

Systems, Definitions and Identity:
The Socio-Political Disability / Illness Identity Triangle

“Who do you want me to be for me to get what I need?

And how severe is enough?”

Submitted by Catherine Ruth McGowan

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Systems, Definitions and Identity: The Socio-Political Disability/Illness Identity Triangle

BY

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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
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MASTER OF SOCIAL WORK

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ABSTRACT

Lived experiences of people with multiple sclerosis (MS) are explored vis-à-vis: 1) disability support program & service systems, & disability organizations, including a Disability Rights Organization & a Disease-Specific Voluntary Health Agency; 2) definitions of disability & chronic illness in Disability Studies, Feminist Disability & Population Health Discourse & definitions in disability policy; &, 3) self & collective identity before & after diagnosis vis-à-vis the first two dimensions. Qualitative participatory methods outlined by Ristock & Pennell (1996) were used. The study was guided by an advisory committee of people with MS, the Manitoba League of Persons with Disabilities (MLPD) & the Multiple Sclerosis Society of Canada, Manitoba Division (MSSC). A sample of 5 women and 1 man, reflecting a broad representation of socio-economic, ethnic background, living arrangement, MS related impairments & association with primarily the MSSC found the following: 1) 'disability identity' is viewed negatively, influenced also by experience prior to MS; 2) the existence of a disconnect between critical awareness of social model definitions, self identity, & group identification; 3) cognitive dissonance caused by contradictions between policy definitions and self identity; 4) perceptions of definitions of 'disability' & 'chronic illness' are as varied as those in the literature; 5) accessing support services pre & post MS is dramatically different. The implications of these findings are discussed.

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INTRODUCTION

People with disabilities, along with other visible minorities in society, have engaged in a struggle for political equality, as well as for positive personal and collective identities (Weeber, 1999). People with disabilities have been working for social and political equality in society for over thirty years, along with women, First Nations and Aboriginal people, and other social minorities (Weeber, 2000). Like other groups have done, people with disabilities have engaged in what Anspach (1979) calls "identity politics": politics that strive to change not only society's conception of and response to people with disabilities, but the self-identity of people with disabilities themselves. Self-identity development with a chronic illness and/or disability is a complex process strongly influenced by how a society defines disability and illness, and the stigma attached to them (Goffman, 1963; Anspach, 1979; Wendell, 1996). The work of people with disabilities in changing how they think about themselves continues as the disability community struggles for self-definition and self-determination, as well as citizenship rights. Weeber has noted that, by developing a broad knowledge base that truly reflects the identity-development process, people with disabilities and chronic illnesses can embrace their own unique way of being in the world, making it possible to experience unity with others (2000).

Like other minority communities, the disability community has called for a research agenda conducted by those who identify with the culture and worldview of the community (Morris, 1992; Oliver, 1990, 1993; Zola, 1993b; Linton, 1997; Davis, 1997). A key component of the feminist and social-political disability

research paradigms is transparency, which includes placing oneself (i.e. the researcher) within the research (Lofland & Lofland, 1995; Ristock & Pennell, 1996). This study's research questions are grounded in my own experience: a) as a woman living within that somewhat liminal space between disability, illness and 'normality' b) as a woman politicized into the Disability Rights Movement (DRM) in my early twenties while completing my Bachelor of Social Work degree; and my discoveries that although I shared the sense of alienation of other people with more visible disabilities, a) I didn't often see myself or my issues reflected in the DRM, and b) I identified more than I anticipated with some of the people with multiple sclerosis I met via my staff role at the Multiple Sclerosis Society of Canada, Manitoba Division (MSSC). I found myself wondering, For people with MS, what, within today's social-political climate, are the factors impacting choice of identification as disabled or chronically ill? How do people with MS view the terms "disability" and "illness" in relation to themselves, before and after they receive their diagnosis?

Having worked in various capacities for a disability advocacy organization, an Independent Living Centre, and a disease specific voluntary health agency, I have had the opportunity to observe the differences between organizations based on the social model of disability and those based on the traditional medical model charity ethic. Issues of identification and membership development arose in each context, although seemingly for different reasons. The disease-specific voluntary health agencies had considerably more resources to draw from, yet involved fewer people with the specific disease in decision-making capacities.

By contrast, the consumer/social model based organizations involved people whose disabilities tended to be visible, stable and permanent in decision-making roles, but struggled to maintain a minimum membership base and basic funding. The question arose, What factors come into play in individual choice to get involved in either a disease-specific volunteer health agency or disability rights organization, or to remain uninvolved?

Identity struggles related to accessing supports and services have been a consistent theme in my life both personally and professionally. As a result, I also wondered, What is the self-identity impact of the struggles people are going through to get the services and supports they need? My work at both the Manitoba League of Persons with Disabilities (MLPD) and the Multiple Sclerosis Society of Canada, Manitoba Division (MSSC) highlighted the often tremendous struggle of people with disabilities in dealing with disability support programs and services based in a rehabilitation paradigm that requires restrictive definitions of disability. People with fluctuating and/or sometimes nebulous disabilities and chronic illnesses, like multiple sclerosis and my own (a unique form of spinal muscular atrophy), are particularly affected. While a staff member at both organizations (at different times), I was often involved in assisting people with applications and appeals for programs and services they desperately needed but were deemed ineligible for.

Finally, my experiences of hearing and responding to sometimes explicit charges in the mainstream media, and society in general, to the effect that people with disabilities are somehow less than complete human beings (i.e. that

as “defects and deviants,” our lives are not worth as much as “normals,”) led me to wonder how a ‘positive disability identity’ was possible within such a social political climate? Ultimately, I developed the following research objectives:

Research Objectives

1. To explore the factors impacting on the self-identification of individuals with multiple sclerosis as either primarily disabled or primarily chronically ill;
2. To develop an understanding of the current research regarding self-identity and definitions of disability and chronic illness being proposed in disability studies, feminist disabilities literature, and population health literature, a disability advocacy organization, and a disease-specific voluntary health agency;
3. To compare, in a social-political context, people’s lived experiences with self-identity and their understanding of definitions of illness and disability before and after a diagnosis of MS;
4. To explore the implications of this information vis-à-vis current definitions being proposed in research in Disability Studies;
5. To explore the implications of this information vis-à-vis disability policy development;

6. To explore the implications of this information in terms of coalition building between disability advocacy groups such as the MLPD and voluntary health agencies such as the MSSC.

Learning Objectives

1. To develop comprehensive understanding and skill in participatory research methods.
2. To develop comprehensive understanding and skill in qualitative research methods.
3. To develop comprehensive understanding and skill in research from a social-political disability framework

Following the introduction, Chapter One provides background information, including the 'disease' context of the research, the partner organizations, a discussion of terms and a literature review of disability definitions, models of disability, feminist disability discourse, population health principles, the chronic illness and disability dialectic, and a brief environmental scan. Chapter two details the methods, and chapter three entails findings and discussion. Chapter four is a discussion of the implications of the research and self-reflections on the work. Conclusions, references, bibliography and appendices follow this.

CHAPTER ONE – BACKGROUND INFORMATION

'Impairment' / 'Disease' / 'Chronic Illness' Context

This study's general intent is to explore the life experiences of those living within the gray area between 'impairment,' loosely described as a medically classified condition, and 'disability,' a generic term used to denote the social disadvantage experienced by people with an accredited impairment. Although the social-political paradigm of disability contends that impairment should not be the primary locus of a study regarding disability (see further delineation of the social-political disability paradigm within literature review), I have chosen to outline the impairment context of MS to provide a background for understanding both how this particular impairment impacts individuals bio-medically and its prevalence. The following information is drawn from information booklets developed in 1999 by the Multiple Sclerosis Society of Canada, National Office and Cynthia Benz's book entitled Coping with Multiple Sclerosis.

Multiple sclerosis is the most common central nervous system disorder of young adults, with onset usually in the late twenties and early thirties. It is not a terminal illness; most people with MS live regular life spans after they are diagnosed. The disease is also cyclical in most instances, with unpredictable patterns of relapse (symptom flare-up or 'exacerbation') and remission (total or partial recovery). Some people with MS also live for years with 'invisible' symptoms which allow them to 'pass' as able-bodied to those who do not know them. The disease is highly variable and unpredictable. Impairments, symptoms and disability can develop at any time with a wide range of severity. Any part of

the body served by the central nervous system may be affected, including eyesight, hearing, speech, short-term memory and cognitive functioning (to a limited extent), emotions, mobility, dexterity and balance. Rarely does an individual experience symptoms, impairments or disability in all of these areas at the same time. The peripheral and autonomic nervous systems are usually not affected.

Canada has one of the highest rates of MS in the world. The incidence of MS in Canada is estimated at between 1 in 750 and 1 in 500 people, with a suspected but unconfirmed higher incidence in the prairie regions.

Partner Organizations

The Multiple Sclerosis Society of Canada was established over 50 years ago in Montreal by a group of women who wanted to raise money for research (MS Canada, January 1994). Ultimately, the MS Society developed into a national organization with divisions in every province. The mission of *"finding a cure for MS and enabling people with MS to enhance their quality of life"* was adopted in 1992. As a disease-specific voluntary health agency, it is fundamentally based in the medical model and traditional charity ethic. A major function of the organization is fundraising, primarily for research to find a cure and effective treatment for MS. Historically, few people with MS have been involved in decision-making roles within the organization, although that is beginning to change. Provincial divisions are coordinated through a national office in Toronto and internationally via the International Federation of MS Societies.

The Manitoba League of Persons with Disabilities is an advocacy organization of and for people with disabilities of all types in Manitoba. Based on the social model of disability, it was established 27 years ago by a grassroots group of people with disabilities to advocate for a Handi-Transit bus service in Winnipeg. The philosophy of the organization is that *"All persons, regardless of abilities, must have access to opportunities in order to exercise their citizenship rights and responsibilities"* (MLPD brochure). Now with several branches around the province, the MLPD is an affiliate of the Council of Canadians with Disabilities, which in turn is a member of Disabled Peoples' International. A key

tenet of the MLPD is consumer control, which requires over half the Board of Directors (called the Provincial Council) to self-identify as having a disability.

Discussion of Terms

As Irving Zola asserts in "Self-Identity and the Naming Question: Reflection on the Language of Disability" (1993), the power of naming is a personal and political issue. There is growing recognition that our awareness of social issues is influenced by the concepts and language we use. Disadvantaged groups, including women, minority ethnic groups, older people, lesbians, and gay men continue to challenge established prejudicial attitudes and stereotypes. In general, researchers from all disciplines have responded positively to these overtures; however, there is little evidence that the same sensitivity has been displayed in writings on disability and people with disabilities (Barnes, Mercer & Shakespeare, 1999).

The question of appropriate terminology remains highly controversial, even among people with disabilities and organizations controlled by them. For most disabled and non-disabled people throughout the English-speaking world, terms such as "cripple," "spastic," "retarded," and "mongol" have lost their original meaning and have simply become terms of abuse. Furthermore, words which depersonalize and objectify people with disabilities such as "the impaired," "the disabled," "the deaf" or "the blind" are considered unacceptable although they appear regularly in the medical and academic literature. Yet while there is growing consensus about the oppressive implications of the term 'handicap,' with its historical allusions to begging and charity, divisions persist as regards to the terms "impairment" and "disability." Some of these divisions will be explored in this study. I also find myself unsure about appropriate usage of words such as

“symptoms” in the context of a social – political analysis of disability and illness; for this reason I have chosen to use quotations around words I think have a somewhat Delphic or ambiguous nature. Although in some parts of the world the term “disabled people” is preferred as opposed to “people with disabilities,” the common usage in Canada remains “people with disabilities.” Accordingly, I will generally use that terminology in this paper.

What follows are the definitions I will use in this paper for other illness-related terms whose meanings are also debated or unclear in this context. In keeping with Susan Wendell’s approach (1996), I will generally base my definitions on ordinary usage of the words, recognizing that ordinary use does not make precise distinctions. As I will be addressing the definition of disability at length in the following section, I do not address it here.

“chronic illness”: Wendell (2001) refers to a chronic illness as an illness that does not go away by itself within six months, that cannot reliably be cured, and that “will not kill the patient any time soon” (p.21). Weeber (2000) notes that the majority of health conditions categorized as ‘chronic illnesses’ are defined as ‘disabilities’ in the Americans with Disabilities Act (i.e., heart condition, post-polio syndrome, arthritis, multiple sclerosis, diabetes, stroke, etc.)

“symptom”: that which attends and indicates the existence of a disease, not as a cause, but as a constant effect. (Webster’s Dictionary, 2002)

“disease”: in this paper, disease will refer to some medically recognized category of symptoms. Not all sicknesses and illnesses are diseases recognized by medicine, and not all medically recognized diseases cause a person to feel sick or ill.

