

Feminizing the Multiple

by Karen A. Blackford

Cet article retrace les changements philosophiques et politiques ainsi que les actions prises par la Société canadienne de la sclérose en plaques au cours des années. Des changements subtils de la part du Mouvement des femmes et du Mouvement pour les droits des personnes qui présentent des handicaps ont indirectement transformé la façon dont les femmes handicapées, leur fémininité et la forme de leurs handicaps sont perçues par la Société.

As a woman with a chronic illness who is also a mother, I know that there are strong societal barriers to mothering with a disability. Women with disabilities have generally been either prevented from having children or constrained when they become mothers (Asch and Fine; Mathews). Constraints often come in the form of inappropriate or inadequate support services (Ridington; Dunn; Blackford, 1993b). Canadian researchers, including feminists, have rarely recognized that disabled mothers exist, much less identified where or how mothers with disabilities have been oppressed.

Over time, however, the Multiple Sclerosis (MS) Society of Canada has begun to recognize and to address the concerns of mothers with disabilities on their own terms. I call this transition a process of feminization.

The MS Society of Canada is an appropriate focus for an exploration of notions of disability and motherhood. Many more women than men have multiple sclerosis

(Wakesman, Reignold and Reynolds) and symptoms usually emerge during childbearing years. Thus the MS Society claims to speak for many women with disabilities. Newsletter publications from the beginning of the MS Society¹ provide a window for viewing how notions about mothers with disabilities have emerged historically, and the interactive way in which change can occur over time.

Medicalization

Medicalization implies that medical diagnosis, treatment, and monitoring are essential for persons with disabilities. It suggests that in planning her life style, a woman with a disability should make the demands of the medical regime her priority. This discourse reflects the belief that disability is a problem located in the individual who must be 'fixed' and overlooks the extent to which disablement is socially created (Oliver).

Ideas of medicalization are based on the male-centered Western notions of rationality, individualism, and normalcy. This 'normal' body is male, with females existing to perpetuate the male lineage. The 'normal' body is white-skinned and Caucasian, with people of other races being viewed with suspicion. The 'normal' body is the perfectly healthy able-bodied one, which means that persons with disabilities are often not considered when transportation is planned or prenatal classes are organized. The values of normalcy and rationality also assume that through

the superiority of scientific theory, 'mankind' can transcend the body and nature. Therefore 'man' can and should control nature.

From its earliest newsletter editions, the MS Society clearly states its main purpose: to raise money for biomedical research into the cause of multiple sclerosis—essentially in order to control nature. From 1957 onward, editorials suggested that "by supporting every medical research programme approved and authorized by our Medical Advisory Board" contributors would be making 1958 (or subsequent years) the "MS (Mystery solved) year of our Society" (*The Bulletin*, 4). Always we read about a "stepped-up demand for research support." The "stepped-up" nature of these demands is clearly based on the wishes of Medical Advisory Board members (*MS Canada*, Autumn 1977: 3).

The notion of saving the afflicted

For humanitarians, medicalization was justified by the need to be charitable and to save those who were "afflicted" with what was seen as the personal tragedy of multiple sclerosis. Women with MS and their children were portrayed as tragic victims, "afflicted by this malady" (*Multiple Sclerosis*, Nov. 2, 1968: 10), "suffering," and "needing gentle care" (5). The inverse of the tragic figure is the individual hero. In the case of the MS Society, we see women with MS portrayed raising funds as Ladies Auxiliary organizers "al-

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Sclerosis Society of Canada

though handicapped with a wheelchair" (*The Bulletin*, 2) or selling Halloween candy (*Multiple Sclerosis*, 1968, (1) 4: 8) and cook books.

That women with MS might be mothers as well as fundraisers, was a secret rarely divulged to readers until 1975 when the following slogan appeared:

Support multiple sclerosis research.
Buy a carnation for Mother's Day
...Taking the link the MS Society has
with Mother's Day and Father's Day,
the chapter came up with the idea of
selling flowers before Mother's Day.
(*MS Canada*, Winter 1975: 1)

Finally, people with MS could be mothers or fathers. Yet, having gone this far, the fabric of life associated with parenting with multiple sclerosis was not portrayed. Instead, the notion of parenting emerged only as a symbolic advertisement of hearth and home to raise research funds. Invisibility and commodification of these mothers occurred through a combination of forces including disability stigma, a notion of the private sphere in which childhood and procreation should be hidden from 'proper' public view (Ryan), and the discourse of medicalization.

