shy as I was.

Another participant remembers making a conscious decision that she has to overcome her shyness and make the first move to establish contact. She ended up connecting with two non-disabled girls who told her that they had been wanting to approach her and several other students with disabilities but did not know how it would be received. These accounts suggest that reservations on the part of disabled and non-disabled kids inhibited the development of some friendships.

Although some participants recounted experiences of active rejection by non-disabled peers, the more common experience was one of subtle exclusion and lack of acknowledgement. One participant noted how she would be used as a “late ticket” by non-disabled peers who would take her books just as she was about to enter class and claim to be late because they were helping her. Another attempted to connect with non-disabled peers by choosing one of them to be excused from class a few minutes early in order to push her chair to the next class.

There was an agreement among the teachers that students with disabilities could leave five minutes before the class ended...I grabbed that moment and took advantage of it because it was my way of connecting with one student in the class. I would pick somebody out and say ‘I need so and so’s help’...a lot of the guys wanted to do that because they got a blast out of taking risks with my chair and we’d go racing down the hall...but it was my way of
being connected with these people.

Despite the enthusiasm to help her from class to class, this participant clearly understood the limits of this friendship, even as a young teen: "I knew that after class I wasn’t going to be asked to join them at the mall." Several participants reported to have found their social niche by linking with other students who were either less popular or otherwise non-mainstream. The participant quoted above recounted the important transition she went through in high school when she decided to re-establish contact with her disabled peers from elementary school. Abandoning previous attempts to be fully accepted and integrated with non-disabled peers, she re-connected with peers with disabilities and found a strong sense of support and community.

A lot of us were struggling with the same stuff of you know, not having relationships, not feeling connected with our non-disabled peers...I had a friend who was not allowed to go on a school trip because he had a disability...I think that the systematic ways that some of us were being excluded really brought us together.

This participant’s reference to systematic exclusion was mentioned by another study participant and is fundamental to the discourse on integration and participation. Some of the same physical and attitudinal barriers that hinder adults with disabilities from full community participation were also at play in participants’ early experiences of social integration. Being integrated into the regular school system still meant that at the end of the school day they were bused right back to their home or residential setting. There was little opportunity to participate in extra-curricular activities or otherwise connect with non-disabled peers outside of the school milieu, a connection which becomes increasingly important during adolescence. A shared day at school does not guarantee social integration, especially in the absence of opportunities for social
connection after school hours.

I had no choice about getting involved in anything because the school bus came and took me right after school...so I wasn't involved in any after school activities. I never went to dances and nobody ever asked me out.

Physical barriers are further confounded by attitudinal barriers; a number of participants resented the assumption that they would only associate with other disabled individuals. This assumption is demeaning in that it portrays the disability as the defining feature of one’s identity.

Reflecting on her relationships with disabled and non-disabled peers, one participant noted:

It’s not that I didn’t like them (disabled peers) as people, it’s that I didn’t want to be labelled...I didn’t want to restrict myself to this group of people and be seen by them (non-disabled peers) as being part of this unit...I wanted to be seen for me.

The reluctance to associate with disabled peers can also be explained as a form of internalized oppression. Living in a society which devalues disability and defines it as a medical condition inherent to the individual, a child may indeed attempt to disavow that part of herself by associating only with non-disabled, non-stigmatized individuals.

Fighting for Self-Determination: Stories of Risk, Stories of Survival

Thus far I have described the salient childhood experiences of study participants as they pertain to family dynamics, psychosexual development, peer relations, and contacts with educational and institutional settings. Permeating most of these stories are the multiple barriers that many have faced in their quest for self determination and control over their lives. Self determination can be defined as “the individual’s ability to pursue chosen goals without excessive frustration” (Olson, 1978, p.45). Pursuing chosen goals cannot take place in a vacuum; it is
contingent upon the ability to imagine oneself in various roles and situations, and having the capacity and opportunities to strive towards those aims.

A number of study participants noted the difficulty associated with not having any kind of role models of adults with disabilities as they were growing up. Children are constantly emulating the adults around them as they try out different roles and identities. Having no exposure to adults with disabilities could significantly hinder a disabled child in her attempts to imagine herself in the future and consider different options. This can pose a significant barrier to self-determination since, as indicated by Ortega y Gasset, who wrote extensively about this subject, “to live is to constantly decide what we are to become” (translated from Spanish, in Prilleltensky, 1994, p. 190).

Having spent most of her childhood in an institution, one woman indicated the difficulty for a child trying to imagine life beyond the institution.

You didn’t see kids there leaving or getting married or having kids... they left and you just never heard from them again....and then a lot of the kids who lived there died.

The antithesis to this was experienced by another participant who became involved in disabled sports as an adolescent:

Being involved in sports, I was exposed to all kinds of people with disabilities older than me who were living very normal lives...they were working and driving and they had kids...it opened up a whole new other world.

Having trepidations about the future due to lack of role models was not limited to those who were raised in an institution. Two other participants raised at home also struggled with who they might become, as all the women in their sphere were so clearly different from them in the physical sense.
The sense of powerlessness and frustration that can emanate from this void can also be found in the literature on women with disabilities: “Growing up...I often felt alien in the homes of my parents and our neighbours, as though I faced people from different cultures across the dinner table and living room floor” (Lisi, 1993, p. 202).

Whereas lacking role models can pose a risk to self-determination, albeit subtly and indirectly, crude and clear-cut impediments were also reported by participants. Numerous examples were given where participants felt totally powerless as children over various aspects of their daily lives, above and beyond the relatively little power afforded to children in general. Earlier in this chapter I discussed the lack of control and self-determination that some participants experienced during medical exams. One participant recounted the lack of control she felt as a pre-pubescent youngster following her injury:

I found it really hard, this sense of having no control over my body...when you’re in the hospital, medical staff determine when and how often your bowels will move and whether you’re going to have a catheter or diapers or... you know, all those things that are so intrinsically personal...I always had a sense that you can’t say no in a hospital...you just abdicate control.

Further discussing this issue, this participant made it very clear that the most troubling aspect for her was the lack of self-determination that she felt, much more so than the loss of physical control over some of her body’s functions.

The most blatant and compelling description of having one’s self-determination completely disregarded came from a participant who reflected about her early years in an institution for children with disabilities.
You had no say in anything...you didn’t have a say about what you ate or when you ate it.
You didn’t have a say about when you got up or when you went to bed. You didn’t have a say about what times you could play or have free time. Even what you were wearing...they were going to open the closet door and pick item a or item b. ..it was a power issue...they were in charge.

The same controlling, undermining attitude that characterised decisions of daily living, was later applied to such critical issues as where patients would go as adults:
You had to leave when you were 18...and they would just dump people wherever there was a spot. I mean they didn’t really care. They would place you out to a nursing home or some convent...it didn’t matter, wherever there was an opening.
The logical conclusion that children may come to under such circumstances is that it really doesn’t matter where they go, because they don’t really matter. Maintaining a sense of self worth is an uphill battle when the pervasive message is one of helplessness and lack of agency and control.

The title of this section is Fighting for self determination: Stories of risk, stories of survival. Alongside stories of hurtful comments and actions, lack of control, and multiple risks to self-determination, participants told other stories, those of fighting for control over their lives and destinies, resisting oppression, and surviving multiple adversities. Two participants commented on the role that anger played in their fight for self-determination. For one woman, the anger she felt over her exclusion in the community and her parents’ bleak outlook about her future options mobilized her to leave home despite her family’s objections. She described her decision to move out as a matter of survival:

If I had stayed there I may not have gone on to university, I may have been in the home
and taken care of... I just wouldn’t have had the strength and the determination, it was almost a challenge to my spirit... here I was accepted to university and the weekend I was to go my dad wasn’t going to take me... he said ‘what are you going to do? where is this going to end up?’... I called up my friend and said ‘are you going? come and get me’. And I left. I had never ever been that determined.

The other participant channelled her anger towards resisting oppressive attitudes and practices at the institution where she was raised.

I was mad all the time, I was just always mad... and I was always in trouble. I was constantly grounded. I was always in trouble because I couldn’t contain it... if a staff member was doing something that I thought was idiotic I would tell them, in whatever language I chose, what I thought of their behaviour... I knew there’d be a backlash but I didn’t care... it was more important to name the score... I also knew that it would let the other kids down if I didn’t fight back because they would expect me to fight back about it... in a way I think they were vicariously fighting some of their fights through me.

She later used her anger to organize her peers and, as a group, demand to be involved in planning for their discharge from the institution. Rather than accept the nursing home placement arranged by the institution, these youngsters successfully lobbied for consumer-directed attendant services which allowed them to live independently in the community.

Another participant, who was rejected by her mother as a disabled girl, noted that she also had blessings in her life to balance out the adversities. Her father was always loving and supportive, she had a close relationship with her siblings, and as a youngster had managed to attract older friends who served as positive role models. “I’ve always been able to kind of find
what I needed along the way.”

These are some examples where participants were able to transcend some of the adversities in their lives and to keep their heads above water, when the odds were stacked against them. In other cases, highly supportive and affirming families provided a solid basis for the development of self-confidence and competence. One participant related how she asserted herself at age 17 with her orthopaedic surgeon by requesting that he change his practice of coming to see her in the hospital at unusual hours:

I said, I don’t want you coming to see me at 1 or 2 in the morning because I’m tired and I can’t listen to the things you’re saying to me and I can’t ask questions. I want you to come and see me during the day when I’m awake...and he did!

From a young age, this participant had the sense that she has some measure of control over her life and her destination; “There are some things as a child that you don’t have a choice about, but I always knew that I had with most things some element of choice.”

Whereas parents have the most impact on their child’s development, other people that are influential in a child’s life can also play hindering or facilitative roles. Earlier in this chapter I discussed the negative experiences that some participants had in medical and institutional settings and how their sense of self-determination was undermined by uncaring or insensitive workers and health care professionals. Whereas negative experiences were more commonly reported by participants, it is important to also present experiences that were described as positive and affirming. Two participants reported predominantly positive experiences in their contacts with physicians and health care professionals. One who spent extensive time in the hospital as a youngster remembers being nurtured and cared for by nurses and physicians who often came by to
visit her and celebrated her birthday with a cake. Another participant noted a particularly memorable encounter with a physician:

I always liked the doctors because they were always really nice to me...some people have really horrible memories of going to doctors, but I really don’t. And I remember specifically one doctor, I must have been getting older. I must have been like 11 or 12 because he said to me, I remember exactly, he said to me: ‘you can grow up, and you can have kids, and you can do everything everyone else does,’ he said to me. And that just stuck in my head...I don’t think he even realized what an impact that statement had, you know.

As she got older and had various questions about the implications of her changing condition, this participant knew that she could count on this physician to be respectful and upfront. He candidly answered her questions and admitted to not having all the answers. Such affirming and esteem-enhancing attitudes by people in positions of power can have a profoundly positive impact on a child, as this participant has clearly noted.

Working the Hyphen...

As I listened to participants’ childhood stories I realized how little I know about the lived experience of girls with disabilities and the extent to which oppressive ideologies and practices frame many aspects of their lives. Drawing on my own experience of living with a physical disability enhances my understanding of participants’ current lived experience. However, the impenetrable wall that divided our childhood experiences can be attributed to the division between non-disabled and disabled more than to our growing up on different continents. When I think about my own childhood, the predominant image is one of carefree playfulness, of hours spent
with neighbourhood kids skipping rope and playing hide and go seek. Our play was interrupted only by the occasional fight or, more consistently, by our mothers calling us to come home.

Sitting with these women, some of them so like myself, I heard stories that conjured very different images. Despite knowledge gained from the literature, I was shocked to hear about the extent of disempowering childhood experiences in schools, medical settings, and institutions.

Throughout this chapter I presented experiences that conjure images of disadvantage and passivity. I struggle with this presentation as I am aware that focusing on such images can be oppressive in and of itself. Jenny Morris, a feminist disability researcher, is critical of attempts to frame the relationship between gender and disability as double disadvantage: "Images of disadvantage are such an important part of the experience of oppression that emancipatory research... must consistently challenge them....I do not think that I, or many other disabled women, want to read non-disabled researchers analysing how awful our lives are because we 'suffer from' two modes of oppression" (Morris, 1992, p. 162-163). By juxtaposing my own childhood experiences with those of some of the participants, I further run the risk of "Othering".

My decision was ultimately guided by my belief that such childhood experiences must be told and exposed. My intention was to tell the stories and thereby illuminate the oppressive factors that frame these experiences. As I wrote about sexual objectification and violations of privacy, I questioned myself about the risks and benefits of such an exposure. Far from wanting to sensationalize these issues in a voyeuristic manner, my aim was to impact readers the way I was impacted, to amplify the voices of oppression and raise a collective outcry against such abuse.

Throughout the chapter and especially in the final section, I attempted to balance images of passivity and oppression with impressive accounts of resistance and survival. The latter are just
as important as the former in shaping participants' experiences, meaning-making, and adult identities. In fact, it is the very sort of women who participated in this study who are the strongest and most passionate advocates for future generations of children with disabilities. They do so by talking and writing about their experiences, by being involved in consumer organizations, and by advocating on behalf of other vulnerable citizens. Although this research focuses on mothering, I hope that it can also contribute to future generations of children with disabilities.

Another point that I wish to make revolves around the role of parents in shaping the experiences of children with disabilities. Some of the childhood experiences presented in this chapter describe parental attitudes that can hinder the development of a healthy identity. I realized, as I read the chapter, that I neglected to situate these attitudes within the larger context in which these parents raised their children. Research focusing on the experience of parenting children with disabilities speaks to the struggles that these parents go through as they attempt to secure services and meet the needs of their children. Some of the earlier literature describes disempowering experiences of parents being denied information, undermined by physicians and other health-care professionals, and devalued by society at large. Their intimate knowledge of their children's limitations, abilities, and needs notwithstanding, parents were historically undervalued and undermined by the professional community of health care providers and educators. Their own experiences and perceptions were also shaped by the medical model which encouraged deferral to medical authority and denial of the personal knowledge which emanates from daily interactions with their children.

Some of the parents of study participants were undoubtedly influenced by this paternalistic ethos which was most prevalent several decades ago when most participants were growing up.
One woman whose privacy and personal agency was violated in medical exams, emphasized that her parents sought her best interest by bringing her to clinics. Another participant whose mother was embarrassed by her resistant and uncooperative demeanour, also alluded to the power of the medical community in shaping her mother’s beliefs. Parental reticence to acknowledge a disabled daughter’s sexuality must also be considered in light of prevailing attitudes towards people with disabilities and parental beliefs that their daughters will suffer rejection. It is also important to note that almost without exception, parents were committed to their daughters. For example, a number of participants noted their parents’ refusal to place them in an institution contrary to medical advice. Stories were also shared of loving parents who were nurturing, supportive and facilitated growth and independence. All of the participants have some contact with their parents as adults, with some having very close connections.
ANALYSIS AND PRESENTATION OF DATA:

PART II – THINKING ABOUT MOTHERHOOD, WEIGHING THE OPTIONS

Given the historically held belief that all women are destined to be mothers, motherhood, as choice, is a relatively modern concept. Today, most women consider motherhood as one option, with some opting for other paths of life. Irrespective of the choice they ultimately make, the majority of women consider motherhood as a viable option, with most becoming mothers at some point in their lives. This second data chapter focuses on the choice to become or not become a mother in the context of a physical disability. While usually motherhood is no longer prescribed for women in general, or proscribed for women who have disabilities, this group of women continues to face particular issues and challenges as they consider their reproductive options.

I begin this chapter by explicating the various messages and perceptions that study participants have experienced with respect to sexuality and motherhood. Next, I discuss participants’ accounts of the many issues they are presently considering or have considered in the past, as they contemplate their reproductive options. Over a third of the women who participated in the in-depth interviews and approximately half of those who partook in the focus groups are women without children. Of those, most have considered motherhood at some point in their lives, and some are still undecided as to what course of action to take. This chapter gives a voice to the desire for children that some participants have expressed, to the challenges and barriers that they envision, and to the ambivalence that was communicated in the interviews and focus groups. The final section of the chapter explores the lives and meaning-making of women who do not have
children. Although participants without children are the main source of data for this chapter, mothers are also included to the extent that the issues they raised predate the birth of their children and are of relevance to this discussion.

Messages and Perceptions about Sexuality and Motherhood

In the previous chapter I reported on the childhood experiences of study participants with respect to psycho-sexual development. A common theme underlying many of the stories was the lack of recognition of one’s sexuality by family members, peers, and the community at large. Having their sexuality denied or undermined was certainly not limited to the growing up years; a number of participants recounted adult experiences of sexual invalidation. Those whose families ignored their sexuality in childhood and adolescence were also more inclined to get negative messages about dating and relationships as young adults. One participant recounted her parents’ reaction to her engagement:

When I got engaged there was this campaign to convince me that I was making the biggest mistake and there was absolutely no way that I could do this...their reaction was ‘how could you do this...you don’t know what you’re doing’ and I thought: ‘Oh God, maybe I don’t, maybe I’m just a complete idiot.’

While this participant was very young at the time, two other participants, both over thirty years of age, noted that their parents are still resistant or at best ambivalent about the idea of them being in intimate relationships. In one case, this was recently manifested in the parents’ reluctance to accept a dinner invitation with their daughter’s boyfriend. It is this woman’s first attempt to introduce her family to a boyfriend, something she has always shied away from:

I’ve had other relationships but they really haven’t been that serious...I always thought
that I’m not going to even raise the possibility of bringing someone home until it’s more definite...because for some reason I felt that if I did introduce them to my family and it didn’t work out they would think that I was a failure in that area...they don’t see my situation as credible.

Luckily, this participant is confident that her parents will eventually come around given the overall positive relationship that she has with them. Furthermore, she interprets her mother’s reluctance as related, among other things, to her fear that she will no longer play an important role in her daughter’s life. Having spent many years providing physical and emotional support, this mother’s identity is strongly intertwined with her role as advocate, nurturer and caregiver.

Of those participants who recounted negative messages from family members about intimacy, most attributed it, among other factors, to their parents’ attempts to shield them from the pain of rejection. One father was somewhat uneasy when his daughter terminated a relationship with a disabled man and began going out with a non-disabled man. This participant, who later married her non-disabled boyfriend, attributes her father’s dis-ease to his concern that she is more likely to be left by a man without a disability. A number of other participants whose parents were initially resistant or, in one case, outwardly negative towards their daughter’s sexuality, were clearly delighted once they realized that their daughter was in a stable and fulfilling relationship. Rather than seeing the daughters as asexual, most parents’ resistance and reluctance was fuelled by their wish to protect them from existing biases and perceptions about sexuality and disability.

Whereas a negative parental attitude about sexuality was not the predominant adult experience of study participants, most reported some experiences of sexual rejection as women
with disabilities. One woman noted the discrepancy between her parents’ consistent assurances that she can expect to lead a similar life to non-disabled peers, and the invalidating messages she got in the wider community.

The message I got was ‘you’re just like everybody else’ and yet I wasn’t…it was sort like a catch because I wasn’t fully non-disabled and I wasn’t fully disabled…there was always this assumption at home that I would grow up to be like everyone else…that’s all I heard when I was younger…when I got teased I would think ‘it doesn’t matter because when I get older I’m going to be like everybody else…

Now a young woman, this participant’s perception is that her family is becoming less confident about her prospects in the relationship domain:

Now that I am getting older, my family sees me as working and doing wonderful things professionally, but ‘we don’t talk about the personal part of her life anymore because it doesn’t seem to be possible’…so it’s sort of reversed…nothing is said to my face, it’s all sort of inferred…and they are worried so they are making me worried…I never thought it was impossible until the rest of the world started treating me differently…until my disability became an issue out there with the way men treat me.

The perceptions and expectations of these parents have been shaped and possibly altered by some of the negative attitudes that their daughter encountered as a woman with a disability.

Several participants described situations whereby men who were initially interested in them had a complete “change of heart” once they became aware of their disability.

The guys that asked me out I met at night clubs and they didn’t get to see all of me they saw part of me... I had some very bad experiences when they did find out.
One participant recounted having several dates with a young man when she began to attend university. Their outings were date-like in that the young man picked her up and payed her way, as was considered appropriate at the time. Nonetheless, he made no attempts to hold her hand or make any move that would express a sexual interest.

Then one time he asked me to go to this university dance. He asked me if I would mind if he brought another person along, this woman...I guess he didn’t realize...he had no sense that I was considering this a boy-girl relationship even though he wasn’t...it was very odd but quite demoralizing...it reinforced this whole idea of I’m just asexual and nobody will want to go out with me...they’ll just continue to have these asexual relationships with me.

Interestingly, three participants reported being pursued by men who were either not available to participate in a sexual relationship or thought that being in a relationship with a disabled woman is the best they could do. Two were asked out by closeted gay men; in one case, a wedding proposition soon followed. The third woman was asked out by a man who told her that he recently learned that he is infertile and therefore considered her to be an appropriate match.

Having described numerous experiences of sexual rejection and devaluation, I do not wish to leave readers with the impression that only negative experiences and messages were reported by participants. The fact that most of the women who participated in the study were in committed relationships at the time of the interviews and focus groups speaks for itself. Of those who participated in the in-depth interviews, most are married women, and many have children. Clearly, these women were ultimately successful in establishing and maintaining an intimate relationship (I do not mean to equate success with being partnered or romantically involved; most participants made it explicit however that this is an important aspect of their lives). My reason for elaborating
on negative messages and perceptions is that they constitute oppressive factors which are directly related to the disability experience and are thus relevant to this study. Furthermore, study participants described and made meaning of their own negative experiences within the context of dis-ablelist and disempowering societal norms. For example, one woman noted that during the initial stages of her relationship with her partner, she used to look at him and wonder what he saw in her. Several other women recounted former notions of not being quite worthy or complete unless they were in a relationship with a man. Indeed, the message that people with disabilities are not sexually desirable, in conjunction with the high value placed on being in a relationship, can be significant risk factors to social and emotional well-being. In light of these risk factors, the ability of study participants to contextualize their experiences within the larger social structure can be considered an important strength which could mitigate the risks posed by sexual devaluation.

Related to the topic of sexuality, and of great significance to this study, are the various messages that study participants encountered or are presently encountering with respect to their reproductive choices. Unlike non-disabled women who are typically free of any restrictive messages about the feasibility of their becoming mothers, study participants, as a group, were exposed to numerous disempowering messages about their reproductive choices. Consequently, most of those who participated in the in-depth interviews related that they never pictured themselves as having children. Several participants noted that although they never discussed the possibility of having children with their families, they know that it was not something that their parents ever considered as an option for them. One indicated that the unspoken message is “if you can’t help yourself with a lot of things how can you expect to look after someone else?” Another woman said that if she were to discuss this subject with her family, they would try to impress
upon her just how difficult looking after a child would be for her. She tested (and verified) this assumption by raising the issue with her family between the first and second interview that we had. Although this participant is not at all clear that she wants to have children, she was perturbed by the fact that her parents questioned her ability to consider all of the relevant factors and make a mature and responsible choice with respect to her reproductive options. For a third participant, exploring this matter with her family is not an option she can even consider at this point in time:

If I ever brought that to them I would have to be so absolutely sure about my decision because they would do everything in their power to convince me that I couldn’t do it...I’d have to be so solid and I’d have to cover all the basis.

Although more participants related experiences of familial opposition to their becoming or considering motherhood, several noted that they were never exposed to such messages. In reaction to some of the stories of discouragement shared at one of the focus groups, one woman related:

My family never put pressure on me one way or the other. I always felt comfortable...I’ve been lucky.

Another woman noted that this subject never came up in conversations with her parents. “Reading between the silence” she reasoned that her parents did not really consider this for her and would likely worry if she were to become pregnant. However, she was quite confident that whatever course of action she decided to take would be respected and accepted.

While parents were often ambivalent and at times outwardly opposed to mothering by a disabled daughter, friends tended to give positive and even encouraging messages. Some participants were openly encouraged by friends to pursue motherhood. One woman recalled:
When we first got married a lot of our friends would say 'Oh, have kids! We'll help you out, it's no problem'...so people were talking to us, most subtly, but some not so subtly. When I asked her whether they were giving her the message that as a woman she should have children, she responded: "I don't think it was so much that I should but it was an acceptance that there was no reason why I really shouldn't." Another participant spoke of friends who think that having children will make her a happier, more fulfilled person:

The people who I am working with have this feeling that if I have a baby, it will solve all the problems that I'm having. I won't be lonely any more, I'll have somebody that will always love me...and that's not necessarily the case.

This woman had a miscarriage some years ago, after which she decided to remain childless. She recounted how friends found it difficult to understand her decision and come to terms with it:

None of my friends could understand why I made the decision after having the miscarriage. They just couldn't understand why my career was so important to me, why I didn't want to have children. And that's really difficult because I was brought up in the era of the "Brady Bunch" kind of thing, you know, it was the happy family...and they just couldn't see why I would choose not to have children...I mean, as old as you are, it's still peer pressure...it never goes away.

In thinking about this apparent discrepancy between the reactions of parents versus friends, I am reminded of an argument made by Barbara Hillyer (1993) in her book Feminism and Disability. Hillyer states that mothers of adults with disabilities are often criticized for fostering dependence within their children. Their experience of rearing and caring for a disabled offspring is often discounted and deemed irrelevant, not only by professionals but also by disability rights and
feminist advocates. "An inevitable effect of mother blaming is that the mother's own perspective, her insight, is discounted. She becomes merely a discredited appendage to the important different person, the identified minority group member, with the real disability" (p. 105). Speaking about adults with developmental delays, Hillyer makes the rather contentious argument that the voices of mothers who seek sterilization for their developmentally disabled daughters need to be heard. These mothers are often vilified as restrictive and oppressive, without paying any credence to the mother's "experienced and realistic belief that the retarded daughter cannot handle the birth and rearing of a child and that the mother herself cannot do so for her daughter" (p. 106).

Hillyer's choice of the pejorative term "retarded" and her reference to individuals thus labelled without distinguishing between different levels of developmental delays, are just some of the concerns that I have with her argument. These concerns notwithstanding, the point she makes about the significant supportive and care-taking roles that mothers often play in the lives of their disabled daughters cannot be ignored. Extrapolating this argument to the present discussion, mothers of daughters who have mobility impairments that would significantly impact their ability to provide infant care, may be understandably concerned about this issue. In the absence of adequate formal support systems, parents may be concerned about the role they themselves will play if their daughter becomes a mother. Friends typically don't have either the depth of knowledge regarding the disability and its implications, nor the moral responsibility to provide tangible, long-term support. This issue will be further discussed later in the dissertation.

A number of participants commented on the interaction they had with physicians about motherhood in the context of disability. One woman was strongly advised to refrain from pregnancy during her first gynaecological exam. In addition to a prescription for birth control
pills, which she had requested, this woman also got the physician’s unsolicited opinion that pregnancy would be unwise for her. Although she has since learned that the information she was given was inaccurate, the physician’s warning had strongly impacted her; “it almost seemed like pregnancy was equated with death for me”. Although she now believes that the doctor did not intend for her to make this association, her warnings with respect to the danger of pregnancy were indeed powerful and stifling.