“diagnosis”: the identification of disease based on symptoms by a doctor.

“hidden impairments” vs. “invisible impairments” vs. “non-apparent disabilities”:

At this time, there does not seem to be consensus in the literature regarding the most appropriate term to use to describe symptoms, impairments, or disabilities that are not obvious to the outside observer, i.e., fatigue, pain, weakness, cognitive or psychological disability. As the participants used “invisible disability” I will use that term, unless quoting others.

“disability supports”: As outlined in the 2000 discussion paper “Full Citizenship: A Manitoba Provincial Strategy on Disability,” the term “disability supports” describes any good or service that assists a person in overcoming barriers associated with a disabling condition to carrying out activities of daily living, social (including political and cultural) activities and economic participation. The goal is independent living as opposed to the medical model goal of curing or rehabilitating a person with disabilities. As a result, there are no fixed sets of disability –related goods and services. A good or service

becomes 'disability-related' when it is used to assist a person or persons in overcoming barriers associated with a disabling condition. The list of disability supports can include but is not limited to

1. technical aids;
2. transportation;
3. support for independent living;
4. job coaching;
5. attendant support;
6. home making assistance; and
7. training, respite and back up for family caregivers.

"ableism" - Linton (1998) defines "ableism" as the unconscious assumption that the non-disabled experience is the normative grounding for all experience, just as racism and sexism assumes the White and male experiences respectively to be the normative grounding of reality and theory.

"self-identity": As there is considerable literature on the meaning of identity (for a comparison of the identity development theories of Erik Erikson, William Cross, Vivienne Cass and Linda James Meyers in relation to people with disabilities see Weeber, 2000), for the purposes of this paper, the terms self-identity, and self-concept will simply refer to how the participants perceive or describe themselves.

Literature Review

The Plethora of Definitions of Disability

How a society defines disability and whom it recognizes as disabled reveals a great deal about that society's attitudes and experiences concerning the body, what is stigmatized and what is considered "normal" in physical appearances and performance, and what activities are seen as necessary and/or valuable and for whom (Wendell, 1996). A plethora of definitions of disability are currently in use and under consideration within the disability community, in disability research as well as by disability policy-makers. As Hahn (1996) states "the proliferation of definitions has resulted in substantial misunderstanding" (p. 31). These "misunderstandings" affect the lives of people with disabilities in a very direct way.

Questions of definition arise in many practical situations, influencing information gathering, (e.g., Statistics Canada Participation and Activity Limitation Survey) and social policies, and determining outcomes that profoundly affect the lives of people with disabilities (Wendell, 1996). These may include economic help for such purposes as education, training and retraining; obtaining equipment such as mobility aids and/or computers for basic communication; modifying a home or vehicle to enable a person with a disability to use it; hiring assistants to help with bodily maintenance and household tasks; even obtaining medical supplies such as medications and bandages. Definitions of disability can also determine people's entitlement for basic income support for food and

shelter, accessible housing and parallel forms of transportation, and disability parking permits (Wendell, 1996).

Socially accepted definitions of disability determine the validation of disability by friends, family, and coworkers. Validation is important not only in order to obtain the help and understanding of significant others, but to ensure that the person may receive the acknowledgment and confirmation of her/his reality, so essential for keeping a person socially and psychologically anchored in a community (Wendell, 1996). Definitions of disability are also important to people organizing for political purposes (as outlined in more detail under "Minority Group Model/Identity Politics/Disability Rights Movement"). Internal debates continue within the DRM regarding whether the terms "impairment" and "disability" should be considered mutually exclusive as some social model theorists currently suggest (see below "Chronic Illness and disability dialectic" for further discussion). And ultimately, definitions of disability affect self-identity (Wendell, 1996). Recognizing oneself as disabled (or not) identifying with other people who are disabled (or not), and learning about their experiences can all help one understand and interpret one's own experience. The discovery that one is not alone, that one's problems are not unique, can have a profoundly empowering effect. But being identified as disabled also carries a significant stigma (Goffman, 1963) and usually forces the person so identified to deal with stereotypes and unrealistic attitudes and expectations that are projected onto her/him as a member of this stigmatized group.

The following are some examples of the plethora of definitions of 'impairment' and 'disability' in Disability Studies discourse:

In 1979, Nagi proposed the following definition of disability:

“an inability or limitation in performing roles and tasks expected of an individual within a social environment.”

In 1991, he subsequently revised his definition to stress the social dimension of this phenomenon: “Disability refers to social rather than organismic functioning”; he also inserted the phrase “socially defined” to qualify the meaning of “roles and tasks,” and he added the words “socio-cultural and physical” as modifiers of “environment.” (Nagi, 1991; Hahn, 1996)

Disabled Peoples' International, an international coalition of advocacy groups by and for people with disabilities, adopted the following terminology (DPI, 1994):

Impairment: a medically classified condition.

Disability: a generic term used to denote the social disadvantage experienced by people with an accredited impairment.

In 1980, The World Health Organization established the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and introduced the following definitions of “Impairment/ Disability/ Handicap”:

Impairment: Any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: Any restriction or lack (resulting from an impairment) of ability to perform any activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual. (Wood, 1980)

Whereas this classification scheme introduced useful distinctions that sharpened the understanding of disability, it has been criticized on a number of levels. First, it tends to place the focus on the individual and the need for the individual to change (i.e., on impairment), diminishing broader social factors that can result in disability. The scheme can also create the impression that the notions “impairment”, “disability” and “handicap” stand in conceptual isolation from each other, which is not the case (Roehrer Institute, 1996; Wendell, 1996). The WHO definitions are currently being revised to reflect the significant role of the environment in disablement. Many schema were proposed in the 1995 Colloquium Proceedings of the Environmental Determinants of Social Participation and the North American Revision Meeting of the International Classification of Impairments Disabilities and Handicaps. The International Classification of Functioning, Disability and Health (ICF), introduced in November, 2001 by the World Health Organization, is a classification of health and health related domains that describe body functions and structures, activities and participation. These domains are classified from body, individual and societal

perspectives. Since an individual's functioning and disability occur in a context, ICF also includes a list of environmental factors (WHO website, www.who.int).

Key definitions of the domains are:

<i>Body functions</i>	the physiological functions of the body systems (including psychological functions)
<i>Body structures</i>	anatomical parts of the body such as organs, limbs and their components
<i>Impairments</i>	problems in body function and structures such as significant deviation or loss
<i>Activity</i>	the execution of a task or action by an individual
<i>Participation</i>	involvement in a life situation
<i>Activity limitations</i>	difficulties an individual may have in executing activities
<i>Participation restrictions</i>	problems an individual may experience in involvement in life situations
<i>Environmental factors</i>	the physical, social and attitudinal environment in which people live and conduct their lives; these are either barriers to or facilitators of the person's functioning.

The scheme has already been critiqued by disability studies scholars as too ambitious, too complicated and still too medically oriented (Disability Research Unit listserv commentary, University of Leeds, 2001).

In the final analysis, Hahn emphasizes that researchers must realize that the definition of disability is ultimately determined by government policy, “Disability is whatever public officials say it is and are shaped by concepts inherited from previous research.” (Hahn, 1985, p. 102) Public policy aligned more closely with either the bio-medical paradigm or the social-political paradigm (described below) affects definitions of the problem, which “...is the heart of the policy, and the key to deciphering its meaning and logic” (Pal, 1992, p 8). Changing the definition of the problem changes the nature of the policy. By the same token, policy-makers are often sensitized or prepared to recognize certain problems because of their own pre-existing values (Pal, 1992); which fact brings us full circle, back to societal attitudes.

Models of Disability

Bio-medical Model

Historically, disability has predominantly been viewed from a “medicalized” perspective – disability as a physical or psychological “defect,” a violation of the “normal” order (Phillips 1985; Longmore, 1987; Davis, 1997; Gallagher, 1995). This view places disability in the category of pathology and disabled people in the category of “sick”, an invalid needing to be cured or, at the very least, corrected as much as possible (Goffman, 1963; Derksen, 1980; Enns, 1981; Longmore, 1987; Kirschbaum, 1991; Zola, 1993a). The majority of disability research in the fields of medicine, biology, psychology and rehabilitation is based in this paradigm. As well, the domination of the field by experts, the positivist perspective of the research agenda, and the location of the research question in

the individual have not changed significantly in recent years (Hahn, 1993; Rioux & Bach, 1994). From this perspective, the disability experience is segmented into separate medical diagnoses, limiting the scope and approach of research to that which can be measured, counted, and used to categorize and project future possibilities (Weeber, 2000). Gill (1987) describes the focus of this medical/rehabilitation research as "disability as pathology." The unit of analysis is solely within the individual having the "disability" or "pathology". Although the seeds of this ideology go back as far as Aristotle (see further discussion under "Feminist Disability Discourse"), the pathology of disability was established and formalized through the use of statistical "norms" developed by avowed eugenicists, (e.g., Sir Francis Galton), committed to protecting the purity of the White race through their "science" of statistics (Nagase, 1995; Weeber, 2000). This new social-Darwinist worldview attempted to establish scientific "norms" which everyone must conform to or face segregation from society (Davis, 1997). This enterprise has not been completely successful, though, as the development of a universal and consistent set of "diagnostic" criteria in "disability" determination has not been achieved (Stone, 1984). Although committed to a social-political model of disability, Hahn suggests that the lack of a general consensus about the nature and meaning of disability is actually a major obstacle in the analysis of disability policy (Hahn, 1985).

Nevertheless, "clinically defined norms," varying according to the profession's special interest (e.g., rehabilitation, employment, psychotherapy, education, income maintenance) make it possible for professionals and

“disability” policy-makers to measure a person’s deviation from whatever specific criteria they have chosen to embody the “norm” (McNight, 1977 as cited in Szymanski & Trueba, 1999). Corrective procedures can then be prescribed to ensure the greatest degree of “normalization” (Gill, 1998).

Normalization

“Normalization” is a concept based on the medical model of disability, and is the objective of rehabilitation. Its goal is to fulfill cultural conceptions of normalcy; it endorses commonly held assumptions about the “ideal” person and what it is to be human. The “myth of success” (Phillips, 1985) embedded in the normalization concept is that with hard work, the disability can be “overcome” or “defeated” and at least the illusion of normality can be achieved.

The social implications of these “norms” are that people with disabilities are considered “victims,” “sick,” and “defective,” not capable of functioning as fully competent human beings and requiring therefore the ongoing supervision of professionals to bring them up to an acceptable and “objective” standard of normalcy (Longmore, 1987). Within this medicalized perspective, there is no place even for the possibility that anything positive could be associated with illness or disability. Hahn (1985), in his discussion of disability, identity, and politics, notes that in a normalization context, a person with a disability would have “difficulty in developing a sense of identity with an attribute that one has been taught to overcome.” The medicalized perspective allows for no common collective experience nor any unit of analysis other than the individual’s assumed pathology or deviation from the “norm.”

Although the disabled individual who subscribes to this point of view may be able to maintain a relatively sanguine and confident attitude toward the self, there is a considerable price to pay. Inevitably, despite such individual's devotion of efforts and energy to minimizing and concealing their disability's effects in order to make themselves fit the norm, the disability will ultimately obtrude upon the social situation, causing inescapable tension. Secondly, "normalization" is premised on a number of contradictory beliefs, resulting in a degree of "cognitive dissonance." Individuals are caught in the contradiction of upholding the "You-can't-judge-a-book-by-it's-cover" ideology while struggling with their actual need to focus on and replicate to the best of their ability the ascriptive attributes upon which the societal "ideal" is based (Anspach, 1979). Further, there is a discrepancy between the norms of polite society, which proffer a superficial acceptance to "The Disabled," and the actual emotional displays conveyed non-verbally by able-bodied or "normals" in social intercourse. Goffman (1959) coined the terms "expressions given" and "expressions given off" to describe this discrepancy. These factors cannot help but undermine any sense of trust between the able-bodied and people with disabilities in a society which subscribes to the concept.

There are two models of disability based on the bio-medical model. According to the **functional/limitation model**, disability is defined by one's physical capabilities; in the **economic/vocational model**, disability is defined by one's ability to be employable - a "productive" member of the labour force. Public policies flowing from these models, which view the individual with the

disability as needing to change to fit the system maintain a “second class citizen” role for people with disabilities in society. From a socio-political perspective, this view is the major barrier to the achievement of full citizenship by people with disabilities (Batavia, 1993; Bickenbach, 1993).

