

Skidmore College Creative Matter

Master of Arts in Liberal Studies (MALS) Student
Scholarship

Academic Departments and Programs

8-31-2004

Facing Uncertainty, Proceeding with Caution, Living with Joy: Women with Multiple Sclerosis and the Motherhood Decision

Anne L. Van Acker
Skidmore College

Follow this and additional works at: https://creativematter.skidmore.edu/mals_stu_schol

 Part of the [Women's Health Commons](#), and the [Women's Studies Commons](#)

Recommended Citation

Van Acker, Anne L., "Facing Uncertainty, Proceeding with Caution, Living with Joy: Women with Multiple Sclerosis and the Motherhood Decision" (2004). *Master of Arts in Liberal Studies (MALS) Student Scholarship*. 35.
https://creativematter.skidmore.edu/mals_stu_schol/35

This Thesis is brought to you for free and open access by the Academic Departments and Programs at Creative Matter. It has been accepted for inclusion in Master of Arts in Liberal Studies (MALS) Student Scholarship by an authorized administrator of Creative Matter. For more information, please contact jluo@skidmore.edu.

Facing Uncertainty, Proceeding with Caution, Living with Joy:
Women with Multiple Sclerosis and the Motherhood Decision

by

Anne L. Van Acker

FINAL PROJECT SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS IN LIBERAL STUDIES

SKIDMORE COLLEGE

August 15, 2004

Advisors: Thomas A. Chambers, Susannah Mintz

TABLE OF CONTENTS

Abstract.....	Page 2
Introduction.....	Page 3
Chapter 1: Disabled Women and Reproduction.....	Page 7
Chapter 2: The Social Construction of Motherhood.....	Page 18
Chapter 3: Multiple Sclerosis: A History of Diagnosis, Treatment, and Relationship to Pregnancy.....	Page 31
Chapter 4: A Group History of Mothers with Multiple Sclerosis.....	Page 44
Chapter 5: Conclusions and Recommendations.....	Page 58
Bibliography.....	Page 64

ABSTRACT

Multiple sclerosis is a degenerative neurological disorder, affecting approximately 250,000-350,000 persons in the United States. Women are diagnosed twice as frequently as men, with the majority of those diagnoses occurring during their childbearing (typically between the ages of 20 and 40) years. For women with multiple sclerosis, the decision to bear children is complicated by numerous factors. First, conventional cultural images of motherhood rarely acknowledge women with disability of any kind as “fit” mothers. For a disabled woman to pursue motherhood often means confronting predominant ideals and frequently having to justify her decision. Second, multiple sclerosis has proven to be an enduring mystery to medical researchers. Discovered over 130 years ago, no causative agent has been identified and current treatments can merely slow the progression of the disease. Because the disease is unpredictable and there is no way of knowing the rate of disease progression, women must evaluate their current level of disability at the time they consider pregnancy and try their best to envision what their future may hold. Other complications include difficulty in accessing healthcare providers that are well-trained in the management of pregnancy and multiple sclerosis, and the limited availability of social programs and services to support mothers with multiple sclerosis. Despite these considerable challenges, women with multiple sclerosis employ strategic, adaptive approaches to their disease. Pregnancy and parenting that enable them to effectively fulfill the role of mother.

INTRODUCTION

The decision to become a mother is complicated for any woman, and requires a number of practical considerations. Not only must the prospective mother make choices regarding health care providers, financial arrangements, and child care, but she must also ask herself if she (and perhaps her partner) is prepared for this major life change. Should the prospective mother have a physical disability, she may have other questions to consider. Even if she is confident in her ability to be a good mother, will society accept her choice as rational, or irresponsible and selfish? Will her health care providers be prepared and willing to give her the kind of care and support services she may need? These concerns are understandable in a society that has very particular and strongly held ideas regarding the definition of a good and fit mother (Dally, 1982; Hays, 1996; Rich, 1986; Rothman, 1994).

The social construction of motherhood is one barrier that physically disabled women confront should they choose to bear children. Powerful media images of what “mother” is have been inescapable; for example, consider the public’s enduring memories of and fascination with made-for-television mothers (i.e., Harriet Nelson, June Cleaver, Carol Brady). Those images have come to be seen as the norm; as Evelyn Glenn states, “for most of the 20th century an idealized model of motherhood, derived from the situation of the white, American, middle class, has been projected as universal” (3). Another aspect of the idealized, socially constructed mother is that of “an unselfish nurturer” (Hays 167). A physically disabled woman will hardly resemble the aforementioned television mothers, and she will certainly have medical needs of her own to meet. Moreover, a disabled mother may face difficulties meeting the social expectations associated with physical aspects of motherhood in such tasks as bathing, chauffeuring, dressing, cooking, and playing with their

children. The physically disabled woman faces formidable challenges when she confronts the socially idealized version of “mother,” for she may differ from that image in many ways.

Authors Ferdinand Lundberg and Marynia Farnham, in their best-seller of 1947, *Modern Woman: The Lost Sex*, maintained that the woman’s role as mother was essential to her validation as a woman (Dorenkamp 228). While it is recognized that this book was written prior to widespread availability of effective contraception and therefore women’s ability to choose whether or not to have children, this concept of motherhood as crucial to the full identity of a woman has a long history. Adrienne Rich notes that recorded history shows a consistent theme wherein “the ‘childless’ woman has been regarded (with certain specific exceptions, such as the cloistered nun or the temple virgin) as a failed woman, unable to speak for the rest of her sex, and omitted from the hypocritical and palliative reverence accorded the mother” (251). To forego motherhood, then, is to be excluded from an institution that is viewed as “the foundation of human society as we know it” (Rich 39). While motherhood may no longer be considered a necessity to validate one’s womanhood, the idealized image of mother is still prevalent in society. Because she deviates from the prevailing norm, the physically disabled woman who desires motherhood may find herself trying to attain entry into a culture club that will only grudgingly, if at all, grant her admission.

Women with multiple sclerosis provide a particularly relevant group study for the examination of disabled women and the difficulties they surmount in attaining motherhood. A chronic neurological condition, multiple sclerosis is frequently diagnosed in early adulthood, is more prevalent in women than men, and is most frequently diagnosed in

women of childbearing age than in any other age group (Centers for Disease Control; National Multiple Sclerosis Society, “Pregnancy” 1). A profoundly complicated disease, multiple sclerosis has defied researchers’ attempts to identify its exact cause; work begun over 150 years ago has yet to provide definitive conclusions (Hickey 43).

As multiple sclerosis progresses, a patient can expect a progressive loss of mobility in her limbs, as well as sensory losses throughout the body, with periods of exacerbations (commonly known as “flare-ups”) during which the patient will experience more intense symptoms. How extensive and severe the patient’s eventual disability may become varies from patient to patient and cannot be predicted. For a woman of childbearing age with multiple sclerosis, the decision to bear a child is made much more difficult, as she has no idea how her disease progression may eventually affect her and her ability to care for a child. Adding to this prospective mother’s uncertainty is the medical community’s confusing messages regarding pregnancy and multiple sclerosis. Before 1950, most women with multiple sclerosis were counseled against pregnancy in the belief that it could adversely affect their disease’s course. After a landmark study in 1950 that found little evidence of pregnancy affecting the course of multiple sclerosis, subsequent studies have found that pregnancy may actually have a protective effect on the patient by reducing the number of exacerbations, especially during the second and third trimesters (Birk and Rudick, 1986; Damek and Shuster, 1997; Dwosh et al., 2003; Lorenzi and Ford, 2002; McNary, 1999; National Multiple Sclerosis Society, “Pregnancy” 1; Watkiss and Ward, 2002).

Damek and Shuster have found that the frequency of childlessness in the multiple sclerosis population is significantly greater than in the general population (1977). This

statistic is the result of numerous factors, including, but not limited to, attitudinal and physical barriers from society and the medical profession. This paper will analyze these factors by examining the reproductive rights of disabled women, the meaning of motherhood in American culture, the medical profession's approach to the treatment of pregnancy and multiple sclerosis, and the personal experiences of mothers with multiple sclerosis. Without appropriate support and care, women with multiple sclerosis are denied a fair opportunity to experience an important aspect of their lives as women and to contribute their valuable and relevant insights on motherhood to society.

Chapter 1: Disabled Women and Reproduction

It is only recently that women have realized their ability to choose whether to become mothers or not. Young girls are now encouraged to pursue any career of their choosing, but according to scholar Ora Prilleltensky, the majority of women still continue to view motherhood as an integral component of their current or future identities (22). Yet, as is the case with other marginalized groups, women with disabilities are actively discouraged from becoming mothers, thus denying them an opportunity to express this aspect of their identities to which they may be perfectly well suited and certainly entitled.

There are many social myths surrounding disabled women that prevent society from viewing them as “normal” mothers. Prevalent myths hold that disabled women are unable to meet the health and competency requirements of most jobs, that rewarding physical and emotional relationships (with men, in particular) are not a realistic expectation, and that disability can only serve as a hindrance, not an enrichment, to any relationship (Mairs 126). These myths underscore the ignorance with which many view the lives and capacities of disabled women, and bring to mind the eugenics movement of the past with its fear of perpetuating disability, both physical and mental, among the human population.

Because disabled women have been actively discouraged by family, friends, and the medical profession from bearing children, there is relatively little published research comparing aspects of disabled vs. nondisabled motherhood. Basic demographic statistics, such as the number of disabled women of childbearing age, their fertility rates, pregnancies, births, and abortions, are rarely published (Prilleltensky 22). In the broader subject area of sexuality and disability, Susan Daniels et al. state that it was not until the early 1980’s that there was a considerable body of literature on this topic (83). This lack of research is

puzzling, given the numerous studies on children with disabilities and the legislation that has been implemented for improving their education and access to it. Do these disabled children not grow up to become functioning adults in society? Rhoda Olkin finds this lack of research on disabled women to be “as if families have children with disabilities and then these children disappear from the face of the earth” (qtd. in Prilleltensky 42).

Indeed, disabled girls do grow up to become disabled women, with many of the same future aspirations as their nondisabled peers, including marriage and motherhood. However, they have often been subjected to societal stereotypes and attitudes that can discourage them from becoming mothers. The myth that being disabled equates with being asexual is well documented in the literature that is available on disabled women (Kallianes and Rubenfeld 205). The perpetuation of this stereotype has continued via parents who, though perhaps well-meaning, have prepared their daughters for a life focused on developing a career, not a family; in addition, medical professionals have not given disabled women adequate and accurate information on sexuality and reproduction (Shaul et al 365; Kallianes and Rubenfeld 205-209).

By denying disabled women any recognition of their sexuality and reproductive capacity, a message is sent which tells disabled women that they are not intended to be mothers, because they are not “normal” women. This message is powerful because it creates an image of disabled women as “other,” lacking in status compared to nondisabled women. Nancy Mairs refers to this state as being exiled from “normality,” and describes its discouraging effect on disabled life:

Whether imposed by self or society, this outsider status – and not the disability

itself – constitutes the most daunting barrier for most people with physical impairments, because it, even more than flights of stairs or elevators without braille, prevents them from participating fully in the ordinary world, where most of life's satisfactions dwell (126-127).

Mairs' words eloquently describe what had been termed in the arena of disability discourse as the social model of disability. In this particular viewpoint on disability, the affected individuals experience numerous forms of exclusion due to the many social barriers that are designed to hinder the life experiences of those with physical impairments. According to Carol Thomas, this "*dis-ability*" derives from "*disableism*": "the ideological antipathy to what is considered to be undesirable physical, sensory, or mentally-related difference or 'abnormality' in Western culture" (623). This viewpoint differs from what is known as the medical model, wherein the focus lies on the specific condition that has given rise to some limitation of physical or mental ability.