Another participant also came to her physician in order to discuss reproductive choices. Although she was merely in her twenties at the time, she did not think that she wanted to have children. Growing up without any role models of women with physical disabilities, let alone mothers with disabilities, this participant, like a number of others, did not envision herself as a mother. She approached her physician about the possibility of having a tubal ligation.

Once I asked my doctor about a tubal ligation. She was ready to pick up the phone and make the appointment. I said ‘wait, not now’... I wasn’t even married at the time, just dating. That doctor was not used to disabilities. Every time that I would see her she thought that everything is related to my disability... finally I switched doctors.

Undoubtedly, a non-disabled woman in her twenties inquiring about a tubal ligation would get a very different response from a physician. Without wishing to stereotype physicians, I believe it is safe to say that most would feel obliged to inform their patients as to the finality and probable irreversibility of such a procedure. Most physicians would make efforts to dissuade a young woman from choosing this procedure and suggest other, less drastic means of controlling fertility.

There is little doubt that this woman’s physical disability was a highly influential factor in the approach taken by her physician. As I indicated in the literature review, physicians as a group
have traditionally discouraged women with disabilities from having children, a trend which only recently has begun to change.

Another participant had an antithetical experience to the two reported above. Having been told throughout her life that she cannot consider motherhood, she was told by a gynaecologist that her reproductive organs are no different than those of non-disabled women. I had gone to a gynecologist and he said ‘you know, you’re normal’, and I started to cry...He’s telling me I’m normal, and I’ve been told all along that I’m not normal.

Another participant, quoted earlier, also noted the memorable experience in adolescence of being told by a physician that she could expect to lead a similar life to non-disabled peers, including having children if she so chooses. Taken together, these diverse experiences clearly attest to the prominent role that health-care professionals often play and to their potentially hindering or affirming roles.

To Have or Not to Have: Weighing the Challenges and the Rewards

Exploring Joys and Rewards

During the course of the interviews and focus groups, most participants gave voice to some of the positive aspects associated with having children. Regardless of the extent to which they see motherhood as part of their future or even strongly desire to become mothers, most participants have at least considered some of the joys and rewards of motherhood. One woman discussed the joy associated with watching children grow and develop:

I think it would be an incredible experience to be able to be part of someone’s life and watch them grow...be there when they are learning things.

Although this participant expressed quite a bit of ambivalence about having children, she
explicated some of the reasons that draw her to still consider this as an option. Two women made reference to the experience of pregnancy and childbirth:

I think that as a woman, I would really like to be pregnant, to have the experience of carrying a human being...I think it’s an incredible experience.

Another participant who is also undecided about what course of action to take noted the close relationship that she and her husband have with their parents. Rather than a present desire for a child in her life, this woman indicated the sort of relationship with adult children that she may miss out on if she decides to remain childless. She also made reference to a comment she had recently heard from a woman at work after the birth of her child:

This is a very successful career woman and she said without any hesitation whatsoever, ‘the most important thing that I have done to date is to have that child’. That just made me think, I thought God, that’s a very powerful statement and to think that I would be missing out on that experience.

Having provided a glimpse of what participants shared about the potential joys of motherhood, it is important to add that something as complex as the desire for children cannot be defined and analysed in formulaic terms; some women simply noted a wish to have children, without breaking it down into specific reasons and components. Some mentioned specific contexts such as baby showers and family get-togethers which tend to trigger the desire for children. One focus group participant, who expressed a strong desire to have a child, noted the birth of her sister’s baby as an important trigger:

The first time I held my sister’s child...brand new baby...it was just a feeling, the maternal instinct...I want my own baby. That’s what I want and that’s what I’m going to have.
Two others, who also noted such contextual triggers, emphasized that the element of desire that they feel under such circumstances typically lessens once the contextual cues are not there and they start to consider the implications of motherhood. Whereas only one study participant identified herself as having no past or present desire to have a child, information obtained via interviews and focus groups clearly suggest that a desire for children is not a unidimensional concept. Furthermore, the intensity of this desire varies greatly from one woman to the next and, at times, from one context to another within the same person. Thus, while some women are consistent in their desire for children, others are more ambivalent and undecided. The childless women who participated in the in-depth interviews are more representative of the latter; while the desire for children is sometimes there, it is often balanced by other interests and pursuits that they have on the one hand, and by the various challenges and barriers associated with mothering with a disability on the other hand. These barriers, as explored by study participants, are reported next.

**Exploring Barriers and Challenges**

Study participants came up with diverse and elaborate responses to the question of what are some of the challenges and barriers that they consider with respect to motherhood. The challenges they raised include, among others, their ability to physically look after a child, the possible impact of pregnancy and childbirth on their health, and the ways in which a child might affect their relationship with their spouse or partner. Women also explored the significant change in lifestyle that is part and parcel of life with a child, as well as the possibility of giving birth to a disabled child and its concomitant psychological and practical implications.

**Can I look after a child?** The issue of physically caring for a child was raised by virtually every participant who is considering motherhood. Several women indicated that they simply don’t
know whether they’ll be able to carry out certain child-care tasks, especially infant care.

I am not informed...as far as my own ability or inability to look after a baby...I am lacking the experience so I really don’t know...I am not saying that I can’t, maybe I can, I don’t know.

Similar concerns regarding lack of experience and basic knowledge about child development were echoed by several other women. Interestingly, these participants have several siblings who do have children and with whom they are in touch. Their reported lack of experience with infants may reflect a discomfort that some parents may have around allowing a person with a disability to handle their infant. This was specifically noted by one woman who indicated that even though she was “allowed” to hold her nephews in their infancy, she always sensed the reluctance of the mother who was never more than a few steps away.

Despite the reported lack of experience of some study participant, all had an awareness of the time and energy that is entailed in caring for a child. Several stated their decreased energy level as a factor that they would have to consider:

The older I get the less energy I have...there’s no way I have the energy that I used to have five or ten years ago...in the last couple of years I’ve been with my friends who’ve had kids...I was really struck by the idea that it is a lot of work...the one person feeding them, the other trying to get the bottle ready...

Most of the concerns were focused on the infancy stage. One woman discussed the possibility of adopting an older child so as to bypass this care-intensive period of a child’s life. She felt a lot more comfortable thinking about a child who is past the “lifting stage” and can respond to verbal instructions and directions. Another women who wondered how she would feed an infant due to a
limited control over arm movements, also envisioned less hurdles with an older child.

It is important to note that a clear distinction was made between the ability to provide physical care and to provide a nurturing and supportive home environment for children. One participant who was not properly mothered in her own childhood admitted that she sometimes worries that she may inadvertently “turn into her mother;” however, she classified this as an irrational fear that she can quickly put to rest rather than a valid concern that has any bearing on her decision. This participant, and several others, were generally positive about their ability to be very good mothers in the social-emotional sense and provide their children with a good home.

I think emotionally and in terms of bringing a child up with values and feeling good about themselves and all...I think I could do all that really well.

Another participant also made a clear distinction between the physical and emotional components:

As far as being emotionally there for the child I think I could do that...it’s the actual physical caretaking that I’d be apprehensive about.

Relationship with spouse. Several women noted the interplay between mothering and relationships with spouses or partners. One participant who is in a committed relationship as of lately, noted that she can now consider motherhood as a more feasible option. Whereas she felt a desire to have children at various stages of her life, she put it “on the back burner” as she did not consider mothering without a partner. Another participant also indicated her preference to parent in partnership but noted that having a partner is not a necessary condition for her as far as mothering goes.

Reflecting on some of her earlier thoughts about mothering, one woman noted that given the severe nature of her mobility impairment, she knew that having children would be feasible only
with a partner who would take on major child-care tasks.

I thought it would probably be difficult and I felt that my partner would have to do the primary care giving unless we could afford a nanny or somebody to do that and I didn't really like that idea.

Similar sentiments were expressed by another woman who described herself as highly ambivalent about having children. She noted that although she sometimes thinks she would like to have children, it is something that her partner would also have to be highly committed to as he would have to do most of the physical care-taking during the initial stages of a child’s life.

I would like it (to have children), but I know he would have to do a lot of the work...I would not be able to care independently for an infant. He would have to be the main one who is taking care of the child and I can’t see him wanting a baby enough to do these things...he really has to want this a lot.

Although she was quite sure that her partner would concede if it was really important to her, this participant emphasized that she would only consider having a child if it was something that her partner also strongly desires -- otherwise, she envisions a major drain on the relationship.

Another participant expressed a concern as to how a child might impact the division of labour between herself and her spouse. She noted the different homes and backgrounds that she and her partner are from as a backdrop to their differing expectations about child-rearing and role division within the home. Her main concern was that her partner, who comes from a very traditional family where the mother stayed home to raise the children, may have similar expectations if they were to have children of their own. Given her partner's higher earning bracket, coupled with his belief that infants should be cared for at home by a parent, she reasoned...
that she would be the one to carry out most child-care and household responsibilities. This participant noted that some of her concerns are probably no different than those of non-disabled women who are contemplating motherhood as she is physically independent and capable of carrying out many household tasks. The disability merely accentuates these concerns, as many tasks are far more onerous and time-consuming than they would be for a non-disabled person.

This section on role division and relationship with spouses suggests an interesting interaction between gender and disability. Several women noted an expectation that they would carry out the bulk of child-care activities, whether it is an expectation that they have of themselves or that their spouses have for them. In one case, this expectation was merely alluded to. In a recent discussion about having children, one participant was asked by her partner whether she thinks she could “handle it,” meaning take care of children. It seems that like their non-disabled peers, some women with disabilities expect to carry out more child-care and household duties than their spouses, whether by choice or by default. One could speculate on whether these concerns of child-care and division of labour are as prominent in cases where the man, rather than the woman, has the disability. Women as a group perform a lot more child-care and household duties than men. Given this state of affairs, parenting in the context of a physical disability may be perceived as more challenging and problematic when the parent with the disability is a woman.

Availability of resources and supports. Virtually all study participants who are considering motherhood made reference to the insufficient resources and supports for parents with disabilities. The participant who was concerned that her spouse would have to carry out most child-care duties, indicated at our second interview that she would consider motherhood as a more viable option if she had access to funded assistance — someone who would help her perform
child-care duties. Given that she does not require any attendant services, this participant would not qualify under the current system in Ontario for any funding for assistance with child-care. Being able to access funded assistance would provide her with an increased sense of options and control, regardless of what she ultimately chooses to do.

Another participant was even more vocal about the importance of funded child-care assistance. She drew on her own experience and described the adjustment that she had to go through before she could accept attendant services that would meet her changing needs:

It’s an adjustment in thinking but I’m now seeing it as OK...if somebody can take care of that...if somebody can help me do the things that I have to do everyday that take a lot of energy from me now, then I have more energy to put into the things that are important. I’ve got more to give to me and to other people and certainly that would work in a mothering situation...if someone can help me there and it makes me feel safe, that will enable me to be there for my child.

Another participant who is considering whether to have a second child attributed her hesitation to the dearth of services for parents with disabilities. Relying solely on an informal support system, she noted how her decision about a second child is directly impacted by deficient formal support systems:

My mother, she’s great and everything but I think...if I told her that I’m having another baby she would die. She’d just probably go ‘Oh my God!’ because it’s easy for me to have a baby but she’s helping raise him...I almost feel like it’s a three way decision.

She mused about how much easier it would be to have access to funded services:

If there were some services where I’d have to be at home but there would be somebody
there (to help)... Oh you know, that would be just so great... then I’d know that that person is there and I wouldn’t have to feel guilty... I’d just feel totally differently knowing that I’m not putting anybody out of the way, that’s just their job.

This participant is in a similar situation to one quoted earlier; not requiring any attendant services herself actually works against her as far as receiving services to help her care for her child. People who rely on attendant services for self care have a greater chance of receiving additional hours to help them care for their children. A situation whereby no assistance is required for self care but is fundamental for providing infant care, is not recognized for accessing funded supports.

Although a number of participants expressed the need for a wider range of services, their projections were that it is highly unlikely that more funding will be forthcoming in light of budgetary cuts to social services in general and to people with disabilities in particular. They noted recent cuts to attendant projects and alternative transportation as indications of more cuts to follow. Given the current socio-political climate, they were not hopeful about the prospects of increased resources for parents with disabilities. The participant quoted above also noted that the current climate of cuts may contribute to greater intolerance towards parents with disabilities by reinforcing the sentiment that people should not have children if they are not able to provide independent physical care.

Study participants who discussed reproductive options were united in their calls for increased resources. Nonetheless, a variability was noticed in participants’ comfort level in making use of certain resources. While some elaborated on how funded assistance with child care would make their lives easier, others expressed reservations about the presence of another person. One participant who is a strong supporter of disabled women’s issues, both in theory and in practice,
noted that her own personal preference would be to interact with a child with as little outside intervention as possible.

I think a part of me wants to prove that I can do this…it’s not that I’m so focused on doing this alone that I wouldn’t consider options but I think it would be really important for me to have that quality time (with a child) to just be...I know I’d probably feel like that other person was a distraction.

Another participant, who has made a decision early in life to remain childless, noted that it would be difficult for her to have other people do things with her child that she herself cannot do:

If I had a child I would like to be able to do everything with him or her...and with an activity such as riding a mountain bike with a child, obviously I wouldn’t be able to do that with my child and I’m not sure if I would be able to handle someone else doing it with my child...that’s just me, I know not everybody feels that way.

Another participant indicated that having child-care assistance would require her to decide exactly what she needs assistance with and clearly communicate her needs and priorities to the assistant. She expressed a concern about her ability to direct such services as it is something that she does not require for personal care. Irrespective of the varying comfort levels expressed in utilizing funded assistance, all participants regarded it as a vital service without which some people with disabilities cannot even consider parenthood as a viable option.

Pregnancy and disability. A number of participants wondered about how a pregnancy might affect their disability, and, in some cases, how the disability would affect the pregnancy.

Before becoming pregnant, I would need to know what sorts of risks I might be at...what to expect during a pregnancy...how it could impact on my disability, on my mobility...I’d
be worried about falling and loosing the baby and that kind of a thing.

Another woman, who had always known that she wished to remain childless, noted concerns with mobility during pregnancy as one of a number of factors that she considered.

Although my body had never experienced it, I knew from observing other people that the last couple of months of pregnancy can be very uncomfortable and cumbersome... and I thought I've got enough of that without adding to it.

It is important to frame this consideration within this participant's overall decision that mothering is not something that she really wants to do. Rather than concerns with mobility being the deciding factor, it was but one consideration among many. Concerns about the impact of pregnancy and the possible long-term effects on physical well-being was noted by another participant:

I had a real fear of opening myself up to all those medical things...to sort of mess around with my body... What if I become incontinent? How am I going to cope with that? I was really terrified about putting myself at the mercy of urologists... all those things terrified me... the sense of having no control over my body.

She related these fears to childhood experiences of powerlessness in medical settings. After years of fighting for control and self-determination, the thought of being in a situation which would require increased medical interventions was perceived as a possible threat to personal liberty and agency.

Also related to this topic is the issue of giving birth to a child with a disability, something that was raised by a number of participants. Two women made reference to this issue in terms of the precautions that they would take, or have taken, during pregnancy.
I'd be very careful not to drink, smoke, or take medication. I'm very judgmental about pregnant women who are taking these things. I would definitely not drink, I probably wouldn't even go to the dentist.

This participant went on to say that if she were to have a child, she would do so before she turns 36 so as to minimize the chances of giving birth to a child with a disability. Although she has no doubt that she would accept and love her child regardless of ability status, it is important for her to do whatever she can to minimize the risks. Risks associated with advancing age were noted by two other participants who also indicated the possible interaction between their own disability status and the increased time and effort involved in raising a child with a disability.

This subject was also explored in one of the focus group discussions in response to a presented question. One woman with a genetically transmitted condition discussed the possible implications of having a child who would inherit her disability.

With the issue of genetics, I would likely pass it on to my child and I have a feeling that my nephew already has it although he hasn’t been tested yet. To me it’s not really an issue because it’s no guarantee that I’m going to pass it on, there’s just a likelihood...but even if I do I think my child would have a very fulfilling life, regardless of whether my disability got passed on or whether they have another disability...That would still be my child that I would love and I would hope that they would have a fulfilling life...

Later on in the discussion, this participant was more ambivalent about this issue:

...Having those days when you’re so angry about being disabled and the frustration of always having to prove to other people that I can do things...and having to see that in my child...seeing my child suffer through the same things that I suffered through...even if I can
share my experience, I can’t help the child go through it, he has to go through it himself...it would probably hurt me.

Despite the consideration of potential hardships, this participant did not consider the risk of disability as a major deterring factor for her. Furthermore, the hardships discussed are predominantly ones that are associated with oppressive attitudes and perceptions rather than with the actual physical condition of the disability. As such, it is highly consistent with the disability rights perspective which problematizes the social construction of disability rather than its biomedical origins.

Social isolation. Two women expressed a concern that having a child would result in isolation for themselves. One noted that she already feels isolated in the winters when her mobility is hampered by weather conditions. Having a child may further restrict her mobility as well as her ability to go and do things at a moment’s notice. Similar concerns were echoed by another participant who spends a significant amount of time doing community work:

    Can I invest enough time and enough of myself to be the kind of parent that I want to be?

    It would mean for me to completely let go of a lot of those other commitments that I have...there’s no way I could be out every night doing my committee work, seeing my friends which for me keeps me really connected. If I had a child I would want to be able to focus my energy but then what am I loosing? Will I end up becoming more isolated?

Social isolation and insufficient time to pursue chosen activities is an experience that many mothers share and many potential mothers worry about. This can be further magnified when a mobility impairment is factored in. People with mobility impairments generally spend a lot more time than their non-disabled counterparts on planning and organizing outings. Arranging special
transportation, ensuring an accessible location and taking into consideration other disability-related needs such as attendant services are some of the things that may have to be considered.

When some or all of the above have to be coordinated with getting a baby ready for an outing and getting to and fro home, baby, diaper bag and toys included, the outing becomes a major endeavour and, in some cases, may not be possible altogether. Indeed, social isolation has been identified in the literature as an important issue for mothers with disabilities and will be further explored in subsequent chapters.

**Exploring Ambivalence**

Study participants who are still undecided about what course of action to take with respect to mothering were highly reflexive and introspective about their decision-making process. One woman noted the importance of pre-planning:

> If I did want to get pregnant there would have to be a plan of action that we would have...like you can’t just suddenly get pregnant and say ‘Oh well, we’ll wait nine months and that’s it...you have to think of places to live, you have to think of people who are going to be helping you, you have to think of assistive devices, etc, etc...I’m basically very spontaneous in a lot of areas but because of my physical limitations I feel like if it’s not planned then I’d be totally lost.

She emphasized the importance of responsible decision making whereby her own disability status is incorporated into the process. Another participant also noted the responsibility that is entailed in parenting, along with critically reflecting on the motivation behind it:

> I know that it would be a huge change for me...and a huge responsibility...I don’t want to make that decision lightly and I think that I need to...if I ever go that route, to think about
what is my motivation around that...is it because I don’t want to be lonely? Is it because I want to leave a legacy?

A third participant put both mothering and non-mothering on the balance and critically explored the motivation for either one.

I’ve always said that I wouldn’t want to have them (children) for the wrong reasons and I wouldn’t want not to have them for the wrong reasons...the wrong reasons not to have them are a lack of confidence...and some irrational thoughts. The wrong reasons to have them are because you want someone to carry on the name or you’re doing it because society expects it of you...you know, so if I’m going to do it I want to do it for the right reasons.

Ambivalence about mothering was a common thread across interviews and was also articulated by some focus group participants. Interestingly, even the participant who indicated her partner’s reluctance as the main barrier to parenting thought that she may herself “pull back” if he were to have a sudden change of heart. She was very open and honest about her ambivalence, noting that some days she really wants to have a child and other days she doesn’t. She brought the discussion to another level when she speculated that making the decision to remain childless may be easier for her as a woman with a disability.

Maybe my disability is an easy “out”...otherwise I would feel guilty about being selfish, about not having a child even though I am in a stable relationship...that maybe I should want to give more of myself.

The freedom to choose a non-traditional lifestyle was noted by several other participants who indicated that they just never envisioned themselves as mothers as they were growing up.
Speaking directly to this issue, one participant explained:

I never felt like I had to follow anybody’s path. I’ve always done my own thing...the traditional path wasn’t set out for me and this allowed me not to go on that route...and probably in the last ten years I’ve consciously welcomed that.

Earlier I discussed some of the oppressive and restrictive elements associated with invalidating messages about sexuality and motherhood. The above comments suggest a more complex discourse on mothering and disability. Despite the undoubtedly negative impact of the barriers to mothering that women with disabilities face, it may have created a space for them to forge an identity apart from motherhood. These issues will be further explored in the following section.

**Exploring Life With and Without Children:**

**Separating Motherhood from Female Identity**

The previous section focused on the decision-making process of women with disabilities who are considering motherhood. More specifically, it explicated their perceptions of the various challenges and barriers associated with mothering as well as its joyous and rewarding aspects. In this section I wish to move beyond an articulation of joys and barriers and to explore the lives and meaning-making of women who do not have children. Of the five childless women who participated in the in-depth interviews, all but one are still weighing their options, although most have indicated that they will likely remain childless. In addition to the in-depth interviews, this section incorporates data from two focus groups held at a conference on women with disabilities and mothering. These were held as two separate sessions; one for women who are considering motherhood and the other for women who are not and will likely not become mothers. The latter
are women who are no longer vacillating between mothering and non-mothering and for whom childlessness is a permanent and stable aspect of their identities. Taken together, the two focus groups and the in-depth interviews with five participants provide the basis for this section on women without children.

**A Woman and Not a Mother**

Study participants explored their lives and meaning-making as women without children. One woman indicated that she considered becoming a parent at a time when she longed for change and renewal in her life.

There was so much growth in my 20s...I went from being a very naive kid who had been institutionalized for years to being a married woman with a good job, a degree, and my driver's license...there was such a period of growth there and then in the last five years...the last big thing that happened was we got this house.

The need for renewal, however, can take many forms; this woman spoke about wanting to travel and become involved in disability issues on an international level. Other women also discussed the freedom to pursue different interests and activities, a freedom they would be less likely to have if they had children.

I knew even as a young teenager that having a child changes your life and to love and nurture that child you have to make sacrifices and changes...my desire to have a child, I'm not even sure if it was there at all, but it certainly wasn’t strong enough to override my desire for time for myself...an hour’s soak in the tub, uninterrupted sleep, that kind of a thing.

This participant continues to cherish the time she has to herself and the freedom of not having to
be accountable to others:

Another reason we decided not to have children is because we have a lot of common interests but we also have a lot of separate interests...he doesn’t tell me where I can go and what I can do and I don’t tell him...and then you know, two or three times a month we actually go and do something together that we both enjoy...and I think that’s another thing...I know that there’s a joy to having children that we’ve missed, or that we haven’t had in our lives but it also frees us up to have the freedom we have in our relationship.

Women who participated in the focus group “Not Every Woman Is A Mother” also explored and even celebrated their lives as women without children. They live as independent women, with and without partners and pets, and have friends and careers that keep them busy and challenged. One woman who likes to travel noted:

I leave my cat with a bowl of food and water and go away for a week...she’ll be fine when I get back...but you can’t do that with kids.

Along with numerous stories of partners and pets, group participants shared some of the issues they face as women without children. They discussed the pressure they feel, or have felt in the past, to have children.

My concern is that society kind of says that a woman should be a mother and puts a lot of pressure on them to feel...that if we don’t have children we are not fulfilled as women some women indicated that they are getting the message that having children means “being normal,” like other women. One participant noted:

It feels like for some of us there is that pressure...that you are given more validity if you can attain that (become a mother)...you are seen as more ‘normal’ and attain more status if
you fulfill those sorts of roles.

Some see these pressures as coming from various sources, including the disabled community:

You go up in status if you have children and that’s the problem even in the disabled community...it’s kind of a status thing for disabled women to have children.

Women who participated in this focus group were highly critical of the privileged status that is afforded to mothers and mothering in society. Some also shared a feeling of being marginalized at the conference on mothering and disability; they felt that the conference was a celebration of mothering for women with disabilities which left little room or space for childless women. They appreciated the opportunity to discuss their issues and priorities with other women who do not have children and felt that their voices need to be included in research on women with disabilities and mothering. In discussing priorities for action, one woman said:

Keep on doing research into this issue...there are those of us who don’t want to have kids and our choices are very valid and should also be considered and discussed.

A number of women who participated in the in-depth interviews emphasized that they do not need to have children in order to be fulfilled as women. One participant reflected on her decision to live her life as a woman without children:

I have many many reasons that I considered before I knew that I wouldn’t be a biological parent...one of them is that I knew that I didn’t have to do that to make me worthwhile.

This participant also noted that although this issue never came up in her family, she knew that it wasn’t an expectation that her parents had for her. Furthermore and perhaps more importantly, both her mother and her grandmother are independent women who may have forgone motherhood had they been born and raised several decades later. Another woman echoed a similar
sentiment as she discussed her relationship with her nieces:

We are really close and I've always felt very comfortable around kids...people are always saying 'you'd make such a good mother', and I don't know...I just think I make a good aunt...my nieces will open up to me and talk to me about stuff they won't talk to their mother about...I feel like I play an important role in their lives and that's very satisfying...I don't know that I need to have a child to have that fulfilled.

The subtitle of this section, “Separating Motherhood from Female Identity”, is borrowed from a book on the lives of childless women (Ireland, 1990). My reason for incorporating it is that it captures the main thrust of how participants view their lives as women without children. Whether they are still weighing their reproductive options or consider themselves permanently childless, these women underscored the point that womanhood and motherhood are not co-terminous. While the former subsumes the latter, the two must be allowed to exist comfortably apart from it if the well-being of all women is to be advanced.

The Importance of Choice

Being able to chart their own course with respect to mothering was an overarching theme in all of the interviews and focus groups. Regardless of where they are personally situated, participants underscored the importance of having control and agency over this aspect of their lives.

I think that every individual, whether you're disabled or not, has the basic human right to make that choice. And nobody should tell you that because you have a disability, whether it be developmental, or physical, or whatever it may be, that you cannot become a mother or be a parent because of how society perceives you...society or anyone else should not
make that decision for you...women have the right to choose not to be a mother as well...but the choice should be clearly our own and not determined by someone else, or even by my parents’ attitude...I mean, they have concerns, I have concerns. But ultimately, it is my decision, my responsibility, my life.

It’s important to understand this participant’s ardent belief in self-determination and her equally strong conviction that motherhood in the context of disability should be carefully weighed and considered. She discussed the potential challenges that she may face as a mother and her own realization that it may not be a possibility for her. Furthermore, she emphasized her ability to lead a full and productive life apart from motherhood. Rather than lamenting on the interaction between her physical limitation and her advancing age which may preclude her from mothering, she emphasized her right to make this important decision in her life. Another participant who attended a support group for women with disabilities discussed the important role it played for her in validating her choices:

The group showed me that I’m not alone, I’m not the only one who is facing this...it showed me that it is possible (to become a mother), that I have choices...and that’s empowering. It’s up to my husband and I to decide -- not friends, doctor, or family members. If my doctor would be shocked -- I would go to another one.