Social control of mothers with multiple sclerosis

Newsletter photographs of women with multiple sclerosis in hospital gowns as research subjects (*Multiple Sclerosis*, 1968

(1) 4: 15) situated them under laboratory conditions, objectified and separated from society. Frequent reports of research findings pointed to germs, viruses (*The Bulletin*, 1; *MS Canada*, Summer 1975: 2) or malformed genes (*MS Canada*, June 1985: 4) as possible causes of MS.

Rhetoric about viruses created fear of getting close to people with MS. Nineteenth century history shows that a miasma theory that disease was caused by garbage fumes (Wohl) kept the upper classes fearful of contact with poor, disabled, or immigrant persons in Britain during the Social Purity Movement. Claims about genetic causes for MS are reminiscent of eugenic ideology during the Boer War and World War II, when the nation's future was thought to be "rooted in the mother's physique" (Wohl, 16).

Given this negative climate for procreation and intimacy established by the scientists, it should not surprise us that any hint about the sexuality of people with multiple sclerosis or procreation was absent from newsletters until the mid 1970s (*MS Canada*, Autumn 1975: 6; *MS Canada*, Winter 1975: 5-6; *MS Canada*, Spring 1978: 3).

Power brokers: physicians and middle class women

The power which physicians have had in determining the direction of the MS Society of Canada is clear from its first organizing meeting in Montreal. By the end of the 1948 meeting, a Medical Advi-

sory Board had won responsibility to decide how the bulk of money raised would be spent. In 1982, the Medical Advisory Board enlarged its mandate to include input into policy issues (Fraser, 10). Physicians maintained power by presenting themselves as servants searching for the key which would "help unlock the mystery of MS" (*The Bulletin*, 1). As credentialled medical authorities, they protected persons with MS from quackery (*MS Canada*, Summer 1975: 6-7). Their medical research provided Canadians with nationalist pride through international publications (*MS Canada*, 1976, 2).

Just as middle class women allied with physicians for earlier purity reforms in Britain (Mort), middle class Canadian women supported the medical model of multiple sclerosis. The 1957 edition of *The Bulletin* provides many excellent examples of alliances between the MS Society and middle class women in Lions Clubs and Junior Leagues.

The first Canadian chapter of the (American) Multiple Sclerosis Society was founded in 1946 by Evelyn Opel, a mother diagnosed with multiple sclerosis. After she heard from her physician, R.C. Russell, about his experiences attending MS Society meetings in New York (Fraser), she formed a Dr. R.C. Russell chapter of the American organization. In 1948, she went on to found the MS Society of Canada, with Dr. Russell as head of its first Medical Advisory Board. The Canadian Paralympic Association had formed in 1945 as

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a self help group of disabled veterans (Tremblay). Yet Mrs. Opel apparently did not consider the self help model. Presumably, power differences related to gender and to the traditional doctor-patient relationship made Evelyn Opel a likely candidate for seeing organizational options and multiple sclerosis through Dr. Russell's eyes. Her class position also brought her into affiliation with middle-class reformers and with the values of seeing MS as a "cause".

Feminizing the organization

Chapter members, primarily women in towns across Canada, raised objections to the continual medicalization of multiple sclerosis, and demanded that more attention be paid to living with multiple sclerosis. However, they were unable to overcome control of policy and spending which rested in central Canada with the national office and the Board of Directors in the early years.

During the 1956-58 period the Society experienced some growing pains, as a result of the Medical Advisory Board's requests for more research funds and the increasing number of chapters forming all across the country. So chapters felt that they should retain most of their funds in their own communities for patient services work. This was in sharp contrast to the policy of the board, which required that chapters keep 25 per cent of all funds raised for their own purposes, and pass on the remaining 75 per cent to the national research programme. The result was an increased emphasis on fund raising. (Fraser, 14)

During the 1960s and 70s, influence from the women's movement, the disability rights movement (Wolf; Driedger), and the discourse of civil rights began to alter public opinion and Canadian society generally. The goal of finding a cure for MS drove all biomedical research directives until 1976. Finally, in that year, women with MS gained an unlikely ally in the Liberal federal government. The Ministry of Health insisted that federal research money, if allocated, must be used to seek improvements in the present life

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condition of persons with MS (*MS Canada*, 1976: 2). In spite of strong protests from physicians within the MS Society of Canada, the government held firm. As a result, occasional "research targeted at helping people with MS now" through projects to improve the physical quality of life with MS was initiated (*MS Canada*, Autumn 1980: 4).