By examining disability from the perspective of the social model, the barriers to motherhood for the disabled woman become very clear. At the base of such barriers lies society's fascination and discomfort with deviation from normal (e.g., the freak shows of Victorian America). Rosemarie Garland Thompson feels these reactions to the extraordinary body are deep-rooted in society, claiming that appearances that stray from the expected norm have always been a source of discomfort and conjecture for those more typical (1). As our society became modernized, the resulting mechanization created a sameness that came to be expected in most aspects of everyday life. This expectation of predictability and uniformity extended to the human body as well, and was reinforced by the rise of a medical profession

that deemed all departures from normal as pathological (Thompson 12).

While the disabled mother may not currently be viewed as pathological, society tends to view her unfavorably. This perspective is fueled by subscription to the myths that disabled women are asexual, dependent, and incompetent. Such myths render an outlook that precludes one from viewing the disabled woman as being capable of discharging the typical functions of mother. If the primary role of mother is that of sole caretaker and nurturer (one who must feed, dress, chauffeur, nurse, discipline), how will a disabled woman possibly accomplish these responsibilities? Susan Shaul et al. claim that the majority of people have difficulty imagining how those with disabilities function and take care of themselves, and so cannot imagine them being able to appropriately care for children as well (374). One problem with this line of thinking is that it focuses on the physical tasks of mothering, with little regard for the human interaction that makes up the essence of parenting. A study by Shaul et al. on disabled women's perspectives on mothering finds that these women are convinced that physical perfection is not a necessity for good parenting; rather, as one disabled mother states, "love, warmth, and a willingness to share that with a child – it has to do with being human and that is something we all share" (374).

The myths surrounding disability contribute to its social construction by narrowly defining our expectations of how specific tasks, such as parenting, are to be performed. This line of thinking rules out alternative methods of accomplishing parenting objectives, thereby denying the validity of a disabled woman's approach to motherhood and setting up this barrier as described by Susan Wendell: "...many women with disabilities are discouraged from having children because other people can only imagine caring for children in ways that

are impossible for women with their disabilities, yet everything necessary could be done in other ways, often with minor accommodations” (39). This lack of accommodation, in terms of social outlook and in physical and environmental assistance, has proven remarkably effective at excluding disabled women from pursuing motherhood.

One aspect of the social barrier that compounds the narrow-minded thinking that prevents society from seeing disabled women as capable mothers is a concept Wendell terms “pace of life” (37). In our automated, wired world, with its overwhelming focus on doing more and doing it quickly, those who have physical or mental limitations simply cannot live their lives in accordance with what have become the expected ways of living. A disabled woman will therefore be seen as one whose performance as a mother cannot keep pace with that of a nondisabled woman, casting doubt on her fitness as a mother. Disabled mothers are assumed incompetent unless they are able to prove themselves otherwise.

Wendell proposes that as the pace of life increases, so must efforts to enhance accessibility for those who must perform at a slower tempo (38). Without forms of accommodation in workplaces and public facilities, society has created disability by excluding people from fully engaging in all aspects of life (Wendell 40). This creation of disability has, at worst, effectively excluded a group of women from fulfilling their roles as mothers, or at the very least, made the attainment of motherhood an unnecessarily difficult journey.

One of the ways in which society has perpetuated its discomfort with deviation from the normal is by failing to incorporate the experiences of those with disabilities into the culture. By keeping images of disability hidden or otherwise ignored, fear of disability is

encouraged as the ways in which disabled people live remain unknown. Media images have portrayed those with disabilities according to various stereotypes (i.e., dependent, asexual), that, unless one has personal experience with disabled people, lead one to believe that these depictions are accurate. It comes as a surprise, then, to see a disabled woman insisting on participating in life events, such as mothering, that go against the stereotypical life we believe her to be living. For example, a California newscaster, Bree Walker, was roundly criticized for becoming pregnant; she was born with ectodactyly, a genetically transmitted trait that causes fusing of fingers and toes. Her story became national news, sparking a fierce debate over her right to bear a child. A story such as Ms. Walker's has tremendous significance for women with disabilities who wish to become mothers, providing that rare role model of a woman who was highly visible in the culture and persisted in pursuing motherhood despite resounding public criticism (Reinelt 63-67).

The debate surrounding Ms. Walker's choice to become a mother not only questioned her ability to become a mother, but also her right to bring a child into the world that might be disabled. A common social belief holds that the life of one who is disabled is a life not worth living (Wendell 53); a corollary might be that for a nondisabled child, a mother with a disability would not be one worth having. A disability indicates something is "wrong," and steps should be taken to correct it. The eugenics movement in the United States during the early twentieth century was a serious attempt to prevent the continuation of various forms of disability within the population. To this day, Kallianes and Rubenfeld believe that there exists a "politics of eugenics" that assumes most disabilities are genetic in nature, and that it is therefore wrong for a disabled woman to reproduce because she may

bring a defective child into the world (209). Apparently, such a politics is not aware of the number of seemingly “normal” parents who bore children that were disabled in some way, nor is it informed by a knowledge of basic genetics. At its core, this cultural belief sees the risk of a disabled woman producing an abnormal child as too great, and so she is not fit to reproduce.

The discouragement of reproduction for disabled women begins at a young age. For nondisabled girls, the identification with the mothering role is encouraged during childhood, and when motherhood is achieved, the experience is a fulfillment of expectations. In contrast, the disabled girl is steered away from this goal; she is told by various elements of society (parents, medical professionals, cultural images) that mothering is an unlikely role in her future. If the disabled woman does in fact become a mother, she has taken the radical step of “transgressing or defying familial and social norms about [her] ‘fitness’ to mother” (Reinelt 171).

Disabled girls often grow up with disability, rather than femaleness, making up the major focus of their identities. To experience pregnancy, childbirth, and childrearing would allow them entrée into one part of the world of women that they may have assumed to be off-limits to them (Reinelt 149). However, in our culture, becoming a mother can be an uphill battle for the disabled woman who believes she has just as much right to bear a child as a nondisabled woman. Kallianes and Rubenfeld give a feminist perspective on one of the underlying elements of this struggle, stating that

Both disabled and non-disabled women’s sexuality and reproductive capacities have been regulated by patriarchal society, but here expectations of women’s traditional

reproductive role are reversed – what is expected, encouraged and, at times, compelled among non-disabled women is *not* expected, discouraged, and proscribed among disabled women (204).

In the face of such strong social and cultural opposition, it would be reasonable to expect disabled women to garner support in their quest for reproductive rights from the women's movement. This support has not been as forthcoming as one might imagine, as disabled women have found themselves relatively ignored by feminists (feminist theorizing on motherhood is notably lacking the disability perspective), and their viewpoint is sometimes diametrically opposed to that of most feminist analysis (Lloyd 716, 720). The relationship between disabled women and feminists is complicated by the fact that reproductive rights for disabled women go far beyond the choice to have a child or not; they also include the right to be seen as a sexual human being, to bear children and to be seen as a fit mother. Support for disabled mothers has been undermined by the feminist challenge to the social training that urges women to see mothering as their major, perhaps only, role in life, as well as social prejudices that see disabled women as unfit to be mothers (Kallianes and Rubinfeld 210).

While disabled women may find some comfort in feminism's defiance of the idea that femininity is best expressed by an ideal body, it is an uneasy comfort in that many disabled women waver between fighting cultural feminine stereotypes and very much wishing to resemble them (Lloyd 718). Whereas feminism strives to remove the cultural focus on women as sexual objects, disabled women are very concerned with having their sexuality recognized. Because they have been viewed as asexual beings for so long, disabled women are keen to delve into questions relating to sexuality and sexual identity, and to claim the

areas of mothering and childbearing as legitimate components of their identities as women. The need to establish themselves as sexual beings sets disabled women at odds with much of the feminist agenda and creates a struggle between rejecting cultural ideals of femininity and desiring to be seen as a legitimate embodiment of those same ideals.

By failing to support disabled women's quest for recognition as women who are fully sexual beings with every right to be mothers, feminism has helped to perpetuate the cultural norms that surround society's concept of motherhood and who is admitted entry to that world. Admittedly, the disabled women's viewpoint on motherhood is at odds with the feminist perspective because they wish to fulfill a traditional feminine role that is simply their right as human beings and which may represent the pinnacle of their lifetime (Lloyd 716). By strongly pushing away from the institution of motherhood, when seen as an instrument of patriarchal control, feminism contributes to the social construction of disability for a significant number of women who must fight disapproval of their wish to fulfill a stereotypically feminine role.

The uneasy relationship between feminism and disabled women is also illustrated in the issue of abortion. In the early years of the women's movement, some feminists held the position that "abortion on demand" should be the right of every woman at any point during her pregnancy. Although this stance was changed to state that women should have the right to choose to terminate a pregnancy up to 12 weeks, with later pregnancies to be terminated solely on medical grounds, the right to an abortion at any point in the pregnancy if the fetus was found to be abnormal was to be unqualified and unquestioned (Lloyd 719).

Understandably, this position was distressing to disabled women, for it inherently devalues

those members of society who do not conform to cultural definitions of normal. The feminist stance on abortion of “defective” fetuses drove another wedge between the feminist and disabled women communities. According to Lloyd, the feminist perspective on abortion had the effect of marginalizing disabled women, and underscored a distinct lack of commitment to the ethical, philosophical, social and legal issues that arise when disability and abortion rights are viewed in context together (719).

Today, feminists and disabled women are coming to realize that their movements do indeed have shared goals, and that supporting each other is not necessarily an exercise in hypocrisy. Lloyd has stated that feminist discourse has “moved from the construction of motherhood as a burden to the rights of women to make choices about and within motherhood, [yet] disabled women are denied the opportunity to exercise such choice, until and unless they can prove that they are capable of fulfilling the stereotypical mother role and function” (720). One specific goal each group is striving for is to eliminate the societal attitudes that define women, both disabled and nondisabled, strictly on the basis of their biological and physical characteristics (Kallianes and Rubenfeld 204). Author Anne Finger, a disabled mother, notes that both the reproductive rights desired by feminists and the rights to motherhood desired by women in the disability rights movement point to a strong common bond in that both groups’ aims are concerned with the fundamental right to control one’s body and one’s life (Kallianes and Rubenfeld 204). Disabled women need the support of the women’s movement to exercise this control, for while it is more commonly accepted today that “normal” women have the right to choose motherhood or not, disabled women are denied this choice because society is still not comfortable with the idea that they are capable

of fulfilling the culturally defined role and functions of mother.

Chapter 2: The Social Construction of Motherhood

Images of motherhood in our society are remarkable for their pervasiveness and their consistency. The ideal mother is visible in all forms of media, and her representation rarely deviates. The prevailing image of mother, and motherhood, has deep roots in our culture and has been the subject of much research. According to Ann Dally, “There have always been mothers, but motherhood was invented” (17). Understanding how this concept developed is critical to appreciating the importance of motherhood’s place in our social consciousness.

During the seventeenth and eighteenth centuries in Western Europe, children were perceived as innocent creatures who were deserving of high levels of attention and care, particularly among the upper classes. In a departure from the Middle Ages, children were deemed worthy of their own specialized clothing, toys and books, schools, and even caskets. Protection from the outside world, with its dirty streets and unsavory people, was desirable, and corporal punishment fell out of favor. In an early precursor to Dr. Benjamin Spock, eighteenth century thinkers Jean-Jacques Rousseau and John Locke both wrote works regarding their philosophies on childrearing, which at this point was not equated with mothering (Hays 25). In contrast to their previous role as either drains on the family finances or the means to help improve them, children had claimed a new and distinctive place in society.