Despite her claim that this decision is hers to make, this participant is frustrated that the topic of motherhood never comes up in conversation with her family; she interprets their silence on the issue as an indication that they don’t consider mothering a possibility for her. Like the one quoted above, this participant has many reservations and ambivalent feelings about mothering. Her frustration is centred not so much on the physical barriers that she would face as a disabled
woman, but on the attitudinal ones.

Participants also expressed their disdain with societal assumptions and expectations that it is only natural that they would not have children as women with disabilities. One participant recently got such a message at a family wedding; she made a point of explaining that it was her choice not to have children. Another participant had a similar discussion with a complete stranger who approached her in the mall:

When you have a disability strangers tend to talk to you...I was wheeling along in the mall one day and I could see out of my peripheral vision this little old lady walking behind me, and I just knew that she was going to ask me something. And she is asking me all of these questions like she’s known me for ten years or something. ‘Are you married?’ ‘Yes’. And I was in the mood to play the game and I’m telling her these things..’Do you have children?’ ‘No, I don’t’. ‘Oh, well, I guess...I can see why’ deal. And I said ‘Oh, we chose not to have children’

Another participant explained the harmful impact of this assumption:

I think...for women with disabilities, if they consciously decide they don’t want to be a mother, people automatically assume that it’s not your decision...that you’re not going to become a parent...then if you don’t become a parent then you’re just...you’re a self-fulfilling prophecy.

The right to choose not to become a mother was discussed at some length in the focus group ‘Not every woman is a mother’. For the most part, focus group participants applauded the message of choice that pervaded the conference on mothering with a disability. However, some were concerned that over-emphasizing choice can have the opposite effect; that women with
disabilities that were once precluded from mothering may in fact experience pressure to exercise their reproductive freedom and choose motherhood. One participant was especially vocal with what she perceived as a pressure from within the disabled community for women to become mothers. Another participant added that non-disabled women who choose not to have children are perceived as strong career women, whereas women with disabilities are devalued for similar choices. Group participants felt that wider options for girls and young women with disabilities should include the option to choose a life without children. This point was also made at one of the interviews:

I think that a message that young women with disabilities also need to have is that just because the majority says ‘It’s OK, now you have a choice over your body…some may feel pressured to have a child…I mean some women really do want their own children and can and should have them but other women might think that they should just because they can.

Earlier I mentioned that the negative impact of restrictive messages notwithstanding, they may have catapulted participants’ ability to forge a female identity apart from motherhood. As such, it is important that the changing perceptions on mothering with a disability do not “leave in the cold” women who are not mothers. As one participant noted:

We went from a place where women with disabilities weren’t allowed to become mothers and now we know that we can…but now we have to go a step further…there are going to be some women who choose to be mothers and need support, and then there are some who choose not to be and they also need support…so it’s finding that balance.
Living in Connection

Along with emphasizing self-determination as imperative to their lives, study participants underscored the value they place on living relational and connected lives. An article on women’s development states that “for women, the primary experience of self is relational, that is, the self is organized and developed in the context of important relationships” (Surrey, 1991, p. 52). Study participants exemplified the centrality of this concept to their lives and meaning making. In interviews and in focus groups, a lot of emphasis was placed on relationships, especially with children and with other women.

All of the childless women who partook in the in-depth interviews as well as some of the focus group participants talked about having children in their lives. One participant noted:

I’ve always had kids in my life...that has always been a big part of my life. My friend’s kids. I mean I was there in the hospital when they were born...and I have nieces and nephews that I’m very close to...I was part of their growing up.

Another participant who is still undecided about mothering indicated that many of her friends are starting to have children “so I’ll have all these kids to play with”. For a third woman, fond childhood memories of the relationship she had with her grandparents trigger thoughts of having similar bonds with children:

Although I have to admit that I never wanted to be a parent, I’m very sad that I won’t be a grandparent because I had wonderful grandparents and they were a very very important part of my life...but that’s where you get your friends’ kids and you make those bonds...At some point in my life I would like to have a bond like that with a child but it doesn’t have to be my child...I have a need for children but I get these needs met at work...and at
Christmas I kind of like to “rent a kid” because Christmas is for kids...so there is that gap but not enough to make me regret making my decision.

Participants also spoke about the central role that friendships play in their lives. One woman discussed the powerful connections she made with other women when she went through college:

It was an incredible program...it was community work. It was part time, all adult students. For the most part it was women who had been oppressed in some way...people who were involved in community work...it was just an incredible group of women...and over the three years, it was a very slow process, we became very tight and there was a lot of kind of touchy-feely sort of classes within this...it was really incredible.

Several other women noted that some of the friendships they made in childhood and adolescence are still central to their lives today. While they have connection within and without the disabled community, they are especially connected to other women with disabilities with whom they share similar past and present life experiences. Several women also mentioned the strong bonds they have with their sisters; in one case, an older sister served the role of protector in childhood and a close friend and confidant in adulthood. Another participant whose parents were reluctant to acknowledge her relationship with men, always felt comfortable bringing her boyfriends to meet her sister.

Along with acknowledging the significance of existing relationships, study participants underscored the importance of creating opportunities to link with other women who are facing similar issues to their own. In the focus groups, several women noted how much they were looking forward to coming to a conference on mothering and disabilities in order to share
concerns and experiences with other women. I also interviewed several women who previously partook in an eight session mutual support group which focused on these issues. One participant emphasized the relevance of this experience:

It’s good to have the information and it’s good to be able to talk to someone who has been through it...that’s why I enjoyed the group so much because you realize that you’re not alone in what you’re feeling and thinking...we all seem to live in such isolation in a way that really these connections are hard to make...and you do make them in a wonderful situation like the group we had.

Women who participated in the focus groups also emphasized the feelings of affirmation and connection that often develop in such contexts. They also expressed a need to form connections with women who have similar life trajectories. In response to a question of how the well-being of women with disabilities who do not have children can be enhanced, one participant emphasized the importance of forming connections with other women without children. Another participant noted the happiness she felt when she met another woman at the conference who, like herself, is not considering motherhood:

I was so happy when Michelle last night said to me ‘Oh, well, I don’t have any children and I’m not planning on it.’ It seems like everybody I was talking to was having children, or decided to have children...so it was just good to learn that there was somebody else that felt the same way.

It’s important to note that a number of women without children came to the conference in order to support friends who are either mothers or who are seriously contemplating motherhood. The expressed need for connections with other childless women need not come at the expense of
relationships with women who have chosen motherhood. One woman who participated in the conference on mothering and women with disabilities summarized her impressions:

For so long there has been such a need for something like that...I really think it’s important to have that kind of a forum for people...I met some really amazing women at that conference and the exchange...I mean, whether I decide to have a child or not, that was really important for me...it was really important to be there...I went there mainly to support my friends (one a mother, the other who wanted to be), and I ended up getting a lot more out of it than I thought I would.

Working the Hyphen...

In the methodology chapter I discussed the importance of “listening to the data” and being open to surprises. My own ability to listen to the data and contend with unexpected directions was put to the test as I considered the stories of participants about their lives and meaning-making as women without children. Guided by my own experiences and priorities and by some of the literature I was reading, I expected to find a greater aspiration for motherhood among childless participants. Wishing to overcome invalidating messages about sexuality and motherhood, I theorized a greater need to carry out traditional female roles. The theme of being “normal,” being like other women, and being seen as capable of caring for others, can be found in the literature on women with disabilities and motherhood. Although I in no way suggest that the quest for children is predominantly fuelled by the social prescription of motherhood, its role in shaping the lives and identities of women cannot be ignored. Contrary to my expectations, most participants who are still weighing their reproductive options noted that becoming a mother is not at the top of their priority list. Some indicated that it played a greater role in their younger days. However, analyzing
their lives from within a feminist lens enabled them to reflect critically on these issues. One interview participant expressed a clear wish to become a mother. This, however, did not prevent her from envisioning a fulfilling and satisfying life for herself as a woman without children. Another participant noted that the expectation that she would not become a mother has in fact been instrumental in building her identity as a childless woman. Regardless of the decision they will ultimately make, these women were highly successful at forming a female identity apart from motherhood.

Study participants were passionate about their right to make choices and the need for these choices to be recognized and respected. Interestingly, no connection was made between the lack of adequate resources and supports on the one hand, and the ability to choose motherhood on the other hand. Although participants articulated a number of challenges and barriers that they would likely come across as mothers, they did not, for the most part, acknowledge that these barriers may in fact limit their choices or even make motherhood altogether unfeasible. Making such an explicit connection may be counter-indicated with the need to feel in control of one’s life and destiny, especially for those who have had to fight for self-determination. This idea gains further credence from the focus group “Not Every Woman Is a Mother”. As I read the transcription of this focus group, I noticed that a number of participants made a point of emphasizing that it was their independent choice to remain childless. From the discussion that ensued, however, it was clear that there were in fact a number of barriers and impediments that at best constricted these choices. Possibly, talking about how barriers constrict choices at the personal level would be an acknowledgement of the limits to self-determination. A history of having one’s self-determination denied or undermined may in fact precipitate a need to feel and
present an inflated sense of control. Ironically, this could be counter-productive if it shifts attention away from providing resources and supports that could enhance choices. The importance of attitudinal changes notwithstanding, they cannot replace the need for more equitable policies and increased resources that would truly enhance choice and self-determination.
VI

ANALYSIS AND PRESENTATION OF DATA:

PART III — MOTHERHOOD IN THE CONTEXT OF A PHYSICAL DISABILITY

In this chapter I focus on the experiences and life stories of mothers with disabilities. The main data source for this chapter are sixteen in-depth interviews (with eight participants) who have children ranging from infancy to adulthood. Almost all are mothers with young and school aged children. Information from two focus group discussions, one for disabled mothers with young children, the other for disabled mothers with older children, are also incorporated in the data.

I consider this to be my main data chapter as it directly relates to mothering experiences. In interviews and focus groups, participants shared a host of issues and experiences relating to mothering children at different phases of development. I heard rich, fascinating, and at times painful life stories relating to different facets of mothering. Knowing that the full breadth and depth of experiences cannot be presented in a dissertation chapter, I divided and analysed the data from different angles in my attempt to represent it as fully as possible. My attempt to remain close to the data is reflected in my liberal use of mothers’ voices. Having said that, I recognize and acknowledge my role as the weaver of events, life stories, and meaning-making. The headings and sub-headings which frame the data are based on what I consider to be the salient themes. Slicing the data from different angles and coming up with similar themes served to increase my confidence in the trustworthiness of its presentation. Notwithstanding my sense that the themes are dictated by, and almost “leap out” of the data, I am fully aware of the major role that I play as its editor, organizer, and interpreter.
An example of my role as editor and organizer is my decision to present one developmental phase (infancy) in an otherwise theme-based approach to the data. While this runs contrary to my affinity for neatness and consistency of style, my sense that this was a better reflection of the data prevailed. The issues related to the initial stages of mothering are unique and require a separate discussion. On the other hand, framing the rest of the data within a developmental perspective would be compromising theoretical links in favour of consistency.

The first major section deals with pregnancy, childbirth, and the initial stage of mothering. I then describe division of labour within families and the use of informal supports. The next section titled “A Ramp to Mothering” focuses on formal resources and supports for mothers with disabilities. I conclude the chapter by presenting the challenges of promoting children’s growth and well-being. Throughout the sections I highlight the lived experience of mothering with a disability with its concomitant highs and lows, joys and tribulations.

The Very Beginning

Great Expectations: Reactions, Perceptions, and Experiences

Study participants discussed their own reactions to their pregnancies as well as those of family members, friends, and health-care professionals. One participant who was told for years that she would not become a mother, described the sense of elation she felt throughout her pregnancy.

I was so thrilled...I never thought that I would have it. I was really excited to be pregnant and my husband was so supportive...food nauseated me, I hated cooking...he was always there making something to eat, saying ‘this baby is yours as much as mine and you’re going to have to eat properly’...he was there coaching me through my childbirth
classes...we were just thrilled, and his family and my family were both thrilled.

For this participant, discouraging messages about mothering resulted from her parents' belief that she would unlikely be successful in the social-sexual arena. On the other hand, her pregnancy did not present a risk factor as far as her disability goes, nor was the disability expected to hinder her ability to perform child-care duties. As stated above, her parents were delighted when she got married and similarly pleased when they heard about her pregnancy.

Another participant who conceived very easily described a sense of satisfaction that this part of her anatomy functioned so well:

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.

Two participants, who had unexpectedly found themselves pregnant, had very different initial reactions to their pregnancies. One knew from the outset that she wished to continue with the pregnancy; her goal became one of gathering information about the possible interaction between the pregnancy and the disability and working to ensure a smooth transition to motherhood. The other participant led a care-free life prior to her pregnancy and had no desire to become a mother. Although she was initially upset when she learned about her pregnancy, this feeling was soon replaced with a strong bond to her unborn child and a likewise strong conviction to continue the pregnancy and keep her baby. She was told that her unborn baby may be at risk due to medication she was taking before she learned about the pregnancy. Given her initial negative reaction, coupled with the perceived risk to the fetus, several health-care professionals suggested that the pregnancy be terminated:
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...maybe 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...I was on this medication and there was a strong possibility that something would be wrong with him (due to the medication) so I guess they thought that maybe if he was born with some kind of disability maybe I wouldn’t want him and I’d be thinking: ‘My God, I wish I had that abortion’...But...I don’t know about you, but I loved him from the start...He’s my baby, if something’s wrong with him, I’ll deal with it...What really bugged me was that sometimes the same nurse would say it again to me you know, and finally I had to be sort of like a bitch you know, make it clear to them that I’m not going to give up my kid.

The pressure placed on this disabled woman to abort her possibly disabled fetus should be considered within the context of the eugenic ideology discussed in the literature review. As an unmarried woman with a physical disability, health-care professionals may have questioned her ability to care for an infant. As the carrier of a fetus at risk for birth defects, they may have questioned her desire or perhaps even her right to produce another “defective” individual. Her initial reaction to the pregnancy may have provided the legitimization for continuing to broach the subject with her. It seems highly unlikely that a non-disabled woman with a low risk pregnancy would be subjected to on-going suggestions that her pregnancy be terminated. Rather, the anti-disability sentiments that often underlie prenatal testing and selective abortions were probably at play in this case. According to these sentiments, no life at all is perceived to be better than life with a disability.
This mother-to-be hoped that her child will not have a disability and did her best to take care of herself throughout her pregnancy. This included staying clean of drugs and alcohol, habits that she found difficult to kick in the past: “I was thinking ‘this kid has enough strikes against him already’, and I did stop, as soon as I found out about the pregnancy.” At the same time, she felt strongly about having and loving her child, irrespective of disability status. Another participant who has a hereditary disability, declined her physician’s suggestion that she undergo amniocentesis. She indicated that she was totally open to having a child with a disability:

From my point of view if my kids inherited my disability, it wouldn’t be an issue for me...because I have a disability, having a child take after me is sort of like being a musician and having a child take after you with their musical abilities...I think I’m the only human being in the continent that feels that way.

In response to my surprised reaction and further probing on this issue, she discussed the many contributions that people with disabilities have brought to our society. Although she agreed that living with a disability may indeed be harder than living without a disability, she emphasized attitudinal and physical barriers as the true culprits:

My kids have said to me ‘mommy, aren’t you upset if you go somewhere and it’s not accessible and you can’t go there? Don’t you wish you could walk?’ And I would say ‘no, I wish they had a ramp’...that’s my perspective...it’s the environment that’s making it inaccessible not the disability that’s making it inaccessible.

As this participant indicated, she is most certainly in the minority with respect to her views on this issue. While people with disabilities generally perceive themselves to be living meaningful and productive lives, most would probably prefer to have a child without a disability. At the same
time, it is imperative that such views be included in the discourse on prenatal testing and selective abortions.

Participants also described the reactions of others to their announced pregnancies. Several indicated that concern was a typical response by close family members. One woman noted that her mother’s subtle messages were that she has a lot on her plate already and should not take on motherhood. As a result, “I didn’t tell her I was pregnant until I was so sick that I didn’t want to hide it from her...and she was really worried.” The participant quoted above described a range of reactions, ranging from thrill and excitement by her co-workers, to nervousness and concern by family and friends, to clear dissatisfaction on the part of the personal attendants she worked with at the time. Her family and friends were mainly concerned about the impact of the pregnancy on her health, whereas the attendants were not used to dealing with her as married, pregnant woman. Contrary to the range of responses in reaction to her first pregnancy, she got consistently positive responses when she announced her second pregnancy. By that time she had moved to another residence with a more open and receptive staff:

By the time I was having the second one the staff were all excited about it, they thought this was great. A lot of them had kids of their own as well. My family had already been through it the first time and knew I was going to live so they were OK...they had also seen that Geoff stuck around for the first one so they weren’t...because I think that was another fear. They weren’t sure if he would stick around... ‘there’s no way a man’s going to stick around to change a diaper...he’ll be out of there.’ But they just didn’t know Geoff and stick around he has.

Study participants had varied and diverse experiences in their dealings with the health care
system during the course of their pregnancies. A theme that came up in several interviews, and one which can also be found in the literature, is the shortcoming of the health-care system in dealing with the dual factors of pregnancy and disability. One participant was hospitalized during her pregnancy for a non-pregnancy related health issue. When her blood pressure became highly elevated, the medical team did not entertain the possibility that it was pregnancy related and planned to release her from the hospital. When she persisted to express a concern about this, a blood sample was taken and she was diagnosed as having toxaemia and immediately transferred to the maternity ward. Her son was born several days later, a month before his due date. One wonders if the tendency to see people with disabilities in “sick” roles results in obliviousness to the other roles they may play in life, in this case a woman in advanced stages of pregnancy.

Whereas this woman’s pregnancy was overlooked as she was treated for something else, two other participants had the antithetical experience of having their disability ignored or under emphasized. One woman was very uncomfortable with her General Practitioner’s casual attitude towards the possible implications of her pregnancy. Although he had no direct experience or even knowledge about pregnancy and childbirth for women with her type of disability, he did not consider her to be at risk or feel that any special measures needed to be taken. She subsequently switched to another physician who was responsive to both her disability and her pregnancy and to the possible interaction between them. Another participant, who is now the mother of five adult children, related her experience with the health-care system during her first pregnancy:

I had no experience and I got pregnant right away...the pregnancy was difficult...I don’t know why, but the doctors didn’t hone into my (disability). They should have...they should have really honed into it...they should have put me on some kind of a diet because I
just blew up like a balloon and darn near had her at six months...she did come early but they gave me something and it stopped it then...I went into the hospital and they gave me needles and it stopped her from coming...but they never even looked into my disability or anything, they just looked into the pregnancy. Other doctors after that did the same thing (in subsequent pregnancies) and of course I thought you know, the disability, maybe it doesn’t matter...but boy did it matter...by the time I had the fourth child I had trouble standing...and the pain was unbearable.

Although she walked with a marked limp, the disability was not probed or considered by the physicians who treated this woman. Being very young and inexperienced at the time, she was characteristically passive and compliant in her interaction with physicians, neither questioning nor suggesting that anything else be considered or explored.

Another participant made a promise to herself after her first pregnancy, that she would do whatever she could in order to retain more control in the future. However, as she found out during her second pregnancy, this is easier said than done:

It’s not that easy...I had a meeting with the anaesthetist when I was about three and a half months pregnant...I didn’t like her right from the beginning...it was just one of these clashes of wills...she was saying that I would have to have an epidural...and I wanted to know if I could have one where I could continue to move around... ‘Why would you want to do that?’ ‘Because I want to do that’...but it wasn’t like she was prepared to discuss this with me...and it’s so frustrating...when the health-care professional doesn’t want to discuss it with you...like they’re not going to tell you why you can or can’t do that... so even though I said that I wouldn’t give up control again, it’s not so easy to do.
It is important to indicate that some of the experiences of study participants in their contacts with the health care system are not dissimilar to those of non-disabled women. Women have traditionally been alienated from the process of pregnancy and childbirth, which used to be seen as the exclusive domain of physicians. Women with disabilities, however, are likely to have more frequent contacts with the health care system over the course of their pregnancies, a system which has traditionally compartmentalized and labelled them as deviating from the norm. Furthermore, 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.

In the current study, a number of women indicated the lengths they had to go to in order to access the information they needed. Fortunately, some dealt with respectful and supportive physicians who did their best to answer questions as well as enhance their own knowledge. The woman who was uncomfortable with her primary physician's blasé attitude about the implications of her pregnancy managed to find an obstetrician with some practical experience and a willingness to learn from other physicians. As I indicated in the literature review, the traditional silence on reproductive issues for women with disabilities is being increasingly disturbed with the burgeoning of recent publications in the field. Hopefully, this will also be reflected in more positive pregnancy experiences for women with disabilities.

A Baby is Born

Several participants discussed the experience of giving birth as well as their stay on the maternity ward. One woman had to convince the staff in the delivery room that she was about to
give birth; she was told that she could not possibly be feeling the labour pains she reported given
the level of her injury. This further attests to the privileged status typically afforded to medical
diagnosis over a woman’s experience of her own body. Another participant recounted her
experiences in the hospital with the birth of her first baby:

Every shift there was a new nurse and I was grilled as to how I was going to bath my
baby, how I was going to take care of her... every single shift, a new nurse would ask me
how I would manage... they grilled me, like ‘how are you going to bathe, have you thought
about that?’ ‘Yes, I’m going to get in the bathtub with this baby and I’ll put her between
my legs and I’ll bath her.’

Fortunately, her unpleasant experiences were balanced with more positive ones. She singled out
one nurse who was most supportive in helping her to overcome breastfeeding problems:

She was working alone that night, although it may have been two of them in the
ward... she took the time, she got all the pillows propped up and she set the baby down
where I could nurse her, and she said ‘you tell me when you’re ready for the other
side’... she was just wonderful.

Nurses on the maternity ward were noted by another participant for their attempts to facilitate her
breastfeeding with different aides and devices. A third participant who gave birth less than a year
ago also recounted a positive hospital experience all around. She was told by a hospital social
worker that parenting with a disability is becoming more and more common and felt a genuine
interest on the part of the social worker to become more knowledgeable about this topic. Her
obstetrician gave her delivery choices:

I was thinking that maybe I can push the baby, that was a big thing for me throughout my
pregnancy...the doctor said, ‘it’s your decision, I’ll support you with whatever decision you make...you can try to push...we really have no way of knowing what strength you have.’

Her appreciation for the physician’s flexibility and support notwithstanding, this participant indicated that it would have been great to have access to information about the birthing experience of another woman with a similar disability. Given the current interest in parenting and reproductive issues for persons with disabilities, it is hoped that women and their doctors will have more resources to draw upon in the near future.

Contrary to some of the experiences reported above, one participant had a generally negative hospital experience:

Well I don’t remember much...I just remember them constantly coming in...people from the hospital’s social service department...and I was feeling really bad...this was before and after the birth...and I guess it must have been the toxaemia but I had also attributed it to the steroids...I just felt icky and headachy and lethargic...not really in control...I felt they were sort of undermining me by coming...I don’t remember much of it because I was feeling so out of it, I just remember this feeling of real intrusion, you know, and even when I’d be like trying to nap they’d come in and ask me questions...it felt very very nosey.

This participant is a highly articulate professional woman who usually has very strong self presentation. Being as ill as she was at that time did not allow her to make use of the internal resources that are typically at her disposal:

I was really sick, I hadn’t washed my hair for days...you know, those little things that you
do to make yourself respectable... I was tired and swollen and had a really bad headache... so I imagine that they took one look at me... and put me in that 'box' (of not coping well).

Having recently given birth to her second child, this participant had a very positive experience this time around. She did not suffer from any complications and was able to negotiate her stay in the hospital without any hurdles. It is quite possible that her ability to present herself as a competent and responsible adult was somewhat compromised during her first pregnancy due to the effects of severe toxaemia. Although hospital personnel is probably accustomed to the side effects of toxaemia, they may have been overly vigilant given that this new mother was also physically disabled.

Most of the participants indicated the great care that they took to plan and organize for the baby’s arrival. From renting equipment that would facilitate their own care in the hospital, to devising a baby bassinet that they could access more readily than the one provided in the hospital, to ensuring that supports would be in place once they arrive home, few stones were left unturned. Hospital staff may feel quite confident discharging a disabled mother who is so well “put together.” However, a different dynamic may operate when, in addition to her disability, the new mother does not present as a model of efficiency and competence. In such a situation, a woman may be scrutinized to a much greater extent than a non-disabled woman with a similar presentation. The participant quoted above referred to a recent case in Ontario where hospital officials called Children’s Aide following the birth of a baby to a blind couple:

I really felt for that blind couple... her transgression apparently was that she had trouble breast feeding... everybody has trouble breast feeding... and she pushed the baby away and
said 'take her away' or something like that. And this was interpreted by the hospital staff as a mother who can’t cope... the hospital called CAS who basically set conditions for the parents to be able to take their baby home.

Emphasizing that the newspaper covering of the story may not be accurate, this participant made the point, none the less, that parents with disabilities may be subjected to a much greater degree of scrutiny than their non-disabled counterparts.

**Bringing Baby Home**

Bringing a newborn baby home from the hospital typically involves major adjustments in routines and priorities for the family. Further adjustments and accommodations often need to be made when the new parent also has a physical disability. A number of participants talked about their early parenting experiences, emphasizing the negotiation of roles within the family, the formal supports that they utilized, as well as their internal experiences as mothers of newborns.

The participant who felt undermined in the hospital by constant visits from social service personnel, also felt intruded upon when she returned home:

Somehow through one of these visits they set up a therapist to come visit me at home. She was just awful... she would come in and she would have no suggestions that were of any assistance to me about how I was going to cope with this baby that I didn’t really have time to plan for (due to an earlier hospitalization), you know, I hadn’t thought about devises or anything like that. She had no imagination at all in terms of equipment or assistive devices. I had really bad postpartum anxiety, I was really hyper anxious... the baby was losing weight, my milk supply was down and it was one of these self-cycling things... I thought that I can’t protect him and stuff like that... you know, I think many new mothers
go through that in varying degrees...and here I am under the magnifying glass of this person. She’d sit there and attempt to suggest really useless things to me about what I could do to cope and then she’d say, ‘Oh I didn’t feel anything like that with my two children. I was just as happy as a clam’ sort of thing...I just hated having her around. It’d be a whole hour and I can remember sitting there and hearing the clock tick while she was there.

This new mother felt that she had no choice but to endure these visits if she were to continue getting home-care assistance several times per week. As far as she was concerned, the visiting therapist was a gatekeeper to needed services, and as such, she had to put up with the visits. She also noted that some of the home-makers who came in to clean the house attempted to engage her in unwanted conversations:

What I wanted home care for was to clean the house and that sort of thing, but some of the home care people felt that their job was really to come in and talk to me and keep me company. And it’s like no, I don’t need to be kept company...I don’t need somebody I barely know coming in and talking to me...I want you to make my life easier for me, I don’t need the social interaction.

This mother was clearly in need of instrumental support versus social-emotional support. She had a wide network of friends and probably wished for uninterrupted time with her new baby. The workers’ attempts to engage her in conversations was thus perceived as an imposition.