Identity Research within a Medical or Rehabilitation Model of Disability

Within the medical paradigm, the identity-related issues thought to be faced by disabled people consist of pathological intra-psychic and social consequences which are believed to follow necessarily from the disabilities themselves (Goffman, 1963; Parsons, 1951, 1964). Goffman’s 1963 treatise on disability and stigma characterized such identity struggles as “spoiled identities,” which resembles “negative identities,” the “ablist” notions proposed by Freud and Erik Erikson. Perceived in this way, the identity struggles of people with disabilities require the development of reactive, defensive strategies to contain and manage society’s stigmatizing of disability (Anspach, 1979; Gill 1998). Such identity constructs have generated considerable research on able-bodied people’s perceptions of disabled people, the self-perception of disabled people, and the development of coping and “identity management” strategies. All were conducted from the medical context, in which the problem is understood to be defined as the pathology within the individual with the disability deviating them from the norm.

In rehabilitation literature, identity issues are always framed as a solitary struggle to “adjust to being disabled.” In a comprehensive review of

rehabilitation research, Livneh (1986) identified a composite five-stage model of psychological “adaptation” to disability reflected in the literature:

1. Initial impact (accompanied by shock)
2. Defense mobilization (leading to bargaining and denial)
3. Initial realization (characterized by mourning)
4. Retaliation (characterized by externalized aggression)
5. Reintegration (involving acceptance and adjustment)

This final phase is characterized by the acceptance of the disability as a “containable obstacle to overcome...adjustment [is] the final positive outcome” (Livneh, p.12). The underlying negative context is apparent in the fact that this model bears a strong resemblance to Kubler-Ross’s (1968) model of the stages of emotional acceptance of death. Useful only in understanding an initial process of coping with a traumatic loss of functioning, this model is here presented as applicable to the entire disability experience. It does not address identity issues of people with lifelong disabilities or the possibility of developing a “positive identity” independent of the external medicalized standard of normality. From a rehabilitation point of view, this adaptation process is always framed as a depoliticized individual problem that does not include how social justice issues of prejudice and discrimination can negatively influence identity. Nor is it considered that a personal rehabilitation struggle could expand into a positive collective identity with other disabled people (Goffman, 1963; Longmore, 1993).

Social Political Model

Within the social-political model, “disability” is understood not as pathology, but as a function of the interaction between the person and their environment. This approach sees “disablement” as largely a social construct, the consequence of a “disabling environment” (Derksen, 1980; DeJong, 1983; Hahn, 1984b; Bickenbach, 1993). As such, this model views “the problem” or unit of analysis, as residing not within, but rather outside the individual. As stated by Hahn (1993), “...the crucial determination of what can be expected from human beings is shaped primarily by modifications of the environment instead of modifying the individual” (p.4). As such, people with mobility impairments, for example, would not be considered “disabled” in an environment equipped with the necessary accommodations and supports, such as appropriate mobility aids (a wheelchair or walker), ramps, appropriate sized doorframes and light-switch levels, etc. Such individuals are no longer disabled, as within this environment nothing is disabling them. They can participate in all activities they choose.

Once they move out of this environment the ‘disablement’ may begin. In another environment they may encounter stairs or curbs without curb-cuts; they may have to interact with medical/rehabilitation based policies and service providers that see them as “defective” and in need of “fixing,” and other able-bodied people who regard them as pitiful, are fearful of them or worse. At this point, the environment becomes disabling, or they become disabled by the environment. They can no longer move about freely and are limited in the

activities they can participate in either by structures or exclusionary policies and attitudes.

Unlike other models and definitions of disability based primarily on professional assessment of disability as degree of "deviation from the norms," the social-political definition reflects a social meaning of disability. This meaning is derived from the concrete lived experiences of disabled people, and represents a major shift in 'disability' research and policy (Hahn, 1985). The social-political model focuses attention on the significance of societal perceptions formed on the basis of visible and permanent characteristics (Hahn, 1983, 1985). The devaluation of people with disabilities is not due to their alleged economic nonproductivity or to their alleged biological inferiority but rather is a result of the reluctance of society to recognize the dignity and worth as human beings of people with disabilities.

The social political model is founded on the realization that all aspects of the environment, including architectural, communications, and other settings that prove a context for human interaction, are fundamentally molded by public policy. Therefore, the solutions to the problems posed by disability must be achieved by policy changes that affect the environment, rather than by an exclusive reliance on alteration of the functional or economic capabilities of disabled individuals (Hahn, 1985). The social-political model also reflects awareness that the discriminatory features of the existing environment are not accidental or coincidental. It acknowledges that policies shaping the environment are reflective of the prevalent social attitudes and values in society. From this

perspective, the study of disability is seen to require a theoretical perspective containing an explicitly political awareness, not only of the striving of people with disabilities but also of the prejudicial impact of public policies.

Minority Group Model / Identity Politics / Disability Rights Movement

The social-political model of disability has allowed for the emergence of a “minority-group model” of disability (Hahn, 1993) or what Anspach refers to as “identity politics”. By defining disability in relation to external resources rather than internal sources and to a disabling environment instead of to personal flaws or deficiencies, the social-political viewpoint has permitted disabled citizens to engage in the process of translating formerly discredited bodily attributes into a dynamic sense of political identity. For some, this has been profoundly liberating, allowing women and men with disabilities to develop a positive feeling of self-identity attached to previously degraded aspects of themselves (Anspach, 1979). It is only within the context of disability as a minority experience that we begin to find the basis for a “positive disability identity” (Weeber, 2000).

The evolution of the minority group model of disability grew out of the identity politics of the 1960's and the “politicization of life” (Anspach, 1979; Shapiro, 1993). The 60's witnessed a widening definition of politics to embrace all aspects of the person. This type of politics is characteristic not only of the disability community but of many social movements, including feminism, the black power movement, and the gay/lesbian liberation movement. While insofar as they seek to effect changes in public policy, such social movements may have strong instrumental components, they also consciously endeavour to alter both

the self-identity and societal conceptions of their participants. Accordingly, people with disabilities involved in minority-group/ identity politics “eschew the telethon’s ‘politics of pity’ and abhor the ‘poster child’ image demanding instead to be regarded (by themselves and others) as self-determining adults” (Anspach, 1979 p. 766). As a result, the disability-rights movement differs qualitatively from two traditional organizational modalities of people with disabilities, the disease-specific voluntary health agency and the self-help group. Since various forms of disability have historically captured the sympathetic imagination of the public (Anspach, 1979), charitable voluntary associations, such as the Muscular Dystrophy Association and the Multiple Sclerosis Society, have proliferated. However, unlike these voluntary associations and lobbies, disability activist groups are composed of people with disabilities themselves, seeking social change through their own efforts, rather than via others acting on their behalf. These groups also differ from self-help groups in that they are political rather than therapeutic in orientation. They seek not to change themselves, but to change society.

The goal of identity politics is to combat the prevailing imagery of the medical/functional/limitation model of disability-as-pathos/pathology/deviance. To this end, a significant effort has been made to establish a clear demarcation between disability and illness (Pfeiffer, 1996 cited in ICIDH and Environmental Factors International Network, 1996). Groups of people with disabilities first formed among individuals with similar disabling conditions (e.g., visual impairment and deafness) and among war veterans with disabilities who came

back from Vietnam unprepared for the negative societal treatment of people with disabilities (Scotch, 1988; Driedger, 1989). By the 1970's, organizations had been formed that crossed disability lines and encompassed individuals with a wide range of physical and mental impairments.

But people with disabilities, unlike other visible minorities, face many obstacles in developing a minority-group consciousness. Identification as part of a community is a key tenet of the minority-group model. Community is defined as "a sub-group within society, which is perceived or perceives itself as distinct in some respects from the larger society" (Rappaport, 1977). Dworkin and Dworkin's definition of a minority group adopted by Fine and Asch (1988), includes the following criteria: "identifiability, differential power, differential and pejorative treatment, and group awareness" (1976, p. viii). Although these criteria and definitions may apply to people with disabilities as a whole, for the vast majority identification as having a disability does not translate into group consciousness or political action. As Zola (1993a) points out, for most of the 20 – 30 years of their history of organization, people with disabilities have not been successful in producing a viable subculture. Their membership has been consistently small in proportion to the disability population. Many other groups develop their own subcultures based on their collective history or social position; for the most part, this has not been true for people with disabilities.

As Scotch (1988) has outlined, the social and political isolation of the vast majority of people with disabilities is reinforced by a number of factors. As people with disabilities face major barriers in obtaining education and entering

the workforce, they tend to be concentrated within the least powerful groups of society – low-income, low education, and low workforce participation (Asch, 1984a). Nonetheless, disability crosses all socio-economic levels. If a person's disability does not result in institutionalization, s/he is likely to spend most of his/her time among non-disabled people. Thus, disability is an individualized experience for most people, and there is rarely a sense of generational continuity (Hahn, 1985). Surrounded by people encouraging a normalization approach, people with disabilities "are understandably reluctant to focus on that aspect of their identity that is most negatively stigmatized by the rest of society and to mobilize politically around it" (Hahn, 1985, p. 100) As well, professionals involved in the "rehabilitation industry" (Albrecht, 1992) promote the image of people with disabilities as dependent and in need of professional help. Thus, they retain control over "program beneficiaries" at the cost of severely constraining the person with a disability (Zola, 1983). Those who seek to avoid such constraint may choose to conceive of and present themselves as non-disabled.

Furthermore, in a society that celebrates the individual (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985) it is all too natural to seek solutions to our problems as individuals rather than as members of an excluded class.

Yet another difficulty in organizing around disability is the lack of an inclusive definition of disability. A unifying concept of disability that includes people with a wide range of physical and mental impairments is by no means easy to arrive at (Scotch, 1988). Beyond the obvious differences that exist between people with, for example, visual impairments, mobility impairments or

those who are hard of hearing, people with cognitive impairments constitute a category of disability from which the disability–rights movement initially tried to distance itself. Groups specifically formulated their names and constitutions to explicitly include the word “Physically Handicapped” to differentiate them from cognitive or psychiatrically ‘handicapped’ (MLPD brochure, 1989). This attempt was attributable to the societal perception of any type of disability being “totally incapacitating” (Hahn, 1985), resulting in bizarre behaviour from able-bodied people such as treating an adult who uses a wheelchair as if they cannot understand basic language, or shouting at someone with a visual impairment as if they could not hear. Only within the last decade has a shift towards more inclusive organizational policies occurred within the disability-rights movement in Canada.

Some consider the social model’s focus on permanent visible physical impairments, and its ardent emphasis on separating illness from disability, a remaining barrier to a fully inclusive definition of disability (Crow, 1996; Driedger, 1999; Wendell, 2001). Over the past decade a range of voices from the disability community have raised questions and suggested developments needed in order to make the model more adequate and more relevant to disabled people’s lives (Morris, 1991; French, 1993; Crow, 1996). These critiques have centred on the inclusion of impairment and personal experience within the social model; they have been hotly resisted by other activists and theorists of the disability-rights movement (Shakespeare and Watson, 1997). The illness and disability dialectic is discussed further below.

Identity Research within the Social Model of Disability

Although there is not yet a great body of research on identity development from a social political perspective, Weeber (2000) identifies 10 studies which focus on lived experiences of their subjects. To varying degrees, these studies are successful in presenting or representing a more holistic view of the disability experience. Of these studies, only two focused on people with chronic illnesses (Admi 1996; Charmaz, 1995); one of those studied people with multiple sclerosis. I was unable to find any research that approached the issue of identity development specifically in terms of interaction with the disability supports service environment. Notwithstanding, I will discuss these two studies in detail, as an example of two somewhat similar research approaches.

Admi (1996) conducted a descriptive qualitative study in order to get an insider's view of young people's experiences of growing up with cystic fibrosis (CF). Retrospective longitudinal life-history interviews were conducted to generate a grounded descriptive theory of that developmental process. The life-history approach explores subjects' perceptions of their interactions with others in their social context, various roles experienced, and different life events over time. Multiple in-depth interviews (60) were conducted with 21 people (10 with CF and 11 family members without) over a period of 8 months in the subjects' homes or hospital clinic where subjects were recruited. Medical records and personal documents were reviewed and all data was analyzed using constant comparative methods. The initial sampling was nonprobable and purposive to represent the typical population served by the clinic; theoretical sampling needs guided further.

subject selection to address gaps. All subjects were White and middle class. Two subjects were married. Four of the subjects were identified as having CF before they were a year old, four between the ages of 3 and 7, and two as late as 10 and 14.