In 1974, a woman was appointed for the first time as national newsletter editor. Values expressed through publications of the Multiple Sclerosis Society of Canada have subsequently changed gradually, so that the existence and importance of family life with MS actually dominated its 1992 advertising campaign.

In 1977, a woman with MS finally inserted the voice and politic of the women's movement (Wolf) and the disability rights movement (Driedger) into the pages of *MS Canada*. She chose to define herself:

I am not a Disease! During my twenty some years of experience with the disease I have been a wife, a mother, a nurse, a student, a research officer, a gardener, a swimmer, etc. I still am most of these things. Just because I receive treatment, or services from professionals or service organizations does not give them the right to own me. I do not belong to them. I do not relinquish to them the right to make decisions for me or to speak for me to my family, the public or the government. (*MS Canada*, Autumn 1977: 3)

Here is a woman and mother who openly resisted regulation by biomedical and organizational forces within the MS Society. She repudiates the label of either passive sufferer or research subject. Instead, she insists on creating distance between herself and a medical order which she dares to characterize as controlling.

A woman executive director was hired in 1979. The Individual and Family Services Division (IFSD) was formed in 1979, with a woman at its head. It established at least one coordinator in each province and introduced literature about family life. The newsletter promoted IFSD pamphlets titled *Multiple Sclerosis: Its Effects on You and Those You Love* and *Should I Have a Baby?* (*MS Canada*, December 1986: 5). In 1988, *Plain Talk: A Booklet about Multiple Sclerosis for Family Members* advocated making a priority of caring not just curing. This text emphasized ways to live more positively in the present, rather than focusing on research which might someday find a cure for multiple sclerosis.

In 1979, there was also a move to allocate resources equally between the financing of biomedical research and IFSD.

In 1988, the newsletter finally gives us a sense of what family life was really like for Evelyn Opel, her daughter and husband. For the first time we read, "She ... married in 1944 and had a baby girl ... the next year. Her devoted family life saw her through many personal struggles." (*MS Canada*, April 1988: 3). Her daughter recalled "that her father had to carry her mother up and down the stairs to their apartment until they were able to find more accessible housing when [the daughter] was five" (3). Although the privacy veil of family life was now lifted, the discourse of medicalization continued. Mrs. Opel was identified as a "long-time fighter" and "MS Society Founder" (3). The passive victim of tragedy was reconstructed as a tragic hero.

Finally, the 1991 Annual Report shows that the organization's mandate has broadened enormously. The following committees now report to the national board of directors: public relations, social action, individual and family services, fund raising, volunteer recruitment, medical policy, and medical advisory board.

Currently, discussion groups for chil-

dren whose parents have MS are held in Saskatchewan and Atlantic Canada at annual conferences. Manitoba provides ongoing programmes for children. Ontario is gathering information about quality of life for individuals with MS and their families. Quebec is assessing the needs of children, teens, and parents with MS.

The lived experience of mothers with disabilities

How does the ideal of controlling nature and the perfectly healthy gendered body become translated into the individual experiences of mothers with disabilities? Today women with MS are often afraid to have children and some mothers with MS anxiously observe their children for signs of inherited disease (Prince Edward Island MS Society, 1990). Interviews I carried out in 1991-92 with eighteen parents who have multiple sclerosis in Ontario revealed many instances in which rationalism, individualism, and the ideal of the perfect body are perpetuated in everyday lives. A single example will provide a flavour of that process.

One mother using a scooter for mobility described how her son avoided recognizing her when he was with his school friends.

Actually it was funny. I was going down the street on my scooter and he was with a lot of his friends. So I thought I would just wait and see what he does. I was actually on the other side of the street.... He did not acknowledge me at all.

In spite of her opening remark about this incident being funny, the story was related with tears in her eyes. While revealing her pain, this woman explained how important it is for her to understand her son's dilemma and his own need for acceptance. She has learned from the medicalized discourse about MS and from traditional notions of womanhood that mothers should nurture their children and make sacrifices for them. They should not exhibit needs of their own and they should certainly not be disabled.

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have an able-bodied mother deny themselves the right to be disabled. Ironically, they simultaneously teach their children to deny disability. Women in situations such as this are only reproducing notions which have been perpetuated through structures like those which initially formed the moral reform movement in Britain and the early Multiple Sclerosis Society of Canada. It is in these lived moments with significant others that the theoretical arguments which explain the oppression of mothers with disabilities become concrete. Within the realm of personal relations is also where its oppression is most keenly felt.