Another participant experienced a sense of relief when she took her baby home from the hospital:

I had trouble breast-feeding him at first...and in the hospital, I was getting different advice
from all these different nurses...one would tell me one thing and then the other nurse
would say ‘I can’t believe she told you that, that’s not good’...they were all giving me
different things...finally I just told them all to go away and I thought ‘OK I’ll just deal with
it...so me and him figured it out ourselves.

Going home allowed her the time and the space to get to know her baby and find a method that
would work for them both. Having her mother there for the first little while gave her the
confidence she needed to later proceed on her own. Although this participant is close to her
mother and appreciated the help she got from her, she was also relieved when her mother left
several weeks after the baby was born. She was especially pleased with her mother’s comment
that she was leaving sooner than expected given the daughter’s ability to handle her new born
baby.

Several participants described the various adaptations they made, either to equipment or
to procedures, in order to be able to care for their babies. One participant noted that her babies
also learned to adapt to her:

When I would pick them up I would use my right side a lot and they’d lean on my right
side. And then as babies they almost automatically knew to reach for my right side, they
would tend to lean in that direction.

Two other participants experimented with different methods of lifting their infants, noting that
their children didn’t mind being lifted in non-conventional methods:

I had to get him out of his stroller one day and I just grabbed his sleeper and picked him
up...I just picked him up a little bit because he was wearing a diaper so it wasn’t like it was
hurting him...so I lifted him up just a little bit to see if he’d whine but he didn’t complain,
so I thought OK, he’s fine...I lifted him a little bit higher and he was still fine, so finally I just picked him up and he just gave me a dirty look because I woke him up when I did it.

But he was fine.

This new mother learned an alternatively safe and comfortable way of lifting her infant. The quote reflects the gentle and gradual manner with which she undertook this “experiment,” checking the baby’s safety and comfort every step of the way. Another participant, who also found it easier to lift her child by his clothes, discovered that dressing her baby in sturdy overalls allowed her to continue to lift him in this fashion beyond infancy.

Having described various accommodations to conventional practices, I find it important to emphasize that not all disabled mothers can simply find alternative methods of caring for their infants unassisted. One participant described the frustration she felt over her inability to hold her infant or care for her without assistance:

I never really felt disabled until I had a kid...because there are times you want to go in the middle of the night and pick them up and you can’t...and that’s the first time it would hit me square between the eyes like hey, you’ve got limits here, there are things that you just can’t do...when you’ve got a little kid howling for something and you literally can’t do it and (husband) has gone down to the store for milk and you know there’s nothing you can do... ‘the baby’s napping, I’m just going to go for a few minutes, I won’t be long’...and of course the minute he’d be gone she’d wake up and you know you can’t do anything...you know she’s OK, she just wants some comfort...and she probably thought ‘Hey, you’re there, why aren’t you doing anything’...nothing helps in these situations, you really have to grit your teeth and bare it...I’d just try to sit by her or play with her and distract her...if
there was anybody I could call I would call them.

Recognizing her inability to meet her daughter’s physical needs, this mother ensured that other people were available to look after the baby. The situation described above, as frustrating as it may be, spanned no more than several minutes. By having other people around to carry out childcare duties, this mother ensured that her infant never had to wait long to have her needs met.

Since the birth of their first child, her husband has been the main care provider while she has been the main breadwinner. When her daughter was still an infant, she also secured funding for what she coined as a nurturing assistant; someone who would work under her direction in order to facilitate her mothering. She described how the nurturing assistant helped her interact with her infant:

It took a little bit of figuring out, it has to be a person who understands that they are just an intermediary facilitator, the way a language interpreter would be...the first person we had, she was very sharp...she really understood what it was that I was trying to do...She’d pick up the baby’s rattle for example, and shake it, and as soon as the baby’s attention was on the rattle, she’d pass it to me...so immediately the baby would shift her focus on me, and then she (the facilitator) was out of the picture.

The role of the nurturing assistant, as this woman perceived it, is to be a help in the background rather than to actively interact with the baby. She noted that in some cases that she is aware of, assistants perceived their role as providing direct nurturance to the baby:

I know some people have had trouble where the (assistant) would come in and kiss the baby, and hug the baby, and play...and it’s like, ‘no, no, no. You’re here so that I can do that. The first thing you should do when you come in the door is pick up the baby and give
the baby to me so that I can give them the big kiss because you're here, not you give them the big kiss because you're here'...you know, it's a very fine line.

Given that the nurturing assistant was only funded for a limited number of hours per week, it was important for this mother that the time be spent on helping her build a relationship with her baby.

Another participant also requires considerable assistance with child-care duties. Although she does not need attendant services for her own self care, she is virtually unable to independently care for an infant. As I indicated earlier in the dissertation, receiving funding for a nurturing assistant can be a lot more difficult under such circumstances. This woman relies on an informal support network consisting mainly of her husband and her mother. Living in the same house with her mother, she and her husband enjoy a great deal of help with child care. In the next section which focuses exclusively on informal supports, I will amplify further on the assistance that this participant receives from her mother. For the present discussion, it is interesting to consider her attitude towards the relationship between her mother and her son:

I remember his first doctor's appointment, I said to the doctor: 'She (grandmother) is like his mom, and I am also his mom...and when we had to hospitalize him once they said that parents only are allowed and I said 'O.K. well, that's one, two, three'... I said 'my mother is like a mother to him and I am his mom and this is his father and that's the way it is...and they (hospital staff) didn't question that at all. And I also said 'I have a disability,' and I explained to them, 'my mother takes care of him, and she doesn't just take care of him like when somebody looks after somebody's child...even if I'm there she still does a lot of things.' And they (hospital staff) totally understood. They didn't cause any problems at all.

This participant's flexible and inclusive use of the term "mother" is particularly interesting within a
societal context that places a heavy emphasis on clear boundaries and nuclear families. I am reminded of my own surprised reaction when a visitor from New Zealand told me that the children of some of her Maori friends also refer to her as “mother.” Although never bearing children of her own, she is rather involved in the raising of other children. The participant quoted above also described a situation whereby her own mothering is not threatened by her mother’s intense involvement with her infant son. Expanding societal notions of what constitutes acceptable and appropriate family constellations can be conducive to families like the one described above. This will be further discussed in the next section which deals with informal supportive networks.

**Negotiating Roles Within the Family: Informal Support Systems**

The word family usually conjures images of loving bonds, common goals, nurturance, and support. Another aspect of family life which tends to receive less attention is the massive amount of work involved in meeting the needs of its members. In this section I focus on the division of labour within families and the use of informal supportive networks by mothers with disabilities. I describe participants’ accounts of varying degrees of familial support, ranging from substantial support to insufficient or non-existent support.

**Division of Labour and Availability of Family Support**

The participant quoted earlier amplified on the division of labour within her family, which includes regular and consistent help from her mother and some help from her sister who also lives with them. She described a typical morning at her home:

The three of us (herself, husband and infant son) all sleep in the same room. It’s a pretty big room...he’s got his crib in the corner. Sometimes the baby wakes up before me and wakes me up...Danny will pick him up and bring him to the bed where I change his diaper.
and get ready for work. My mother, because she lives at home, she’ll hear me around and she’ll knock on the door and she’ll pick him up.

Help is also available in the evening as she is preparing dinner for herself and her husband. When I inquired if it is not difficult for her to make dinner, she explained:

It would be difficult if it would be just me by myself. Because my mom’s there, somebody is available all the time. So if I’m making dinner I’ll just leave him with somebody because my sister also lives at home...somebody will be watching him or they’ll bring him down for me and put him in the high chair and I’ll talk to him while I’m cooking. That works out...I don’t know how I could do it without that, you know.

This mother also emphasized that having someone bring the baby to her allows her to carry out tasks such as changing the baby’s diaper, something that she enjoys doing herself. The division of labour within their family means that her husband gives the baby his baths and attends to him when he wakes up at night. Despite the input by all family members, she singled out her mother whose constant presence and support is a testament to her dedication. She further stated that although her husband is appreciative of the help they’re getting, she wonders at times if he is really aware of all the work that her mother does.

I think he realizes that. But because he’s never experienced not having my mom in the house I sometimes wonder if he knows how much help we’re really getting, you know. Because I say to him, ‘you know, if my mother wasn’t there it’d be a totally different situation. And he says ‘I know, I know’...but like I think that I think about it a bit more than he does.

Another participant whose parents live in another city, described how wonderful it was for
her when she took her infant son to visit her parents:

I didn’t do anything. My mother would take care of him and she’d feed him his pablum in the morning. When he was hungry (for breast feeding) they would give him to me. It was like I could have a vacation from him but didn’t have to be away from him. It was perfect.

During our third interview, this participant was eagerly awaiting her mother’s visit, indicating how it will allow her time to get things done. She jokingly commented on her mother’s attempt to spend as much time as possible with the baby:

She warned me in advance, she said ‘I’m just going to totally monopolize your kid when I’m here’...and that’s good...I have a lot of stuff to do, I’m really behind. Now that he’s bigger, it’s really difficult because I have to plan everything to the point of having to plan when I can go pee. When my mom will be here it’ll be fun because I get to spend time with him still but she’ll do everything...I know she will.

It is interesting to note that although this woman is no longer romantically involved with the baby’s non-disabled father, he co-habits with them and is reportedly involved in the baby’s care. Despite the high level of tension between them which results in frequent fighting, she considers him to be a good father. Several references were made to the father’s involvement in his son’s care; however, it is clearly not as helpful for this woman as what her mother does during her visits.

Whereas the participants quoted above receive help from their mothers, a third participant spoke fondly of her committed mother in law and sister in law, both of whom live in the same apartment building. In this particular case, the father is the main care provider for the children while the disabled mother works outside of the home. The family also has funded nurturing
assistance which allows the mother to spend time with her children and carry out tasks that she would be unable to perform on her own. Despite this, she is highly appreciative of the informal supportive network that she has:

They (mother and sister in law) have been super in helping and being around...Whatever they can do. There have been times when one lives out of town or one is busy with work, or whatever, but when they’re around they’re like 110%...When (husband) first started working on Saturdays they (kids) were still young and there would be times when someone would want juice and there wouldn’t be juice. I had a booking, an attendant would be coming to help me with lunch at 12:00 so at 12:00 I could make them juice, but not at 11:00 when they were screaming about it...It’s like ‘do you think you could wait an hour?’ and they’d say ‘no’, and I’d say ‘well you know, let me call grandma. If grandma’s there then you can have juice. Otherwise you’re just going to have to wait’...and she would trot right up and do it.

The father being the main care provider in addition to the support of the nurturing assistant means that this family does not depend on informal supports for the day to day functioning of the family. Nonetheless, it is reassuring and affirming to know that this familial network is willing and able to help when the need arises.

All of the participants quoted thus far, in addition to several others, discussed the sharing of family responsibilities between themselves and their spouses. One participant noted:

Phil has always done...not the bulk of child care, but certainly child entertaining. Like he’s much better at playing blocks with him and lego and all those things. Like he’ll do that for hours whereas I get really bored after a while. So they spend more time together.
This trend is beginning to change somewhat as this participant’s son is getting older and is beginning to enjoy card games and other activities that require thinking and concentration. These are the types of activities that she enjoys doing with him. In this case, the division of roles in terms of child entertainment are based more on personal preferences. The dedication of this father notwithstanding, this woman noted that it is she, rather than her husband, who carries the bulk of the domestic responsibilities.

Another participant commented on the disparity between her current family situation where work is shared between herself and her husband, and the culture in which she was raised where women did all of the care taking.

My husband spends so much time with the kids...like they are involved in hockey and baseball and their dad is always there with them. It’s really nice to see, where in my culture it isn’t something that men would do. Men didn’t change diapers, men didn’t make meals. It was the woman’s job. It could be that from that perception... I may not have been able to cope with the standards of motherhood of that particular culture.

She spoke with great fondness about her husband’s commitment to the family and the sharing of duties at home, noting that “the disability in some ways has allowed for more equality to take place in our relationship.” However, when I asked for a more detailed breakdown, it appeared that she still carries out a larger portion of the work.

I can’t do the laundry very easily so the kids have seen that their dad’s done that. That’s their dad’s job. I still do the cleaning and...you know, I like to garden and he doesn’t like that or I like to paint so I would paint...but John has been very good with some of the nurturing...he is very patient...he’s got a very soft, nurturing way with the kids.
During our second interview, this participant also commented that when the basement was a mess and needed to be cleaned, it was she, rather than her husband, who took a day off work and worked along with a cleaning lady to get the job done.

I take that kind of responsibility. If it’s upside down, I feel sick, you know. My husband can walk away from it...When it’s not done it makes me sick because it’s a reflection on me.

This mother is training her own sons to carry out chores and duties that in her cultural background would be considered inappropriate for males.

The topic of role division and sharing of responsibilities came up in another interview. The participant, a mother of two teenagers, described the things that she does for her family.

My life revolves around my family, mostly the kids. Having two teenagers gives me a lot to think about. I don’t go grocery shopping anymore but I still do the shopping list because I do all the cooking...Craig still likes that whole idea that I can still get dinner ready. You know, he doesn’t have to do that when he gets home. I mainly keep track of the kids because I have the time...I have all day to worry about them. I also write all the cheques — that’s what I did yesterday -- and I pay the bills. It doesn’t sound like much but it takes me a while. Having people over is not a regular occurrence because it tires me out...I (conserve my energy) so I can make dinner at night and sort of be half awake when the kids get home. It’s mostly my family that I’m dealing with.

Fatigue is a major issue for this participant. She performs tasks at a slow pace and requires rest periods throughout the day. Despite the effects of the fatigue, she clearly prefers to perform some of the household tasks herself:
Sometimes I get asked, 'Why do you do that?' Why don’t you have the kids do that and then you will have energy to do something else that you want to do instead of doing the cooking’...Robin (a neighbour), I am sure she can see me sitting at the sink peeling potatoes thinking: Why doesn’t Jodi (daughter) do that? Robin, she’s often said, ‘the kids really don’t help you much, do they?’ But there are a lot of things I don’t mind doing...I mean I can sit there and peel potatoes, you know, I look at it as something I can still do.

When my hands start shaking then I won’t be able to do it any more

Carrying out certain tasks provides this woman with a sense of productivity and usefulness. She also emphasized the many things that her husband does for the family, noting that she would probably be in a far worse physical shape if it wasn’t for his help. She believes that unlike her husband, many men would not stand by a wife with a disability: “when I think of a lot of men I know, they’d just say ‘bye bye, see you...’ and just leave.”

Insufficient or Lack of Informal Support

The experiences presented above reflect varying levels of informal supports for mothers with disabilities. Rather than being a dichotomous construct, informal support lies on a continuum, with some having more than others at different phases of their lives. In this section I present the voices of participants who fall on the low end of the continuum as far as informal supportive networks are concerned. I first present situations where supportive networks were either totally absent or minimal and far outstripped by the number of stressors. Reference will also be made to situations where some needs are met by informal supports while others are neglected.

One participant described a particularly difficult time in her life after the birth of her
youngest child when her yet undiagnosed illness was playing havoc with her body:

I had two babies 18 months apart and I didn’t have supports. Our families thought that I just couldn’t handle it. What did I do this for? It’s my own fault kind of thing. Why did I have these 2 children so close together? My husband pulled away, not knowing how to deal with it himself. Nobody worked together...and it just tore us apart.

She noted a sense of relief following her diagnosis, as it provided a framework and a context for some of the things she was experiencing. The diagnosis did not, however, result in the mobilization of informal supports:

To me it (the diagnosis) came as a relief. To everyone else it was like ‘Oh, my goodness, we should have recognized that maybe something was going on here...we really feel bad about it...’ and they still pulled away. I’m talking about existing friends at that time and family from both sides. I would ask for help but there was very little that was given...I did ask and it didn’t make a difference. When there’s such an overwhelming amount of work, one little thing doesn’t make a big difference but it does help.

This woman’s newly diagnosed disability, coupled with the health problems of her new born infant, precipitated the breakdown of her marriage:

As it progressed (the disability), it very definitely was a factor. All these things (stressors) kept piling up and piling up, and more and more responsibilities were being demanded of both of us. I was going down hill, and he wasn’t understanding any of it...nor could he cope with my being labelled with the illness, nor could he cope with the youngest having so many problems. So you see, all those things are just so intertwined...it’s enormously overwhelming, the whole picture...not having supports in place, not knowing what this
other world is like from the other side of the fence, you know.

When this participant realized that she had done all she could to mobilize her informal support system, she turned her attention on identifying and utilizing formal supports. This will be further described in the following section.

Another participant who is now the mother of adult children had to be hospitalized for extended periods of time when her children were young. She reflected on some of the hardships she encountered as she tried to raise her children almost single handedly:

He was a very hard man to live with, he wasn't any help. Whenever I was ill or had to go to the hospital he would run. When I was pregnant and I needed him to be around he would run. He was always running when there was something wrong like an illness.

She described the difficulties associated with having a disability and trying to care for five young children:

I was so worn out...it was so difficult because (even when he was home) he was not much of a help...and I had all these little kids...I had to bathe them, put them to bed. He was out in the back yard with the guys fooling around with cars instead of being a father where he'd be in there helping me. He wasn't that type of a father.

This young mother knew that her husband could not be trusted with the children and that the full responsibility for their health and well being rested with her. She described the very painful decision she had to make shortly after the birth of her youngest son:

When he was 6 months old I think they did the surgery and it was like hell...it was really bad...the surgery didn't turn out. I was laid up...it made me more disabled than I had ever been. It was really a hardship and my husband was like no help at all. And then I realized
that if I was going to go to Toronto to have surgery to correct what that doctor did
there’s no way I could leave those kids with my husband. Anyway it boiled down to that I
couldn’t leave them with him, God knows what would have happened to them. So when I
had to go into the hospital I had to make a big decision. I called the Children’s Aid
because I was always told that they’re to help you. Well, I called them and they took the
children into care while I was in the hospital because I was there sometimes 6 to 8 months
(at a time). My kids spent practically their whole childhood going in and out of the
Children’s Aid.

This young disabled mother of five felt that she had no other option but to put her children into
care. I asked her where her extended family was in all of this:

They (sisters) were all busy with their own families. Mind you, my mother did take my
daughter when she was younger. But my mother was in her 60's and 70's so she couldn’t
take all the kids. She tried my son once but he was too much for her. I can understand...5
kids are a lot, you know. But no...my mother in law wouldn’t say ‘I’ll take one or two
kids’ or my sisters say ‘I’ll take a kid’, no...they were busy with their own lives...they
weren’t interested.

Of the eight mothers I interviewed, this participant had the most heart-wrenching stories
to tell of her plight as a young disabled mother devoid of all informal sources of support. Along
with the other participant quoted in this section, her situation exemplifies extreme gaps between
stressors and informal supports. Several other participants, who are higher on the continuum of
informal support, may nonetheless feel isolated and/or unsupported in certain domains. One
participant who acknowledged some of the help that she gets from her son’s father also discussed
the stressors that are part and parcel of this relationship:

Tony (baby’s father) is so miserable all the time... he’s totally different than he used to be... We get along sometimes but a lot of the times we don’t... probably more times it’s just fighting or not talking to each other or yelling at each other... it’s like a sitcom, you know, two people who don’t go out anymore, fight a lot but are still together for the kid.

She also expressed frustration over the clutter in their small apartment which makes it difficult for her to get around and find things that she needs. Furthermore, almost every waking moment is consumed with meeting the baby’s needs, leaving her with little time for herself. It appears that despite the physical presence of the non-disabled father, the brunt of child care and household management falls on this mother’s shoulders. Furthermore, his constant presence may also constitute a risk factor given the frequent tension and fighting.

Another woman who described the many things that her husband does for the family, also expressed some negative sentiments. She indicated that she occasionally feels undermined by her husband who sometimes disregards her opinion and makes decisions single-handedly. She talked about the high allowance that her daughter gets. When I asked her who makes these decisions, she answered:

Well, my husband and I do but I can say ‘I wouldn’t give her that much’... ‘Here, take it’, he says to her... you know, he can say that just right in front of me. He knows I disagree but he goes ahead and gives it to her anyway.

It is important to indicate that this was one of the few critical comments made about a spouse who was generally described in very positive terms. It seems, however, that while this participant gets a high level of instrumental support from her spouse, she is left somewhat wanting when it
comes to respect and social-emotional support. Her reported tendency to keep things to herself rather than communicate her frustration, may also reinforce this undesirable state of affairs.

In this section I focused on relationships with spouses, division of labour within families and other informal supports for mothers with disabilities. The presented data points to two interconnected issues related to women and caring: The division of labour within the nuclear family and the availability of informal support beyond the nuclear family. The experiences of study participants point to a general similarity between caring tasks of disabled and non-disabled mothers. A number of examples were given which suggest that like their non-disabled counterparts, mothers with disabilities take prime responsibility for home and children. Their involvement in child care and domestic labour seems to be more prominent than that of their spouses. Further to that, several of the accounts indicated a breakdown of the family system when the mother was not well enough to hold it together. As to the issue of informal supports beyond the nuclear family, it is again mothers, and at times sisters, who provide this support. While referring to the gendered nature of extended family care giving is stating the obvious, women’s caregiving responsibilities across the lifespan have been largely ignored in the past. The issue of women as care givers to adult family members was all but absent from the feminist agenda of the 60s and 70s which focused instead on young women’s issues (Hooyman & Gonyea, 1995).

Recent feminist literature on family care reminds us that “in most instances, family caregivers is a euphemism for one primary caregiver, typically female” (Hooyman & Gonyea, 1995, p. 3). As a feminist researcher, I also fell into the trap of not questioning the supports provided by female family members. Upon hearing the heart-wrenching story of the young mother who had to place her children in care, it was her mother and sisters, not her father and brother, that I found myself
angry with. Indeed, balancing the needs of adults in need of care, many of whom are women, with the needs of those who provide the care, almost all of whom are women, is a challenge that the feminist movement is currently grappling with.

**A Ramp to Mothering: Formal Support Systems**

Having described informal supports in the previous section, in this section I focus on the formal support systems utilized by mothers with disabilities. The idea of describing formal supports as a ramp to mothering comes from a 1992 court hearing on discrimination against parents with disabilities. In her testimony, Leigh Campbell-Earl, the disabled mother of a non-disabled infant, equated assistance with child-care for parents with disabilities to a ramp. She noted: “Just as a ramp (to the court house) enables me to exercise my civic rights today, I need a ramp to parenting -- a ramp to enable me to exercise my human rights and to fulfil the responsibilities that go along with parenting” (Disability Rag & Resource, 1993, p. 11). In this section I present participant accounts of the ramps that facilitated their ability to care for their children. I begin by describing situations where such ramps were either not available or were ill-equipped to meet the needs. I then describe situations where formal supports do a good job of facilitating mothering activities and are therefore worthy of the title “ramps to parenting.”

**Mothering: An Unramped Territory**

The young mother who phoned Children’s Aid when she had to be hospitalized felt that she had no other avenues of keeping her children fed and cared for. She described the first time her children went into care, the youngest being only 6 months old:

> When they first went into care, oh, I cried...I cried to see my little baby going. They came and got him. Oh God, it was such a traumatic time. And he was crying, he didn’t want to
go, and oh, my God...my daughter was crying because she was losing her little brother because they promised they’d put them together but they didn’t...they separated them which was especially difficult for the youngest and the oldest...she was sort of trying to watch over him because he was so small...it was very traumatic for both of them to be torn apart...These are scars that they’re going to have for the rest of their lives.

This mother’s lengthy stays in hospital, coupled with the total absence of informal support systems provided the context for the intervention of social services. The children were in care as long as this mother was in hospital while her husband was liaising with other women. Whenever she returned home after one of her surgeries, she immediately set about getting the children back from care:

It was very important (to get the kids back)...They were my kids and I wanted to take care of them...they were going into care because they would have better care than if they’d stayed home with their father...but it was very important that I get them back...that was the driving force. I never thought of ever you know, keeping them in care. It never crossed my mind.

Ironically, this mother felt that her ticket to getting her children back after hospitalizations was to get back with the children’s father; the same father who could not or would not look after his own children in her absence. Although she initially contacted Children’s Aid on her own initiative, she later experienced their involvement as a hindrance rather than a support. Other than having conditions placed on getting the children back, this mother did not receive any assistance with re-integrating her family:

Children’s Aid basically took the children into care and kept them there while I was sick.
But they didn’t try working with me after to try and help out... You know, it was really traumatic coming home... and I didn’t get the kids back right away because they were going to make sure that I could do things. And like I said, if my husband wouldn’t have been there, I wouldn’t have gotten the kids back because they would have felt I wasn’t capable of taking care of them.

When I questioned further about what possible supports could have been instituted, this participant responded:

In those days there was no home care, there was no long-term care, there was nothing... I’m really thankful now that they’ve got all this in place, I think it’s fantastic. But in those days, it was stay in the hospital, go to a convalescent home... you know, like they didn’t take the family into consideration.

The formal supports that this mother received amounted to her children being taken into care during her hospitalizations. In addition to being separated from their siblings, some of the children had been abused while they were wards of the state. Upon their return home from care, it was increasingly difficult for this mother to assert authority over her growing children. With no professional assistance to help her re-integrate her family, she was faced with challenges that appeared insurmountable at times. In her plight to get the children back from care in the early years and keep their behaviour in check as they got older, she continued the cycle of resuming a relationship with their father. The “system” clearly failed this young mother, leaving her to parent in a hostile and unramped territory.

Whereas this participant received no formal supports besides having her children taken into care, another participant received home making services shortly after the birth of her
daughter:

We had a home-maker for a few years after Jodi was born. The doctor arranged it...but I think that really screwed her up. It was through the visiting home-makers...but they kept changing. Like every 2-3 months they’d send somebody new because they didn’t want them to get attached. I was in bed most of the time and the home-maker was supposed to take care of the children.

Fatigue being the most problematic aspect of her disability, this mother found it exhausting to go through the routines time and time again, as the home-makers changed. She also noted that the home-makers did not form a connection with the children. Although the kids were fed and kept clean, this participant feels that their social-emotional needs were not met by the visiting home-makers. She described an incident that took place when her daughter was two years old:

I remember when she was two years old, Daniel would have been four at the time...I was in the kitchen at the time, sitting down...and Jodi, she was two years old, marked a line with a chalk across the floor and she said to the home-maker ‘don’t cross the line’...and that just threw me ...because she just didn’t get along with any of them. Well, the ones she did get along with, then, you know, all of a sudden they were gone.

As an interviewer, I experienced this participant as a somewhat passive woman who does not readily adjust to unfamiliar people and novel situations. Her reported difficulty to trust people she doesn’t know, together with the fatigue associated with the disability, probably contributed to the negative recollections she has about the home-makers:

As far as home-makers go, I don’t know if you’ve ever had one but some of them you don’t trust. Like I remember this one time I was lying down upstairs and I could smell
something burning. So I came downstairs to the kitchen and here’s the home-maker sitting at the table reading a comic book... with the potatoes on the stove burning... well, that’s it... well anyway, after that I started taking this drug that made me feel less tired.... I could finally stand up for more than a minute... I said to Craig, ‘the first thing we’re doing is getting rid of all of them’... and I phoned them right away and said ‘don’t send any more.’