The model that emerged was that of an “ordinary lifestyle,” in which CF did not have a central place in the participants’ sense of self. Admi found that these young people were involved in a balancing process to manage their own sense of their condition, other people’s perception of them, and environmental factors that influenced both. Admi found four areas of importance to these young people, which she perceived as following a “normative schedule” of the interrelated psychosocial, cultural, social, and biological elements of human development:

1. Perceiving the self and the centrality of their disease over time
2. Constructing the view of others’ perceptions of people with CF
3. Managing disease-related information
4. Managing medical regimes

The subjects defined themselves as ordinary, active children and young people whose only sense of being different focused on the necessity of regular health management regimes. These young people had high ambitions and led their lives with vitality, refusing to allow their lives to be overly medicalized. The subjects identified as having a “health problem,” and refused to be referred to as patients outside of medical settings. Admi reported that the subjects’ understanding of their condition moved from an initial childhood disinterest in the

larger “disease issues,” through an early adolescent preoccupation with its role and meaning in their lives, and finally to a self-determined management of their own health. The subjects were very aware of others’ stigmatizing misconceptions of CF and developed complex and varied “telling” strategies to meet different situations and audiences.

The strength of Admi’s analysis is in her discussion of her findings as contrasted to previous research in the medical and psychoanalytic literature (Weeber, 2000). Her understanding of disability as a socio-political minority experience gave her a broader analytic framework. She found that subjects were possessed of strength, self-efficacy, independence and competency - qualities never alluded to in the psychopathology-oriented literature. She found no evidence of the preoccupation with a shortened lifespan that was assumed of all people with CF. This lack of preoccupation with a shortened lifespan was a phenomenon historically “diagnosed” by researchers and practitioners as a defense mechanism of denial or avoidance. Subjects did not view themselves as the deviant, sick, handicapped victims of the psychopathology literature, nor was disability the “master status” of their lives. She found the subjects had highly sophisticated communication strategies determined by realistic appraisals of people in their environment. She also found positive family relationships supportive of subjects’ self-directed strategies, in contrasting to the pathological patterns reported in medical and psychological literature.

The limitations of Admi’s study are linked to the fact that she continues to locate her discussion in a medicalized framework. Characterizing CF as a

“diagnosis” of chronic illness and equating that illness construct with disability are markers of a medicalized a worldview. While her analysis found an “ordinary lifestyle,” it did not explore the possibility that such a self presentation may also be a strategy of resistance to being viewed as “brave soldiers or heroes” in their social worlds or to counteract professionals’ attempts to over-medicalize their lives (as indicated by some subjects’ health management behaviours. There was also no speculation about or exploration of the subjects’ involvement with the disability community and what influence such involvement could have on their sense of self. While the information Admi presented could have dissonance-producing effects over time, there was no questioning of the assumed rightness of the dominant role of medical professionals in the lives of disabled people. Researchers with a “disability consciousness” would likely have known of numerous possible motivations for any given presentation of self and inquired about them, as well as known about the critical role of the disability community on a developing sense of self. It is unlikely that such a researcher would let the assumed rightness of the dominant role of medical personnel go unaddressed, however subtle the challenge or whoever the audience.

Charmaz (1995) conducted a study that examines issues of identity and multiple sclerosis. In this study, Charmaz explored the role of the body in identity issues as individuals adapt to the impairments of chronic illness, constructing new identities from meanings derived while acting in the world with their “problematic bodies.” She analyzed 115 previous interviews on chronic illness for references to the “body in illness,” then conducting twenty-five in-depth

interviews specifically focused on the topic, using autobiographical accounts from other people with disabilities to check developing concepts. She described certain stages of “adapting to impairments” which may serve as a means for discovering and understanding the experience of illness. In “experiencing an altered body,” subjects experienced guilt and shame because they felt betrayed by and alienated from their bodies. An initial distancing from the body, in anticipation of full recovery, gradually became an attentive listening to the body and accommodating its nonnegotiable needs. “Coping with changes in bodily appearances” included unseen limitations which subjects found were less likely to be validated due to lack of visual markers. The visibility of ‘illness/disability’ greatly influenced subjects’ choice of new identity goals. When the ‘illness/disability’ was reducing, its visibility was seen to limit its effect on subjects’ lives and relationships. The bodily changes that triggered or required “changing identity goals” were influenced by emotions and social relationships. Subjects tended to view identity conflicts which arose when the changes required the balancing of relational and work roles with bodily needs in terms of “lowering” identity goals. “Identity tradeoffs” were seen as conscious choices to give up some valued aspect of identity in order to maintain others, choices that in turn were strengthened by validation from others in the subjects’ social environment. Charmaz describes a final stage as “surrendering to the sick body” in which subjects actively chose to cease pushing bodily limits, to cease seeking victory or control over their condition and instead flow with its realities. This choice then became a point of reintegration with the body and, thereby, an opportunity to

transform the self-identity. Charmaz reports that illness (or disability) can present an opportunity to construct a conscious unity of body and self by learning more fully who one is from the very struggle to live consciously with the body.

The information which Charmaz presents directly from the perspective and processing of identity struggles as related by her subjects is very powerful and rich. The emotional struggles of the subjects are presented in a vivid manner that communicates the intensity of their experience. Her summary remarks indicate that she has listened well to her subjects, for they convey a clear composite picture of her subjects' truths. The problems with her work lie in the contextual framework and worldview within which she categorizes and interprets what she hears. She holds a thoroughly medicalized view of disability, demonstrated by her use of "illness" language to describe the long-term effects of disabling health conditions. She introduces language of assault and catastrophe, and labels themes and categories with language equating disability with sickness even when the content does not reflect her choice of words. For example, the theme "surrendering to the sick body" actually deals with subjects' positively experiencing liberation and wholeness by honouring their bodies' reality, rather than experiencing their body as sick.

As evidenced by her exclusive use of "chronic illness" literature, Charmaz obviously predetermined her framework of equating disability with chronic illness, and only relates to data through that filter. In a manner consistent with all medical/rehabilitation literature on disability, Charmaz's "identity struggles" were framed as a depoliticized individual struggle taking place within a completely non-

disabled world. There was no allusion to the existence of a disability community, or evidence that a critical disability consciousness informed any part of Charmaz's study. Even the personal accounts chosen to validate her theoretical constructs featured only one person with a critical disability consciousness. The identity construct Charmaz utilizes is also problematic in that it allows the individual with a disability no alternative context for the construction of an identity except in differentiation from non-disabled others around them or by having a social identity conferred on a disabled person by non-disabled others. Whether Charmaz views her construct as a reflection of how identity is universally constructed or whether she chose it post facto to describe the isolated identity struggles of her subjects is not explained. Whatever the reason, this rather fragmenting symbolic interactionist construct does not allow for the possibility of choosing a collective disability identity based on common experiences that can be constructed independent of validation from non-disabled people (Weeber, 2000).

Feminist Disability Discourse

Although there is no single feminist perspective or practice in used in feminist disability discourse or social work, there are three main feminist orientations: liberal, radical and socialist (Heinonen and Spearman, 2001). Liberal feminists stress the need for women to have equal rights with men. Societal structures are not challenged, but barriers to women's equal access need to be removed. A radical feminist approach considers that the root cause of women's oppression is a patriarchal society. A radical feminist promotes

individual and political change with the goal of eliminating patriarchy and its oppressive effects on everyone (Nes and Iadicola, 1989). A socialist approach focuses on an analysis of the forms of work done by women and men, and it recognizes that capitalism oppresses both sexes (Dominelli, 1997 as cited in Heinonen and Spearman, 2001). Despite these different orientations, there are some core principles to them all. These include: consciousness-raising, validating women's strengths and experiences, reducing power differences, promoting self-disclosure and sharing of knowledge, and creating supportive environments (Russell, 1989; Van Den Bergh and Cooper, 1986).

Women with disabilities have brought attention to the experience of living in a society that discriminates against both females and those who have disabilities (Heinonen and Spearman, 2001). Over the past twenty years a growing feminist disability discourse is developing to bridge the gap between disability studies and feminism. Groups of women with disabilities such as the DisAbled Women's Network (DAWN, Canada), since their inception in 1985, raise awareness of their unique perspectives within the male dominated disability rights movement and the able-bodied dominated women's movement.

Michelle Fine and Adrienne Asch and the contributors to their 1988 volume, Women and Disabilities, have made a major contribution to our understanding of the complex interaction of gender and disability. Barbara Hillyer-Davis has written in depth about the issue of dependency/independence as it relates to disability and feminism (Hillyer Davis, 1993). Fine and Asch

(1988) contend that any theory of disability should be feminist, as more than half of people with disabilities are women, and 16 percent of women are disabled.

Rosemary Garland-Thomson (1997) indicates that both feminism and the disability-rights movement challenge existing social relations: both resist interpretations of certain bodily configurations and functioning as deviant; both question the ways that particularity or difference is invested with meaning; both examine the reinforcement of universalizing norms; both interrogate the politics of appearance; both explore the politics of naming; and both participate in positive identity politics (1997).

Many parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Placing disability studies in a feminist context allows feminist theory's recent inquiries into gender as a category, the body's role in identity and selfhood, and the complexity of social power relations to be brought to bear on an analysis of disability. Garland-Thomson contends that:

Both the female and the disabled body are cast within cultural discourse as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a valued norm which is assumed to possess natural corporeal superiority. (1997, p. 279)

The seeds of the concept of an ideal versus an aberrant person, and the intertwining of disability and women, can be traced as far back as Aristotle in the fourth book of Generation of Animals (trans. A.L. Peck, 1944). In this book Aristotle introduces his discourse of the normal and the abnormal in which he

refines the Platonic concept of antinomies so that bodily variety translates into the hierarchies of the typical and the aberrant (Garland-Thomson, 1997):

[A]nyone who does not take after his parents is really in a way a monstrosity, since in these cases Nature has in a way strayed from the generic type. The first beginning of this deviation is when a female is formed instead of a male (Aristotle, Generation of Animals, Trans. A.L. Peck, 1944, as cited in Garland-Thomson, 1997, p. 279).

In this narrative of embodiment, Aristotle employs a spatial metaphor which places a certain corporeal figure that is deemed the “generic type” at the normative centre of his system. On the outer margin is the “monstrosity,” the corporeal consequence of Nature’s having “strayed” from a central paradigm along a path of deviance. But the first stop along the path is the female body. Next comes the “monstrosity” – whom we today term “congenitally disabled.” He then continues along a course leading away from the definitive norm.

Aristotle here reveals the source from which all otherness arises: a normative, generic type against which all corporeal variation is measured and found to be different, thus inferior and insufficient. As well, by focusing on femaleness, which he defines as deviant, rather than on the maleness he assumes to be essential, Aristotle initiates the discursive practice of marking what is deemed aberrant while concealing the position of privilege it occupies by virtue of this assertion of its normativeness. In this way, Garland-Thomson (1997) contends we witness possibly the origination of the logic which has become so familiar in discussions of gender, race or disability: male, White, or

able-bodied superiority is naturalized, remaining undisputed and obscured by the ostensible problem of female, Black or disabled deviance. What also is made clear though, is that without the pathological to give form to the normal, these taxonomies of bodily value that underwrite political, social and economic arrangements would collapse.

This persistent intertwining of disability and femaleness in Western discourse serves as a useful context for explorations of social identity and the body. As well, applying feminist theory to disability analyses “infuses it with feminism’s politicized insistence on the relationship between the meanings attributed to bodies by cultural representations and the consequences of those meanings in the world.” (Garland-Thomson, 1997 p. 281) Particularly useful may be feminism’s often conflicting and always complex dual aims of politicizing the materiality of bodies while rewriting the category of woman. Garland-Thomson (1997) suggests that the strands of feminist thought which coincide most harmoniously with disability concerns are those which go beyond a narrow focus on gender alone: they undertake a broad sociopolitical critique of institutionalized inequitable power relations, based on binary social categories grounded in the body.

Disability, according to Garland-Thomson (1997), perhaps more than other forms of difference, demands a reckoning with the “messiness of bodily variegation” (p. 283). The concept of disability unites a highly heterogeneous collection of embodiments whose only commonality is being considered abnormal. The unique experiences within this “collective of embodiments” must

be heard. Standpoint theory recognizes the local and complex quality of embodiment. Individual material situations are understood to structure the subjectivity from which particular women can perceive and speak with authority. As such, standpoint theory and the feminist practice of explicitly situating oneself when speaking make way for disabilities or more broadly, the category of corporeal configuration (as in such attributions as fat, disfigured, abnormal, ugly, or deformed) to be inserted into our considerations of identity and subjectivity (Garland-Thomson, 1997). Even so, the feminist movement has sought to overcome the boundaries of social categories, and to focus on the common experiences of women. According to DAWN Canada (1988), this process has been incomplete as "...no larger gap remains than the gulf between women with disabilities and non-disabled women" (www.dawncanada.net/twho.htm, 1988).