In Puritan America, the philosophy on childrearing was dramatically different. The child was not viewed as an innocent creature to be protected and nurtured, but as a being with a sinful nature that would require strenuous discipline to subdue. Elements of childhood entertainment were replaced with hard work. A lazy child was considered a moral failure, and play was discouraged to the point of making it a legal offense (Hays 27). The Puritans

placed the utmost importance on the words of the Bible, and generally referred to it for guidance in childrearing. What little on the subject was written during this time was directed to fathers, never mothers. The Puritan patriarch ruled over all aspects of home life, as the prevailing belief was that women were too weak-willed and emotional to contribute to the disciplining of children (Hays 28).

However, the Puritan mother did play a respected role in the character development of children by virtue of her affectionate nature, which was frequently noted in the writings of prominent evangelical ministers of the period. William Caton, born in 1636, echoes the writings of his contemporaries in this recollection: “When I was a child I was nurtured and tutored with such fatherly care and motherly affection as my parents at that day were endued with” (qtd. in Greven, 23). Early Puritan ministers, such as Reverends Thomas Shepard and Increase Mather, described their mothers as having a major impact and lasting positive influence upon their lives (Greven 23). Philip Greven, a scholar of early American childrearing practices, states that for the above-mentioned evangelical leaders and many others, “pious parents, and in particular devoted mothers, shaped their earliest consciousness and character and remained fixed in their memories for the rest of their lives” (24).

It was not until shortly after the American Revolution that mothers were acknowledged as having an larger and more influential role in domestic life. The postwar years saw the development of the Republican Mother: an intellectually sophisticated woman who used her education to enhance her capabilities as a wife, household manager, and mother of the next generation of (primarily male) patriots (Kerber 117). Women were also increasingly seen as paragons of virtue, whose job was to inculcate their children with

the characteristics of upright and productive citizens. Dorenkamp has noted that social commentators of the nineteenth century were of the opinion that “ the health of the Republic itself depended on mothers” (128). As the nineteenth century progressed, evangelical religious teachings promoted the message that home was to be a fortress against the corruptive forces of the outside world. Hays states that during this era, a “cult of domesticity” was established, whereby “women ensconced in the home would provide the ‘moral and emotional substance’ for their families, creating a more virtuous world” (30).

While the father of the household remained the primary authority figure in the household, the concept of “mothering” was growing into an important domestic function. In opposition to the rigid and harsh approach to parenting shown by the Puritans, mothers of the nineteenth century were encouraged to exhibit sentimentality, a quintessential feminine trait. The mother-child relationship became suffused with affection, and the mother was seen as the best person to care for her children, without outside assistance from servants, older children, or other women. During this period, the rise of factories meant men would be working away from the home and mothers were therefore able to apply increased focus on childrearing efforts. Anne Boylan points out that these women strove “through reformers like Catharine Beecher, to elevate motherhood to a cultural virtue and to carve out a separate (but equal) sphere for themselves in American life” (157). By the second half of the nineteenth century, childrearing had become synonymous with mothering (Hays 29).

During the 1820’s – 1830’s, media representations of motherhood brought the idealized image of mother into American homes. This period saw the development of mother’s magazines, domestic novels, and childrearing manuals. Phrases such as “home

sweet home” and “there’s no place like home” further underscored the importance of a mother’s contribution to the creation of domestic bliss. Many mothers were involved with various reform groups (maternal, revivalist, temperance), which was yet another way of reinforcing the image of mother’s superior moral virtue. In a world perceived as cold, corrupt and competitive, mothers were given the charge of creating and keeping home as a nurturing, protective sanctuary for the betterment of their families and society (Hays 30).

This sentimentalized view of motherhood was primarily embraced by the urban middle class, whose women were financially in a position to subscribe to the social prohibition of a married woman working for a wage. The accoutrements of “good” mothering became increasingly expensive, as children (who were no longer expected to join the labor force at an early age) were to be given the right kind of clothing and playthings until they had finished school. The concept of what constitutes good mothering was developing: the ideal (middle class) mother devoted herself entirely to the domestic sphere, as opposed to the mothers of the working class that had neither the time, energy or money to cultivate a haven-like home, casting a shadow on their credentials as mothers (Hays 37).

As the nineteenth century ended, the ideal of mothering underwent another radical shift. Whereas a woman’s “innate” sentimental nature and ability to raise her children with lavish attention and affection had been viewed as the keys to successful mothering, these characteristics were no longer sufficient. In order to be a good mother, sentimentality and affection were to be replaced by the guidance of scientific experts who promoted newer, supposedly better, ways of childrearing. The early pioneers of science-based parenting, such

as Drs. Luther Emmett Holt, G. Stanley Hall, and John Watson, had no confidence in women's ability to mother. In their estimation, women were too emotional and irrational to mother effectively, but they could be "trained" to overcome their deficiencies. An ideal of motherhood centered on devotion and loving care was completely at odds with a new scientific approach that called for emotional detachment (i.e., letting the child cry without interference) and behavioral modification that recommended strict scheduling of life's activities, from meals to daily bodily functions (Hays 39-40).

The rising prominence of children and motherhood in American culture gained momentum during the 1920's, which saw the creation of the kindergarten movement, child labor laws, settlement houses, the Century of the Child, and the establishment of Mother's Day. Throughout the 1930's, a more permissive approach to mothering emerged, with a focus on child development through fulfillment of the child's desires; childrearing had moved dramatically away from the previous goals of bettering the family and the nation. To engage in this intensely child-centered form of mothering, a woman was required to invest considerable emotional energy and financial resources in her children (Hays 46).

With childrearing considered the sole province of women, and good mothering of great importance to society, mothers found themselves in a precarious state in which they were "either held responsible for all that was good in children and morally desirable in society or blamed for their children's individual psychological disorders and the larger social ills that resulted from them" (Hays 48). It is not surprising, then, that women would eagerly embrace any mothering advice that would keep them from receiving the blame for the

downfall of society. Dr. Benjamin Spock's Baby and Child Care, published in 1946, was the answer to many an uncertain mother's questions. The timing of this book was fortuitous, arriving at the very beginning of the postwar baby boom (1946-1966). While birth rates from 1917-1945 never exceeded 200 births/10,000 23 year old women, birth rate during the baby boom period rarely went below this figure, peaking in 1957 at 268.8 (Elert, par. 1). Spock's book was well-received by an American public that viewed science as the source of a better future, and advice from a scientific expert was surely preferable to that of family and friends. Additionally, as more Americans moved away from their hometowns, the advice of extended family became less readily available, making books such as Dr. Spock's a primary source of mothering advice for many women (Hays 47).

As World War II came to a close, the women who had taken jobs outside the home to assist the war effort were encouraged (or forced) to return to the management of their homes and families. The ideology that woman's greatest fulfillment was to be found in domestic life became deeply rooted in American culture. The invention of television became a powerful medium through which to reinforce the message of the contented mother and homemaker, glowingly and glamorously depicted in such programs as *Leave It to Beaver*, *The Donna Reed Show*, *Ozzie and Harriet*, and *Father Knows Best*. Although not all women were convinced that home life was the epitome of happiness, this ideology has remained fixed in our social consciousness despite numerous challenges to its veracity.

The post war period saw the beginnings of what Hays has termed the model of "intensive mothering," in which children are viewed as precious innocents that must be brought up primarily by a mother who is tuned in to their every need, using methods

prescribed by scientific experts, with no regard to time, energy, or money invested, because this kind of mothering is what children need and deserve (21). This model of mothering has its own ideology, which suggests that society's ills can be alleviated by the unselfish efforts of dedicated and devoted mothers. Women are supposed to derive so much satisfaction from their contributions to a better society that they forget to notice that they receive little or no social and financial compensation for their labors. While intensive mothering does seemingly little to reward the mother for her work, other segments of society receive various benefits. For example, mothers' dedication to good childrearing helps the state by the production of citizens who will pay their taxes and train for responsible jobs that will keep them off welfare; men benefit by not having extra competition in the workplace; capitalism thrives as mothers purchase more to meet their children's needs and desires, thereby preparing the next generation of consumers (Hays 162). The ideology of intensive mothering simultaneously valorizes motherhood while maintaining women in a social position that is subordinate to men. This contradiction is summarized by Dally's observation that "on one hand the importance of mothers is emphasized. On the other hand little is done to help them and they are used shamelessly by governments, local authorities, schools and male chauvinists as public and private conveniences and cheap sources of labor" (18).

During the progression of motherhood toward an ideal like Hays' model of intensive mothering, a number of stereotypical images of mothers' appearances and actions developed over time, and with help from the media, continue to do so today. Prevalent among these images: the "Soccer Moms," who not only chauffeur their children to all of their sporting events and coach and/or cheer from the sidelines, but are always available to support their

children in any of their endeavors; the “Superwomen,” who keep an impeccable home and raise great children while working at a demanding and lucrative career; the mother with no recognizable label but who cooks, cleans, perhaps works outside the home and takes care of the family while maintaining her physical condition and attractive appearance. For disabled women, achieving the ideal mother image may be impossible in terms of appearance and certain kinds of mothering activities. In defining motherhood with a strong emphasis on capacity for performing numerous physical activities, the cultural ideal of mother overlooks an important aspect of mothering that Sara Ruddick terms “maternal thought: the intellectual work, attitudes and values that make up the *discipline* of mothering” (qtd. in Rothman 154). Mothering is far more than a physical relationship; it is also an intellectual activity that disabled women are fully capable of performing.

If the social definition of mothering is expanded to include an emphasis on maternal thought, more emphasis can be placed on a mother’s actions instead of her appearance. Rothman observes that this radical way of thinking about motherhood enables us to see mothering beyond the ideal image, even beyond gender:

...the similarities in behavior of mothers has more to do with the similarities in their situations, in the demands they face from their children and from their societies, than it has to do with the similarity in the women. And so the person engaged in this discipline of motherhood need not be a mother, need not be a woman, to engage in these activities, this way of thought and practice that is mothering (155).

From this viewpoint, the pool of potential mothers contains many more acceptable candidates

than simply the socially constructed ideal image. Deconstructing a deeply held ideology is no small matter, and disabled women will have a difficult time doing so on their own.

One way in which disabled women could obtain the support they need to help reshape the cultural ideal of motherhood is by enlisting the backing of the feminist movement. To remain true to the feminist goal of equal opportunity and choice for all women, the women's movement should take an active role in supporting the motherhood choices that disabled women are entitled to make, even if those choices seem antithetical to prevailing feminist thought. Disabled women are seeking motherhood as valid means of self-determination, an avenue for expressing their ability to lead autonomous lives and make crucial decisions about important life events. It may be time for feminism to take a step back from its disdain of motherhood as an instrument of patriarchal domination in order to realize that, for disabled women, motherhood can be a meaningful, and much desired, element of a fulfilling life that has long been denied them. Patricia Hill Collins has found that the majority of feminist theorizing on motherhood has been lacking in diversity, presenting the concerns of white, middle-class women as representative of all women (Glenn 6). If feminism is serious about representing all women's issues in an equitable way, it is surely time for strong voices to be heard in support of disabled women who choose to become mothers.