Although this mother received home making support which made it possible for her to rest, she did not perceive this service as helpful or supportive. Possibly, her lack of involvement in arranging this support (it was arranged by her physician) and the lack of communication between herself and the home-makers contributed to her dissatisfaction. It also appears that there was a discrepancy or at least a lack of clarity between how the role was perceived by the mother versus the workers. Furthermore, the frequent change in home-makers was disruptive to the children and taxing for the mother. Her conviction to terminate this arrangement, as soon as she managed to curb the impact of her fatigue, attests to the overall failure of this formal support system to meet its target.

**Formal Supports as a Ramp to Mothering**

Contrary to the two examples presented above where formal supports were either unavailable or ill equipped to meet the needs, two participants described formal supports that enhance their roles as mothers. One participant described the backdrop to the inception of a supportive role that she coined as nurturing assistance:

> When Erin was an infant and I was going back to work, I would come home from work and would want to hold her for a while and play with her. But because she was so little and I don’t have the strength, I was afraid to hold her, that if she squirmed that I would
drop her. (husband) had been in that role all day...he wanted to have a break, you know, not to sit there beside me and help me hold the baby and play with her. So I thought ‘gee, if I’m going to have a relationship with my baby and not be part of the furniture’...like I want to be her mother in some sense of the word, I want to be a person she can have fun with. So when she was a few months old I started pushing for that.

This participant managed to secure funding for a nurturing assistant, a person who would come in to help her facilitate her mothering by performing tasks that she could not carry out independently for and with her children. She listed some of the activities that the nurturing assistant might help her execute:

Hold them, play with them, finger paint, organize closets, sew on buttons, take them out for walks, go to the park — like with me, not for me...it took a bit of figuring out...it needs to be the right kind of a person, someone who is secure enough to be just an intermediary facilitator, you know, the way a language interpreter would be in the middle.

Earlier I described the role that the nurturing assistant had when the children were babies. As they got older, the role description changed while the philosophy behind the concept remained the same. The nurturing assistant continues to work under the direction of the mother, enabling her mothering, rather than making independent decisions about the children:

If one of the kids would say to an assistant ‘can I have a piece of baloney?’ they’d say ‘well, if it’s OK with your mom’, or ‘you’d have to check with your mom.’ Like they’d just never take it upon themselves to decide that because they understand that’s not their role. And then if it’s ‘no,’ then they’re (the kids) mad at me, they’re not mad at them.

That’s one of the things that tells me that it has achieved what I wanted it to achieve.
Because they see me as the person who says ‘yes, you may, no you may not, or yes you may but later on’...I want them to see me as an authority figure and as someone whose opinion they have to respect.

The nurturing assistant can also help reinforce consequences that the mother has spelled out, such as taking the child to her room for a time-out period. This would all be discussed ahead of time to ensure that the nurturing assistant is indeed prepared to follow through on the mother’s decisions; “we would have that all laid out so that there would be no surprises.” Having a nurturing assistant has facilitated a strong relationship between this mother and her children. As the children get older, the need for this assistance is diminishing with a consequent reduction in hours that she is requesting:

I’m winding it down now because as Jamie gets older I just don’t need it as much. There’s still somebody here a couple of evenings a week. The next budget year I’ve already said that I’m giving up one of these nights...I decide when it’s phasing down and I’ve been keeping my commitment on doing that because that was one of the selling points. It’s not like my ongoing disability that I’ll need help with for how ever long I live for. This is just something I needed for that span of time when they were very young.

Having broken new ground with obtaining this assistance, this participant has written and lectured about the role of a nurturing assistant and has been instrumental in helping other people obtain similar supports. Several years ago, she got a call from another province regarding a young single mother with a similar disability. Using her own experience as an example, she recommended that as a single mother with an infant, the young woman be given 24 hour support, more than what she herself received in a full week:
She got 24 hour nurturing assistance. The last I heard she was doing fantastic, you know. When the baby was two years old she sent me a Christmas card and some pictures. She found people in the building where she lives, she sort of organized it that they’d be on call and then she’d pay them when she called them. So they weren’t like glued to her side all day. But she needed someone so she had to purchase a support circle because she didn’t have one.

As this participant asserts, a formal support circle becomes critically important in cases where informal supports are inadequate or are unavailable. Another study participant described how formal supports have enabled her to continue to meet her children’s needs as a single mother devoid of assistance from friends or extended family:

It’s a real roller coaster life because you don’t know when you’re going to be feeling OK and not OK with the energy level and everything...the children don’t understand that at all...and to me, they shouldn’t have to understand too much. They sort of get upset and angry that mom is not feeling well or mom has to lie down or whatever, but I feel it’s very important to have people in place to pick up the pieces for that...good, supportive people. That’s why I’ve advocated so much for parent-directed child care assistance, which is part of the attendant services that I get.

Giving it a different title than the participant quoted earlier, this mother also described services that facilitate her role as the children’s mother. As a single disabled mother who does not receive help from extended family, she requires a lot more assistance than the mother who negotiated for a funded nurturing assistant. The fluctuating nature of her disability precludes her from providing independent care to her children on a consistent basis:
With my energy level going up and down, well there are times when I just can’t get out of bed and can’t tell when that’s going to be. Those days (spent mostly in bed) are few and far between because I don’t allow them to happen until they’re extreme...and then I call everybody and say ‘please come and help’...I’ve got three reliable part time attendants who come at different times of the day. I have a morning person, a mid-day person, and a night person...it’s an excellent case scenario, a role modelling of how things should be done for families.

She emphasized her role in directing the care of the children even when she is resting and the assistants are in charge. Resting when an assistant is present allows her to conserve her energy for the in-between time when she is alone with the children. The efficiency of the system is evident from the following description of the evening routine:

She (assistant) helps with supper, supper clean-up, baths. She’s a real relief for me because by that time I’m usually really wiped out and so I’ll just rest and direct from the couch. And by 9 o’clock she turns the light out. She’s very responsible. It’s like having a mother put you to bed...she makes sure that the kids are in bed and reads to them and stuff like that. And if they’re not asleep by the time she’s ready to leave then I lie down with them and we’re all put to bed. Then when they fall asleep I get myself up and just make it to my own bed.

In describing the smooth operation of the system she has in place, this mother noted the importance of maintaining good communication and an amicable relationship with the assistants:

There’s excellent communication between all of the part time attendants that I have and myself...we all work together in unison. If one can’t do something then someone else will
try ...and they know that I’m the primary source to speak to. We have a really nice, family-like kind of communication and especially with the children it’s really helpful because they feel that these are great people that help us.

The two participants whose formal support systems provide a ramp to mothering are highly involved in every aspect of the service provision. They lobbied for the services, trained the workers and are continuously managing and monitoring the supports. The participant quoted above indicated that although she is getting a relatively high level of support, “it gets taken up really fast due to the amount of work that has to be done to run a family”. A lot of her time is spent advocating for herself and for her children, ensuring that they continue to have access to resources and supports:

They are making me present my case every year now...the price is the amount of energy that’s required to make it almost a legal argument, it’s like writing a paper every time, like a legal case. I’ve been called a hysterical mother...but I believe that if we do a whole family profile, we’re entitled to the services...each individual has the right to fight...if enough strong, vocal people in the community have the needs that I have (and express them), then people at the top would be forced by lobbyists like myself and they’ll have to put more money into the pot...because it’s only the loudest that get heard.

The strong advocacy skills of these participants, and their insistence on directing their own services, are important contributing factors to their overall positive experiences. It is important to indicate that directing one’s services need not necessarily be interpreted as being on hand to direct every single activity. During my second interview with the participant who had a negative experience with home-makers, I asked her whether having more control may have resulted in a
better outcome. Her answer was that directing services is very tiring for her; "I would find it tiring to have to instruct the person in what to do... I would be thinking: I may as well do it myself." She made reference to a more recent experience with a home-maker where the latter wanted every activity to be consumer-directed. This really defeated the purpose of home making support for this participant, who suffers from extreme fatigue and requires a more hands-off approach.

Another participant also noted that some service-providers will not allow an attendant to shop independently for a consumer as the service has to be consumer-driven. In her case, it is much easier to send the attendant with a shopping list and conserve her own energy for her children, rather than having to come along on a shopping trip. These experiences attest to the need for an open-minded and flexible approach to the definition of consumer driven services. While directing one’s personal care or the care of one’s children is of ultimate importance, having a say in how the chicken will be cooked for dinner may be more involvement than some consumers wish to have. Clear and open communication between a consumer and a service provider should serve to alleviate many such barriers.

**Being a Mother with a Disability: The Challenges of Promoting Growth and a Caring Relationship With Children**

Thus far I have focused on the perinatal experiences of mothers with disabilities, their access to informal support systems, and their interaction with formal resources and supports. In this section I present specific issues relating to raising children in the context of disability. The tasks of promoting growth and a caring relationship with children are ridden with challenges. Fostering a positive family climate entails nurturing as well as setting boundaries for children. Parents struggle to provide a nurturing and well structured environment in order to minimize
conflict with their kids. I begin with participant accounts of some of the issues they grappled with or are grappling with in the present, with respect to discipline and behavior management. Next, I focus on the more general issue of enhancing children’s well-being. Finally, I discuss participants’ accounts of relationships with children at different phases of development.

The Challenge of Setting Boundaries and Managing Children’s Behaviour

The subject of discipline and behaviour management is one of the most widely discussed parenting issues. The scores of books, video-tapes, workshops and presentations are testament to the ongoing interest in this topic. Nurturing a caring relationship goes hand in hand with managing behaviour in a constructive way. Discipline and control are not ends in themselves; they are part of fostering congenial and harmonious relationships with youngsters. Parenting in the context of a physical disability may have specific implications for discipline and behaviour management. Some parents with disabilities may not be able to catch a toddler who is trying to get away or pick up a child in the midst of a temper tantrum. Furthermore, the ongoing demands of parenting which are energy-taxing for most parents, may be especially challenging for those who deal with fatigue on a regular basis.

Some of the study participants discussed the disciplinary challenges they have come across as parents as well as the strategies and techniques used to overcome them. One mother noted the difficulties she came across during the toddler stage:

When they were little toddlers and they wouldn’t dress or whatever, my husband was always there to help out with that...and at that point we also had to sit down and sort out disciplinary procedures because I couldn’t chase after them, and when they ran off when I was trying to dress them, I couldn’t always do it. My husband could pick up and spank but
that wasn’t going to work for me so we needed to come to some kind of a compromise and some consistency...because how he dealt with it had implications for how I could deal with it.

Taking a parenting course helped these parents come up with disciplinary measures that would work for both of them. They began using a system of contracts and consequences, giving as many choices as possible in accordance with the children’s level of maturity and development. Another participant who “braced herself” for the challenging toddler years, also dealt with misbehaviour on a verbal level:

Because of my disability I’ve never been able to hit them or spank them. I just can’t. So even if it was my style which I sometimes think it probably would have been, I couldn’t do it. So I had to learn all that parenting stuff that other people are trying to learn now. You know, about other ways of parenting like helping them understand logical consequences ...I’m much more of an explainer and I try to reason with them even when they’re quite little. I always wanted them to be able to deal with me on that verbal level.

Although this mother described her style as a necessary alternative to physical punishment, her reference to spanking was probably a tongue in cheek comment, given the reported flexibility and latitude which characterizes her parenting style. Now that the children are older, it is increasingly easier to rely on verbal explanations and logical consequences as demonstrated by the following scenario:

Close by there is a big open pool and they like to go swimming...I don’t get in the water with them. I’m there to watch what’s going on and if anyone gets in trouble, call a life guard’s attention to it. But then of course they never want to come out of the pool and
come home. Right from the outset I’ve said to them: ‘I’m here and I’ve got the time and I’m willing to take you. But it means you’ve got to come out as soon as I say it’s time to come out. If you don’t do that I just won’t be able to take you on my own. You’re going to have to wait until your dad feels like taking you’ and that’s like once a week not once a day...like he can just pull them out and there you go, whereas I’ve got to talk...can you imagine talking a kid out of a pool in July? Like the last thing they want to do is leave the water. But you know, they do, because the first time one of them wouldn’t come when I called, then the next day it’s like ‘I’m not taking you swimming today and this is why’. I have to be (consistent). It’s the kiss of death if I’m not. And they go ‘Oh, we’ll be good today, we’ll go out’ and I say ‘no, that’s what you said yesterday so today you won’t go swimming. Tomorrow I’ll give you another chance.

This participant gave various other examples that attest not only to her consistent parenting style, but also to her attempts to accentuate the positive and reinforce desirable behaviour as much as possible. Her strong parenting skills notwithstanding, she jokingly indicated that “believe me, I don’t do it as perfectly as it might sound that I do...(sometimes) it just all falls apart and I scream at them.”

Another participant who is a single mother also relies on verbal communication and logical consequences for misbehaviour. She also encourages her two young children to solve problems with words:

It’s a totally non-violent atmosphere that I have here. You have an anger problem, let’s sit down and talk about it. I’ll actually get them together and I’ll say: ‘OK, you sit here and you sit there and I’ll sit here. Now what is it that you’re upset about? How can we make
this better?' It's like a therapist... the other day, the seven year old says 'mom, you sound like a judge.'

Two of the three mothers quoted above have access to funded assistance with the type of child care that I described earlier. This support can have important implications for behaviour management, especially where young children are concerned. Whereas the one mother had assistance in following through on "threats" if necessary (such as taking a young child to her room), the other mother conserves her energy by having someone else carry out household tasks as well as provide direct care when she is in need of rest. Being able to get the rest she requires to replenish her strength allows her to be a more effective and compassionate parent. This point is further accentuated by a comment made by another mother who participated in a focus group for mothers with disabilities. Reflecting on the years when she raised her son as a single mother, this participant noted:

Around the discipline issue, there are two things. One is the energy level, again depending on what your situation is. I couldn't be consistent to follow through on stuff because I was just wiped out. I felt that if I asked for help around that stuff I was giving up my child and in fact on one occasion someone did suggest the Children's Aide. I had wonderful help but not enough of it. Part of it was that it's not out there automatically and part of it was that I was afraid to disclose the need.

The mother whose children were in care during her hospitalizations also experienced major obstacles around discipline. I asked her what it was like when her children returned home from care:

It was very hard when they came back. Of course, whoever they were staying with had
rules and regulations and things that they did and then I would have to try to get them to
do what I wanted. It was really difficult. And then you had a man there that did a lot of
yelling and spanking.

This mother spoke about the negative impact of frequent changes, an unstable family
environment, and harsh and inconsistent disciplinary measures. Consequently, she felt that her
children were often out of control as adolescents. The mother who had frequent change of home-
makers, and little involvement in their activities, also experienced behavioural challenges, this time
with a pre-schooler:

She’d come home at lunch and she’d walk through the door and start screaming...just
screaming about stuff. That went on for two or three years...it got to the point where I
didn’t talk to her hardly because it didn’t matter what I said, it made her mad... I can
remember thinking: ‘I’m not surprised some children get the shit kicked out of them by
their parents, you know, because I can think of two or three times where I was just ready
to strangle her.’

Most parents who are honest with themselves can relate to this candid description of a
highly intense situation where emotions run amok. Such scenarios are by no means unique to
families of disabled parents, nor can they be said to characterize them. Nonetheless, this quote
demonstrates that a wide discrepancy between stressors and supports can constitute a significant
risk factor. The combined experience of study participants suggests that having access to
appropriate resources and supports can have a facilitative impact on discipline and behaviour
management. Mothers who were low on supports were likely to experience their disability as an
impediment to their ability to provide proper parenting and manage their children’s behaviour. On
the other hand, mothers who have access to formal and informal supports are better equipped to set boundaries, follow through, and promote cooperative behaviour.

**Promoting Growth and Enhancing Well-Being in Children**

Setting boundaries and promoting cooperative behaviour is only one aspect of the overall task of fostering children’s well-being. The other major component is of course the provision of a nurturing and caring atmosphere where physical and emotional growth can take place. This entails facilitating the expression of feelings, open lines of communication, and ensuring that children feel loved and protected. It also involves meeting children’s physical and emotional needs and making sure that the challenges they face are appropriate to their developmental phase.

Promoting their children’s growth and enhancing their well-being was a central theme in most of the interviews and focus groups. Mothers reflected on past experiences, discussed current issues with respect to nurturance, and, in one case, explored future parental actions that can promote growth. Several mothers talked about keeping children safe from harm. One mother noted that when her children were old enough to sit on the foot rest of her wheel chair, she’d take them out for a walk on her own. Although it was satisfying to be able to take them out unassisted, she had some concerns about safety issues; she knew that she couldn’t physically defend a small child if someone decided to grab her and run. Her solution was to be highly vigilant about who was around and to always leave information as to where she was going and when she expected to return. As her children got a little older, this mother emphasized the importance of listening to instructions:

From a young age I taught them that if they listen to me I can keep them safe. So if we’re shopping and they’re wondering around I’ll say ‘come over here’ and if they don’t come,
then I can’t keep them safe. So like I explain to them that if they listen to me then I can do things. Like if a fire alarm goes, if they just listen to what I tell them they’ll be safe you know, they’re not going to burn to death. I think it’s very important for children to feel safe. I don’t want them to feel anxious like if they’re home alone with me that there’s more of a threat to their security than if they’re home alone with their dad. Because even though there are things that I can’t do, they still see that I get it done somehow. Like I know who to call or what to do or I can teach them to do things themselves.

Keeping her children safe meant that this mother was never alone with them for more than a few minutes when they were babies and could not respond to verbal instructions. Having funded assistance to facilitate her mothering is her way of ensuring that her children always have their needs met.

Another participant cannot always be available herself to meet her children’s needs due to the nature of her disability. As she is separated from the children’s father, it is of top priority for her to ensure that other people are around and that the children are well cared for:

I want to be such a mother and always wanted to be a mother and parent these children. I miss the physical part (of parenting)...I can give them love and nurturance, but with bad headaches and bladder pains, I often have to lie still and be quiet and they don’t understand that. But no matter how bad I feel I manage to come through...or have someone else who I know is there for the children.

This participant is an ardent advocate for her children, negotiating with a host of agencies and institutions in order to ensure that the children have access to growth-enhancing resources. She asserts her right to have input into the educational programming for her son who has special
You have to be labelled disabled before you’re taken seriously. I’ve had to fight so hard for my rights and his rights because we’re not severely disabled. Right now we’re dealing with that because he’s not up to par. And they (educators) want to push him into grade 1. And I was like ‘no, you’re not doing that.’ So I’m taking the time now to make sure that all the assessments are done properly to see if we have to hold him back just so that he is developed mentally and socially. Because if you put him in an ordinary grade 1 he’s going to be trampled on. I’ve seen that happening with my oldest one so I won’t allow it to happen now. I’m going to fight for my kids.

Another participant also had dealings with the school system in order to ensure that her son’s academic needs would be met and that his self-esteem would be enhanced. She initiated contact with the school when her son began to refer to himself in derogatory terms:

My son was having difficulties at school. He was coming home crying, saying that he is stupid. But we weren’t going to let anyone categorize our son... The teacher wasn’t going to refer him for resource support but we insisted. We also involved him so that he didn’t feel that we were talking about him in the third person. He was part of the process. This year we’re working with him to help him understand his difficulties. That he needs a bit more time and he needs a quiet environment where there’s little distraction... Yesterday he had a math test and received 78% so he’s realizing that he’s not stupid. I don’t want people underestimating him just like I didn’t want people underestimating my potential (as a child). I don’t want him frustrated because people don’t expect him to do well.

A theme that ran across a number of interviews and focus group discussions is the attempt...
to shield children from any burden related to the maternal disability. A number of participants emphasized that they do not want their disability to become a source of burden for their children. One mother noted that although she encourages her children to help out, she doesn’t want them to feel that they need to look after her:

They are developing skills to be a little more independent. But I don’t want them to be adultified children. Even the thought of taking care of mommy... I don’t want my children to take care of mommy. To be kind and respectful and to listen and to be responsible for their actions and to do simple things sometimes -- that’s great. To me, that’s teaching morals and values of life. But for my children to take care of me I think is wrong. I think children should not be taking care of their parents.

Almost identical sentiments were expressed by another participant:

I don’t want my children to take on or have a sense that they have to take care of me. I am their parent. I think that a child has to be able to feel that they can be kids. And I guess you need to be able to say to yourself I’m going to take care of myself if it means getting the resources out there to help me take care of myself but to set a limit on what you expect of your children.

Another woman who relies on attendant services for personal care, also emphasized that it is important for her that her personal care be performed by hired service providers rather than her spouse and children. She expressed a concern that attendant services that are now publicly funded may be targeted for cuts in the future:

I wouldn’t want to rely on my husband to do my attendant care. And I wouldn’t want to rely on the kids to help do that because I didn’t have them to do that. Some people think
had them so they could help me out but I didn’t have kids for that reason. That’s why I live in a setting where there is attendant care available so that I can just be doing what I would be doing as a member of the family, regardless of the disability. I’m independent for that (self care). Like there are times when they might help out with different things but we help each other out and that’s normal, right?

This mother indicated that her older daughter has recently begun to do a little laundry. She emphasized however that it is something she instituted as a way of promoting her daughter’s independence and sense of self-efficacy:

I want them to be independent when they get older. When they move out on their own I don’t want them to be in a big shock like don’t know how to do laundry, don’t know how to cook, don’t know how to budget...that should be so easy to deal with and you should be so used to dealing with it that you get your house stuff done and then you get on with your life. I’d like them to be that way, you know, I don’t want them to be dependent.

The theme of shielding children from the effects of the disability can be better understood in the context of the institution of motherhood on the one hand, and the medical model of disability on the other hand. Motherhood as institution was predicated on romanticized notions of ever-present, all-giving, self-sacrificing mothers. Feminist critiques of these romanticized notions notwithstanding, mothers continue to be at risk for self-erasure in the process of caring for children. This risk may be exponentially higher for mothers with disabilities. In their relationship with children, they are “supposed” to be on the giving end and not on the receiving end of care. As people with disabilities, they have to fight stereotypical images of being dependent and in need of care. Furthermore, as noted in the literature review, traditional literature on parenting with a
disability tended to emphasize the risks of parental disability to children’s well-being. The more recent literature on children who perform caring roles in families (dubbed young carers) also tends to portray them as victims who have been robbed of their childhood. This literature largely ignores the context in which caring takes place, failing to distinguish between restrictive and potentially facilitative caring roles (Olsen, 1996).

My decision to take a theoretical diversion from the data derives from my belief that this framework can enhance our understanding of participants’ desire to shield their children from the burden of care. It is not surprising that as mothers with disabilities they are especially sensitive to images of children providing care to ill or disabled parents. This is exemplified in the quote in which a mother repeatedly noted that she did not have children so they would care for her. Of course, all parents have a responsibility to monitor the quantity and quality of helping tasks that they assign to their children. Study participants are probably no different than other parents in wanting to ensure that their children’s freedom is not excessively infringed upon by caring tasks. However, there may also be the added dimension that I alluded to above, of making extra efforts to minimize the effect of the disability on children.

A related topic raised in a focus group for mothers with disabilities has to do with protecting children from the burden of worry. Interestingly, several women noted that the “super mom” role model that their own mothers provided as they were growing up, made it difficult for them as mothers with disabilities:

When I was growing up the image that my mother portrayed is that you have to let your kids think that everything is fine...to constantly portray the image that everything is O.K. even though you feel like shit...That was the image that I grew up with and that was the
image I also felt I had to continue with my own kids and I think that caused a really severe depression because I couldn’t do it...I couldn’t be that super mom (symposium p. 67).

Focus group participants struggled with how much they should share about their disability and how that might impact on their children. These issues are clearly more complicated in cases where the disability is degenerative and has changing implications for the mother and the family. One focus group participant made eloquent connections between women’s reflections on their own mothers on the one hand, and their attempts to protect their children from burden on the other hand:

We talk about our parents who looked as if they are so strong and everything is just fine and then behind it we realize that we try to do that too sometimes with our own kids simply because we don’t want to burden them with the worry. We’re there to make their life better, that’s how we see ourselves and we don’t want to get that stuff that we hear about ‘you’re treating your child as a parent, you’re overburdening them with all your feelings’ and those kinds of things.

The mothers quoted above describe their attempts to ensure their children’s well-being. The young mother who had frequent surgeries over the course of her children’s childhood felt that the only way of protecting them from harm and ensuring their well-being is to place the children in care. She noted that even though she knows that she had no other choice at the time, she continues to feel guilty about this decision and its impact on her children. Furthermore, she feels that her now adult children still hold her responsible for what had happened:

And then I come to find out years later that putting your children in the Children’s Aide isn’t the best thing to do. Apparently there are foster homes that are very abusive and that.
But I didn’t know that then. You know, I always felt that my kids blamed me for what they went through...I still have that feeling. I did talk about it with all of them and explained it and I know they know what their father was like. They have no illusions what so ever about what their father was like but I think deep down they still blame me...I’m the one that had the operations so of course it’s my fault. If I wouldn’t have had the operations they wouldn’t have had to go to children’s aide.

This mother agreed with my comment that since the children’s father was never available to begin with, you can’t blame someone who you never expected anything from.

That’s it, right. And so when I wasn’t there...I guess I was the force that kept things together and when I wasn’t there everything fell apart. So I guess they blame me for making things fall apart.

The current relationship between this mother and her children will be further discussed in the next section. Relevant for the present discussion is the feeling of this mother that she was ultimately not successful in protecting her children and that they hold her responsible for their childhood misfortunes. As we know from the literature on mother-blaming, mothers have been blamed throughout history for their children’s ailments, misfortunes, and mishaps. Barbara Hillyer (1993) asserts that children themselves, along with the rest of society, engage in mother blaming: “In middle class, white American culture, blaming mother for children’s difficulties is institutionalized. The child, longing to evade responsibility for his or her life and culturally discouraged to see its socio-cultural components, turns to the most convenient and least dangerous target, mother (p. 94, italics added). Whereas the hardships that these children endured in care should not be minimized, it is equally important to see the socio-political context within which their experience
I would like to complete this section by presenting the words of yet another study participant, this time a mother of an infant. Throughout the three interviews that I had with this mother, she reflected on what she can do to foster her son’s growth and enhance his well-being. Holding her unplanned but much loved baby, she talked about how she would respond to a question that he may pose in future as to whether he was planned or not:

You know, I was thinking, if he ever asks if he was planned or not...I was thinking, I always watch the show Roseanne. I love that show. Anyway, one of her kids asked: Was I a mistake? and she said, I can’t even remember what words she used, but she said: ‘mistakes are things that happen that you think back and you say oh, I wish it would never have happened....You weren’t planned for but we’re happy we had you and we would never have changed anything. We would never hope that you weren’t around’. And I was thinking: that’s the kind of thing I would say to him.

Recognizing that nurturing an infant and meeting his needs are but the first steps to a healthy upbringing, she talked about how she sees herself dealing with many issues that may come up as her son gets older:

A lot of the music I listen to is very sinister...Tony went out with him for a couple of hours and I was playing music really loud that I like to listen to but for the most part I think that I don’t want him exposed to that kind of music..but (when he gets older) I’m not going to be the type of parent who says ‘you’re not allowed to listen to that’. It’s his choice...but I’m going to pay attention to what he does listen to and if there are lyrics that I think he shouldn’t be listening to, I’m not going to say ‘you’re not allowed to listen to
that.' I'll sit him down and I'll say 'you know what this is about, don’t you?'