In developing a hybrid of feminist and queer theory, Eve Sedgwick (1990) has proposed a distinction between a "minoritizing" and a "universalizing" view of difference. One minoritizes difference by imagining its significance and concerns as limited to a narrow, specific, relatively fixed population or arena of inquiry. In contrast, a universalizing view sees issues surrounding a particularized form of difference as having "continuing, determinative importance in the lives of people across the spectrum of [identities]" (1990, p. 1). Such a conceptualization makes possible, among other things, the recognition that "disability" is a category which structures a wide range of thought, language, and perception not explicitly articulated as "disability" (or gender or homosexuality). These semantics emerging from feminist theory can be enlisted to dislodge the persistent

assumption that disability is a self-evident condition of bodily inadequacy and private misfortune whose politics concern only a limited minority – just as femaleness so easily seemed before feminism. The danger here, however, is that the deconstruction of oppressive oppositional categories can neutralize the political aspects of material differences. If disability is universalized, could that diminish the importance of accommodating difference?¹

One issue on which feminist disability politics diverges from mainstream feminist assumptions is sexual objectification. Feminism, quite legitimately, has long decried the sexual objectification of women. But women with disabilities often encounter what Harlan Hahn has called “asexual objectification,” the assumption that sexuality is inappropriate in people with disabilities. The judgment that a woman with a disability is asexual and unfeminine creates what Michelle Fine and Adrienne Asch (1988) term “rolelessness,” a kind of social invisibility and cancellation of femininity which the culture denies them. A feminist disability politics would uphold the right for women to define their bodily differences and their relationship to womanhood for themselves rather than acceding to received interpretations of their embodiment. As well, women with disabilities sometimes must defend their choice to have children. Whereas for able-bodied women motherhood is often seen as compulsory, women with disabilities are often denied access to or discouraged from motherhood. This may be connected to the equally problematic fact that feminist abortion rationale

¹ see also Susan Bordo (1993) Unbearable Weight: Feminism, Western Culture, and the Body, Berkeley: University of California Press, pp. 215-43; Judith Butler (1993), Bodies that Matter: On the Discursive Limits of “Sex” New York: Routledge; and Betsy Erkila, “Ethnicity, Literary Theory and the Grounds of Resistance,” American Quarterly 47, 4 (Dec, 1995): 563-94)

seldom questions the prejudicial assumption that “defective” fetuses, destined to become people with disabilities, should be eliminated.

In 1988, DAWN Canada conducted a study of women with disabilities, based on the issues raised at their 1985 founding conference, culminating in a position paper entitled “Who Do We Think We Are?” (DAWN, 1988). A questionnaire was mailed to 1200 women involved with disability rights groups, women’s centres and organizations for people with disabilities across the country. Interviews were also conducted with 50 women in the Atlantic Provinces, Alberta and the Yukon Territory. Of the mail-in questionnaires, 245 were returned. The study focused on four areas: early childhood experience; experience in the educational system; sexuality and relationships; and, role models and media images of women with disabilities. Other issues the study explored included experiences of women with disabilities within the medical profession, personal and social relationships, parenting, and poverty. The study did not include women who live in institutions nor women who identify as lesbians.

Self-image was ranked as the most important issue overall. A strong self-image, according to DAWN (1988), is essential to gaining access to the world of work, to developing strong, egalitarian intimate relationships, to effective parenting, and to resisting the violence that pervades our society. As one DAWN study participant noted, “You’ve got to start with self-image. If we can learn to feel good about ourselves, everything else will fall into place” (1988, www.dawncanada.net/twho.htm).

In exploring the question, What early factors lead to the development of a strong self-image? DAWN researcher Shirley Masuda considered the importance of unconditional love in childhood, acceptance by one's peers, and media images which project positive role models with which women with disabilities can identify. Unconditional familial and peer support are rare for women with disabilities, particularly those with congenital disabilities. The birth of a child with a disability can send a family into crisis. Many emotions are experienced by parents of infants with disabilities, most commonly feelings of guilt, particularly the mother, leading often to overprotection or conversely, distancing from parents. If parents are told their child may have a shortened life span, parents may be reluctant to bond closely with the child. Several women in the DAWN study reported very strained and/or distant relationships with their parents, particularly their mothers (DAWN, 1988).

Social relationships are also often less than supportive for women with disabilities, particularly in childhood and adolescence. Many women with congenital disabilities reported being segregated from their non-disabled peers in school (DAWN, 1988). Even for those who were not, social events were regularly held in inaccessible locations. Several women reported embarrassing, stigmatizing comments and actions directed at them from both peers and teachers: "children and adolescents are extremely susceptible to peer pressure; few of us escaped the devastation of being the butt of jokes, most adults are ignorant about disabilities, and kids are even more so" (DAWN website, 1988). Whether a girl with a disability goes through a segregated school system,

sometimes without family support, or is permitted to attend the “mainstream” school system, it can be hard for her to establish a network of strong friendships. Bonds made with schoolmates who share her disability may be arbitrarily cut off when they are considered no longer the responsibility of their “special” school.

Difficulties establishing friendships can continue into adulthood. Women with congenital disabilities may have difficulty seeing themselves as adults worthy of respect and caring (DAWN, 1988). Disabilities such as MS, Lupus and rheumatoid arthritis which often manifest in early adulthood, or even adolescence – just as women are completing their education, establishing themselves in careers and long-term relationships, put considerable strain on all personal and professional relationships. Women who become disabled in early adulthood experience a body they can no longer rely on to respond as it used to. Where they have established an identity built on skills that may now be lost to them, the adjustment can be emotionally devastating. One respondent in the 1988 DAWN study developed severe MS after establishing a career as a weaver and university administrator. The disease process gradually caused visual impairment and mobility impairment such that she could no longer see or use her hands well enough to weave, read or write. She has had to make the transition to living on long-term disability pension and cope with the loss of the joy weaving brought her.

Rates of separation and divorce are also high for women with disabilities (DAWN, 1988). Almost half of the women in the DAWN study reported they were single (43%). Of those who became disabled while in a long-term

relationship, thirty-four percent indicated the relationship had ended or changed after the onset of their disability. Adjusting to reduced strength, accepting a body that sometimes seems like an enemy and gives more pain than pleasure, and coming to terms with the image in the mirror that will never again resemble the one in the high-school yearbook is experienced by all women at some point in their lives, but for women with MS and other disabilities acquired early in life, this usually happens in early adulthood. As a result, the span these women have as “desirable” in the eyes of society may be shortened (DAWN, 1988).

Fear of violence can also restrict the ability of women with disabilities to participate in social activities. Women in the DAWN study reported they do not go out by themselves, particularly at night. High rates of violence against women with disabilities indicate that these fears are well founded and illustrate a problem with accessibility that men with disabilities experience to a lesser degree. As stated by DAWN, “street violence is any woman’s fear, and many women’s reality. The more vulnerable we are, the more we are at risk” (DAWN, 1988). For a woman whose disabilities require help for personal care and household tasks, being dependent can mean spending time frustrated, neglected, exploited and/or sexually abused. Due to high turnover in attendants, care can be inconsistent; attendants may be poorly trained and poorly monitored. The intimacy of the care required leave women with disabilities in a highly vulnerable position, and caregiver abuse is not uncommon (DAWN, 1988).

Twenty-two percent of women in the DAWN study reported they were married (1988). While some women said they got both respect and caring from

their spouse, more spoke of the difficulties their partners had in coping with their disability. Parenting with disabilities also has many unique challenges. It is impossible to be a perfect mother, but the struggle for women with disabilities is particularly difficult. For mothers with disabilities, children are often called on to help at an earlier age than their peers. Children may be needed to take greater responsibilities for siblings and household tasks than their friends do. Mothers with disabilities reported feelings towards themselves of anger and frustration as a result. One mother reported feeling guilty that her sons had to take on greater responsibility when she was bed-ridden for two years. As well, normal childhood misbehaviour can be particularly hard to deal with for mothers with disabilities. It can be difficult to discipline a child who is much more physically able than you.

Thus, without support, parenting for women with disabilities can be quite a struggle. At the same time, reaching out for support can be dangerous for mothers with disabilities due to the stereotype that women with disabilities are incapable of motherhood. Some women have experienced having their children immediately apprehended on that premise. The DAWN study noted that mothers identified child-care and transportation for their children as the major problems (1988).

It was found that although women with disabilities are more reliant on the medical profession than are able-bodied women, in many cases, doctors do not display respectful behaviour towards women with disabilities (DAWN, 1988). Not telling women what is going on with their bodies, counseling them to have hysterectomies and ignoring requests for contraception, and treating physical

complaints with psychological medication are common occurrences for women with disabilities. As well, many doctor's offices are inaccessible, or have inaccessible examining tables. DAWN (1988) indicates that women report being consistently misdiagnosed, and treated in extraordinarily patronizing ways. Such incidents undermine the self-confidence of women with disabilities, particularly in the area of sexuality. Requests for contraception were reported as being met with incredulity by health professionals who see women with disabilities as asexual. Furthermore, symptoms that indicate sexual abuse and incest in able-bodied women are often overlooked in women with disabilities, as they are viewed as "cases of disease or impairment" rather than women, according to DAWN (1988).

Women with disabilities also have difficulty accessing primary health care procedures. During an internal examination, one woman reported to DAWN that she fell off the examining table. As she couldn't find a doctor who had an examining table that raised and lowered, it was some time before she was able to have another examination. By that time, she had cancer in the lining of her uterus, advanced to the point she needed a hysterectomy and other treatment (DAWN, 1988). Given the continued difficulty in finding offices with accessible examining tables, this is unlikely to be an isolated incident.

Poverty was also a key issue for the DAWN study respondents. It is hard to feel good about yourself when you are poor (DAWN, 1988). It is also hard to be well-nourished, to dress adequately and attractively, to have a pleasant place to live or to participate in social and recreational activities. Many women

involved in the DAWN study were not participating in the paid labour force. Their source of income was either social assistance, or public or private disability pension. Many women with disabilities find it hard to find clothing that fits and allows freedom of movement, particularly if using a mobility aid. Often, this type of clothing is expensive. DAWN contends that a lack of appropriate clothing can make it even more difficult for women with disabilities to get jobs. Social assistance programs, based in the concept of last resort funding, only provide assistance at basic survival levels. It is very difficult for women with disabilities to acquire needed supports on this level of funding (DAWN Canada, 1988).

In western society, the media creates a background against which we form our images of ourselves. DAWN Canada (1988) indicates the media helps to shape public understanding of the disability community. It influences the climate of public opinion within which public policy is based. Images of young, thin, mostly White supermodels that foster feelings of insecurity in able-bodied women, few of which meet that ideal, can be devastating to a woman with a disability whose body or brain reacts in ways she can neither anticipate nor control. A woman who has gained a good deal of her sense of self from her physical appearance and then becomes disabled can experience serious depression triggered by these images (DAWN, 1988).

Women with disabilities may judge themselves not only in terms of how society expects a woman to look, but also in terms of the socially constructed myths surrounding "the disabled" (DAWN, 1988). The media which stereotypes women also stereotypes people with disabilities. It can also influence the self-

identity of women with disabilities. Men with disabilities also experience the repercussions of media promoted stereotypes. However, women with disabilities are more likely to internalize the identity of the victim, the vulnerable, dependent, incompetent object, as it is congruent with the stereotypical view of the feminine (DAWN, 1988). The DAWN study also notes that appeals to charity which so degrade the recipients are often based on inaccurate reports in the media reflecting patronizing attitudes geared to elicit feelings of pathos. Reduction to objects of charity dehumanizes individuals with disabilities and lowers ones self-esteem (DAWN, 1988).

Although the common principles of consciousness-raising, validating women's strengths and experiences, reducing power differences, promoting self-disclosure and sharing of knowledge, and creating supportive environments of feminism are reflected in feminist disability discourse, the DAWN study illustrates that women with disabilities experience unique issues of self-identity within the disability community and within the women's community. DAWN contends that these issues are not adequately addressed by either the disability rights movement or the women's movement. A combination of the minoritizing or standpoint approach and a universalizing approach, as suggested by Sedgwick (1990) has the potential to support a feminist theory of disability as called for by Fine and Asch (1988), Garland-Thomson (1997) and others (e.g., Wendell, 1993, 1996, 1997).

Population Health Paradigm

The population health paradigm has developed parallel to but unrelated to the social-political paradigm of disability (Hayes, et al, 1994). Population health contends we need an increased understanding of the social determinants of health, such as income, employment, and environment, among other social characteristics (Mustard and Frank, as cited in Hayes, 1994). Like the social model of disability, the population health paradigm contends that the social structure, and not merely individual behaviour, must be the focus of analysis. Paradigms of 'health' and ideas about appropriate kinds and levels of performance are culturally dependent (Wendell, 1989). "Health" has traditionally been defined as "the absence of illness or injury" (Mustard & Frank, 1994 cited in Hayes, 1994). This limited definition of health hampers broader considerations of the meaning of health.