Due to the efforts of many dedicated feminists, women have more opportunities and choices available to them than previous generations. In a time when women sit on the Supreme Court, run major corporations, and fly into space, it can be forgotten that not all women are comfortable with the vast array of life choices available to them. It has become

socially uncomfortable for many women to state that they would prefer to remain in the home instead of joining the work force. Dally offers a reminder that “some genuinely feel drawn to domesticity. Many women are more fulfilled at home, however relentless the chores and however demanding the children, than they would ever be in an office or a profession or out elsewhere in the world” (271).

While many disabled women who have children may also work outside the home, becoming a mother is almost more important than a career, for this is something they have frequently been told would not be in their futures. Despite feminism’s challenges to traditional definitions of femininity, the idea that by having a child a woman proves her femininity to herself and society is still a common notion (Dally 271). The staying power of this belief is not surprising, given the valorization of motherhood throughout American history and the promotion of scientific beliefs during the early twentieth century that “normal” women wanted children, while those who did not were rejecting their femininity (Glenn 9). Hays states that motherhood “has been one of the few avenues for achieving status left open to women” (165). For disabled women, the attainment of such status can be a critical element in the expression of a feminine identity that moves them beyond, or perhaps enhances, their identity as one who is disabled.

Changing the social construction of motherhood to fully incorporate a diverse range of women that do not fit the idealized image of mother appears to be a monumental task. The ideas of Susan Wendell on the social deconstruction of disability could be applied to facilitate some degree of change. One of the largest issues, as Wendell sees it, is the way society views disability: “The cultural habit of regarding the condition of the person, not the

built environment or the social organization of activities, as the source of the problem, runs deep” (46). To move beyond the belief that disabled women are not fit to be mothers because they cannot perform all the functions that society has come to deem as necessary to good mothering would require challenging our ideas of what mothering functions are truly necessary, and to provide the appropriate assistance may be needed for disabled women to mother well. In order to be a “good” mother, must a woman be able to do all the physical activities her child wishes to do? Is a mother not “good” if she cannot cook, sew, do laundry, make craft projects, coach sports without assistance? Wendell also argues for recognition of a societal obligation to effect changes that will increase the ability of disabled people to participate as fully as possible in life’s activities (52). For disabled women, this would mean providing the assistance they may need for effective mothering as a matter of course, from household and childcare assistance to adaptive furniture and fixtures, to the point where disabled women feel no discomfort in asking for such assistance and society shows no hesitation in providing it.

Another important element in Wendell’s proposal for the social deconstruction of disability is to eliminate what she terms the “personal misfortune” or “lottery” approach to life, wherein “individual good fortune is hoped for as a substitute for social planning that deals realistically with everyone’s capabilities, needs and limitations, and the probable distribution of hardship” (53). Wendell believes that this haphazard approach, if applied to social necessities such as emergency health care and general education, would be unacceptable to persons without disabilities; the prevailing expectation is that such services will be available and accessible (53). A striking feature of this lottery approach, besides its

unfair nature, is a callous disregard for the quality of life for a specific group of people; their misfortune can conveniently be blamed on fate, as if society were powerless to do much to minimize the impact of disability. The assistance given disabled people tends then to express society's pity for the "unfortunates," rather than a true concern for helping them live fully realized and productive lives.

To move away from this charity-based viewpoint, it is Wendell's belief that society should "start with the assumption that people should receive a reasonable amount of help to make significant contributions to society according to their potential, both for their sakes and for the benefit of society" (50). For disabled women, this would mean a much easier journey to motherhood, one in which the appropriate supports for maternal and child care are available and accessible, and the choice to become a mother is no more fraught with anxiety than for nondisabled women. While this position of egalitarianism seems to be far from achievable in the short term, it is a place to begin thinking of how to effect change for all disabled women in the future.

Similar thinking must be applied to the current social construction of motherhood, for it is one that deliberately excludes disabled women. This elimination denies disabled women the opportunity to engage in one of life's major experiences, and continues to foster society's discomfort with and general ignorance of disability. By reserving the title of "mother" for only able-bodied women, disabled women experience a disenfranchisement in much the same way as women of color do in society, becoming "scapegoats in a society that rations health care and other services" (Kallianes and Rubenfeld 211). It is time for society to step away from its limiting and long-held image of "mother," and to reassess what truly makes a

woman fit to be a mother.

Chapter 3: Multiple Sclerosis: A History of its Diagnosis, Treatment, and Relationship to Pregnancy

Similar in its chronic nature to other diseases such as diabetes and asthma, multiple sclerosis continues to mystify medical researchers to this day. A profoundly complex disorder, there is no consensus on a causative agent, nor are there any means for predicting the course an individual's disease will take. Primarily located in the central nervous system, the lesions indicative of multiple sclerosis denote sites of nerve tissue damage that affect the patient's neurological function in either an episodic or gradual progression of deterioration. The basic sequence of events appears to indicate that a specific type of white blood cell, once activated, causes nerve damage by destroying myelin, the protective covering of nerve cells. Myelin may be repaired by the body, but any damage to the nerve cells is permanent (NMSS 3). The diagnosis of multiple sclerosis can be difficult because it shares certain characteristics with other autoimmune diseases, and presents in numerous variations (Hickey 1999; Lublin and Reingold 1996). Researchers estimate that multiple sclerosis currently affects just over a quarter of a million persons in the United States, with women diagnosed twice as frequently as men (Whitaker 339).

The first descriptions of what eventually came to be termed multiple sclerosis appeared in the medical literature in France in the early 1830's. American neurologists began their work on the disease around 1870, and by the early 1940's, an extensive body of literature had been developed. The research contained numerous theories regarding the origins of multiple sclerosis, as scientists reported numerous clinical and pathological variations of the disease that appeared in their patients. The unpredictable nature and disparate symptoms of multiple sclerosis led physicians to try a wide range of treatments for

their patients. During the late nineteenth century, an experimental treatment approach known as “therapeutic activism” utilized electricity, arsenic, strychnine, sulfur baths, opium, and codeine in an effort to destroy a supposed infectious agent (Talley 877). Theories and treatments abounded; Richard Brickner, a New York neurologist, was convinced that patients with multiple sclerosis had a blood abnormality and could be effectively treated with quinine (Talley 878).

During the early to mid-twentieth century, researchers persisted in trying to determine if an infectious agent was the cause of multiple sclerosis. Factors such as geographical distribution and the involvement of the immune system were also considered for a possible role in the development of the disease. Viruses came under scrutiny as a potential cause during the early 1970’s, with theories ranging from an altered measles virus to a more generalized idea that multiple sclerosis was a virus-induced immune disease (Sutherland 3). As the 1970’s progressed, emphasis moved from a viral cause to a possible allergic response. Continual improvements in the resolution of the electron microscope (introduced in 1930) provided no evidence that a virus was a causative agent, and allowed for the isolation of other specific cell types within multiple sclerosis lesions. Through this technology, researchers were able to identify the presence of various cells involved with inflammation, which were known to cause damage within the body in the same way as in other diseases such as rheumatoid arthritis and lupus (Hickey 40; Sutherland 7).

Further technological developments in medical research gave scientists the ability to examine multiple sclerosis lesions using the sensitive technique of immunohistochemical analysis. This technology enabled scientists to integrate their knowledge of immune

system function and the body's inflammatory process, potentially pointing to a malfunction within the immune system as the cause of multiple sclerosis. This has not proven to be the case, and while the published data and numerous new tests for multiple sclerosis have been helpful in many respects, they have also done little to clarify an already complicated disease. Hickey states that the development of multiple sclerosis lesions is believed to occur via numerous immunological pathways, rather than a single, defined route (40). Other researchers have not ruled out a relationship between a virus (or parts of a virus) and the various components of the central nervous system (McDonald 667). In an article written in 1983, Sutherland felt that little had been learned about multiple sclerosis over the previous 50 years and called for a multidisciplinary approach "to solve the mystery of multiple sclerosis in the foreseeable future" (7). Twenty years after Sutherland's article, despite the development of drugs to abate the disease's symptoms, the etiology of multiple sclerosis remains unknown and the development of a cure is far from imminent.

The history of multiple sclerosis treatment is one of aggressive experimentation. The therapeutic activism begun at the end of the nineteenth century continued into the 1950's, and incorporated various practices such as blood manipulation, moving to a warmer climate, exercise, dietary changes, hydrotherapy, and morale building, presumably to alleviate the depression that is still frequently documented in multiple sclerosis patients (Talley 878). Patients were just as willing as physicians to try new forms of treatment for their symptoms. Prior to the founding of the National Multiple Sclerosis Society (NMSS) in 1946, many patients perceived their situation as hopeless as disease knowledge was very limited; social isolation and job loss due to decreased mobility were commonly experienced. To help

counteract the fear and anxiety that accompanied a diagnosis of multiple sclerosis, the NMSS made physician and patient education an early objective. While the NMSS cautioned patients against an impending cure, it did encourage them to be active in the management of their disease (as early as the 1950's), creating some feeling of empowerment for multiple sclerosis patients.

Stories of patients who had “recovered” from their multiple sclerosis through hard work and vigorous exercise during the 1930's through the 1960's gave rise to an “ideology of work” which was popularized in numerous magazine articles found in publications such as *Today's Health* and *Cosmopolitan* (Talley 895). Patients looked to the American Protestant work ethic for the inspiration to achieve on their own what medicine was unable to provide. In the late 1950's and early 1960's, scientific developments enthralled the American public, and many patients were quite willing to accept any experimental therapy for multiple sclerosis. Physicians who believed that multiple sclerosis was linked to a blood disorder recommended vasopressor (blood vessel constricting) drugs or transfusions in the hope that the blood of healthy subjects contained a factor that was lacking in their patients (Talley 889). The UCLA protocol, a combination regimen similar to those used in the current management of many chronic diseases, recommended a low fat diet in conjunction with vasoconstrictors and anti-inflammatory medications, physical therapy and bed rest in order to inhibit or prevent the destruction of myelin (Talley 879). None of these approaches to the treatment of multiple sclerosis were proven to be therapeutically effective (or safe) through the process of clinical trials, so physicians were free to experiment at will. To their credit, the NMSS refrained from endorsing any particular form of treatment during this time

(Talley 889).

As the twentieth century progressed, the treatment of multiple sclerosis became a joint venture between the specialties of neurology and rehabilitation medicine. During the 1970's, four multiple sclerosis treatment centers were established that integrated neurological and rehabilitative care, taught patients methods for developing coping and adaptive skills, and educated entire families on life with multiple sclerosis (Burks 113). Throughout the 1980's, the trend toward comprehensive care strengthened, bolstered by the efforts of the NMSS and the Multiple Sclerosis Association of America. Rehabilitation of multiple sclerosis patients became a standard component of specialty training in neurology and rehabilitation medicine, Veteran's Administration hospitals opened multiple sclerosis clinics, and collaborative international research increased (Burks 113).

The rise of managed care in the 1990's has threatened the comprehensive approach to the treatment of multiple sclerosis. Health Maintenance Organizations (HMOs) frequently provide incentives to primary care physicians to limit the number of referrals to specialists, thereby delegating the majority of care for multiple sclerosis patients to physicians that may be lacking an awareness of the best techniques for managing such patients. An equally ineffective care scenario develops if the specialist (typically a neurologist) becomes the patient's principal care provider, as the patient's other health needs may be overlooked. (Burks 113). Managed care has forced many multiple sclerosis patients into choosing between seeing their primary care physician or their neurologist, depriving them access to the kind of care that could best address their overall health and the specific needs of their disease (Burks 115,116).