Throughout our interviews, this mother gave a number of examples of how she would like to handle various situations that may come up in the process of raising her son. From current issues of striving to reduce the high level of stress in her life so that it doesn’t negatively impact the baby, to future scenarios of how she would talk to him about alcohol and drugs, this mother emphasized her commitment to the well-being of her child. As a low income single mother, she dreamed about moving to a safer neighbourhood, getting her son involved in wholesome activities, putting money aside for his future education. Her unflinching love and commitment notwithstanding, she struggles with multiple and unabating stressors that compound her difficulties as a mother with a disability. Alongside declarations of love and commitment and the visibly strong bond that she has with her infant, this mother shared the difficulties associated with accessibility problems, lack of money, and constant demands on her time, just to mention a few. She noted, for example, that her child is so demanding these days that she even has to plan when she can go to the bathroom. The stressors she enumerated can indeed present a risk factor to growth and well-being, unless they are mitigated by various resources and supports.

In the literature review I critiqued publications that describe parental disability as an obvious risk to children's wellness. I noted that among other limitations, such publications shed no light on the mechanism by which parental disability impacts family life and children’s well-being. The experience of study participants suggests that the welfare of children need not be compromised due to parental disability. Study participants gave numerous examples from their daily lives that describe their attempts to ensure their children’s welfare. They also described loving relationships and positive communication with the children, as well as their pride in
children who are well adjusted, caring, and appreciative of human diversity. Alongside these accounts, and sometimes intertwined with them, are indications of how stressors such as poverty and lack of support can compound difficulties related to the disability. It is safe to say that in the presence of internal and external resources and supports, parental disability in and of itself need not present a significant risk factor. This will be further discussed in the final section of the dissertation.

**Relationships with Children**

The sections on setting boundaries for behaviour and enhancing children’s well-being provide a backdrop for the types of relationships that study participants have with their children. Although many issues that touch upon relationships were alluded to in previous sections, in this section I focus on participant accounts with respect to past, present, and even future relationships with their children.

The participant who successfully lobbied for a funded nurturing assistant noted that it enabled her to play a more significant role in her children’s life. Consequently, she feels that she has a solid connection with her children that can be separate from their father’s relationship with them:

> It’s been good in that sense because I do feel that I have my own relationship with them that’s separate than, you know, (their dad’s) relationship with them. I met a gentleman from out west...he wished that he had something like that because he found like his two year old did not relate to him very much. Everything was the mother. (The child) didn’t know how to relate to him or sit with him. Like my kids at a very young age if they wanted me to read to them they knew they could either sit on my lap or beside me on the
bed or if it was a heavy book they knew they'd have to help me hold it up. And they just
did that quite spontaneously.

These adjustments that the children intuitively learned as toddlers are a lot easier to negotiate as they get older. Now that the relationship is based less and less on physical care-giving, this mother feels that she can play an even greater role in the children’s lives. She jokingly referred to this period in their lives as the “golden years” when the children are no longer toddlers and have yet to enter the potentially rocky adolescent phase. When I asked her how she envisions her life ten years from now, she reflected on future relationship with her children:

I anticipate that the children will probably be doing well in school and that they’ll have some tools and self-discipline to be able to do that. I imagine that they’ll have some friends and they’ll be doing lots of stuff I’m not going to approve of with them. But I hope you know, that they maintain the trust. Like if they ever did get in any kind of trouble or if they were getting offers to get into trouble that you know, they’ll still feel O.K. to come and talk to us about it and not that we’re going to go through the roof and flip out, and so far we really don’t. Calamity has happened and we don’t flip out about stuff like that.

Another participant also noted the close relationship that she has with her children.

Having been told early in life that she would not become a mother, she often stops to treasure the joys of life with children:

I don’t know if this is just a mother or whatever, you know, but when they go to their kindergarten classes and they do things that are so touching. You know, like I think I’m so lucky to be where I am at this date and time because I may not have ever had the opportunity to enjoy this.
In a focus group discussion, this mother also shared the joy she feels over the open display of affection from her now preadolescent children:

I really treasure it when my eight year old still, you know, when I’m sitting on the couch, will curl up on my lap and put his head on my shoulder. Or my eleven year old when we’re walking down the street, will put his arm around me. You know, that kind of a thing.

The humorous response of another focus group participant that “it will break your heart when it stops,” was well received by all group members who emphasized the more difficult and challenging adolescent years. Throughout the focus group discussion, many humorous references were made to “raging hormone syndrome” and “wonderful adolescent roller coaster ride.”

Recognizing the dynamic nature of mother-child relationships, one mother talked about what things might be like years from now, when her infant son grows up. When I asked her how she envisions life five or ten years from now, she answered:

You know what I think? I wonder if his friends will make fun of me. I wonder about that and I wonder if it’ll be hard for him having a mom who is in a wheelchair. I wonder if he’ll be embarrassed. But then I think, maybe he’ll stick up for me.

The issue of how children respond to mother’s disability came up in a number of interviews and is relevant to the discussion on parent-child relationships. Several participants noted that their children are quite comfortable with disabilities in general and are not embarrassed about their mother’s disability. One focus group participant noted that her disability was not a factor for her now adult children:

I never went through the stage of my children being embarrassed of me. I became disabled when I was 18 months old so my children didn’t know any different. I never seemed to get
any negative feedback and if they did hear things at school they never repeated it to me, so
I don’t think they did. I’m pretty sure they would have come back and said something.
Another woman related a conversation she overheard just the other day as she came to pick up
her son from day care:
He said something yesterday. I went to pick him up from day care. I was just watching
him play with other kids in the sandbox and he was getting up to leave. One of the little
girls whom I didn’t recognize said: ‘Why is your mom in a wheelchair?’ And he just said:
‘Oh, she broke her back as a kid.’ That’s all he said. It was sort of like matter of fact. I
was so proud of him the way he said that, you know, I thought: you couldn’t give a better
answer to another kid than that. It was just so matter of fact.
This mother talked about the importance of mothers with disabilities being present at children’s
activities. Several other mothers who participated in focus group discussions also emphasized the
importance of being visible and involved in their children’s schools and activities. Some came to
their child’s class to speak about disabilities. In one case a boy was teased by his classmates about
his mother’s disability. Things improved considerably after the mother came to speak with the
class. While being involved in children’s activities can foster tolerance and a good parent-child
relationship, some locations are inaccessible, thereby restricting disabled parents from full
participation in their children’s lives. One mother noted that due to the inaccessibility of many
facilities, her husband has been the more involved parent in extra-curricular programs and
activities.
Contrary to some of the above quotes which point to acceptance and comfort with
mother’s disability, another participant noted that her daughter did not want to be out in public
with her when she was little:

I had the scooter then. She’d sit on my lap but she’d never go for a walk. You know, my husband could take her to the park but I couldn’t. I think she was embarrassed even when she was 4 years old.

Interestingly and perhaps significantly, this is the same little girl who had frequent and unexpected changes in caregivers for the first few years of her life. It is a factor to which the mother attributes various difficulties that she has had with her daughter throughout the years. Being disagreeable and uncooperative as a young child, she became somewhat distant as a teenager, preferring to spend most of her time at friends’ houses. Although it is impossible to make any definitive connections between early experiences with home-makers and the distant mother-daughter relationship, such a connection is certainly plausible. This gains further credence from the experience of the young mother whose children spent time in foster care. This participant spoke about the negative reaction that her children have whenever illness or disability is mentioned:

Because of me being so sick (when they were children) my daughter runs when you mention sick. She’s scared to death of it. And the other ones I think are about the same. They’re kind of afraid of being...you know, of someone being sick. I can’t count on them...When I had the car accident and I came back home, I never saw my daughter for months. She didn’t come down or anything...when I’m feeling better, then they’ll come around.

Although her explanation was that the children “take after their father” who never stayed in the face of illness and disability, this mother agreed with my suggestion that her children may be
reacting to what her illness meant to them as children:

Interviewer: I’m wondering also if to some extent they’re reacting to a pattern in their lives. As you were saying, whenever it is that you were sick things fell apart for them.

Interviewee: Yeah, that’s right, that’s exactly right.

Interviewer: As children, you being sick meant things falling apart and therefore you being sick again is just something that doesn’t signal good news somehow.

Interviewee: Yes, that’s right and so they stay away so that they’re not affected. I’m sure that’s it. They won’t admit it but I’m sure that’s the way it is. But you know, it’s not like they’ll disown me. They will call and ask how I feel. But if I need help I definitely won’t pick up the phone and call my kids. This is where I phone my friends.

This participant also suggested an association between the diminished connection she felt with her siblings as a young child, and the relationship she has with her own children. Having spent a year and a half in hospital as a toddler, she never formed a close alliance with her siblings who were also significantly older than she was. Her frequent hospitalizations as a young mother provided a formidable barrier to the formation of a close alliance with her children:

The bonding that I was talking about when I went away to the hospital and I didn’t bond with my siblings, I think the same thing pretty much happened with my kids, depending on which kid and what operation. Like my daughter, I wasn’t having operations so I bonded with her and I had her for a while before having my sons so we sort of had time together so we bonded. But as time went on and I started having surgeries I wasn’t bonding with the kids like I probably should have. And with them being pulled away all the time, I don’t think they had a chance to bond with anybody either because they were going to different
homes and everything. So we really both lost.

The mother who described relationship difficulties with her adolescent daughter may also have been affected by her reportedly limited contact with her daughter as an infant, the latter being cared for mostly by home-makers and by the father. In both cases, the maternal disability was a precursor to some degree of inconsistency in the children’s care. It seems safe to say that it is not the disability itself but its possible implications for the affected children that can be a determining factor in the relationship between mothers with disabilities and their children. While maternal disability can constitute a risk factor as I suggested in the literature review, negative outcome or in this case, difficulties in the parent-child relationship, cannot be predicated solely on the existence of the risk factor. Rather, the overall context in which the risk factor is embedded appears to be of more relevance to the outcome. In situations where the contact with mother is stable and continuous despite her disability and the children receive consistent and nurturing care when she is unavailable, the relationship has a greater chance of being a close and fulfilling one.

Having presented two examples of relationship difficulties, I find it important to emphasize the obviously complex and dynamic relationship between all parents and their children, regardless of disability status. By their very nature, relationships go through ebbs and flows, peaks and valleys. Even the closest of relationships experience periods of greater distance and lessened intimacy. Clearly, maternal disability is but one of many factors which could affect the relationship between mother and child. The dynamic and changing nature of mother-child relationships is also reflected in the accounts of the two mothers noted above. For one mother, the difficulties she experienced with her daughter were somewhat tempered by the overall positive relationship she has had with her son over the years. Furthermore, she has recently noticed a positive change of
attitude on the part of her daughter and an increased willingness and interest to spend more time at home, especially with mom.

The mother who described the relationship with her adult children as rather distant, has made efforts over the years to talk with each one of them about what they all went through as a family. She was especially successful with one son who has since passed away:

My son, the one who passed on, he came down here, he was living in Toronto and he’d come down to visit and we’d have long long talks and we really cleared the air. He was very understanding of what had gone on. I tried to do that with each one of them.

In addition to being receptive to deal with and resolve past wounds, this son also gave his mother affirming messages about her parenting:

He said to me ‘I really understood what you were trying to tell me’ and he’d make quotes of what I used to say. And I’d think: he was actually listening. Like I can’t believe that he would. But I guess some of the stuff did come through and he wanted me to know that.

When her adult son was on his death bed with a terminal illness, this mother stayed by his side day and night. She wanted to keep him as comfortable as possible and to make sure that he was not alone at the time of death. She was consistently present for him during this period, something she was unable to do when he was a young child.

I would like to complete this section on relationship with children with the words of a mother whose son is still a baby. Reflecting on the type of relationship she would like to have with her son as he gets older, this mother noted:

I’d like to be his friend, I don’t want him to just think of me as his mom. I want him to come home from school and sit down and tell me what he has learned...I’d like to have a
relationship like that. And when he gets older he can tell me his girl problems.

She also gave numerous examples of the strong bond and intimacy that she has with her baby and the sense of "oneness" that new mothers often describe:

I always think that it's too good to be true. I love him so much... and I feel so protective of him. I know what he needs, I know when he's complaining. I always know what he wants. I know exactly what he wants.

The love that flows between mother and child is nicely depicted in the following scenario:

When I was up at my parents' cottage, I'd go into the room and I'd wake him up by mistake. I'd turn the light on and he'd wake up and he'd just sit up and I'd go 'I love you' and he'd smile at me. And I thought: What a nice way to go to sleep.

Amidst descriptions of the joyous moments of motherhood, this participant candidly described other, less harmonious scenarios. She noted the frustration associated with having almost no time for herself, living in cramped, unkempt quarters in a crime-infested neighbourhood, and having frequent conflicts with the baby's father:

I have way too much stress in my life. A lot of the time he's gone (the father). I have a lot of money stress. I have a lot of stress about him getting bigger. I never feel sorry for myself about my disability but I do worry. I am stressed out, definitely. You see, I thought that babies, once they weren't newborns anymore, then everything gets easier. But now I'm getting to realize that that's really the easiest time... I get in a fight with Tony and we yell at each other and half the year I can't get around, you know? And it's hard to find stuff. Like today I was looking for stuff and the exerciser was in the way. You know, I just think I don't like being here. I'm not very happy here, you know.
She also admitted, with clear self-reproach, that the baby is often witness to the yelling that goes on and that she herself may be less than patient with him in the midst of a fight.

I chose the above quote not to undermine or cast a dark shadow over this mother’s descriptions of the joys and rewards of mothering. Rather, I see it as a candid reflection of the delicate co-existence of barriers and difficulties on the one hand, and joyous and rewarding moments on the other hand. By choosing to present them concurrently in this section, I also hope to underscore the role that context plays in relationships. Many factors impact and will continue to impact the relationship between this mother and her child. Her strong love and commitment notwithstanding, the number and magnitude of stressors in her life, if left unmitigated, can present a risk factor to the relationship with her child. Relationships are not formed and maintained in a vacuum, nor can they be nourished by good intentions alone. Although the people involved in the relationship enact the lived experience of being together, their behaviours are not just a reflection of personal intentions but of extraneous forces as well. Negative distal and proximal factors like economic deprivation, crowded housing, and insufficient formal and informal supports penetrate the interactions between otherwise loving partners. These powerful influences can slowly erode ties created by much individual effort on the part of parents and children.

Working the Hyphen...

As I listened to and reflected on the mothering experiences of study participants, I thought about the role that my own mother has played in facilitating my mothering. Like the mothers of some of my participants, she has provided a great deal of instrumental support since the birth of my son more than ten years ago. Knowing how much I wanted to have a child and the various complications that are involved, she even wondered if she, as a healthy, non-disabled woman, can
carry the pregnancy for me! Interestingly, what sounded like an outrageous suggestion some thirteen years ago has become plausible today.

My mother’s help and support has taken many forms over the years and has changed along with the growth and development of my son. When he was a baby her assistance was more physical in nature. I knew I could always count on her help when my husband was out of the house for an evening or away for several days at an out of town conference. Such back-up was invaluable in that it allowed my husband to pursue some non-family or work-related interests — a healthy situation for any family. Over the years, my mother has picked our son up from school when needed, helped with some household chores, and enabled my husband and I to enjoy some time together away from our child. She also played a role in helping us advance our own careers. Providing the best possible nurturance and care in our absence has provided us with some guilt-free time to pursue academic interests and activities.

I chose to expand on my mother’s availability as it speaks to the relationship between mothers with disabilities and their own mothers. Reflecting on my relationship with my mother has helped me understand the source of my disappointment with grandmothers who didn’t come through for disabled daughters. As it turns out, my failure to apply feminist principles to the lives of grandmothers has been recently raised in feminist literature. Hillyer (1995) asserts that “Her (daughter’s) ability to find a feminist solution depends in large part on her ability to see her mother as also a woman and herself as one who has felt entitled to abuse or exploit that woman, her mother” (p. 95). While I recoil from such terms as “abuse” and “exploit” to describe the relationship I have with my mother, it is an ongoing source of challenge not to take her unfaltering availability for granted.
GENERAL DISCUSSION

In this final chapter of the dissertation I integrate knowledge gained from the literature and the three data chapters. I use the emergent knowledge as the basis for recommending practices and interventions that can enhance wellness amongst girls and women with disabilities. Moreover, I distil the implications of the research for advancing the well-being of children growing up with a disabled parent.

Striving for Wellness

A number of factors contributed to my decision to use wellness promotion as the main organizing principle of the chapter. As a therapist who has worked with both children and adults, I am excited about the growing interest in resilience and protective factors that has been evident in psychological literature of the past two decades. This approach can be seen as antithetical to the pathology-based tradition in psychology which focused on diagnosis and treatment of dysfunction and disease. Unfortunately, the burgeoning literature on children and adults who cope successfully with adverse life circumstances has seldom been applied to women with disabilities (Nosek, 1996). This gap has recently been addressed in a study on women with physical disabilities and sexuality which emphasized wellness promotion. I believe that the data which emerged from the current study on motherhood can both inform and be informed by a wellness framework.

In an invited address to the American Psychological Association, Cowen (1991) made reference to his failed efforts to find a dictionary meaning for the word wellness. “Does the word wellness really exist? Who knows? It should exist! But whether or not it does, the functional point to stress is that allocations of our energies and resources must go increasingly toward building
wellness rather than toward struggling, however compassionately, to contain troubles” (Cowen, 1991, p. 404). He further states that the 21 century should be marked by significant movement toward wellness in both research and action.

In an effort to counteract the negative impact of deficit-oriented medical models, Cowen has promoted the concept of wellness (1991, 1994, 1996). Inspired by the health-promotion movement and by a more inclusive definition of health by the World Health Organization (1986), Cowen offers concepts as well as interventions to strengthen health-enhancing mechanisms, not only for people at risk, but for the population at large. He believes that the time is overdue for shifting the reigning paradigm in mental health from one that emphasizes pathology to one that fosters well-being. Wellness may be conceptualized as a state of psychological, physical, and material well-being. Cowen (1991, 1994) identifies several key constructs that can synergistically guide potential health-enhancing interventions. In his 1994 article he describes five pathways to wellness promotion: “(a) forming wholesome early attachments; (b) acquiring age-appropriate competencies; (c) exposure to settings that favour wellness outcomes; (d) having the (empowering) sense of being in control of one’s fate, and (e) coping effectively with stress” (p. 158). Cowen emphasizes the interactive nature of wellness promotion. These five pathways complement each other and should work in tandem in order to achieve wellness. They are rooted in the four key wellness constructs identified by Cowen in his 1991 Distinguished Contribution to Psychology in the Public Interest Address: competence, empowerment, social system modification, and resilience.

The concept of competence implies the ability to meet life’s challenges effectively. These challenges are multifaceted in nature and include the successful negotiation of physical, academic,
affective, and social tasks. Experiencing a sense of mastery early and throughout life enhances the ability to cope effectively with stressful situations and circumstances (Garmezy, 1994; Gore & Eckenrode, 1994; Haggerty, Sherrod, Garmezy, & Rutter, 1994; Rutter, 1987).

Empowerment, the second building block for wellness, refers to interventions and social policies designed to enhance people’s control over their lives. This concept has been particularly useful to the plight of marginalized and powerless groups, as their suffering is marked by a profound lack of power and control over their fate. This is not to say that these groups lack the ability to direct their lives, but rather that oppressive conditions and ideologies restrict their access to power (Cowen, 1991, 1994; Lord & Hutchison, 1993). As has been amply documented, restoring a measure of empowerment has salutary psychological and material effects at the individual and community levels (Serrano-Garcia & Bond, 1994; Zimmerman & Perkins, 1995).

Social system modification, another important contributor to wellness, highlights the need to change social structures inimical to the fulfilment of human needs. Numerous are the organizations and social barriers that interfere with the promotion of wellness. “Whereas some institutions act coincidentally to enhance wellness, others, oblivious to incidental outcomes effects, may pose unintended obstacles to wellness” (Cowen, 1991, p. 407). Schools, hospitals, social agencies and work sights are all examples of social institutions bearing on the well-being of the population.

Resilience is the fourth pillar of wellness identified by Cowen (1991). It refers to the ability evidenced by some people for adaptive and healthy outcomes despite exposure to extreme adversity (Consortium, 1994; Cowen, 1991, 1994, 1996; Garmezy, 1994; Rutter, 1987). Studies documenting the life course of individuals exposed to risk at a young age, reveal that a significant
proportion of them develop in adaptive ways. Much can be learned from these individuals and the ecological climate surrounding their development for the promotion of psychological well-being. These are individuals who overcome the odds and manage to stay afloat when all indicators would have predicted that they would sink (Cowen, 1991).

These constructs are highly relevant to some of the challenges faced by people with disabilities. Competence, an important ingredient in the promotion of wellness, is contingent upon exposure to learning opportunities. Unfortunately, many people with disabilities have been denied such opportunities due to prejudice and diminished expectations. Traditionally, people with disabilities have been viewed as eternally dependent and in need of care and thus, in little need for competency training.

The relevance of empowerment for the promotion of wellness in people with disabilities is made crystal clear by Fawcett and colleagues (Fawcett et al., 1994). They claim that

When people with disabilities, ethnic minorities, older adults, women, and others lack power, they usually experience adverse conditions disproportionate to other members of society. Empowerment -- the process by which people gain some control over valued events, outcomes, and resources -- is an important construct for understanding and improving the lives of people of marginal status (p. 471).

Empowerment is a process that can have beneficial effects for people with disabilities at the personal, communal, and societal levels (Fawcett et al., 1994; Lord & Hutchison, 1993). Whereas most attempts to promote empowerment have targeted the individual level, Cowen (1991) states that “a primary goal for empowerment theorists is to promote policies and conditions that enable people to gain control over their lives, on the assumption that doing so will reduce problems in
living and enhance wellness” (p. 407).

Social system modification applies to the lives of people with disabilities in multiple ways. Whereas architectural barriers that restrict full participation in public life are being gradually removed, attitudinal barriers are more resistant to change (Nosek, 1996). Although significant gains have been made in recent years in both physical and sociological conditions, much remains to be done to facilitate full participation by people with disabilities in society. Furthermore, many adults with disabilities have been subjected to oppressive institutional practices in their early contacts with educational, health, and social services. As the literature suggests, and participants in this research attest, improved accessibility and appreciation for disabled people’s contributions have increased the quality of life for disabled people in significant ways.

Eminent scholars like Michael Rutter (1987, 1994), Norman Garmezy (1994) and Emory Cowen (1991, 1994, 1996), are pushing the mental health field to adopt a wellness orientation based on the concepts of strength and resilience. They maintain that the human capacity to overcome adversity has been overlooked in an incessant search for pathology. People faced with a number of life adversities have been shown not only to cope with stressors but to develop their capacities in fulfilling ways. Even though the concept of resilience could be fruitfully applied to study the lives of people with disabilities, this research avenue has seldom been explored. Nosek (1996) states that “although resilience has been studied in reference to survivors of war and children who survive family violence, it is seldom applied to women with disabilities” (p. 20). Women in my study showed me how unjust this gap in the literature really is. As I listened to their stories, I realized how important the concept of resilience is in understanding their meaning making and life trajectories.
Given the lack of attention to resilience in the disability literature, and its tremendous potential to elucidate complex patterns of coping, I choose to discuss my data in light of resilience and allied concepts such as risks and protective factors. Resilience is the outcome of dynamic interactions among risk and protective factors. Risks may be defined as personal characteristics, events, or circumstances which enhance the likelihood of a negative outcome. Conversely, protective factors are personal characteristics, events or circumstances which enhance the likelihood of positive mental health outcomes (Haggerty et al., 1994). Risks and protective factors can operate at the personal, familial, and societal levels. Individual risk factors include organic vulnerabilities, low intelligence, and genetic predispositions to mental illness. At the family level, some common risk factors include marital discord, divorce, and parental mental illness. Societal risk factors known to affect psychological well-being include poverty, urban violence, exposure to drugs and alcohol, and discrimination.

Like risk factors, protective factors may be clustered in the following categories: attributes of the individual (high intelligence, good temperament, good problem-solving abilities, positive social orientation, competence and self-efficacy, etc.); attributes of the family (bonding with parents, family cohesion, supportive relationships, adequate parental supervision, etc.); and attributes of the environment (supportive networks, schools that encourage mastery and competence, social safety net, responsive social agencies, lack of prejudice and discrimination) (Consortium, 1994).

It is important to realize that single risk or protective factors can have different meanings in different contexts. For example, while the death of a parent is always a stressful event, the outcome for the child is contingent upon the particular context surrounding the loss. In situations
where adequate financial and emotional supports are available to the child and the loss does not result in inadequate care, he or she would likely overcome this tragic event. On the other hand, when such supports are unavailable to the grieving child, the negative impact of the death will be much more pronounced. Another example of the importance of context in interpreting the meaning of risk and protective factors, is the case of parental divorce. For years, mental health professionals have warned against the negative repercussions of parental divorce. While divorce is always a stressful event for a child, it does not necessarily lead to negative outcomes. Moreover, the lack of parental separation may result in exposure to high degrees of discord and/or domestic violence, the outcomes of which can be more damaging than the divorce itself. A child’s exposure to divorce may be more or less damaging depending on events and circumstances that precede and follow it (Gore & Eckenrode, 1994; Rutter, 1994).

The importance of context in the interplay between risks and protective factors shown above, has important implications for understanding stress and coping in the lives of women with disabilities. As I indicated in the literature review, parental disability has traditionally been considered a major risk factor to children’s well-being. However, as research on risks and protective factors demonstrates, “a focus on isolated life events is not the most appropriate way of viewing most stressors” (Rutter, 1994, p. 355). When parental disability is accompanied by sufficient formal and informal supports and adequate resources, children may be at no higher risk than children of non-disabled parents. Moreover, the particular challenges associated with parental disability can have a steeling effect so long as the situational demands do not exceed children’s capacities. This is supported by literature which suggests that exposure to mild stressors and challenges can in fact enhance children’s sense of self-efficacy (Garmezy, 1994;

In order to fill the gap in the literature concerning an analysis of risks and protective factors in the lives of women with disabilities, I present below a summary of my research and its implications for wellness promotion. Based on the three data chapters, I present three tables describing risks and protective factors for girls with disabilities, young women with disabilities and those who do not have children, and mothers with disabilities and their families. This conceptual framework will provide the basis for formulating recommendations for wellness promotion in the three groups. The discussion of risks, protective factors, and interventions in each group will be divided into three levels of analysis: micro, meso, and macro levels. By micro level I refer to personal, interpersonal, and familial factors. The meso context includes mid-level organizational structures such as schools, hospitals, social services, and community agencies. The macro level of analysis pertains to social policies and cultural norms that determine the ideological climate of society and the allocation of resources in the community.