In his opening remarks to the April 2002 conference on Health and Disability, Dr. Gro Harlem Brundtland, Director-General, World Health Organization stated:

Improving the health of an individual, or the population as a whole, is not merely a matter of reducing premature death due to disease and injury. Health is also about human functioning, the capacity of individuals to live a full life as an individual and as a member of society. But to improve health, we need tools to measure it and to measure the changes brought by interventions. (WHO website, www.who.int/)

The new International Classification of Functioning, Disability and Health seems to be an attempt at combining a population health and a social model approach.

Health Canada and the provincial and territorial governments have committed to a health determinants approach (Health Canada, 1999). This approach recognizes that many factors in addition to health care determine the health status of an individual. Health Canada has identified twelve determinants:

1. Income and social status
2. Employment
3. Education
4. Social environment
5. Physical environments
6. Healthy child development
7. Personal health practices and coping skills
8. Health services
9. Social support networks
10. Biologic and genetic endowment
11. Gender
12. Culture

These determinants are viewed as highly interactive. Income, employment and education, for instance, are interrelated and have implications for other determinants such as environments, child development and personal health practices. Gender is seen to have strong influences on all determinants. For example, wage gaps, low occupational status and poverty are commonly

observed in any analysis of women's socio-economic status. As a result of interrupted participation or non-participation in the paid labour force, or of low wages and few benefits, the lives of women seniors are more likely than those of men to be marked by poverty (Statistics Canada, 1995).

I was not able to find a study within population health literature in which "disability" was identified, like gender, as having a strong influence on the above listed determinants of health. Statistics Canada has begun collecting information regarding the "Participation and Activity Limitations" of people with disabilities; this information indicates that people with disabilities are also profoundly influenced by poverty, low education levels, and low labour market involvement due in large part to inaccessibility and lack of accommodation in social and physical environments. People with disabilities also have difficulty accessing primary health care due to inaccessible doctors' offices.

In a population health study of immigrant women, one woman described health as follows:

Able to do all the things physically that you can and that you want to. Feel joyful. Can do many things, feel energetic, don't feel tired, feel happy, enjoy what I am doing. Can do all the things I have to do with my family, my father and my children. Walk, think, and work. When you are healthy, you can do anything you want. (Maritime Centre of Excellence for Women's Health, 2000, p. 6)

The meaning of health that emerged strongly in this study was related to the ability to do what one wants to do, to go to work, to go to school, to be

involved in one's interests (Maritime Centre of Excellence for Women's Health, 2002).

Mustard and Frank speculate that the modifying effect of the social environment on improved collective health may be especially linked to changes which give individuals a greater sense of belonging to a social group as well as greater control over their circumstances and fate. Population health demands that we consider why it is that some people are healthier than others, why these differences are systematically distributed across identifiable social characteristics, and how public expenditures ought to be deployed to maximize the health status of the general population. This approach challenges the bio-medical model, questioning the social benefit of a narrow definition of "health" (i.e., 'health care') and proposing an equitable distribution of public resources within the welfare state (Hayes, et al 1994). For example, a World Health Organization study indicated that unemployment and economic instability are linked to a significant increase in levels of mental ill health (as well as to adverse effect on the physical health) not only among the unemployed but among their families and the communities as well (Westcott, G et al, 1985). Accordingly, there is a strong thrust in population health literature for increased focus on social and economic supports for social participation - paralleling calls within the disability-rights movement for wide ranging supports for the social and economic participation of people with disabilities.

Chronic Illness and Disability Dialectic

As mentioned earlier, the initial effort of people with disabilities to organize occurred largely in reaction to the biomedical model of disability and the medicalization of their lives (De Jong, 1979; Driedger, 1989). As a result, the relationship between illness and disability is a problematic one (Wendell, 2001). As Pfeiffer points out, being disabled does not mean that one is not healthy. From the socio-political perspective of disability, there is a real difference between health and disability, a difference not recognized in the biomedical/functional/limitation models of disability (Pfeiffer, 1995). Pfeiffer contends that the danger of the medicalization of disability is the proclivity of medical personnel to make decisions about the quality of life of people with disabilities, a tendency which Pfeiffer connects directly to eugenics. The definition of "health" as the absence of impairment or disability is likely the foundation of this sensibility. And the threat is very real, (as outlined below under "Environmental Scan.") This being the case, it is understandable that the DRM rebels against the definition of disability as a health issue.

But to date there has been little focus on issues related to 'impairments' or 'chronic illnesses' within the DRM. According to Driedger (1999), the insistence of the disability rights movement on clearly separating illness from disability has contributed to the stigma attached to having a chronic illness.

Many people are disabled by chronic and/or life-threatening illness, and many people with disabilities not caused by illness have chronic health problems as consequences of their disabilities. Susan Wendell maintains that the social

constructionist analyses of disability, in which oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices are seen as the primary causes of disability, can withdraw attention from those disabled people whose bodies are highly medicalized because of their suffering, their deteriorating health, or the threat of death (2001). Some people with disabilities experience physical or psychological burdens that no amount of social justice can eliminate.

There is a danger that acknowledging these facts might provide support for those who prefer the individualized, medicalized picture of disability. Thus, it is argued that it is safer and more comfortable for the DRM to focus on people with disabilities who are healthy (Crow, 1996; Wendell, 2001). What is more, the issues of people with disabilities who have chronic illnesses are primarily women's issues, as more women than men are likely to be disabled by chronic illness (Morris, 1994; Trypuc, 1994) Wendell contends that accommodating chronic illnesses in disability politics and feminism is essential to many disabled women's participation. As Liz Crow points out, ignoring impairment can reduce the relevance of the social model of disability to certain groups, such as women.

Wendell (2001) does not address the narrow definition of "health," while still attaching the term to "healthy and unhealthy disabled." Rather she defines "healthy disabled" as people whose conditions and functional limitations are relatively stable and predictable. These may be people born with disabilities who were disabled by trauma or illnesses later in life. They regard themselves as "healthy" not "sick" (Wendell, 2001). Wendell notes that many people with

chronic illness do not necessarily regard themselves as "sick," either - which again raises the ambiguous nature of these terms. Diseases like MS and rheumatoid arthritis can behave like recurring acute illnesses, with periods of extreme debility and periods of relative normality; they may be characterized by virtually constant symptoms or by recurrent acute episodes that leave behind permanent loss of function.

Identity dilemmas are created by the questions "Is my illness temporary?" and "How long will it last?" They often go unanswered or answered uncertainly by medicine. This creates difficulties of identity both for the person who is ill ("am I disabled or just sick for a while?") and for other people (Wendell, 2001). Moreover, those with chronic illnesses often do not fit most people's picture of disability. The paradigmatic person with a disability is healthy disabled and permanently and predictably impaired. Both attitudes toward people with disabilities and programs designed to remove obstacles to their full participation are based on that paradigm. Many people with chronic illnesses are not obviously disabled; to be recognized as disabled, one must remind people frequently of needs and limitations. That in itself can be a source of alienation from other people with disabilities because it requires repeatedly calling attention to impairments (Wendell, 2001)

Wendell says that the separation of impairment from disability is analogous to the separation of a person's body/mind and disability: seeing disability exclusively as a socially constructed disadvantage is a source of difficulty, damaging to the holistic integrity of the body-mind unity. It is her

contention that this separation connects impairment to the medical institutions that measure structure and function and set the standards of "normality." This connection has contributed to neglect of the realities of impairment in disability activism and disability studies; from this perspective, issues of impairment have been regarded as irrelevant or even rejected as being in conflict with the social constructionist analyses of disability. Illness is equated with impairment in ways that disability is not.

One example of the disability-related issues connected to impairment is the different accommodation needs of people dealing with chronic fatigue, stamina and pain: Concerns of pacing and flexibility are paramount in employment as well as the activist milieu. As Iris Marion Young (2000) has pointed out, from the perspective of most employers, the norm of the 'hale and hearty' worker is an essential element of current workplace discipline:

The 'normal' worker is supposed to be energetic, have high concentration abilities, be alert to adapt to changing conditions, and be able to withstand physical, mental or interactive stress in good humour. Workers who fail to measure up to one or more of these standards are 'normally' considered lazy, slackers, uncooperative or otherwise inadequate. All workers must worry about failing in the eyes of their employers... (Young, 2000, p. 172)

Given the difficulties which have been experienced in achieving the most basic accommodations (i.e., ramps), some disability activists have taken great pains to emphasize the general message 'Remove the barriers that have been erected arbitrarily against our participation, and we will perform as well as anyone else.'

Insisting on accommodations of pace and time however, may jeopardize this message, because working according to the employer's schedule and at the pace he/she requires are usually considered to be aspects of job performance, even in jobs where these are not critical to the adequate completion of tasks (Wendell, 2001). With restructuring and cutbacks of the past decade, many people are feeling the increasing pressure of the workplace. This may lead to what Young calls "the politics of resentment" – a situation which the law requires employers to make accommodation for employees with disabilities, while many non-disabled may find the demands placed upon themselves next to unbearable. As such, many people who do not identify as disabled would benefit from "more humane and individualized workplace accommodation" (Young, 2000, p.173).

People with invisible impairments must also deal with suspicion and doubts about the legitimacy of the disability for which accommodation is requested (Wendell, 1996). Suspicion comes from medical professionals, friends, relatives, co-workers, and, understandably, from other people with disabilities. In a British study of a group of people with disabilities, Jill C. Humphrey discovered a conspicuous silence about impairment and associated suspicion as to whether certain people belonged in the group – in other words, whether the people with invisible disabilities were disabled (Humphrey, 2000). As Wendell (2001) points out, this is the flip side of being able to "pass" as non-disabled.

The ability to pass is a common, though not universal, difference between "healthy and unhealthy" people with disabilities. Although there are definite

advantages in avoiding the overt prejudices and daily acts of discrimination and patronizing behaviour experienced by people with visible disabilities, the disadvantage of “invisibility” is the need to raise attention to one’s accommodation needs, frequently. As Wendell emphasizes, so much depends on recognition, in terms of both accommodation and community acceptance. The “politics of resentment” (Young, 2000), has conducted to an atmosphere in which the trustworthiness of people who claim to be disabled but “do not look it” is always in question. This can lead to very toxic work environments for people with “invisible disabilities.” According to Wendell, people with invisible disabilities may also be subjected to greater blame and responsibility for their disabilities than those whose disabilities are visible. Such blaming can occur during the seeking of a diagnosis, as well as during flare ups (Register, 1987; Charmaz; 1991) Furthermore, society’s current emphasis on “taking control” and being responsible for one’s health has generated an abundance of popular theories which assert that anyone can become healthy with the appropriate diet, exercise, attitude, relationship, drug, or religious beliefs. Therefore, if you remain unhealthy there is a clear implication that you must be acting irresponsibly (Wendell, 2001).

As with identity politics (discussed earlier), one of the goals of disability politics is to replace the fear and stigma appertaining to being disabled with the understanding that disability can be a valuable difference and that people with disabilities can be proud of their differences from non-disabled people. The question is, does this goal make sense in relation to disabling chronic illnesses?

As Wendell (2001) indicates, comparing “Thank God I am not disabled” to “Thank God I am healthy” highlights the difficulty of applying disability pride to a chronic illness.

This review highlights many issues faced by people with chronic illnesses and non-apparent/invisible disabilities which to date have not been high on the Disability Studies or DRM agenda. The pressing need to develop an inclusive model of disability is clear when this matter is viewed from a social political perspective.

Environmental Scan

The dangers associated with being or “coming out” as disabled may not be as ragefully hostile as the murders of known homosexuals, but they are a real threat nonetheless (Weeber, 2000). The number of parents who murder or abandon their disabled children is on the rise, the refusal of health care to people with “involved” disabilities goes largely unquestioned, and genetic testing and engineering for birth defects are seen as medical miracles. The current push to legalize physician-induced death in the USA reflects an inability to even acknowledge the danger inherent in the medical profession’s endemic belief that life with a disability is not worth living (Gallagher, 1995). The fact there was no outcry over the fact that 75% of the people Kervorkian was responsible for killing were not people with “terminal illnesses”, but rather had disabilities from chronic health conditions, shows the societal level of acceptance of doctors’ perceptions of disabled people’s quality of life. Taking up the challenge of finding one’s way to a community so devalued and embattled is an act of courage which speaks of

the fundamental human need to be with others who can appreciate and understand the totality of one's self (Weeber, 2000).