For a woman with multiple sclerosis who wishes to have children, the coordination of care becomes more complicated as an obstetrician/gynecologist (OB/GYN) and/or midwife joins the patient's list of health care providers. Finding a women's health specialist who is knowledgeable about multiple sclerosis and pregnancy is not as difficult as it once was, but the medical profession has a history of discouraging women with multiple sclerosis from having children and confusion still exists as to the best approach to managing the disease during and after pregnancy. Clarification of the issues surrounding pregnancy and multiple sclerosis is difficult due to the unpredictable nature of the disease, but as it is more prevalent in women of childbearing age than among any other group, and the frequency of childlessness in this population is significantly greater than in the general population, continued research in this area is imperative for these women to make informed choices about motherhood and to receive appropriate care and support (Damek and Shuster 977).

Prior to 1950, the vast majority of women with multiple sclerosis were counseled to avoid pregnancy as it was believed to adversely affect the course of the patient's disease (NMSS 3, 1). This conviction was the result of an 1893 study that claimed multiple sclerosis began during pregnancy, went into remission postpartum, and would reappear during subsequent pregnancies in a more debilitating form (Damek and Shuster 977; Dwosh et al. 39). An influential study by A. Tillman, published in 1950, was the first to demonstrate that pregnancy had no significant impact on a woman's level of disability. This study has been cited as changing the standard medical advice given to prospective mothers with multiple sclerosis from almost total discouragement to guarded optimism (Watkiss and Ward 49).

The research on multiple sclerosis and pregnancy that succeeded Tillman's study has

failed to demonstrate any negative effects on the long-term course of multiple sclerosis (Birk and Rudick 1986; Damek and Shuster 1997; Dwosh et al. 2003; NMSS 4, 2004; Watkiss and Ward 2002). Dwosh et al. find that although the majority of such studies on this topic contain numerous biases and lack consistency in their terminology and inclusion criteria, they do provide considerable evidence that pregnancy is not contraindicated in women with multiple sclerosis (41). In fact, many of the studies have shown that pregnancy provides a protective effect by decreasing the periods of active debilitation (exacerbations), especially during the second and third trimesters (Birk et al 1988; Carty 1998; Damek and Shuster 1997; Lorenzi and Ford 2002). This protective effect has been illustrated mainly in women with the relapsing-remitting form of multiple sclerosis, in which the patient experiences alternating periods of active disease or no symptoms in an unpredictable pattern.

In one of the longest studies to examine the effect of pregnancy on multiple sclerosis, Runmarker and Anderson followed 28 patients and 55 controls for up to 25 years, finding that patients who became pregnant after the onset of multiple sclerosis showed a significantly lower rate of converting from their relapsing-remitting form to a chronically progressive disease course (Damek and Shuster, 983). A study on the rate of relapses after pregnancy by Rouillet and colleagues showed that women who became pregnant after being diagnosed with multiple sclerosis experienced lower relapse rates over time than women with multiple sclerosis who never became pregnant, further supporting the idea that pregnancy has no long term negative effect on the course of the disease (Damek and Shuster, 983). In a review of the literature on pregnancy and multiple sclerosis, Dwosh et al. warn that although the protective effect of pregnancy has been documented many times, “women need to be aware

that this protective effect is not a universal finding; in the absence of well-controlled trials, no objective scientific data provide a predictive model” (40). Furthermore, studies of this type have not been conducted in women with more progressive disease, and many physicians still counsel against pregnancy in such cases (Watkiss and Ward 49).

It has been theorized that a genetic component for susceptibility to multiple sclerosis may exist, although the genes involved have yet to be identified (Watkiss and Ward 46). A 1994 study by Sadovnick investigated the possibility of genetic transmission of multiple sclerosis, finding that the risk to a daughter of an affected mother is 50 times greater than in the general population, and much lower for a son, given a prevalence in the general population of 0.1 to .02% (Carty 365). Ebers et al. looked for a genetic component by studying the incidence of multiple sclerosis in twins, finding that the risk of disease to a non-identical twin where the other twin is affected is the same as for a non-twin sibling; if an identical twin has the disease, the other twin was found to have approximately a 25% chance of developing multiple sclerosis (Watkiss and Ward 46). Despite these studies, the genetic link to multiple sclerosis susceptibility remains controversial and is not considered a valid reason to forego pregnancy (Damek and Shuster 982).

The relationship between pregnancy and multiple sclerosis, like the disease itself, continues to be fertile ground for further research. The majority of studies conducted to date have been retrospective in design, and the few prospective studies have utilized small sample populations and short time frames. As is the case with other chronic diseases, conducting prospective longitudinal studies is not practical due to patient retention and the possibility that new and effective treatments may be introduced which would alter the long-term

results (Damek and Shuster 998). Physicians and patients can take some assurance from the knowledge that no study has clearly shown that pregnancy exerts a negative effect on the long term course of multiple sclerosis, and that 18 studies conducted between 1950 and 1995 have supported the conclusion that patients with relapsing-remitting disease, while subject to an increased risk of exacerbations during the first 6 months postpartum, are likely to experience decreased relapse rates during the 2nd and 3rd trimesters of pregnancy (Damek and Shuster 979-981).

The lack of conclusive research on pregnancy and multiple sclerosis, in addition to prevailing stereotypes of disabled women as asexual beings, can lead to inadequate and poorly informed health care for women with multiple sclerosis who desire to bear children. The myths regarding disabled people as asexual, childlike, unable to have satisfactory sex lives, and likely to produce disabled children have produced societal reactions that have caused the health care profession to unfairly ignore the real sexual needs of this population. Daniels et al. have found that surveys of disabled people indicate a strong desire for sexuality services (i.e., counseling and education); their own 1979 Sex and Disability Project survey found that respondents would use at least 1 of the 12 sexual education and counseling services offered, with an average of 4.4 services indicated per respondent (87). Such services are important for those disabled in childhood to enhance self-esteem and encourage healthy sexual relationships. For those disabled as adults, health professionals should be able to clarify myths surrounding sexuality and disability, explain the effects of a specific disability on sexual functioning, and provide the support necessary for maintaining sexual self-image (Daniels et al. 91).

Besides identifying that disabled people desire sexual education and counseling services, Daniels et al. also found that they expect physicians to be able to provide the same. In the Sex and Disability Project, 64.2 % of the respondents expected physicians to offer such services, and 50.6 % ranked them as the professionals the primary source for sexuality information. A gap in the disabled patient-health care provider relationship was shown by the responses of OB/GYNs and urologists in the survey that expressed hesitancy to provide sexual education and counseling beyond what they provided to non-disabled patients; in fact, many disabled people responded that they were not receiving this information from these physicians (Daniels et al. 103). For many disabled people, the lack of information from the source expected to provide it had led to frustration, unanswered questions, and self-doubt. As the physician is most likely to be the first professional consulted by a patient after the onset of disability, he or she will be the first source to which the patient will look for information. Medical school curricula do not provide adequate training in addressing the sexual concerns of disabled patients, leading busy physicians to avoid a subject with which they are not conversant, and thereby allowing for the perpetuation of the negative, asexual stereotype (Daniels et al. 103).

A similar lack of knowledge regarding the relationship between pregnancy and disability contributes to an unequal distribution of health care services to disabled women. Lipson and Rogers find that many health care providers are unaware of how pregnancy affects disability, citing a lack of research in this area and noting that only one major comprehensive resource for disabled women and their health care providers has been published in the last 13 years (12). Given the wide array of topics beyond the interaction of

pregnancy and disability that should be considered by a disabled woman and her physician (potential effects of medications on the woman and the fetus, any necessary lifestyle modifications, possible family adjustments, coping with reactions of family and society), the need for a collaborative approach to managing pregnancy and disability seems obvious. It is not reasonable to expect primary care physicians to have extensive knowledge of all kinds of disabilities, but some knowledge can make a difference in the quality of maternity care that a disabled woman receives. Lipson and Rogers report that disabled mothers had good maternity experiences when health care providers worked as a team, providing specialized support and care (23). Women who received less comprehensive maternity care stated that their OB/GYNs were unable to provide them with useful information on their specific disability and pregnancy, failed to anticipate or address specific support needs during pregnancy and postpartum, and did not refer patients to the appropriate resources for such information (Lipson and Rogers 18). Unfortunately, the time and cost restraints of managed care do not encourage physicians to communicate with one another or to learn more about the appropriate care of disabled patients. Only under optimal conditions will disabled women receive the standard of health care nondisabled women have come to expect as standard.

For women with multiple sclerosis, prenatal care, labor management, delivery, and incidence of complications is approximately the same as for women without the disease (Adelson 1; Birk and Rudick 724). However, the need for communication between the OB/GYN and neurologist is important if the patient requires drugs to manage symptoms such as incontinence, depression and spasticity during pregnancy, or pain-management medications during delivery (Adelson 4). Creating an open channel of communication between OB/GYNs and neurologists for the care of pregnant women with multiple sclerosis

has not been easy. In addition to the restraints imposed by managed care, there has been very little published to guide the management of pregnancy and multiple sclerosis. As of 1986, some texts were still recommending that patients with active disease should be dissuaded from becoming pregnant because of the risk of progressive disability (Birk and Rudick 723). In recent years, both neurology and obstetrical texts and many journal reviews have supported the idea that there is limited rationale for discouraging pregnancy in women with multiple sclerosis, and that the woman should base her decision to have a child on the basis of her desire to become a parent, while taking into account her existing physical impairment (Birk et al 208; Birk and Rudick 723).

Physicians who specialize in the treatment of multiple sclerosis state that the majority of their patients who become pregnant do so in the early stages of the disease, have only limited mobility, and have good general health in between relapses (Adelson 7). For women who fit these characteristics, successful pregnancy is a reasonable expectation. In such cases, the physician has acknowledged the patient may have a knowledge of her disability that exceeds his own, leading to better communication and attention to a patient's specific needs (Carty 364). The use of specialized medical equipment to compensate for lower limb weakness or spasticity, and alternative birthing positions may be all that is required to make the delivery of a woman with multiple sclerosis "normal" (Watkiss and Ward 50). With appropriate postpartum planning for any necessary support services for mother and/or child, Lorenzi and Ford conclude that there is not sufficient evidence to discourage pregnancy in women with multiple sclerosis (463).

Adelson writes that "MS does not rob women of motherhood, but the disease does require extra attention to ensure that the pregnancy is safe, comfortable, and as happy as possible" (1). Based on the medical literature regarding pregnancy and multiple sclerosis,

and to respect the reproductive rights of women with multiple sclerosis, it is irresponsible and unfair to offer them anything less.

Chapter 4: A Group History of Mothers with Multiple Sclerosis

For a woman with multiple sclerosis, the decision to have a child is weighted with a great deal of uncertainty. Not only will she confront the typical concerns of a prospective mother (i.e., arranging for OB/GYN care, preparing the home for the baby's arrival, dealing with pregnancy's physical and emotional effects), but she will have to deal with reactions (potentially quite negative) from her physician, family, and strangers; she may have worries over the possible effects of pregnancy on the course of her disease and her ability to care for a child; she may worry about her ability to access the kinds of care and support services she may need to parent her child to the best of her ability (Smeltzer 147). The unpredictability of multiple sclerosis and the lack of information available to address the aforementioned concerns make the complicated choice to bear a child exponentially more so for a woman with this disease.

A study by Smeltzer examined the motherhood decision-making process in women with multiple sclerosis in order to clarify their issues of greatest concern (2002). Most respondents reported that the greatest contributor to the difficulty of their decision was the lack of definitive and reliable information on pregnancy and multiple sclerosis (147). Due to the unpredictability of the disease, and therefore uncertainty about the extent of future disability, many women were motivated to actively search for as many resources as possible in an effort to draw their own conclusions and help guide their decision-making (Smeltzer 154). The women in Smeltzer's study turned to physicians, family, friends, local Multiple Sclerosis Society chapters, support groups and other women with multiple sclerosis to piece together a mosaic of information, most of which was verbal; many women reported a frustrating lack of written information (Smeltzer 147). Without a definitive resource or guidelines to turn to, some respondents were compelled to contact neurologists in other parts of the country and Europe for additional opinions and information (Smeltzer 147).