This conceptual framework should be regarded as flexible and permeable and not as a rigid grid. Overlap among the various levels is natural and expected. The purpose of dividing interventions into three distinct levels is to avoid perpetuating the problem of focusing exclusively on person-centered strategies and interventions. As Prilleltensky and Nelson have pointed out, most therapeutic and preventive interventions in the field of mental health tend to focus on the individual at the expense of crucial changes needed at both the meso and macro levels (I. Prilleltensky & Nelson, 1997). The main advantage of identifying clearly the three levels of intervention is that policies and interventions can be formulated at multiple points of entry. Parallel interventions at the three levels are typically needed in order to achieve enduring changes.
Micro level changes aimed at enhancing personal competency must be accompanied by transformations in the realm of social policy. Likewise, social systems change cannot be effective without a sense of personal efficacy and control. In essence, the three levels of intervention compliment one another and each one of them should be given due consideration.

I will discuss in the text only a few examples from the data pertaining to risks, protective factors, and possible interventions. The purpose of this discussion and accompanying tables is not to provide an exhaustive coverage of these issues, but rather to illustrate the potential utilization of this conceptual framework.

**Girls with Disabilities: Risks, Protective Factors, and Possible Interventions**

The life stories of all participants who grew up with disabilities suggest the presence of some risk factors at the micro level of analysis (see table 1). At the familial level, a common theme was a lack of any reference to a disabled daughter’s sexuality and sexual identity. One set of parents sheltered their daughter to the point that no opportunities were afforded for developing self-help skills and competencies. In another case a disabled daughter was openly rejected by her mother. Most participants had no role models of adults with disabilities in their homes, schools, or communities. Some suffered rejection and/or exclusion by non-disabled peers. Several women recounted having poor self-esteem in their childhood.

The impact of these risk factors can be moderated by the presence of micro level protective factors. Stories were told of nurturing and supportive parents whose love and commitment were unfaltering. Some parents actively promoted the development of competencies in social, academic and practical domains. Beyond the parental home, links with disabled and non-disabled peers in school and in the community respectively, provided friendship, affirmation, and
Table 1: Girls with Disabilities: Risks, Protective Factors, and Possible Interventions.

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<th>Micro Level</th>
<th>Risks</th>
<th>Protective Factors</th>
<th>Possible Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>* parental rejection</td>
<td>* parental nurturance and support</td>
<td>* foster the development of self-help, academic, and practical skills at home and at school</td>
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<tr>
<td>* parental over-protection</td>
<td>* parental promotion of competence and independence</td>
<td>* provide experiences of mastery and control at home and at school</td>
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<tr>
<td>* parental reticence</td>
<td>* exposure to disabled adults via sports</td>
<td>* encourage the development of a healthy sexual identity</td>
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<tr>
<td>to acknowledge girl's</td>
<td>* strong ties with peers with disabilities</td>
<td>* provide ample opportunities to interact and develop friendships with peers with and without disabilities</td>
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<tr>
<td>sexuality</td>
<td>* links with non-disabled peers</td>
<td></td>
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<tr>
<td>* inaccessible house</td>
<td>* high intelligence</td>
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<tr>
<td>* lack of role models of</td>
<td>* competence and independence</td>
<td></td>
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<tr>
<td>adults with disabilities</td>
<td>* recognizing oppression and fighting for control and self-determination</td>
<td></td>
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<tr>
<td>* rejection/exclusion</td>
<td></td>
<td></td>
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<tr>
<td>by non-disabled peers</td>
<td>* lacking of privacy during medical exams</td>
<td></td>
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<tr>
<td>* poor self-esteem</td>
<td>* academic under-emphasized in special schools</td>
<td></td>
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<tr>
<td>* internalized oppression</td>
<td>* being labelled in regular schools</td>
<td></td>
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<tr>
<td>* lack of self-esteem</td>
<td>* powerlessness in institutional and medical settings</td>
<td></td>
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<tr>
<td>* lack of role models of</td>
<td>* a focus on deficit and disease that characterized the above settings</td>
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<tr>
<td>adults with disabilities</td>
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<td></td>
<td></td>
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<tr>
<td>* professionals who</td>
<td>* teacher who set high academic expectations</td>
<td></td>
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<tr>
<td>engendered pessimism in</td>
<td>* respectful and supportive medical personnel</td>
<td></td>
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<tr>
<td>parents</td>
<td>* professionals (Occupational therapist and Counsellor)</td>
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<tr>
<td>* being placed in an</td>
<td>* who encouraged exploration of sexuality</td>
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<tr>
<td>institution</td>
<td>* recreational counsellor who facilitated involvement in disabled sports</td>
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<tr>
<td>* sexuality not acknowledged</td>
<td>* satellite program (independent living) for physically independent teens at an institution</td>
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<td>in segregated settings</td>
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<td>* violations of privacy</td>
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<td>during medical exams</td>
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<td>* academic under-emphasized</td>
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<td>* a focus on deficit and</td>
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<tr>
<td>disease that characterized</td>
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<tr>
<td>the above settings</td>
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<tr>
<td>* lack of resources to fund wheelchair</td>
<td>* wheelchair and other needs funded in an institutional setting (but not while living at home)</td>
<td>* provide funded respite to parents of children with disabilities</td>
<td></td>
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<tr>
<td>* lack of resources to</td>
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<td>provide respite from</td>
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<td>care to parents</td>
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<tr>
<td>* policy that enabled school</td>
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<td>to reject a severely</td>
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<tr>
<td>disabled child</td>
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<td></td>
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<tr>
<td>* oppressive societal</td>
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<td></td>
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<tr>
<td>attitudes about disability</td>
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<td></td>
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<tr>
<td>which impact families,</td>
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<tr>
<td>institutions, and</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>communities.</td>
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242
social support. Personal attributes such as high intelligence and independence were highly protective in some situations. Another important attribute mentioned by several participants is their ability as children to recognize the oppressive factors and ideologies that framed their experiences. Anger over the injustice in their lives mobilized some girls to fight for self determination.

Beyond global lists of micro level risks and protective factors, it is important to attend to the specific contexts and circumstances that surround them. For example, the girl who was openly rejected by her mother was the same one who was later introduced to disabled sports and thus came in contact with adults with disabilities who served as positive role-models. Another girl whose severe disability and poor prognosis could have resulted in extreme dependency, had a mother who pushed her to attain as much control and independence as her condition would allow. The early training for independence in conjunction with her obviously strong intellectual abilities were important protective factors for this youngster who suffered multiple adversities at all three levels of analysis. Conversely, the childhood stories of another participant reveal minimal exposure to risks and maximal exposure to health-enhancing protective factors.

Risk factors can also be found at the meso level of analysis in the lives of girls with disabilities. The pessimism engendered in families by professionals is an important backdrop to the familial interactions and dynamics reported above. Some parents were told that their daughters would die, others were counselled to place them in institutions, and yet others were advised to expect little in the way of normal development. Girls were also impacted directly by iatrogenic practices in medical, educational, and institutional settings. Violations of privacy during medical exams accentuated the risks to a healthy sexual identity posed by parental reticence to
acknowledge sexuality. In segregated settings, a greater emphasis was accorded to physical therapy often at the expense of imparting academic skills and competencies. This lax approach to skill building can severely limit future opportunities and thus pose a significant risk factor. In one case, the reluctance to provide adequate study space at an institution amounted to clear suppression of academic talents. This participant’s strong will and strive for self-determination ultimately gained her satisfactory conditions for studying.

The above example of a girl’s struggle for her right to proper learning space illustrates the interaction between different levels of risks and protective factors. In this situation, as in several others, micro level strengths (high intelligence, determination, self-advocacy skills) were protective in fending off meso level risks (being denied learning opportunities). Furthermore, strengths at the micro level were probably instrumental in eliciting protective factors at the meso level of analysis. In an institutional setting otherwise described by this participant as oppressive and disempowering, there was a teacher who recognized her strong academic abilities and pushed her to excel. The woman whose childhood involvement in disabled sports provided an important turning point in her life, singled out a recreational counsellor who facilitated this involvement. Like in the previous example, this girl had a number of micro-level strengths that probably served to activate protective factors at the meso level. As she herself indicated, “I’ve always been able to kind of find what I needed along the way”. These examples support claims made in the literature regarding the tendency of protective factors to co-occur. Other meso level protective factors include professionals (an occupational therapist, a counsellor) who encouraged the development of a healthy sexuality and a physician who fostered hope for achieving stage-appropriate milestones in personal and professional domains. Sadly, all examples of meso level protective
factors pertain to single individuals who stood out in otherwise disempowering institutions.

The inter-connection between various levels of risks and protective factors can also be illustrated at the macro level. A policy that enabled a school to reject a severely disabled child could have significantly and irreversibly restricted her social and academic development and her ability to develop future competencies. Likewise, the one case of parental rejection occurred in a family that was exposed to other societal stressors. It could well be that having formal respite from care may have served to buffer the stress of a disabled child in an already stressed family situation. The inadequate level of resources and supports extended to families of disabled children mirror the discriminatory practices of dominant societal institutions at the time.

As can be expected, the data is rather scant with respect to macro level protective factors in the lives of girls with disabilities. Several women made reference to the process of conscientization that they went through in adolescence. Conscientization refers to the process whereby people attain an increased level of awareness concerning the deleterious impact of societal ideologies and conditions on their lives (Freire, 1971; I. Prilleltensky, 1994). One participant noted the ameliorative impact of this process as she, along with other peers with disabilities, became aware of the systemic oppression that they were subjected to at school. In another case, conscientization motivated a girl who had been institutionalized throughout her childhood to fight for her right to live independently in the community. Along with her peers, she successfully lobbied for consumer-directed attendant services which facilitated independent living for young adults with disabilities. Efforts such as these pave the way for other macro level changes which enhance the self-determination and well-being of marginalized groups.

The interplay of risks and protective factors are helpful in elucidating possible
Interventions at the three levels of analysis. Beginning with the micro level, a number of themes emerge from the data as particularly germane for wellness enhancement. Competency and self-efficacy are important protective factors for all children. In the case of girls with disabilities, it is crucial to develop self-help, academic, and practical skills to compensate for physical challenges associated with the disability. In order to gain as much control over their lives as possible, homes and schools have the responsibility and the opportunity to provide girls with experiences of mastery and control. Imparting cognitive and problem solving skills lays the foundation for future experiences of success at school and at work. As demonstrated by the data, the educational system has traditionally been remiss in affording children with disabilities opportunities for growth and autonomy. In the context of teaching self-help skills, it is imperative to adapt existing programs to the unique profile of the child. Fostering independence does not necessarily mean meeting all of one's physical needs unassisted. A child whose disability requires her to obtain help with personal care, should be helped to articulate her needs and wishes and negotiate for proper services.

Interventions in the social and affective domains might include exposure at a young age to peers with and without disabilities. Several participants emphasized the value of having peers with disabilities as they were growing up. One woman referred to this as the main benefit she derived from a segregated setting. In the current context of integrated settings, the importance of connecting with other children with disabilities should not be undermined. The family and the school can play an important role in facilitating contact with other children with disabilities as well as in building friendships with peers without disabilities in the school and in the community. Most study participants experienced some difficulties in their interaction with non-disabled peers. For
some, this resulted in social isolation in Junior High School, a time when social support is especially critical for adolescent girls (Gore & Eckenrode, 1994). Along with early exposure to peers, girls with disabilities can be helped to explore ways of initiating and maintaining meaningful friendships. The many existing programs designed to enhance social skills can be adapted to the particular needs and challenges of girls with disabilities.

Another major theme that has direct implications for intervention is the need to foster a healthy sexual identity. Most participants described experiences at home, at school and in the community that pose a significant risk to a healthy sexuality. Conveying positive messages about a disabled girl’s changing body and her wishes to form intimate relationships, can be affirming and health-enhancing. In attempts to foster a healthy sexual identity, parents and educators may help disabled girls to explore the impact of negative societal messages pertaining to sexuality and disability. This process of conscientization can result in de-blaming and may also lay the foundation for taking a stand against oppression.

In keeping with the interventions suggested at the micro level, institutions such as hospitals, schools, and social service agencies must work to eliminating discriminatory and unjust practices that place vulnerable individuals at risk. Such meso level changes are already occurring as suggested by some of the current literature on disability. For example, the outcry of people with disabilities against powerlessness and violations of privacy in medical settings, have resulted in changes to hospitals and clinics. In addition to protesting against oppressive practices, people with disabilities have taken an active role in training service providers to better serve individuals with a range of disabilities (Odette, 1994; Saxton, 1996).

Educational reforms have also occurred since the time that study participants attended
school 20-30 years ago. However, while segregated settings are probably the exception rather than the norm, the education of children with disabilities may still be compromised if active steps are not taken to enhance their sense of efficacy and control. Furthermore, schools also have a major role to play in fostering a climate of tolerance and diversity where children with different challenges and abilities can feel at home. Exposing disabled and non-disabled children to competent professionals with disabilities be they teachers, clinicians, or individuals in the community, can also serve to dispel myths and promote tolerance.

Macro level changes are needed that can enhance micro and meso level interventions. Parents who raise children with disabilities need resources and supports that will enhance their parenting efforts. A more just allocation of societal resources will result in less stress for such families. In the current economic climate of cutbacks to social programs, there is a serious risk of reducing already scarce resources available to such families. Therefore, disability rights organizations and independent living movements have an important advocacy role to play in preserving programs. These organizations serve as the conscience of the public and strive to hold governments accountable to the needs of marginalized populations.

**Women Who Are Not Mothers: Risks, Protective Factors, and Possible Interventions**

A number of micro level risk factors have been identified in the data for young women with physical disabilities and for those who are not mothers (see table 2). Although my particular focus is on women without children regardless of their age, I also make references to risks and protective factors faced by young adult women with disabilities. Women who experienced a lack of sexual acknowledgment in childhood were susceptible to similarly devaluing messages in their adult lives.
Some families actively discouraged disabled daughters from pursuing an intimate relationship. Others avoided the subject altogether, probably out of concern that a disabled woman is likely to experience sexual rejection. A closely related risk factor is a lack of acknowledgment that women with disabilities have the same right to reproductive freedom as women without disabilities. An undermining of their reproductive options sometimes resulted in women having limited information about the choices that are available to them, including their ability to safely carry a child and to care for a baby following its birth.

The ability to separate motherhood from their identity as women is the most salient protective factor at the micro level of analysis. Most study participants demonstrated a strong sense of self as women without children. Their criticism and rejection of traditional ideologies helped them forge a positive female identity apart from motherhood. One woman explicitly referred to this when she noted that she always knew that she doesn’t have to be a mother to be a worthwhile person. Having strong bonds with other women and being active in careers, grassroots organizations, and leisure activities, were also important protective factors. Receiving positive and affirming messages about their right to reproductive self determination was also conducive to well-being. The interplay between micro level risks and protective factors can be illustrated in the relationship between one participant and her parents. Although these parents were reluctant to acknowledge their daughter’s sexuality in childhood and were ambivalent about her being in relationships as a young adult, they were described by the daughter as very loving and supportive. Now a mature woman, this participant attributes her parents’ attitude to discriminatory and oppressive societal norms regarding sexuality and disability. Her love for her parents notwithstanding, she further asserts her right to choose her own course in life.
### Table 2: Women Who Are Not Mothers: Risks, Protective Factors, and Possible Interventions.

<table>
<thead>
<tr>
<th>Micro Level</th>
<th>Risks</th>
<th>Protective Factors</th>
<th>Possible Interventions</th>
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<tbody>
<tr>
<td></td>
<td>* sexuality not acknowledged by family members&lt;br&gt; * experiences of sexual rejection and devaluation by men&lt;br&gt; * being discouraged from choosing motherhood&lt;br&gt; * choices not being acknowledged and respected&lt;br&gt; * concerns about division of labour within the family (i.e. will partner be an active participant in child care?)&lt;br&gt; * concerns about social isolation&lt;br&gt; * not knowing how the disability might impact own ability to carry out child care duties</td>
<td>* families that recognize sexuality and respect choices&lt;br&gt; * affirming messages from friends&lt;br&gt; * strong sense of self as a childless woman (separating motherhood from female identity)&lt;br&gt; * strong bonds with friends, some of whom are also women with disabilities without children&lt;br&gt; * having rewarding relationships with children (nieces, nephews, friends' kids)</td>
<td>* form connections with other women, including women with disabilities who do not have children&lt;br&gt; * affirm the right to reproductive self-determination in contacts with family, friends, and the community at large&lt;br&gt; * obtain information on motherhood in the context of disability, including available resources and supports that may be accessed</td>
</tr>
<tr>
<td>Meso level</td>
<td>* being discouraged from having children by health-care professionals&lt;br&gt; * not getting sufficient information that could expand choices&lt;br&gt; * concerns that negotiating for formal supports with child care will be difficult and perhaps futile</td>
<td>* an information and support group organized by a women's health organization&lt;br&gt; * a mothering conference which provided opportunities for information and networking</td>
<td>* in medical settings, convey positive messages to women and families re: reproductive choices and the right to self-determination&lt;br&gt; * furnish women with information that can serve to expand their options&lt;br&gt; * keep up-to-date on the most recent literature on parenting with a disability</td>
</tr>
<tr>
<td>Macro level</td>
<td>* societal messages that women with disabilities are undesirable as sexual partners&lt;br&gt; * societal messages that such women are in need of care and cannot provide care&lt;br&gt; * insufficient and inconsistent allocation of resources that could facilitate parenting tasks</td>
<td>* active participation in feminist and disability consumer groups that strive to expand images of womanhood and motherhood</td>
<td>* resist and strive to change restrictive and oppressive images of female sexuality and attractiveness&lt;br&gt; * resist and strive to change restrictive images of motherhood</td>
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</table>
Risk factors at the meso level of analysis include a lack of information about reproductive options in the context of a particular disability. I include this as a meso level risk as it speaks to the void in information made available to women by physicians and other health-care professionals. In some cases health-care professionals actively discouraged women from considering motherhood. An example in point is the physician who was eager to schedule an appointment for a tubal ligation for a young patient who was merely inquiring about her options. The disparity in knowledge about the reproductive health of disabled versus non-disabled women was noted in the literature review and can be detrimental to the well-being of women with disabilities. Participants were also uninformed as to what formal supports might be available to help them carry out child care responsibilities. More importantly, they were pessimistic about their ability to receive this assistance in the current political climate of competition for scarce resources.

As I indicated in the previous section, risks at the meso level can often be counteracted or buffered by micro level protective factors. Women were critical of institutions and professionals who undermined their right to make choices. Some also demonstrated their intent to fight discriminatory practices should they choose to pursue motherhood. One very specific meso level protective factor was a support group initiated by a women’s health organization. The intent of this group was to provide an opportunity for women with disabilities to explore mothering-related issues in a supportive environment. Despite the initial intent that this group would serve women with and without children, it was attended by a small group of women who were interested in exploring motherhood. This eight session information and support group covered various areas of interest such as childbirth options, assistance with child care, and behaviour management for parents with disabilities. Two participants who attended this group made reference to its positive
impact on their lives and meaning-making. They especially noted the salutary effect of sharing stories and experiences with women who face similar issues. Involvement in feminist and disability grass-roots organizations can also serve an important protective function.

At the macro level, risk factors pertain to both cultural perceptions and allocation of resources. Images of women portrayed in print and electronic media, leave no doubt as to what is considered desirable in a woman. Images of women with disabilities rarely fit that picture. The prevailing culture of sexuality makes no room for the inclusion of women who do not fit the prototypical image. Experiences of rejection conveyed by study participants are reflective of the restrictive concept of the desirable woman. A poignant example of this was given by two participants in almost identical stories. Both recounted how men they met at nightclubs were interested in them so long as their disability was not apparent. The men promptly took their leave when the disability became obvious.

Societal portrayals of the ideal mother are similarly constricting. Almost without exception, mothers are portrayed as young, vibrant and with an unlimited reservoir of energy and strength. This invisibility of mothers with disabilities in the public eye, is reflected in the meagre supply of resources available to them. The impact of scarce resources is felt in the relationship between women with disabilities and their families. Restrictive messages from parents reported by some participants, may well relate to the former’s concern about the lack of practical and financial assistance accorded to parents with disabilities. In the absence of such resources, parents may envision themselves as having to provide such supports. This is an example whereby a risk at the micro level is exacerbated by dynamics operating at the macro level. Expanding images of motherhood to include women with disabilities, and expanding images of femininity to include
women without children, may prove to be an important macro level protective factor.

The risk and protective factors outlined above can guide strategies and interventions at the three levels. The importance of connections with other women suggests that this is a worthy investment for women with disabilities. The definition of a family need not be restricted to spouse and children or even to blood relatives. Strong and lasting friendships often take on family-like characteristics and can be conducive to wellness. Affirming the right to reproductive self-determination is another important micro level strategy. Several participants gave examples of educating others within their families and communities about these issues. This awareness promotion can have a positive effect not only for the women themselves but also for future generations of women with disabilities. Beyond affirming their right to reproductive self-determination, disabled women without children should avail themselves of information pertaining to motherhood in the context of disability. For some participants, the decision to refrain from motherhood was intertwined with the scarcity of information available to them. Information can be a source of strength and should serve as the backdrop to whatever reproductive choice women ultimately make.

Meso level strategies and interventions are contingent upon empowering and respectful attitudes of health care and other professionals. Professionals who come in contact with parents of children with disabilities can convey positive messages about future prospects. In the case of girls with disabilities, this should include visions of mature women making informed choices about relationships and reproductive options. The potential that this can have in enhancing the self-determination of adult women was alluded to by two focus group participants. One woman lamented that within her own family and ethnic community, “it’s difficult to get it into their heads
that women with disabilities can become mothers". The other participant added: "My family needs some awareness...of the possibility of me having a child". Professionals can play an important role in facilitating this awareness. The importance of empowering messages notwithstanding, furnishing women with information that will expand their choices is within the purview and the responsibility of health care professionals. In the literature review I mentioned the recent interest and surge of information on reproductive issues for people with disabilities. It is imperative that information on research being conducted in large medical and rehabilitation centres be disseminated to and accessed by service providers.

Macro level protective factors have clear implications for macro level interventions. Changing restrictive and oppressive concepts of female sexuality and attractiveness must take place at a variety of settings such as schools, hospitals, and grass roots movements. Hegemonic notions of sexuality that permeate these institutions should be resisted and deconstructed. The same strategy of resistance should be applied to restrictive images of motherhood. Narrow conceptions of motherhood limit the scope of available resources. Different types of mothering require different types of resources. An expanded notion of motherhood would naturally lead to a wider definition of acceptable resources. This would give more meaning to the notion of reproductive choice for women with disabilities. "Choosing" to remain childless due to lack of appropriate supports might well be considered a contradiction in terms.

Mothers with Disabilities and Their Families:

Risks, Protective Factors, and Possible Interventions

Data pertaining to mothers supports claims made in the literature regarding the scarcity of information on pregnancy and disability (see table 3). This was a micro level risk factor for some
of the mothers who participated in the study. One woman noted how she longed to speak to another pregnant woman with a similar disability. Another pregnant participant had difficulty getting information even after contacting the umbrella organization associated with her disability. The birth of a baby precipitates other stressors for mothers. At the micro level, these stressors pertain to insufficient or inadequate supports from partners and others and to a generally weak informal support system. One mother described her daily routine whereby all of her time and energy is expended on meeting the needs of her baby. Another mother recounted the difficult period following her diagnosis. Having a toddler, an infant, and a recently diagnosed disability, support was not extended by her then-husband, family, or friends. Another micro level risk factor is the lack of communication between one young mother and the home makers who were contracted to help the family. I include this as a micro level risk due to the interpersonal nature of this variable. The inability to carry out certain activities with children was also noted by several participants and can be taxing for families.

The risk factors noted above notwithstanding, the data is rich with examples of micro level protective factors. At the personal level, these include creative alternatives for traditional methods of caring for babies, working with assistants while maintaining the role of primary caregiver, and having strong communication and advocacy skills to obtain services for children. The interplay between micro level risk and protective factors is apparent in the case of the mother who found herself newly diagnosed and devoid of informal supports. With an infant who was experiencing health problems in conjunction with her own failing health, this mother and her family were clearly at risk. Her ability to advocate and set in motion a host of health-enhancing formal supports was a crucial buffer in moderating a potentially overwhelming situation. This
mother, and several others, emphasized their role in coordinating and directing the supports they are receiving. Hence, regardless of the extent of their disability or the activities with which they require assistance, they clearly function as effective parents. Other micro level protective factors include supportive spouses and assistance from extended family members, typically mothers.

The stories of mothers with disabilities are replete with examples of meso level risk factors. At the pregnancy phase, some physicians undermined the significance of the disability. One participant, now the mother of adult children, attributes the worsening of her condition to negligent physicians. As a very young and inexperienced recipient of health services, she did not think to question her physicians’ judgment. Conversely, another participant switched physicians when she came across a similar attitude. A confident and mature woman and an informed consumer, this participant had the internal resources that served as a buffer against meso level risks. Another participant was advised and even pressured to “consider” an abortion by health-care professionals. Other meso level risk factors include negative experiences on the maternity ward and contacts with professionals (home makers, child protection workers) who were perceived as burdensome rather than supportive.

Meso level protective factors were also noted by participants. The same woman who encountered intrusive questioning on the maternity ward, also had positive experiences during her hospital stay. She spoke fondly of a nurse who facilitated her efforts to breast-feed and of a young doctor who expressed confidence in her ability to cope with the new situational demands. Another participant who faces multiple stressors, was encouraged by an affirming message from an occupational therapist. When she was feeling vulnerable and overwhelmed by the demands of motherhood, the therapist responded by pointing out how happy and well cared for the baby
Table 3: Mothers with Disabilities and Their Families: Risks, Protective Factors, and Possible Interventions.