In political economic terms, the inherent underlying structure of a society shapes and affects the problems it faces (Albrecht, 1992). The social political landscape of health care is changing radically. Devolution of government responsibilities at all levels and increased involvement of pharmaceutical companies in research and development of new treatments, biotechnology and genetics research are key to the changing social political climate of health care. New alliances are being formed locally, nationally and even internationally to influence health policy, particularly alliances between 'patients' groups, disease-specific voluntary health agencies and pharmaceutical companies. "Patient's organizations" have proliferated (Usher, 1998). Disability specific voluntary health agencies and patients' rights groups are being significantly funded by pharmaceutical companies (these resources that have not been tapped by the DRM because of its reluctance to place disability issues within a health framework.) Canada has seen unprecedented increases in bio and health technologies and the globalization of these industries (Day, 1991). These technologies include disease modifying pharmaceuticals, new reproductive technologies, genetics testing and gene manipulation. The media periodically feature sensational accounts about developments in gene mapping and cloning technologies. As well, we can now terminate pregnancies if a fetus is identified as impaired in some way, and evidence suggests that women are often

counseled to do so. The abortion rate after a "defect" has been identified is 90% (Day, 1991).

On the other hand, technological advances have allowed more seriously disabled children and adults to survive. People with disabilities can now participate in society in ways that were much more difficult before recent technological advancements -- if they have access to these resources. The potential reality of a future in which disability-causing disease may be prevented is countered by the already present reality of discrimination against individuals identified as having disease causing genes, particularly by insurance companies and potential employers. Skyrocketing health care costs for these hi-tech capabilities force cost/benefit analysis; health care policy makers must prioritize whom we can afford to help and people with disabilities are often not the priority. For example, people with disabilities are often not listed high on waiting lists for donor organs. We have also seen marked societal sympathy for parents who kill disabled children, increased interest in concepts such as assisted suicide, euthanasia and "mercy killing" (e.g., Kevorkian, Latimer cases) and debate over the application of "Do Not Resuscitate" orders by doctors. These environmental factors raise the question, **How** supportive and accepting a social climate do people with disabilities and chronic illness find themselves living in today? How do these environmental factors affect the self-identity of someone diagnosed with a disabling chronic illness such as MS?

Disability Support Program definitions Accessed by Participants

Each of these program definitions is based fundamentally in the medical / functional / limitation model of disability.

Canada Pension Plan Disability Pension:

According to the CPP legislation, a person is eligible for disability benefits “only if he or she is determined in prescribed manner to have a severe and prolonged mental or physical disability.” In Section 42 (2) of the Canada Pension Plan, a “severe” disability is defined as one that impairs to such an extent that a person is “incapable regularly of pursuing any substantially gainful occupation”. (Human Resources Development Canada, 1999)

Disability Tax Credit:

“According to the *Income Tax Act*, eligibility requires an individual’s mental or physical impairment to be ‘prolonged’ (lasting for a continuous period of at least 12 months) and to ‘markedly restrict’ an individual from performing ‘all or substantially all of the time, even with therapy and the use of appropriate devices and medication,’ one or more ‘basic activities of daily living.’ For this purpose, therapy does not include that which is essential to sustain a vital function of an individual and is required at least three times a week for a total duration of at least 14 hours per week. Basic activities of daily living include perceiving, thinking, remembering, feeding, dressing, speaking, hearing, eliminating (i.e. bowel or bladder functions) and walking” (Longfield & Bennett, Sub-committee on the Status of Persons with Disabilities report to the Standing Committee on Human Resources Development, March 2002)

Disability Parking Permit:

Anyone who needs the full-time assistance of a mobility aid such as a wheelchair, walker, cane, or crutches is eligible for a Parking Permit.

Certification from a doctor or therapist is mandatory. (Society for Manitobans with Disabilities website, www.smd-services.com/wheelchair/parking_permit.html)

Home Care

A professional assessment of individual needs, existing supports and community resources will determine eligibility for the Manitoba Home Care Program and the type and amount of services an individual may receive. The Manitoba Home Care Program is responsible for ensuring the provision of reliable and safe assessed service in the home, education setting or workplace.

To be eligible for the Manitoba Home Care Program an individual must be a Manitoba resident (3 months residency in Manitoba), be registered with Manitoba Health, require health services or assistance with activities of daily living, require service to stay in their home for as long as possible, and, require more assistance than that available from existing supports and community resources. (Winnipeg Regional Health Authority website, www.wrha.mb.ca/healthsrv/CommunityCare/homecare)

Manitoba Employment and Income Assistance:

A person with a mental or physical illness or disability that is likely to last more than 90 days and prevent him/her from earning enough money to meet basic needs, may be eligible for Manitoba Employment and Income Assistance

(section 7.1.1, Employment and Income Assistance Administrative Manual, Government of Manitoba Website, www.gov.mb.ca/fs/programs/eia/policymanual).

Summary

This literature review delineates the evolution of the concepts of disability and chronic illness within Disability Studies and feminist disability discourse, the considerable confusion still manifest in definitions, and the interesting parallels between these areas of discourse, both feminist and population health theories. Flowing from the lived experiences of people with disabilities involved in the DRM, these discourses challenge the traditional medical paradigm in which people with disabilities and chronic illnesses are viewed as sick, “totally incapacitated” objects in need of pity and charity. As well, recent work within Disability Studies and feminist disability discourse also notes the difficulty in clearly demarcating the distinction between ‘impairment’ and ‘disability.’ Feminist disability discourse reveals the striking parallels between feminist issues and disability issues, how women, like people with disabilities, are also categorized as “deviant,” and the similarities between the issues of embodiment of the two groups. Fine and Asch (1988), Garland-Thomson (1997) and Wendell (1999), among others, call for a feminist social model of disability, one which entails recognition of the role of impairment on identity and discrimination. Garland-Thomson (1997) also suggests a combination of feminist standpoint theory with Sedgwick’s (1990) universalizing approach. This may provide the basis for the incorporation of difference across a spectrum of identities. Wendell

(2001) notes the need for validation of the role of impairment in discrimination as a precursor to accommodation.

The environmental scan identifies the eugenic foundation for the advancement of biotechnology and disability policies which are still fundamentally grounded in the medical/functional/limitation paradigm. It outlines the truly hostile climate people with disabilities and chronic illness are living within today. However, as Weeber notes: "without a clear critique of a culture that holds up independence and virility as essential and necessary virtues, while at the same time eschewing dependency and lack of physical control, it is impossible to interpret current trends as violence stemming from prejudice and fear" (2000, p. 48).

Given this reality, the need for research based in the lived experiences of the community is vital, both to extend our understanding of our experiences and to raise awareness of the need for change.

CHAPTER TWO: RESEARCH DESIGN, METHODS, AND PROCEDURES

This project was naturally suited to qualitative participatory methods as it is an exploratory research project from a social-political paradigm of disability. The social-political paradigm of disability in research calls for validation of the concrete lived experiences of people with disabilities and a broad analysis of social political influences creating disablement (Hahn, 1985).

“Starting Where You Are”

An integral component of the research design is transparency and defining the problem from my own experiences. As a feminist social worker with a congenital impairment (spinal muscular atrophy) though largely ‘non-apparent’ disabilities, I was politicized into the disability rights movement in my early adulthood. To that point in my life I had experienced ten years of experience growing up in a society and school system unprepared to accommodate even my mild accommodation needs, and ten years of ‘medicalization’ and ‘alienization’ through frequent hospitalizations in my adolescence. Since this time I have worked professionally as a social worker in a hospital setting, as well as within an Independent Living Centre, and both partner organizations in this study. Due to my closeness to the subject matter, I conducted regular self interviews (Glaser and Strauss, 1967) via journaling. I also met regularly with a confidential objective third party to debrief as necessary. I also strove to enhance rigour by memoing in order to identify the rationale for my coding process (Padgett, 1998. See appendix for example).

Role of the Advisory Committee

The role of the advisory committee was fundamental to the project to ensure the findings were grounded in the concrete reality of people's lives upon which the study was based (See appendix for list of advisory committee members). The advisory committee, consisted of people with MS and a representative from the Manitoba League of Person's with Disabilities and the Multiple Sclerosis Society of Canada, Manitoba Division, was involved from the initial stages of clarifying the ethics protocol; reviewing and approving the research design; aiding in the development of the semi-structured interview guide; piloting the interview guide; assisting with recruitment; and providing feedback to draft reports. As well, the advisory committee provided both support and constructive criticism to me as researcher. And finally, the advisory committee will provide input into dissemination of the research findings. In recognition of the key role of the advisory committee in the success of the project and to cover expenses they incurred in the course of the project, a honourarium was provided due to the funding assistance of the Canadian Centre on Disability Studies.

Recruitment

Recruitment was conducted in a non-probable and purposive fashion, guided by the need to reflect a broad range of types of MS, socioeconomic levels, involvement within the MLPD or MS Society, gender and ethnic background. As twice as many women as men get MS, a greater emphasis was put on recruiting women. Some advisory committee members assisted in

identifying potential participants; I also approached participants from my experience outside the MS Society. In keeping with ethics procedures, I did not approach any participants with whom my only contact was through my role as a staff member of the MS Society. Consent forms were reviewed with each participant before signing, and a list of counseling resources was made available to participants as requested.

Sample

I interviewed six participants: five women and one man ranging in age from early 40's to late 50's. Three were married, one had a live-in partner, and two were divorced. Two had young children living at home. Two lived in rural communities outside Winnipeg, with the others residing in Winnipeg. Three were homeowners and three rented apartments, with one participant dwelling in subsidized housing. At the time of the interviews, only one participant was involved in the paid labour force (part time): 4 received Canada Pension Plan Disability Pensions; one receiving provincial Social Assistance; and another was provided with an employee's private long term disability pension and is in process of applying for CPP. Three participants were non-White: one Métis, one East Indian and one of Jewish decent. Two of the participants were not born in Canada but immigrated here in early adulthood. The others were all born in Canada. The length of time from diagnosis ranged from 10 years to 30 years, with diagnosis having occurred in the early 20's for three participants and the mid 30's for the other three. The types of MS ran the gamut from benign to relapsing-remitting to secondary progressive to primary progressive. Two

participants had primarily invisible disabilities, including sensory, fatigue, visual, bowel and bladder symptoms/impairments. The other participants experienced many of these impairments as well, and used either walkers or wheelchairs for mobility assistance. One participant disclosed a mild cognitive impairment. Only one of the participants was a member of the MLPD, but two other participants had been involved with the Independent Living Resource Centre, a “sister” organization of the MLPD (based on the same principles of consumer control and citizenship for people with disabilities but with more of a service and individual advocacy focus). Five participants were involved in various capacities with the MSSC; ranging from involvement as an office volunteer to peer facilitator of self-help programs to board member. One participant was a staff member of a disease-specific voluntary health agency and one was not involved with either organization.

Data Collection Methods

The data collection methods used were: a literature review of current research from three perspectives of self-identity and disability / chronic illness: 1) disability studies, 2) feminist disability discourse, and 3) population health discourse; brochures and public documents of the partner organizations; disability definitions within policies, programs and services the participants indicated they accessed or attempted to access; and, semi-structured individual interviews.

Research procedures

Although the literature review and document collection was ongoing throughout the data collection and analysis phase, the bulk of the literature review was completed prior to conducting the interviews. I met with the advisory committee regularly in the initial stages of the research and communicated via email during the report writing phase due to difficult committee schedules. The semi-structured interview guide was piloted with two advisory committee members. The revised semi-structured questionnaire was then conducted with participants at their choice of location. Four participants requested the interview take place at their home; one interview was conducted at the Canadian Centre on Disability Studies, and one at my home. All interviews were taped and transcribed by myself. Participants were offered the opportunity to review their transcript for accuracy. Although I had initially intended to meet with the advisory committee throughout the data analysis phase, a combination of factors led to my decision to wait until after the analysis was complete and the first draft report could be presented. I found myself dealing with a dilemma similar to that noted by Janice Ristock in her study of Unionization within Women's Shelters in terms of maintaining a collaborative ethos while still adhering to the principle of naming differences that might be unsettling for some of the participants. While the participants seemed unaware at times of their definitional contradictions and the seeming disconnection between their critical analysis and their described self-identity, the process of 'Principled Creativity' allowed me to analyze the information and move between the participants positions with more objectivity

then the participants themselves could have. In this way, I could understand their positions through the constant comparative coding process and then “disrupting logics” or challenging the binary aspects of the concepts using Greimas’ Semiotic Squares where binary codes emerged, until I could present a summary that responded holistically to my initial questions about the social-political impact of definitions and systems on self-identity.