The inability of medical researchers to solve the many unanswered questions about multiple sclerosis, specifically in regard to disease progression, creates a situation in which the prospective mother must perform a risk/benefit analysis if she is to have any confidence in her decision to become pregnant. Although strong evidence shows that pregnancy has no effect on the long term course of multiple sclerosis, women report conflicting views from the same kind of specialists (Smeltzer 145). To cope with the uncertainty created by the lack of definitive information, participants in Smeltzer's study reported that careful planning was their most effective means of allaying concerns about motherhood, supplemented by prayer and optimistic thinking (148-156). It should be noted that the women in this study were largely middle-class and well-educated, which raises serious concern for those women with multiple sclerosis without similar access to the resources used by the study participants.

Apart from the physical concerns surrounding multiple sclerosis and pregnancy, the decision to become a mother is also influenced by other factors. McNary has identified psychological, cultural and historical aspects of the motherhood decision-making process (1999). In her survey of women with multiple sclerosis, four themes emerged from the participants' responses:

1. The influence of motherhood culture on the women's concept of themselves as mothers and their sense of the importance of motherhood. This was reflected in the participants' comments regarding their mothers' mastery of homekeeping tasks, the work shown by others in parenting and jobs outside the home, and in questioning their abilities to do the same.
2. The ideal of an independent Superwoman, capably handling career and family. Statements expressed the respondents' desires to triumph over the disease and any limitations it may cause, and that they could handle mothering along with all of

their other life activities.

3. The need for support from society and family. Due to unpredictability of the disease, respondents' stated that family support was a necessity for bolstering their sense of security. Some participants advised serious research into available support services prior pregnancy. Lack of spousal support was an area of frustration and resentment.
4. Perception of multiple sclerosis as a family disease. All participants described their disease in this way, exhibiting an acute awareness that multiple sclerosis has an impact on all family members, not simply the diagnosed individual (McNary 96-98).

These themes illustrate the impact of cultural and social norms upon the motherhood decision-making process, and underscore how complicated this decision can be for women with multiple sclerosis. McNary's study was limited to a very small number of participants; given the scant literature available on this topic, more surveys such as this would enhance the quantity and quality of information that could assist women with multiple sclerosis in making a more confident choice.

There is an element of fear in the decision-making process of women with multiple sclerosis. Because of the likelihood of increasing disability with the passage of time, many prospective mothers worry about falling and dropping their baby, about their ability to parent according to social norms, or transmitting the disease to their children (genetically or through breast milk) (Birk and Smeltzer 211). It is fair to say that most prospective mothers have at least some degree of fear about raising a child, but having an unpredictable disease adds to the apprehension. Some mothers with multiple sclerosis have learned to put their

fears into perspective, as Sylvia Gomez has managed to do so well: “I fear dependency, loss of privacy, becoming a burden. I fear discomfort, physical and emotional. So much for the myth of the courageous cripple! My mutual dependence with the children, however, is a source of strength, of insight: after all, who among us is truly independent?” (174). Gomez’s questions our perceived independence, and also provides a reminder that one day we will all experience disability to some degree and will certainly be dependent upon others.

The importance of motherhood plays a large role in defining the lives of women with multiple sclerosis. Smeltzer found that the women in her study described having a child as something “normal” that they could do that shouldn’t be forfeited because they had multiple sclerosis: “There are so many other things that we have to give up that this is not one of them that you should give up” (150). For many women who feel increasing frustration at the increasing disability manifesting itself throughout their bodies, having a baby provides a comforting sense of satisfaction that their reproductive organs (and therefore, according to societal norms, the essence of their femininity) are capable of working quite well (Prilleltensky 26).

Once the decision to become a mother has been made, a woman with multiple sclerosis must prepare herself for the reactions of the medical profession and society. Unlike the nondisabled woman, a woman with multiple sclerosis must be prepared to defend her choice to have a child. Societal perceptions of disabled mothers range from one end of the spectrum to the other, as described here by Michele Wates, a mother with multiple sclerosis:

The media loves to present the lives of disabled people in terms of how *exceptional* they are, their bravery and determination in the face of

adversity and tragedy, and so on. At the same time, there is a contrasting but equally artificial, tendency to blame disabled people for being so *irresponsible* as to have children. (95)

Such strongly negative reactions are as likely to come from immediate family members as from strangers. Carrie Killoran, a mother who is wheelchair-bound due to multiple sclerosis, was told by her father that she was irresponsible for having a baby because she would make an unfit mother. Like other disabled mothers, Killoran feels that her fitness as a mother is not defined in terms of physical capacity, but rather, “it 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). Whereas her father cannot see beyond the cultural construction of the ideal, “fit” mother, Killoran has come to terms with her body’s physical limitations, and is convinced that her ability to parent is not compromised, no matter how diminished and impaired her body may appear.

Whatever the underlying reasons may be, the reactions of family and strangers to the announcement of pregnancy by a disabled woman are rarely neutral (Carty 366). The long-standing myth that disabled women are asexual effectively prevents many people from considering the idea that such women would ever consider motherhood, leading to a response of shocked surprise. Others react with varying degrees of concern or disapproval, due to the perception that disabled women as being more likely than their nondisabled counterparts to be at risk for producing children with disabilities (Prilleltensky 23). One “positive” reaction is that of amazement, viewing the disabled woman as superhuman for attempting mothering, a perception that is frequently depicted in the media. Christa Van

Kraayenoord points out that news articles about disabled women with titles such as “Mother Courage” and “Tests of Courage” only serve to foster stereotypes and maintain a sense that motherhood for disabled women is nothing short of miraculous, does not quite belong to them (221).

In studies by Smeltzer (2002) and Lipson and Rogers (2000), women with multiple sclerosis reported that initial negative reactions to their pregnancy by family members were mostly followed by support later in the pregnancy. For some women, this change in attitude was viewed with skepticism, but others accepted the concern expressed for their health and physical functioning during pregnancy (Lipson and Rogers 15). In reading first-hand accounts of mothers with multiple sclerosis, it becomes clear that these women are disappointed with the negative reactions they receive, as well as frustrated by the perception that their decision to become pregnant was not well thought out, as related here by Killoran:

Why do some people act so alarmed at the idea of a disabled woman having a child or another child, and feel it is their duty to warn us about how hard it will be? ... The disabled women I know, myself included, think extremely carefully before becoming pregnant, continuing an unplanned pregnancy, or adopting. We weigh the pros and cons, make contingency plans, and start to set up support networks. I wish everyone would think as carefully as I did before having children. (125-126).

For Killoran and many other disabled women, society expects a justification and defense of their decision to become mothers, in a way that is rarely expected of nondisabled women.

The pregnancy announcement of a woman with multiple sclerosis is often greeted with the question, “How are you going to manage?” rather than the customary congratulations that a nondisabled woman would receive. Killoran notes that this question may not simply imply societal disapproval of disabled motherhood, but since society does so little to truly accommodate disabled persons in general, the questioner may be legitimately wondering how a disabled mother will negotiate life for herself and her child (121). All women with multiple sclerosis face the necessity of having to adapt to environments that are unfriendly toward their changing physical limitations; many have undoubtedly devised clever solutions to accomplish the various tasks involved in everyday living, and so are prepared to apply similar adaptive skills to childrearing. Because society rarely acknowledges or may not be aware of these coping skills, the disabled mother’s parenting can become the object of unfair scrutiny, as recounted by Wasser et al. : “Parenthood is the hardest job any woman will ever have. Yet, the physically limited parent may be the only one in the neighborhood toward whom the community directs anxiety about the difficulty of the job” (334). The doubt and skepticism society directs toward potential mothers with multiple sclerosis (or any disability) does much to deprive these women of the usual joy and anticipation experienced by nondisabled women during pregnancy.

As with her family and friends, the healthcare providers of a woman with multiple sclerosis may not respond positively to the news of her pregnancy, or to her desire to become pregnant. Killoran claims that her doctor never discussed such issues as plans for child care, adaptive equipment, or ways to best manage any special needs that could arise during pregnancy or delivery, although her nurse practitioner did express her opinion that Killoran

and her partner could not possibly be prepared for parenthood (Wasser et al. 329). Her experience is not uncommon, as studies of the reproductive experiences of disabled women frequently cite insensitive healthcare providers, inadequate information, and inappropriate or inadequate assistance as their major maternity issues (Lipson and Rogers 2000; Thomas and Curtis 1997).

For a disabled woman, her physical limitations may not be as disabling as the physical environment she encounters. Everywhere she goes, she faces access issues: housing, public structures, transportation, schools, and employment present significant challenges unless designed for disabled and nondisabled alike. For a disabled woman, these access difficulties contribute additional stress and anxiety to pregnancy. Although the Americans with Disabilities Act, enacted in January, 1992, was designed to provide protection against discrimination in public facilities (including hospitals, clinics, and other health care settings), the maternity experience of disabled women can be personally unfulfilling and unnecessarily complicated due to rooms and bathrooms that will not accommodate wheelchairs, difficult-to-access hospital beds, inability to access the birthing pool, and healthcare providers' inability to provide practical advice and equipment (Thomas and Curtis 205).

Depending on her level of disability, and living in an environment that creates more disability, a woman with multiple sclerosis will likely need some form of help to guide her through pregnancy and life with her child. Requesting any form of assistance can create an uncomfortable situation for the woman who is already under scrutiny as a potentially inadequate mother. Many disabled women fear asking for help because they wish to present

themselves as capable of coping and to avoid having their right to care for a child called into question (Thomas and Curtis 208). By requesting assistance, disabled women feel that they are sending a message that they cannot manage, instead making a positive statement that they can manage with the appropriate kind of assistance.

For disabled women to receive the kind of assistance she needs, open communication with the healthcare provider is a necessity. The societal assumption that to be disabled equates with being dependent can lead some healthcare providers to overwhelm the patient with assistance that may not be necessary or wanted. Although the healthcare provider's intentions may be good, imposing this kind of disempowering aid can undermine the patient's confidence in her mothering abilities, which may be shaky to begin with (Thomas and Curtis 207). For example, Carrie Killoran was not allowed to keep her baby in her hospital room overnight because the nursing supervisor was certain that Killoran was unable to get the baby in and out of its bassinet safely, although Killoran had figured out a solution. Awakened in the night by a baby crying, she asked to go to the nursery to see if it was her child; it was not, but Killoran burst into tears of frustration at having to leave her baby again. Fortunately, the night nurse was more understanding than her supervisor, and arranged to have Killoran's baby brought back to her room (Wasser 332). Had the nurse supervisor taken the time to observe Killoran's ability to work with her limitations, this incident could have been avoided and Killoran's maternity experience would undoubtedly have been much more pleasant.

Without readily accessible aid from the medical community, many with chronic diseases like multiple sclerosis have been forced to assist themselves in coping with their

physical limitations. Given the increased cost and depersonalization of American health care in recent decades, self-care is now viewed as critical to the successful management of chronic illness with its focus on the amelioration of debilitating symptoms (McLaughlin and Zeeberg 315). For women with multiple sclerosis, fatigue is one of the symptoms that can severely impact their ability to function effectively as a mother. In a 1997 study by Alexa Stulfsbergen and Sharon Rogers, subjects stated that the fatigue associated with multiple sclerosis was comparable to the crushing “polio wall,” a quick onset of exhaustion after physical activity, or to fibromyalgia’s fatigue, which is claimed to “paralyze as well as punish initiative” (3). In order to cope with this debilitating and invisible symptom, multiple sclerosis patients have employed a number of self-care strategies, including efficient home organization, rest, and medication (Stulfsbergen and Rogers 7).