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<thead>
<tr>
<th>Micro Level</th>
<th>Risks</th>
<th>Protective Factors</th>
<th>Possible Interventions</th>
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<tbody>
<tr>
<td></td>
<td>* having inadequate information on pregnancy and disability</td>
<td>* detailed planning for the baby’s birth facilitated a smooth transition to motherhood</td>
<td>* strive to be an informed consumer of services and a proficient self-advocate</td>
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<td></td>
<td>* insufficient or inadequate supports from partners and others</td>
<td>* strong communication and self-advocacy skills</td>
<td>* network with other mothers with disabilities for the sharing of information, expertise, and mutual support</td>
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<td></td>
<td>* expending all time and energy on meeting children’s needs</td>
<td>* ability to find alternative methods of caring for baby or arranging for others to provide care</td>
<td>* develop effective parenting skills</td>
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<tr>
<td></td>
<td>* inability to carry out certain activities with children</td>
<td>* contributing to the care and well-being of the children despite the limitations</td>
<td>* seek and/or create alternative ways of caring for children, taking into consideration both the needs of the child and those of the mother</td>
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<td></td>
<td>* difficulties communicating with homemakers</td>
<td>* having adequate supports (mainly from partners and mothers)</td>
<td></td>
</tr>
<tr>
<td>Meso Level</td>
<td>* pressure to terminate pregnancy</td>
<td>* professionals (nurses, physicians) who are encouraging, supportive, and focus on strengths</td>
<td>disability consumer organizations should:</td>
</tr>
<tr>
<td></td>
<td>* disability either under-emphasized or over-emphasized by physicians during pregnancy</td>
<td>* workers (such as nurturing assistants) who facilitate mothering</td>
<td>* facilitate networking opportunities for mothers with disabilities and their families</td>
</tr>
<tr>
<td></td>
<td>* unhelpful reactions/attitudes on the maternity ward and by attendants</td>
<td>* teachers who do not regard the parental disability as a detriment to the child</td>
<td>* provide training opportunities that enhance mothers’ abilities to be informed consumers of services</td>
</tr>
<tr>
<td></td>
<td>* professional involvement (i.e. home makers, child protection workers) that is perceived as unhelpful by the mother</td>
<td>* organizations and consumer groups that facilitate networking opportunities and help mothers become better consumer of services</td>
<td>* provide training opportunities for service providers and professionals that come in contact with mothers with disabilities and their families</td>
</tr>
<tr>
<td>Macro Level</td>
<td>* insufficient and inconsistent allocation of resources that could facilitate parenting tasks</td>
<td>* having access to funded assistance with child care (as needed)</td>
<td>* consumer organizations should strive to expand their mandate to include challenging unjust policies that have an adverse effect on mothers with disabilities and their families</td>
</tr>
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<td></td>
<td>* professional and research literature which focuses on the risks of parental disability to children’s well-being</td>
<td>* professional and research literature which focuses on conditions and contexts that promote wellness for mothers with disabilities and their families</td>
<td>* feminist organizations should include mothers with disabilities in political and academic discourses on motherhood as well as actively lobby for resources that would meet the needs of these mothers and their families</td>
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<td></td>
<td>* societal attitudes which presume same as above</td>
<td>* changing trends in the professional literature in the above-mentioned direction</td>
<td></td>
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<tr>
<td></td>
<td>* mother blaming in professional and research literature and in society at large</td>
<td>* consequently, greater tolerance by the public for diverse ways of parenting and difference paths to wellness</td>
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appears. She further noted how impressed the professional team is with the mother’s ability to cope. This affirming and empowering message had a positive impact which remained with this mother. Two mothers have funded assistants who help them with child care. The assistants work under the direction of the mothers in order to facilitate the latter’s mothering tasks. Having had a number of such helpers over the years, both mothers reported consistently positive experiences. One mother who has a number of part time helpers, described a collaborative, family-like relationship between the assistants and the family.

The most pernicious and wide-ranging macro level risk factor is the insufficient and inconsistent allocation of resources. The presence or absence of financial and practical supports is determined by government priorities. Social policies set by elected officials shape the extent and quality of services available to citizens. Agencies operating at the meso level work within the financial parameters established by higher level officials. The political context within which workers make decisions affects their ability to render valuable services. Ultimately, what mothers with disabilities receive in the way of funded assistance, is directly related to the importance cabinet ministers ascribe to the well-being of this population. Therefore, one must examine the level of services available in light of prevailing social norms and resource allocation established by politicians and their helpers.

However removed and hidden from the public eye are the offices where budget allocations are made, they have a direct and unrelenting impact on the lives of people experiencing vulnerability. As Prilleltensky has noted, when obscure legislative changes minimize benefits to disempowered groups, “we can’t easily tell who is to blame, even though there is a definite human hand writing that legislation” (I. Prilleltensky, 1996, p. 315). Much like there is a human being
producing these policies, there are real women and families suffering from their consequences.

Two brief examples, one deriving from my research and the other from the experience of a community member, illustrate this notion. Both cases involve mothers who are independent as far as their own self care is concerned but are physically incapable of caring for young children unassisted. Both rely rather heavily on their personal support system in looking after their children. These mothers have been unsuccessful in their efforts to obtain funding for assistance with child care. Their goal was to secure some funding that would enable them to hire an assistant that would be at home with them rather than in their absence - much like the examples of the two participants who have such assistance. Ironically, having the ability to carry out their own self care unassisted, thwarts the likelihood that these mothers will receive the help they need in order to care for their children. One of the mothers was recently turned down for short-term assistance with her toddler so that her husband could attend an out of town convention. The other mother hoped to alleviate her heavy reliance on her own mother by getting some funded resources. Inability to access such resources runs the risk of eroding a rather solid informal support system by overtaxing it. A partner should be able to attend the occasional out of town convention and a grandmother should not be the sole source of help.

As can be expected, examples of macro level protective factors are few and far between. Two such examples are the families who have funded assistance which facilitates the mothers’ caring tasks. While one mother receives only a few hours of assistance a week, the other mother receives supports that are significantly more extensive. Dissimilar contexts and family constellations likely account for this difference, as one mother has a wider informal network than the other. The allocation of services according to a global assessment of needs, illustrates a
constructive meso/macro level approach. It further illustrates the futility of making global assumptions about resources required by mothers with disabilities as a group. Rather, the need, and the consequent allocation of resources, should be determined by a multiplicity of factors. The mother’s functional strengths and limitations and the availability of informal supports are but two examples of factors that need consideration.

Before shifting the focus to possible interventions, Another macro level protective factor is briefly noted. In the literature review I critiqued professional and research literature which magnifies the risks posed by parental disability, thereby perpetuating oppressive ideologies. Conversely, literature can be found which focuses on conditions and contexts that promote wellness for mothers with disabilities and their families. Just as the former can constitute a risk factor, the latter can have protective attributes. In addition to making a positive contribution to knowledge, such literature can foster tolerance by professionals and by the public at large for diverse ways of parenting and different paths to wellness.

The shrinking of the social safety net and fierce competition for dwindling resources, has implication for strategies and interventions at all levels of analysis. Beginning with the micro level, mothers with disabilities who are in need of services and resources need to be strong self advocates. Examples from the research demonstrate the benefits of knowing how to advocate for oneself and one’s family. The importance of being a persistent and determined consumer was articulate by one mother. In response to my question of what advice she would give to a disabled woman who wishes to become a mother, this participant replied:

You have to be strong in your commitment...you have to find out about resources and find people like myself who are willing to go the extra mile to help you...you have to fight for
them (services) and not buy into other people’s beliefs of you can’t do this and you can’t
do that. Don’t let other people’s agenda be yours. Have your own agenda of what you
want to do and stick to that even though many obstacles are put in your way. You have to
find ways to overcome them. If I can’t get in the front door I go in the side door. Or the
back door. Or I create a door.

This forceful quote illustrates not only the importance of being a strong self advocate, but also the
benefits that can be derived from collective action by people engaged in a same cause.

Furthermore, networking with other mothers with disabilities can serve an important supportive
function. Mothers can also learn from the experience of others who dealt with similar challenges
and circumstances.

Another important micro level strength and one which is related to advocacy, is the ability
to clearly communicate needs and priorities. The participant who reported negative experiences
with home makers, may have benefitted from assistance in communicating with her helpers. Data
gathered from this participant suggests a wide yet unarticulated rift between her conception of a
home maker and that of the assistant.

It is also important to pay attention to the development of effective parenting skills.
Establishing clear communication and consistent boundaries with children from an early age,
facilitates a favourable and cohesive family climate. Several participants showed a good deal of
ingenuity in fostering an enjoyable yet manageable family atmosphere. These mothers can be a
source of knowledge and inspirations to disabled and non-disabled mothers alike. The benefit of
mutual exchange of expertise, underscores once again, the need for networking and peer support.

Forming networks that connect mothers with disabilities is not a simple task. Meso level
service organizations and consumer groups can do much to aid in the formation of such networks. Efforts of this nature have been launched with some success in Ontario by consumer organizations like the DisAbled Women’s Network and the Centre for Independent Living. Some of their efforts include creating a registry for disabled parents and hosting support meetings in accessible locations. The unquestionable merit of such initiatives notwithstanding, these programs haven’t always struck a responsive cord in their intended audience. It is quite likely that consumers expect from these groups more than what the organizations can provide in the current financial climate. Expectations of practical help by consumers, cannot always be satisfied by the agencies. An example in point is the unsuccessful attempts of some mothers to receive funded assistance with child care. Although consumer organizations can help such mothers manoeuvre their way through bureaucracies, there is little they can offer by way of material assistance. Once again we witness at the meso level, the impact of macro level cut-backs.

The limitations noted above notwithstanding, I have witnessed through my involvement with several consumer organizations how helpful some of their initiative really are. In addition to the important role they play in helping people become more informed consumers of services, they also offer training to professionals in meso level organizations. In doing so, they reinforce the notion that change ought to take place not only within the recipient, but also within the provider of services. These initiatives should be continued and extended to meet the particular needs and challenges of parents with disabilities.

Consumer organizations have a mandate to develop and implement interventions at the micro and meso levels. Extending their mandate to macro level strategies may be a politically contentious issue. As macro level efforts may include challenging policies set by those who fund
them, these organizations walk a delicate tight rope. The unquestionable desire to help consumers may be at odds with the limited mandates set by funders. Given the constraints experienced by these organizations, it is important that their efforts be supported by independent and progressive groups. Independence from governments affords social action bodies an opportunity to challenge unfair policies without apprehension of jeopardizing funding.

Feminist organizations have a clear role to play in promoting the well-being of women with disabilities and their families. Along with disability consumer groups, they must insist on the inclusion of mothers with disabilities in political and academic discourses on motherhood. One such noteworthy effort was the inclusion of disabled mothers' issues in a feminist conference on mothering at York University (September 1997). The call for papers clearly noted disabled mothering as one of the themes that should be addressed. Hopefully, efforts such as this can stimulate both academic and action research aimed at improving the lives of women with disabilities.

Concluding Comments

The thrust of this discussion has been the promotion of wellness for women and girls with physical disabilities. As I bring this dissertation to a close, I would like to switch the focus and remind the reader of the potential of this group of women to enhance the wellness of others. Beyond their ability to nurture children and families, women with disabilities make significant and valuable contributions to other marginalized groups and to society at large. I need only scan my data to find examples of such contributions. There is the trailblazer who advocated for supported living in the community and for nurturing assistance. Her efforts paved the road for other people with disabilities. There is the woman who knew that she had to leave home in order to protect her
spirit. The plight she went through as a child was a driving force in choosing a helping profession: “I had made a promise to myself that some day I would get into something where I can help another person. Help another disabled child who was going through those struggles.” There is the young mother who, in spite of the stressors in her own life, makes time for volunteer work with teens at risk. And there is the mother of adult children who dedicates most of her time and energy to volunteer work: “I thought that I’ve got to do something with my life...I just had to do something, I couldn’t just waste away and not mean anything. Life has to mean something.” Indeed, the stories of these women underscore how valuable their lives are, not only for themselves and their loved ones, but also for the rest of us.

These snippets of participants’ lives and meaning making give credence to the centrality of the concept of resilience discussed earlier. However, as one of the leading forces in resilience research reminds us, there is both great promise and danger in this concept (Garmezy, 1994). The danger “lies in the sudden popularity of the concept of resilience. Risk has its base in epidemiology; resilience has its base in drama. The drama is that of the ‘American dream’, the Horatio Alger legend - the mistaken view that any and all could succeed were they to work hard. These are myths that need rejection” (p. 13). The dramatic stories of courage and determination I was privileged to collect in the process of the research, should not lead us to romanticize the notion of resilience. Despite the inspirational value of these stories, Garmezy’s caveat should not go unheeded. Our attention should not be diverted from the potentially deleterious consequences of sustained exposure to disempowering living conditions. The struggle of women with disabilities is intimately tied with the struggle for social justice. For as long as governments have their policies set by powerful interest groups concerned with economics more than with human needs,
the welfare of people with disabilities and other vulnerable groups will continue to be at risk (I. Prilleltensky, 1996).

Striving for social justice for a marginalized group requires that its members be given a voice in the struggle. This research afforded a voice only to a segment of women with disabilities. For the most part, women who participated in my study are well-educated professional women who lead productive lives. None are members of a visible minority or belong to a lesbian community. Thus, the research is limited in its ability to explore the intersection of gender and disability with other social constructs such as race and sexual orientation. Also unexplored are the implications of this research to women who live with different types of disabilities. These limitations notwithstanding, the findings and framework for analysis and interventions articulated in the study may prove beneficial to future researchers.

Back to the Personal

The end point of a dissertation is inevitably arbitrary. There is always more to explore, more to think, more to write. I choose to end the dissertation by coming “home” to the personal and sharing a meaningful story of being myself a mother with a physical disability.

It was a bitterly cold winter morning in Winnipeg, the sort of morning you want to stay in a nice cozy bed. Of all days, my husband had an early morning meeting at work and could not take three and a half year old Matan to pre-school. I would have to take him on my way to work. There was only one child to be dropped off and the pre-school was immediately next to our home. However, this seemingly simple task was not easy for me as a disabled mother. There was no parking right next to the building so I decided to walk Matan to pre-school and then come back for my car.
Matan was somewhat fussy that morning; young children have a special talent for taking their time when they sense parental pressure to hurry. We left later than we should have, I walked faster than I should have and promptly found myself on a cold, snow-covered ground. For a moment, I felt a mixture of irritation and concern. I was irritated with my husband who had to leave early, and with my young son who took his time. Befittingly, my knee-jerk reaction was: “We should have left earlier.” However, Matan’s question of “Is it my fault mom?” quickly dissipated my irritation. I assured him that he is in no way responsible and that we will find a solution. I was still on the ground, however, unable to get up unassisted. Concern took over. It was -25 and there was no one in sight. Several cars past by; however, I doubted that they could see us behind the colossal snow banks that separated the sidewalk from the road. Matan extended his little arm: “I’ll help you get up, mom.” I explained as best I could under the circumstances, that he is not strong enough to lift me up; only an adult could do that. I felt the chilling wind and noticed that Matan’s face was getting red from the cold. Doing my best to stay calm, I told him to walk to the building and ask someone to come and help me. He took several steps forward and then backtracked. “But the door is too heavy for me, I won’t be able to get it open.” He was on the verge of tears; I did my best to reassure him as I considered my next step.

Another few cars passed by and the two of us waived at them frantically. I breathed a big sigh of relief when I noticed a car slowing down. I was further relieved when I saw a woman getting out; I always feel more comfortable getting this type of assistance from women. I still remember the petite and cheerful teacher who lifted me to my feet. I was impressed that a woman so small could be so powerful. We thanked her and ever so carefully, walked to the pre-school. We came in, got Matan out of his boots and snowsuit and into the class. His teacher was very
sympathetic and helped me comfort my clearly distressed child.

Along with my concern for Matan, I started to think about the meeting at work that I would undoubtedly be late for. I was a clinician in the school system and on that morning, arranged to meet with a parent and with the school. The mother, a young woman of a visible minority, was highly reluctant to come to the school. It took some convincing on my part to get her to agree to the meeting. I had assured her that I would be there. I phoned the school to inform them that I would be late and slowly, carefully, walked to my car. Luckily, I had an extra set of car keys in my wallet, as my key holder was buried somewhere under a pile of snow. When I arrived at work, I was relieved to hear that the mother called to say that she would be late. After phoning the pre-school to hear how Matan is doing, I sat down in the staff room for a cup of coffee. Finally, I had a few moments to think about myself and the impact that this experience had on me. I could not deny that it left me shaken.

Safely at home at the end of the day, Matan and I told dad what had happened. The distress no longer there, Matan was nonetheless bothered by the incident. "But I didn’t help you up," he kept repeating. I sat him on my lap and explained that he did the best he could. Following my instructions as well as he did was the best help he could have provided. A little later, Matan came up to me with some of his little toy cars. He wanted to play what had happened. "One car goes by, and doesn’t stop. Another car goes by and doesn’t stop. Another car goes by and stops." He demonstrated with his cars as he spoke. Going along with his game, I said: "This must be the nice lady who came to help us." Matan raised his head from his cars and looked at me with his brown eyes. "No mom, this is me when I am an adult. I get out of the car and help you up."
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IX

APPENDICES
APPENDIX I:

SAMPLE LETTER OF INFORMATION TO FOCUS GROUP PARTICIPANTS

DisAbled Women's Network Ontario

September 22, 1994

Dear ________

Thank you for signing up for the discussion group Disabled Mothers of Young Children, to be held at the upcoming conference. The purpose of this letter is to tell you a little bit about the group.

My name is Ora Prilleltensky. I am a physically-disabled woman, a mother, and a student. Along with the DisAbled Women's Network (DAWN) Ontario, I am doing research on the needs of mothers with disabilities and those who are considering motherhood. This discussion group is part of this research. We hope that it can help DAWN and other organizations to do a better job of meeting the mothering-related needs of women with disabilities.

The discussion group will have a leader (myself) and a helper (name of helper). We will be discussing different issues related to women with disabilities and mothering. As a participant, you will be invited to share your own ideas and experiences. Before we start the discussion, you will be asked to sign a consent form which I will review with you. This will allow me to use material from this discussion as part of my doctoral research. Your name or any other identifying information will not be used.

Thank you again for signing up for this group. I look forward to your participation. If you have any questions or concerns, please phone (name of person) at DAWN Ontario (1-800-561-4727) or myself (519-579-8377).

See you soon,

Ora Prilleltensky
APPENDIX II

EXPLANATION TO FOCUS GROUP PARTICIPANTS AND CONSENT FORM
Dear participant:

My name is Ora Prilleltensky. I am a physically disabled woman, a mother, and a graduate student. Along with the DisAbled Women's Network (DAWN) Ontario, I am doing research on the needs of mothers with disabilities and those who are considering motherhood. Toward this end, I am holding several discussion groups during this conference. The purpose of these groups is to hear different perspectives and gain a deeper understanding of mothering-related experiences, issues and priorities.

For the next hour and a half we will be discussing different issues related to women with disabilities and mothering. Although we would like your input, participation in this group is completely voluntary. Some of the things we will be discussing touch on sensitive and personal issues and may stir different feelings and emotions. Please feel free to share ideas and experiences according to your level of comfort. Also keep in mind that this is a group which is meeting one time; it is not an on-going therapy or support group. (Name of person) and I are trained counsellors; please approach either one of us if you feel you need to talk afterwards.

While I lead the discussion, a co-leader will be taking notes, which will allow us to fully capture the discussion. I would also like to tape the session to help me process the information. Myself, and possibly one other research person, are the only ones who will see the notes and listen to the tape recordings which will be kept in a locked file and eventually erased. The discussion will not be taped if any member of the group objects to this.

During the course of the discussion, some personal information may be shared with the group. In order to protect your own and other women's confidentiality, it is extremely important that all information that is shared in the room stays in the room. In the next page there is a consent form that we would like you to sign. By completing this form, you acknowledge that you understand the purpose of the discussion and you know your name and any other identifying information will not appear in any report or publication. You also indicate your commitment to respect other women's confidentiality.
and keep all discussion material anonymous and confidential.

Feedback information about this project will be available to you at a later date. All participants will either be invited to a feedback session or sent a written report. On behalf of DAWN Ontario and myself, I would like to thank you for your willingness to participate and share your knowledge and experience. Your contribution to this project is valued and appreciated.
CONSENT FORM

I am willing to participate in a focus group discussion about women with disabilities and mothering. The discussion will be led by Ora Prilleltensky, a graduate student at OISE, and may be used as part of her doctoral research. I understand that my participation is completely voluntary and that I may withdraw at any point.

Yes [ ]
No [ ]

You may quote my comments in a report or publication. I understand that you will not use my name or other identifying information.

Yes [ ]
No [ ]

Your name: __________________________
Your signature: __________________________

I understand that personal information may be shared during the course of the discussion. In order to protect the confidentiality of all participants, I agree not to discuss any personal information that is shared by group members.

Your signature: __________________________

I would like to receive feedback about this project:

Yes [ ]
No [ ]

Name: _______________________________________
Address: _______________________________________
____________________________________________________________________________________
____________________________________________________________________________________
Telephone: (____)________________________
APPENDIX III

FOCUS GROUP GUIDES
FOCUS GROUP GUIDE FOR WOMEN WITH DISABILITIES CONSIDERING MOTHERHOOD

1. Would each participant (including moderator and assistant) briefly introduce yourself and tell us something about your reasons for coming to this conference and what you hope to learn and/or gain.

2. How is mothering generally viewed in our society?

Probes

What mothering-related messages do women and girls receive?
Is that any different for women with disabilities?
how?

3. Thinking back, what were some of your earliest thoughts (that you are comfortable sharing) regarding yourself as a mother/not a mother?

Probes

Who did you share these thoughts with?
What was the response?
Did these thoughts/plans change following disability?

4. What messages have you received over the years with regards to mothering?

Probes

Positive messages?
Negative messages?
How have you been affected by these messages?

5. What have been some of your thoughts and feelings (past and/or present), about yourself as becoming a mother or not becoming a mother?

Probes

What are (or have been) some of the motivating factors?
What about the reservations?
What barriers do you anticipate?
How can they be avoided or minimized?

6. How, in your opinion, could the well-being of disabled women be enhanced for those who would like to pursue mothering as well as those who cannot pursue mothering or have decided not to?

7. What would you like to see DAWN and other disability consumer groups do in that regard?
FOCUS GROUP GUIDE
FOR
DISABLED MOTHERS OF YOUNG CHILDREN

1. Would each participant (including moderator and assistant) briefly introduce yourself and tell us something about yourself, your child/ren, your reasons for coming to this conference and what you hope to learn and/or gain.

2. How is mothering generally viewed in our society?

Probes

What mothering-related messages do women and girls receive?
Is that any different for women with disabilities? how?

3. What messages have you received over the years, regarding motherhood?

Probes

Before you had children?
When you announced your pregnancies?
After you had children?
How have you been affected by these messages?

4. As a woman with a disability, what is being a parent like for you?

Probes

Joys and rewards
Barriers and dilemmas
Impact of disability on children and family life
Impact of family life on general well-being
What role does the presence or lack of social support (from partner, family, friends, etc) play in your life?

5. What do you wish for or did you wish for in the past, that would make your job as mom easier or more rewarding?

6. What can you share regarding your child/ren's adjustment or reactions (past or present) to having a disabled mom?
7. What would you say to a woman with a similar disability who is considering motherhood and turns to you for advice?

8. What would you like to see DAWN and other disability consumer groups do to enhance the well-being of disabled mothers and their families?
FOCUS GROUP GUIDE
FOR
DISABLED MOTHERS OF OLDER CHILDREN
(ADOLESCENCE AND UP)

1. Would each participant (including moderator and assistant) briefly introduce yourself and tell us something about yourself, your children, your reasons for coming to this conference and what you hope to learn and/or gain.

2. How is mothering generally viewed in our society?

   Probes

   What mothering-related messages do women and girls receive?
   Is that any different for women with disabilities? How?

3. What messages have you received over the years, regarding motherhood?

   Probes

   Before you had children?
   When you announced your pregnancies?
   After you had children?
   How have you been affected by these messages?

4. As a woman with a disability, what is being a parent like for you?

   Probes

   Joys and rewards
   Barriers and dilemmas
   Impact of disability on children & family life
   Impact of family life on general well-being
   What role does the presence or lack of social support (from partner, family, friends, etc) play in your life?

5. What do you wish for or did you wish for in the past, that would make your job as mom easier or more rewarding?

6. What can you share regarding your child/ren's adjustment or reactions (past
or present) to having a disabled mom?

7. "If you had a chance to do it all again..." What would you do differently?

8. What would you say to a woman with a similar disability who is considering motherhood and turns to you for advice?

9. What would you like to see DAWN and other disability consumer groups do to enhance the well-being of disabled mothers and their families?
FOCUS GROUP GUIDE
FOR
WOMEN WITH DISABILITIES WHO ARE NOT MOTHERS

1. Would each participant (including moderator and assistant) briefly introduce yourself and tell us something about your reasons for coming to this conference and what you hope to learn and/or gain.

2. How is mothering generally viewed in our society?

Probes

What mothering-related messages do women and girls receive?
Is that any different for women with disabilities? How?

3. Thinking back, what were some of your earliest thoughts (that you are comfortable sharing) regarding yourself as a mother/not a mother?

Probes

Who did you share these thoughts with?
What was the response?
Did these thoughts/plans change following disability?

4. What messages have you received over the years with regards to mothering?

Probes

Positive messages?
Negative messages?
How have you been affected by these messages?

5. What have been some of your thoughts & feelings (past and/or present), about yourself as becoming a mother or not becoming a mother?

6. What, in your opinion, could enhance the well-being of women with disabilities who do not have children?

7. What would you like to see DAWN and other disability consumer groups
do in this regard?

APPENDIX IV

CONSENT FORM FOR IN-DEPTH INTERVIEW

I agree to participate in an in-depth interview on the subject of women with disabilities and mothering. The interview will be conducted by Ora Prilleltensky, a graduate student at OISE, and will be used as part of her doctoral research. I understand that my participation is completely voluntary and that I may withdraw at any point.

Yes______ No_______

I am willing to have the interview tape recorded

Yes______ No_______

I understand that I will have an opportunity to read transcripts of the interview for corrections and clarifications and take out any part that I am uncomfortable with. Furthermore, I will have an opportunity to review and edit all direct quotes that will be used in the final version of the study. My name or any other identifying information will not be used.

Participant's name: ______________________

Participant's signature ____________________

Date:______________________________

Witness:___________________________
APPENDIX V

INTERVIEW GUIDES

Women with disabilities who are considering motherhood

1. Please tell me a little bit about yourself so that I can get to know you better

Probes:
* what do you do/what is a typical day in your life?
* who are the important people in your life?
* what can you share about your disability?

2. Tell me about what it was like for you to attend the conference on women with disabilities and mothering

Probes:
* what were you hoping to gain from the conference?
* in what ways were your expectations met or not met?
* what effect did the conference have on you?

3. Thinking back, what were some of your earliest thoughts (that you are comfortable sharing) regarding yourself as a mother/not a mother?

Probes:
* who did you share these thoughts with?
* what was the response?
* did these thoughts/plans change following disability? (for those who became disabled later in life)

4. What messages have you received over the years about mothering?

Probes:
* positive messages?
* negative messages?
* how have you been affected by these messages?

5. What have been some of your thoughts & feelings (past and present) about yourself as becoming a mother or not becoming a mother?
Probes:
* what are (or have been) some of the motivating factors?
* what about the reservations?

6. Where would you like to see yourself ten years from now?

7. How could the well-being of disabled women be improved for those who would like to become mothers? How about those who cannot become mothers or have decided not to?

**Women with disabilities who are not mothers**

Variations of questions 1 through 6 from previous guide can be used with this group. In addition:

8. When you look back, is there anything you wish you would have done differently in your life?

9. What else would you like to contribute to this discussion? Are there any important issues that we missed?

**Mothers with disabilities**

Questions 1 & 2 from first interview guide

3. What messages have you received over the years regarding motherhood?

Probes:
* before you had children?
* when you announced your pregnancies?
* after you had children
* how have you been affected by these messages?

4. What is being a mother like for you?

Probes:
* joys & rewards (past and present)
* impact of disability on children & family life
* impact of children on your own health and well-being
* what sort of supports do you get (from partner, family, friends, etc.)
5. What do you wish for or (did you wish for in the past), that would make your job as a mother easier and more rewarding?

Probes:
* what are the implications for your children of having a mother with a disability?
* in what way are things different or the same for them in comparisons with other children their age?

6. How do you see your life ten years from now?

7. What would you say to a woman with a similar disability who is considering motherhood and asks for your advice?

8. “If you had a chance to do it all again...would you?” What would you do differently?

9. What, in your opinion, could be done to improve things for mothers with disabilities?

10. What else would you like to contribute to this discussion? Are there any important areas that we have missed?
IMAGE EVALUATION
TEST TARGET (QA-3)

150mm

6"

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