Linking the past to the present

My intent in this historical review is certainly *not* to characterize the MS Society of Canada as an unqualified success with regard to feminizing an institution. However, we should recognize the widespread impact which the civil rights movement, the women's movement, and the disability rights movement have had on our society. We should credit ourselves with change that empowers women with disabilities, when that credit has been earned through the DisAbled Women's Network, or other similar minded organizations.

This review also helps us to take apart the process of change, and to locate the roots of our past and current values. This history teaches that action *by* women does not always bring about action *for* all

women. Women at the turn of the century were responding to nationalist sentiment, and to fears of difference and change which were prevalent in their time. In 1948, women including Evelyn Opel were again in the midst of high nationalist sentiment following World War II. War victory brought a new hopefulness that 'man's' science and technology could indeed successfully control nature through creating bombs or through biological research. The idea was that through masculine power, nature and the body could be transcended (Brittan and Maynard). The ventures of maternal feminists were helpful in showing that women could speak and act in the public realm. Ironically though, by privileging particular ideas about what 'normal' means in terms of the two-parent, middle class Caucasian family, and the perfectly healthy body, these women left no room for appreciating mothers whose bodies do not fit this ideal, or who are part of different family forms. Only through critical thinking about values can feminists today consider what sort of actions would be *for* a broad range of women.

Not another dualism

In this issue, both Sharon Dale Stone and Susan Wendell discuss transcending the body. Stone reminds us that when all our intentions are geared to overcoming or ignoring bodies, we discount and devalue part of who we are. Feminists before her have used this argument to protest against the marginalization of the female body. She writes to protest the marginalization of the disabled body.

Susan Wendell appears to take an opposing position. She questions feminist assumptions that transcendence of the body is necessarily wrong for women. Experience has shown her that the pain and fatigue of the disabled body is something which she deliberately transcends, by taking a rest or putting herself in a comfortable position, in order to then ignore her body for a time. She uses this time to move beyond the body with thoughts and creative ideas. She questions the one-sided perspective of feminists who absolutely oppose transcending the body through rationality.

Throughout this review of the MS Society, I have objected to male-driven scien-

tific ideas about transcending the female disabled body which lead to objectification and commodification. Since these ideas still dominate science, feminists must continue to question and to object strongly when advocating transcendence of nature hides a subtext of needing to measure up to some ideal male norm. Where science is used to control nature in this particular way we must argue for living in harmony with nature to some degree, and for appreciating the body in all its manifestations. We should insist on respectful recognition of difference, open dialogue, and the inclusive day-to-day social connectedness that is necessary for living with and nurturing each other in the present. Process is important, not just outcome.

However, while we should continue to advocate for living in harmony with nature in some form, and while we should definitely object to the masculine ideals which currently dominate science, it is not helpful to create yet another competition between only two alternatives. Forced choices between objective/subjective, male/female, people of colour/Caucasians, humans/nature, have not gotten us very far. When we see living in harmony with nature as the only simple answer, we make nature and the body into yet another unobtainable ideal.

If we look at individual or collective life histories, we can see that in practice, people move between these positions of transcending the body and living in harmony with it. Susan Wendell, for example, first recognizes and respects her body by taking a rest or getting into a comfortable position. Then, she chooses to transcend the present and the body, to think creatively about a better future world. Initially, a future ideal cure for multiple sclerosis was the only goal of the MS Society of Canada. When under pressure to change direction, the organization began to show an appreciation of life in the present by seeking ways to reduce symptoms, while continuing the search for a cure.

When we single-mindedly oppose transcending nature through science, we forgo the great benefit that some science can bring. Someday, science may bring a cure for multiple sclerosis. It may at least address much of the fatigue or pain which multiple sclerosis brings to a woman's everyday life. We can appreciate living in

the present and still dream of the future. Diane Goodwillie makes the point that science can overpower and control women like us. However, "through understanding the technologies, uniting with friends and concerned groups, we can create the world we want and need." (Goodwillie, 104). Theorizing about women with disabilities can broaden our understanding of feminist theory generally. Furthermore, a critical historical perspective of the values which keep us apart can bring us together.

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Karen Blackford is an activist and researcher regarding issues of women with disabilities, sole-support mothers, women in public housing, and returning women students. On faculty at Laurentian University in Sudbury, Ontario, she is currently completing a doctoral degree in sociology at York University.

¹The library of newsletters housed at the Toronto Offices of the MS Society of Canada includes only one edition of *The Bulletin* (No. 22, December, 1957), all editions of *Multiple Sclerosis* and all editions of *MS Canada*. Some of the newsletter analysis presented here has been described in a different article which focused upon moral regulation of disabled mothers in the MS Society's early years (see Blackford, 1993a).

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