Stulfsbergen and Rogers’ study of fatigue and self-care strategies in multiple sclerosis found a variety of strategies employed by patients to reduce and minimize the effects of fatigue; chief among these were attention to lifestyle patterns (i.e., physical exertion, nutrition, rest and sleep), environmental factors (heat, direct sunlight, cold), and perceived stress from sources such as work, family, and economic issues (6). Studies by Stulfsbergen and Rogers (1997) and Judith McLaughlin and Ib Zeeberg (1993) shared the finding that the self-care strategy of energy conservation was commonly used in various aspects of living to enhance both quality of life and parenting ability. Choosing to do less, accepting help from others and spending energy in judicious ways allowed patients to prioritize energy use, saving it for the responsibilities of parenting, as described here by a mother with multiple sclerosis: “Is it more important to walk a mall [as opposed to using a wheelchair], or is it

more important that I have some energy left at the end of the day to be with my children?" (Stulfsbergen and Rogers 7).

In the aforementioned studies on self-care strategies for managing the fatigue associated with multiple sclerosis, very few of the study participants learned about self-care from their health care practitioners. While many patients discovered helpful information regarding fatigue management from printed materials such as the National Multiple Sclerosis Society newsletter, other strategies were developed through trial and error and other creative ways (Stulfsbergen and Rogers 8; Deatrck et al. 207). In a world that frequently makes life for the disabled especially challenging, more assistance from health care providers in teaching the self-care techniques to manage fatigue would be welcome. Not only would the patients' quality of life improve at a faster rate, but the patients would more quickly realize the feelings of independence and security that effective self-care can provide (McLaughlin and Zeeberg 326).

It should be remembered that there are numerous families where the mother has been diagnosed with multiple sclerosis. These families are functioning very much along the same lines as any others, in that the disease has not taken over their lives: it is simply a part of it. In a four-year study examining families and their perceptions of life with multiple sclerosis, Rehm and Catanzaro found that the reactions of each spouse and at least one school-age child in the family described an essentially normal life that was not deemed fundamentally different from that of other families (1998). Parents viewed themselves as performing well in their role, regardless of their level of disability (27).

Despite some regret that their children had not been able to experience life with them

prior to their disability, parents felt that life with multiple sclerosis had virtually no negative effects on their children. In fact, some felt that the disease provided certain advantages, such as the opportunity to spend more time with the children (instead of at work); the independence gained by children at an earlier age by being directed in chores that the disabled parent could not perform; and the development of a compassionate attitude and greater understanding toward others with multiple sclerosis and other disabilities (Rehm and Catanzaro 32,33). Although increasing disability levels necessitated the alteration of family activities, parents made every effort to make sure their children's lives were not restricted or diminished in any way (Rehm and Catanzaro 35).

Children's responses to life with multiple sclerosis reflected an attitude that the disease was a factor in their lives, but not an overwhelming presence. As the study progressed, they became increasingly proficient discussing the physiological characteristics of multiple sclerosis and the effects that the disease had upon their parents; for example, they were aware that stress could cause a flare-up of symptoms and knew what actions to take that would reduce anxiety for the parent with the disease (Rehm and Catanzaro 29-30). The children were comfortable discussing multiple sclerosis with their friends, who either thought the disease was "no big deal" or found the wheelchairs and other adaptive devices "interesting" (Rehm and Catanzaro 30).

Writer Nancy Mairs, who was diagnosed with multiple sclerosis in her thirties, acknowledges that she felt a degree of guilt for not fitting the social construct of "mother," and she feared her disability would have a traumatizing effect on her children. Such worries seem unnecessary when her children, asked their thoughts on having a crippled mother,

replied, “it’s all we’ve known, not anything extraordinary” (Mairs 34,35). Mairs tells of trips to museums with her children during which her son willingly took on the responsibility for pushing his mother’s wheelchair and clearly had a great time doing it (perhaps too enthusiastically for Mairs’ comfort) (35). The point is that the mother’s disability is something that doesn’t cast a shadow of gloom over family life. Mairs’ children were able to live normal lives, and Mairs’ ability to mother was in no way diminished by her disability, as confirmed by her son’s questions: “So you call my mother disabled? Pray tell, how? What important ability does she lack?” (35). These questions, coming from Mairs’ son as an adult, make it quite clear that he has navigated childhood with a disabled mother and emerged unscathed by the experience, with a viewpoint on mothering that society would do well to adopt.

Clearly, multiple sclerosis cannot negate a woman’s parenting skills. While the disease may impose physical limitations that necessitate the use of adaptive equipment or supportive services, such restrictions have little to do with the interactions between mother and child that are the essence of parenting. Wasser et al. find that pregnancy for women with multiple sclerosis provides an opportunity for the women and their healthcare providers to engage in a mutual learning process, whereby each group could develop a better understanding of the disease, of the kinds of help and assistance available, and the best ways to request or offer it (337). More studies such as that of Rehm and Catanzaro can provide the kind of information necessary for healthcare providers to improve their communication efforts and understanding of the (quite normal) lives of mothers with multiple sclerosis.

It will doubtless take many years to eliminate the various social, medical, and

environmental barriers faced by women with multiple sclerosis who choose to pursue motherhood. Although the studies published to date are limited in number, a review of the literature on mothers with multiple sclerosis finds that they are fully capable parents, have fundamentally normal family lives, and have developed various strategies for raising well-adjusted children. There is no valid reason for women with multiple sclerosis to face a more difficult road to motherhood than nondisabled women. Rather, an overhaul of social and medical attitudes should embrace as normal these women who, in spite of significant obstacles, have found motherhood to be an extremely enjoyable and rewarding component of their lives. Sylvia Gomez, a single mother with multiple sclerosis and a ten-year-old daughter, can't imagine life without having a child to take care of, and feels she is doing a fine job of it: "Under my tutelage, she has learned to skate, to bike, to swim. She can read chapter books, and do her times tables up to 12. She sings in the chorus, and attends an endless round of birthday parties, excursions, and play dates. She is happy, and she knows it" (173). It seems apparent that Gomez is filled with happiness, too.

Chapter 5: Conclusions and Recommendations

In the face of considerable challenges, women with multiple sclerosis make the decision to have children and find motherhood to be a fulfilling aspect of their lives. Without a cure for multiple sclerosis on the horizon, many more women will continue to be diagnosed with the disease during their childbearing years and have to wrestle with the decision to become mothers. In order to alleviate some of the uncertainty and create a more encouraging environment for women with multiple sclerosis who decide to pursue motherhood, changes in social and medical attitudes toward disabled motherhood and continued research on multiple sclerosis in women are imperative.

The social construction of motherhood presents a major obstacle to women with disabilities who choose to bear children. Our culture's perception of the physical rather than the emotional and nurturing duties that are deemed necessary for good mothering will certainly eliminate many disabled women from being considered "fit" to mother. If a disabled woman decides to proceed with motherhood despite social disapproval, she may still live in fear that she is being judged "not good enough" to keep her child, and have to push herself to the limits of her physical abilities in an effort to prove herself worthy of being a mother. The need to portray oneself as a "fit" mother comes at a price, as described by Thomas: "Living with the fear of losing the right to care for their children forces some mothers to go to great lengths to 'present' themselves and their children as managing 'normally' – often at significant personal cost in terms of comfort, and emotional and physical well-being" (635). Redefining the "fit" mother would help to alleviate this fear by removing society's emphasis on the physical aspect of mothering. Kallianes and Rubenfeld provide an excellent rationale for broadening the definition of "fit" motherhood by reminding

us that “if child welfare laws define parenting in terms of physical capacity rather than love and nurturing, anyone who is temporarily able-bodied is vulnerable to losing their child(ren) due to future disability, injury or illness” (211).

The cultural bias which states that women with disabilities cannot and should not bear children is supported by various institutions. Health care practitioners have often failed to address the needs of disabled women in the areas of family planning, obstetric/gynecological care, and early childhood management (Shaul et al. 364). If the medical profession were to give the aforementioned needs the equivalent amount of attention to both disabled and nondisabled women, many of the cultural myths surrounding physical disability (i.e., disability renders a woman asexual and dependent; disability is contagious or genetically transferred; physical mobility essential to mothering; disability makes life not worth living) could be dispelled. To support health care professionals in this endeavor, a greater quantity of research into disabled parenthood would provide a much-needed guide; at this point in time, such research is very limited (Prilleltensky 2003; Shaul et al. 1981).

Disabled women faced coping decisions on a daily basis; for motherhood, this frame of mind is especially advantageous. Because the energy demands on disabled mothers can lead to exhaustion, specific coping strategies are necessary. The early years of a child’s life can be the most difficult for a disabled mother to manage, and it takes an extensive amount of searching to track down the programs, daycare, and services to accommodate mother and child (Kocher 130). Strong support networks can address the needs of disabled mothers, connecting them with others who have the same disability, and reassuring them that, even for the most able-bodied mothers, parenting is never an easy undertaking (Shaul et al. 367, 369).

Through the Looking Glass (TLG) is an excellent example of the kind of organization that, ideally, should be available to all disabled mothers. TLG provides a wide range of services designed to assist disabled parents, educate professionals and increase the public's awareness of the issues faced by disabled parents. Extremely comprehensive in its advocacy of disabled parents, TLG conducts research into the areas of pregnancy and birthing, develops specialized parenting equipment, educates professionals and parents on issues related to specific disabilities, and unites parents with similar disabilities to benefit from shared experiences and first-hand knowledge. This broad-based approach to support for disabled parents is making a large difference in many lives; according to TLG, 15% of all American families with children include at least one parent with some form of physical or mental disability (1).

For a significant number of families, the disability will be multiple sclerosis, and the parent most likely to be affected will be the mother. As more women are diagnosed with this disease, the need for reliable information from health care professionals will increase. Lack of coordination of care between primary care, OB/GYN, and rehabilitation/neurology specialists has led to less than optimal care for pregnant women with multiple sclerosis, and is difficult to achieve in an era of managed health care, but is absolutely essential to ensure the kind of maternity experience these women are entitled to receive (Daniels et al. 1981; Lipson and Rogers 2000). Lipson and Rogers recommend that medical school curricula include clerkships in rehabilitation services such as occupational and physical therapy in order to broaden physicians' awareness about the scope of these adjunctive healthcare services and their importance to patients with multiple sclerosis (19). For example,

appropriate referral to rehabilitation professionals could greatly alleviate the balance and mobility issues faced by women with multiple sclerosis toward the end of pregnancy.

Without the coordinated expertise of various healthcare professionals, the ability of a woman with multiple sclerosis to maintain her own health and that of her child through pregnancy, labor, birth and the postpartum period is unfairly compromised.

Despite the enactment of social policies such as the Americans with Disabilities Act, women with multiple sclerosis still experience forms of discrimination in hospitals and physicians' offices. Creating equal accessibility to hospital rooms, exam tables, and bathrooms is only the beginning. Carty emphasizes that women with disabilities face not only physical obstacles, but also social and political issues that can lead to significant psychological stress; therefore, healthcare providers should develop the appropriate skills and attitudes to address this element of maternity care (367). Women with multiple sclerosis (or any disability, for that matter) deserve care that will reduce the gap between their capabilities and the disability caused by their physical environment. This is a tall order, as it asks the healthcare profession to look beyond the medical model of disability and combine it with the social model of disability. Combining medical care (medications, lifestyle and behavior changes) with modifications to the physical environment (adaptive devices, specialized medical equipment) may not only reduce anxiety for the expectant disabled woman, but may also improve the outcome of the pregnancy experience (Carty 364).

As the worldwide prevalence of multiple sclerosis continues to increase, women may benefit from research into alternative therapies for the treatment of the disease. Patients with multiple sclerosis have sought symptom relief from acupuncture, chiropractic, homeopathy,

naturopathy, and herbal medicine; some patients found their quality of life to be significantly improved, whereas others were disillusioned with the outcomes of their treatments (Fawcett et al. 39-41). The research on alternative therapies on patients with multiple sclerosis is almost non-existent; Fawcett et al. found no such studies after performing a computer search of the past 25 years on this topic (37). An initiative to produce scientific validation for alternative therapies was created by the National Institutes of Health, which established the Office for the Study of Unconventional Medical Practices in 1992. Publication of the findings from this initiative and other research efforts can augment healthcare providers' abilities to customize modes of therapy that may prove helpful for the many individual manifestations of multiple sclerosis.

By recognizing and addressing the specific needs of women with multiple sclerosis who decide to bear children, the choice becomes one that is eagerly anticipated and shared instead of being angst-ridden and frequently defended. Dispelling the myths surrounding disability and clarifying a medical consensus regarding multiple sclerosis and pregnancy would enable women with multiple sclerosis the opportunity to define themselves as women first, without the label of "disabled" taking precedence. A wish to be perceived as a "normal" mother is evident in this statement from Carrie Killoran:

Imagine a woman in a wheelchair carrying a tiny baby. Not being discharged from a maternity hospital, where *every* woman must ride in a wheelchair, but at the grocery store, with the baby in a front pack and a cart full of groceries. Imagine her getting self, baby, and wheelchair into the car alone, and driving away. Imagine her independent, sexual, competent, mature, busy, happy, and

like practically every new parent I know, exhausted and short of money. To you, she may be truly an amazement. To me, I just feel like myself. (126)

Killoran's words could not provide a more compelling rationale for society to broaden its definition of "mother" to one in which women with multiple sclerosis (and all disabilities) are unequivocally included.

Works Cited

- Adelson, Rachel. "MS and Pregnancy: The Main Event." Inside MS. 21.2 (2003): 45 pars.
14 Feb. 2004. http://www.nationalmssociety.org/IMS_Apr03-MainEvent.asp
- Birk, Kathy. "Reproductive Issues in Multiple Sclerosis." Multiple Sclerosis Clinical Issues 2.3 (1995): 2-5.
- Birk, Kathy, and Richard Rudick. "Pregnancy and Multiple Sclerosis." Archives of Neurology 43(1986) 719-726
- Birk, Kathy, Suzanne C. Smeltzer, and Richard Rudick. "Pregnancy and Multiple Sclerosis." Seminars in Neurology 8.3 (1988): 205-213.
- Boylan, Anne M. "Growing Up Female in Young America, 1800-1860." American Childhood: A Research Guide and Historical Handbook. Ed. Joseph M. Hawes
And N. Ray Hiner. Westport: Greenwood Press, 1985. 153-184.
- Burks, Jack. "Multiple Sclerosis Care: An Integrated Disease-Management Model." The Journal of Spinal Cord Medicine 21(2): 113-116.
- Carty, Elaine M. "Disability and Childbirth: Meeting the Challenges." Canadian Medical Association Journal 159.4 (1998): 363-369.
- Centers for Disease Control. National Center for Health Statistics. NCHS Data on Multiple Sclerosis. 21 Feb. 2004. <http://www.cdc.gov/nchs>.
- Dally, Ann. Inventing Motherhood: The Consequences of an Ideal. New York:
Schocken Books, 1983.
- Damek, Denise M., and Elizabeth A. Shuster "Pregnancy and Multiple Sclerosis." Mayo Clinic Protocols 72 (1997): 977-989.
- Daniels, Susan M., et al. "Sexuality and Disability: The Need for Services." Annual

- Review of Rehabilitation 2 (1981): 83-112.
- Deatrick, Janet A., Daniel Brennan, and Mary Emily Cameron. "Mothers with Multiple Sclerosis and Their Children." Nursing Research 47.4 (1998): 205-209.
- Dorenkamp, Angela G. et al, eds. Images of Women in American Popular Culture. New York: Harcourt Brace College Publishers, 1995.
- Dwosh, E., et al. "The Interaction of MS and Pregnancy: A Critical Review." The International MS Journal 10 (2003): 38-42.
- Elert, Glenn, ed. "The Number of Births in the US." 24 June 2002.
<<http://www.hypertextbook.com/facts/2002/SamuelBernard2.shtml>>
- Fawcett, Jacqueline, et al. "Use of Alternative Health Therapies by People with Multiple Sclerosis: An Exploratory Study." Holistic Nurse Practitioner 8.2 (1994): 36-42.
- Glenn, Evelyn Nakano. "Social Constructions of Mothering: A Thematic Overview." Mothering: Ideology, Experience, and Agency. Eds. Evelyn Nakano Glenn, Grace Chang, and Linda Rennie Forcey. New York: Routledge, 1994. 1-29.
- Gomez, Sylvia Dick. "Intervals." Bigger Than the Sky: Disabled Women on Parenting. Michele Wates and Rowen Jade, eds. London: The Women's Press, 1999. 171-175.
- Greven, Philip. The Protestant Temperament: Patterns of Child-Rearing, Religious Experience, and the Self in Early America. New York: Alfred A. Knopf, 1977.
- Hays, Sharon. The Cultural Contradictions of Motherhood. New Haven: Yale University Press, 1996.

- Hickey, William. "The Pathology of Multiple Sclerosis: A Historical Perspective." Journal of Immunology 98 (1999): 37-44.
- Kallianes, Virginia and Phyllis Rubinfeld. "Disabled Women and Reproductive Rights." Disability and Society. 12.2 (1997): 203-223.
- Kerber, Linda K., and Jane Sherron De Hart, eds. Women's America: Refocusing the Past. New York: Oxford University Press, 2000.
- Killoran, Carrie. "Women with Disabilities Having Children: It's Our Right Too." Sexuality and Disability 12.2(1994): 121-126.
- Kocher, Meg. "Mothers with Disabilities." Sexuality and Disability 12.2 (1994): 127-133.
- Kraayennoord, Christa Van. "The Media's Portrayal of Mothers with Disabilities." International Journal of Disability, Development and Education 49.3(2002): 221-224.
- Lipson, Juliene G. and Judith G. Rogers. "Pregnancy, Birth and Disability: Women's Health Care Experiences." Health Care for Women International 21 (2000): 11-26.
- Lorenzi, A.R. and H. L. Ford. "Multiple Sclerosis and Pregnancy." Postgraduate Medical Journal 78(2002): 460-464.
- Lloyd, Margaret. "The Politics of Disability and Feminism: Discord or Synthesis?" Sociology. 35.3 (2001): 715-728.
- Lublin, Fred D., and Stephen C. Reingold. "Defining the Clinical Course of Multiple Sclerosis: Results of an International Survey." Neurology 46(1996): 907-911.
- Mairs, Nancy. Waist-High in the World: A Life Among the Nondisabled. Boston:

- Beacon Press, 1996.
- McDonald, W.I. "Attitudes to the Treatment of Multiple Sclerosis." Archives of Neurology 40 (1983): 667-670.
- McLaughlin, Judith and Ib Zeeberg. "Self-Care and Multiple Sclerosis: A View From Two Cultures." Social Science Medicine 37.3(1993): 315-329.
- McNary, Mary Elizabeth. "Themes Arising in the Motherhood Decision for Women with Multiple Sclerosis: An Exploratory Study." Journal of Vocational Rehabilitation 12 (1999): 93-102.
- National Multiple Sclerosis Society. "Health Insurance – Availability and Price." Advocacy Issue Brief. Spring 2002. 1-12.
- National Multiple Sclerosis Society. "The History of MS: The Basic Facts." Brochure. 26 March 2004. <http://www.nationalmssociety.org/Brochures-HistoryofMS4.asp>
- National Multiple Sclerosis Society. "Pregnancy." The MS Information Sourcebook. 10 Feb. 2004. <http://www.nationalmssociety.org/Sourcebook-Pregnancy.asp>.
- Prilleltensky, Ora. "A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities." Sexuality and Disability 21.1 (2003): 21-47.
- Rehm, Roberta S. and Marci L. Catanzaro. "'It's Just a Fact of Life': Family Members' Perceptions of Parental Chronic Illness." Journal of Family Nursing 4.1 (1998): 21-40.
- Reinelt, Claire. Motherhood and Disability in the 20th Century: Historical Constructions and Contemporary Experiences. Diss. Brandeis University, 1996.
- Rich, Adrienne. Of Woman Born: Motherhood as Experience and Institution. New York: W.W. Norton and Company, 1995.

Rothman, Barbara Katz. "Beyond Mothers and Fathers: Ideology in a Patriarchal Society."

Mothing: Ideology, Experience, and Agency. Evelyn Nakano Glenn, Grace Chang, and Linda Rennie Forcey, eds. New York: Routledge: 1994. 139-157.

Shaul, Susan, Pamela Dowling and Bernice F. Laden. "Like Other Women: Perspectives of Mothers with Physical Disabilities." Journal of Sociology and Social Welfare 8.2 (1981): 364-375.

Smeltzer, Suzanne C. "Reproductive Decision Making in Women with Multiple Sclerosis." Journal of Neuroscience Nursing 34.3 (2002): 145-157.

Stulfbergen, Alexa K. and Sharon Rogers. "The Experience of Fatigue and Strategies of Self-Care Among Persons With Multiple Sclerosis." Applied Nursing Research 10.1 (1997): 2-10.

Sutherland, J.M. "Multiple Sclerosis: Fifty Years On." Clinical and Experimental Neurology 19 (1983): 1-12.

Talley, Colin. "The Treatment of Multiple Sclerosis in Los Angeles and the United States, 1947-1960." Bulletin of the History of Medicine 77(2003): 874-899.

Thomas, Carol. "The Baby and the Bathwater: Disabled Women and Motherhood in Social Context." Sociology of Health and Illness 19.5 (1997): 622-643.

Thomas, Carol and Penny Curtis. "Having a Baby: Disabled Women's Reproductive Experience." Midwifery 13 (1997): 202-209.

Thompson, Rosemarie Garland, ed. Freakery: Cultural Spectacles of the Extraordinary Body. New York: New York University Press, 1996.

Through the Looking Glass. Parents with Disabilities. 1 Mar. 2004. <<http://>

www.lookingglass.org/parent.php>

Wasser, Andrea M., Carrie L. Killoran and Sarah S. Bansen. "Pregnancy and Disability."

AWHONN'S Clinical Issues 4.2 (1993): 328-337.

Wates, Michele. "Are You Sure You Can Cope?" Bigger Than The Sky: Disabled

Women on Parenting. London: The Women's Press, 1999. 94-97.

Watkiss, K., and N. Ward. "Multiple Sclerosis: Pregnancy and Parenthood." Nursing

Standard 17.3(2002): 45-53.

Wendell, Susan. The Rejected Body: Feminist Philosophical Reflections on Disability.

New York: Routledge, 1996.

Whitaker, J. M. Editorial. New England Journal of Medicine 339.5 (1998): 339-340.