Data analysis

Given the congruency of the principles of research from a feminist perspective and research from a social political model of disability, the data analysis methods drew heavily on those outlined in Janice Ristock and Joan Pennell’s Community Research as Empowerment (1996). In empowerment research, one strives for reflexivity - including oneself in what is being studied (Hammersley and Atkinson, 1983), and transparency - revealing who one is and how one’s location shapes the research process (Klein, 1986). I grounded the research in my own experiences as a feminist social worker with largely invisible disabilities who was politicized into the disability rights movement in early adulthood while still personally dealing with the disability / illness dialectic due to frequent hospitalizations during my adolescence. The research methods of “Principled Creativity,” outlined below, and self interviews, allowed me to reflect on my own experiences while still grounding the research in the participants experiences and challenging the binary either/or categories that arose in the thematic analysis.

I found it particularly important to maintain the rigour of the research by challenging not only widely held beliefs but also my own perspectives on the subject in question. Developed by Janice Ristock and Joan Pennell (1996), the essential principle of creative analyses is “thinking outside the confines of dominant assumptions and the researcher’s own interpretations, to invent alternative truths,” (Ristock and Pennell, 1996, p. 79). Principled Creativity also involves four other principles:

1. expanding dichotomies

- advances a critical analysis of power by increasing the range of possible constructions of reality and thus disrupting the usual binary (either/or) oppositions, which helps to bridge the gap between different positions.

Following Janice Ristock’s approach, I used Greimas’ Semiotic Square for this purpose. Greimas’ Semiotic Squares involved a table of four squares, the first square represents the key starting position or one binary category. The opposite square is its contrary, or the other binary category. Below this square is the contradiction to these categories, and the final square, below the first square, is the implication of the contradiction to the binary category squares. As binary categories arose in the theme analysis (i.e., positive versus negative disability identity), I used these Semiotic Squares to expand my thinking processes to consider options I may not otherwise have recognized. (See appendix for example of a Semiotic Square).

2. speaking with those about whom I am speaking

- fosters a responsible use of power by keeping the study 'grounded' in the subjectivities of the people in question. Using constant comparative analysis of the transcript data in an iterative manner with Greimas' Semiotic Square, I was able to challenge my thinking process and ensure it remained grounded in the interview data. First by reading and re-reading the transcripts, I began to recognize common units of meaning. Gradually these units of meaning could be combined in categories and ultimately connected to themes. By returning frequently to the transcripts, themes and categories could be expanded or revised to reflect deeper and richer truths. I kept a journal of coding memos to maintain a record of my category decisions, in order to be clear regarding the logic of my decisions, share them with the advisory committee for feedback, and to enable myself to reflect back on them and make changes as necessary after using a semiotic square. (See appendix for example of memos).

3. appreciating discourses:

- helps to make sense of a range of positions while making their respective holders feel appreciated as well as encouraged to expand their understanding. I reviewed theory from three disciplines: disability studies, feminist disability and population health. Including concepts from other disciplines, along with the use of Greimas' Semiotic Squares helped to expand my thinking processes. I found it useful to continue reviewing literature while conducting the data analysis. I found I was less likely to fall back on theoretical precepts during thematic analysis if I was constantly

encountering new concepts. This also encouraged me to develop a Semiotic Square if a theme or category was developing that seemed to involve only binary opposites. This often resulted in a new avenue of thought, leading to the fourth principle, displacing logics.

4. displacing logics

- is a reminder that each position has a respectable logic that can be turned back on itself to spin power relations off balance and towards a new balance. Again through an iterative process via Greimas' Semiotic Square and constant comparative analysis I was able to challenge logics by avoiding a binary either/or analysis and to ground them in the interview findings.

As stated by Ristock and Pennell: "Together, these four principles not only maintain the analyst's links with the research participants and, more broadly, with movements for social change, but ensure that as successive modes of interpretations, consistent with each principle, are adopted, earlier conclusions are disrupted"(p. 80). I found these principles to offer an extremely appropriate and very useful way of challenging my own assumptions, while at the same time connecting the work with the interview findings.

Strengths and Weaknesses of Methods

Strengths

Consciousness raising

All of the participants indicated during the interviews that these issues had not been considered by them before. They indicated they found the process of exploring program and policy definitions, vis-à-vis how they defined themselves in relation to their experiences of trying to “fit” into eligibility criteria, and their choice of group involvement useful and enlightening.

One participant articulated this as follows:

This is useful cause I've never really thought about it in these terms. This has forced me to think about it in those terms. I just know that when I get pissed off and I - but not sufficiently at any point to sort of fight it. I mean they weren't big enough things, and as I said I didn't apply for the Tax Credit, I'll see what happens this time, all right? I'll come back to you in six months, I may have a (laugh) a different story.

The participants all also indicated they enjoyed the report and learned a great deal from it. Most reporting they found it empowering to hear of others having similar experiences as them. Much of the feedback indicated that they felt they did have a positive identity.

Perspective as a researcher with disabilities

As a researcher with a disability I also found this process very powerful and deeply personally empowering. I believe my ability to identify with the

participants aided the interview process by instilling a sense of trust and rapport. Having a critical disability awareness was fundamental to the success of the study, as I was able to view issues from a social political perspective and raise questions that may not otherwise have been raised.

Holistic, respectful view of participant's experiences

In this study, the participant's experiences were presented in a more respectful and holistic manner than in research conducted from a medical model. Participants also had considerable control over the direction of the research, how their information was presented, and input into the project's final report, giving the report deeper and richer significance.

Sample

Considering the small sample size, there was quite broad representation across socioeconomic levels, ethnic backgrounds, types of multiple sclerosis, impairment symptoms and accommodation requirements, age, involvement with organizations and living arrangements.

Data Analysis

The process of Principled Creativity - expanding dichotomies, speaking with those about whom we are speaking, appreciating discourses, and displacing logics - provided an excellent means for me to challenge not only my own thought processes and those of the participants but also those proposed in the literature review. By cyclically developing themes, challenging concepts and returning to the participants' responses and my original questions I was able to

develop ideas and connections which lay beyond set logics and paradigms and which I may otherwise have been unable to see.

Use of an Advisory Committee

By incorporating an advisory committee of people who were stakeholders in the research itself, I was able to ensure the research was both grounded in and guided by the people upon which the research was based. In this way, the advisory committee is more invested in the results of the project, and may be more likely to see it through to dissemination and action steps.

Weaknesses

Sample

Although quite representative, the sample size was still very small. As such, the results are quite localized and may not be as reflective of the broader community as I would have hoped. It would have been useful to interview more people, particularly those involved in the MLPD and those not connected with either partner organizations.

As I only interviewed one man, I did not explore gender differences to any great extent. It would also have been useful to have interviewed more people actively involved in the MLPD. Unfortunately, two potential participants were unable to participate due to timing, health and other practical issues.

As well, none of the participants identified as gay or lesbian.

Starting where you are is a “double edged sword”

I found that the issues raised in this project triggered significant issues for me personally: because of this, I had to take a leave of absence part way into the research to attend to my own disability needs. As a result a period of about 6 months elapsed between the time when I conducted the interviews and analyzed the transcripts. I actually anticipated that delay would have a greater impact than it did on the research process. I requested the participants to review their transcripts and let me know if they would like to change or update anything; none of the participants indicated that anything had changed significantly despite the time lapse. I also felt I did not stay as connected to the advisory committee over this period as I would have liked, as I think their sense of involvement in the project diminished during the hiatus.

Advisory committee

The requirement to schedule and meet and/or communicate regularly with the advisory committee may have slowed the process down somewhat. Arranging meetings to coincide with busy schedules and a range of accommodation needs wasn't always easy. Some feedback from advisory committee members was also quite challenging at times, though usually always constructive and helpful in the long run. It was important for me as researcher to be sensitive to personalities and clear about my dual role as researcher reporting to the committee, as well as being a key stakeholder in the final outcome of the project, as a master's student.

Data analysis

The process of iterative constant comparative analysis and Greimas' Semiotic Squares was very slow and tedious at times. I sometimes wondered if I was, in fact, invalidating experiences by questioning logics – but by ensuring I always returned to the transcripts, I was able to keep the analysis from heading in a direction away from the concrete reality of the participants.

CHAPTER THREE - FINDINGS/RESULTS

What follows is an analysis of the transcripts of the participants, flowing from their experiences and perceptions of disability and chronic illness prior to their diagnosis with MS through to their experiences and perceptions post diagnosis. Experiences accessing supports is markedly different before and after diagnosis, with experiences post diagnosis causing considerable socio-emotional dissonance. Themes “fitting into designer labels” or arbitrary definitions and lack of control through requirements to access health care professionals to get needs met create disconnections for people between their critical awareness and self identity. Perceptions of disability and illness vary considerably as well, although it is clear that previous experiences seem to influence perceptions of self identity. Ultimately, it seems that these participants are working towards resolving the dissonance producing effects of contradicting self identity definitions and support program definitions in ways that still allow them to feel a positive sense of self, though not necessarily a positive sense of disability. Most of these participants did not feel they identified with the DRM at the time of the study.

Experience Prior to Multiple Sclerosis: seeing through an able-bodied filter

Disability and Chronic Illness: “objects of pity, shame or ridicule”

To explore the relationship between previous perceptions and experience with disability and chronic illness vis-à-vis present perceptions, I asked the participants to think back to before they were diagnosed and tell me how they used to perceive those terms and how they thought they came to their

perception. One participant had significant direct personal exposure with MS prior to her own diagnosis via her mother's MS. She notes:

I have only just started to understand the fluctuations of my mother. Because as a kid, it always bewildered me that she had friends in and would laugh and talk and be the hostess with the mostess, and afterwards she would just have to flatten out. She would be on the sofa and she couldn't move. I think that's part of the MS.

This participant noted considerable tension between her mother and herself as she was growing up, particularly during her teens. At the time of the study, this participant had been diagnosed for approximately 30 years. She also spent many years concealing her own MS and disability, suggesting that past experience with disability and chronic illness does not necessarily make the road ahead any easier; it may even make it more difficult, depending on the nature of the experience.

The most commonly reported perception of prior experience to disability or chronic illness was one of such people as objects of pity, shame or ridicule.

Referring to a family friend, one participant noted thinking:

Just – I'm glad it's you not me. We used to go over there and see him running around, looking like a fool.

At the same time though, this participant noted this friend was not excluded from recreational activities, even though:

...he just had trouble walking up the stairs...It's just how he is and how he will always be. I never paid attention to why. I only found out he had Polio when we buried him.

One participant who grew up in a cultural context outside North America noted:

I never thought about it... When I was there, it was a shame. I know one of my neighbours had a mentally retarded son. She would never bring him out, because people would make fun of him? They would not show you they had a disabled child. My husband's relatives when she was a child her mother had been working on the meat grinder, and she didn't notice the child had put her fingers in the grinder. She lost two fingers or so. Every time you would go to their place, when the girl would bring you coffee or tea, she would always have a tissue over her hand and hold it with her thumb so as not to show it to you. They couldn't see that there was nothing wrong with it.

Despite this comment, this participant later attached a negative connotation to disability in reference to herself.

The participants seemed to have universally developed negative perceptions of either disability and/or chronic illness prior to their own diagnosis with MS. In reflecting on the report, some participants were reminded of more positive perceptions they had prior to their own diagnosis, but these reminiscences did not arise during the interview itself. As a result, it is likely their present perceptions of the terms have been strongly influenced by these prior negative experiences.

Getting Help prior to MS

"Pretty Routine"

Several participants referred to quite a number of programs and services from which they were able to receive help as able-bodied persons. One participant noted:

Prior to having MS, you know it's a funny thing when I think about it.

Because I have somehow accessed services and help and special programs a lot of my life.

Among these participants, no one reported having had significant difficulty accessing needed programs and services prior to their diagnosis. In referring to the Employment Assistance program one participant indicated:

Going on UI [now Employment Insurance] which I did quite often when I was younger at various times between jobs or whatever was always a pain cause you had to show them that you had applied to this many jobs and fill in all these forms and that kind of stuff - but it was pretty routine.

Another participant listed many programs and services from which she had benefited prior to her diagnosis:

When I was 18 and went to Israel and became a new immigrant the government is committed to helping Jews in returning to Israel if they want - "The Law of Return" it's called. If a Jew wants to make their home there, they will always have a home there. So they try to offer as much help as they can to help you settle. So there are programs where you attend a kibbutz, or attend language classes half days. That in itself is highly

subsidized. They will give you a subsidy towards your apartment; loans that are really forgivable. It was very easy to get them. When I came back here, I was living with my mother and my baby, and I was connected to the Women's Employment Counseling Centre where I did receive counseling and choice of programs. I don't remember any difficulty accessing these programs. I didn't need any doctor's notes....

Another participant worked for a union and said, "I never had any trouble getting help before this MS. I worked for a union and they called me." It would have been helpful to explore if the union was helpful post MS, as some issues have been noted within disability rights organizations regarding union accommodation of disability conflicting with seniority issues, for example.

This information is interesting as it clearly indicates that these participants have accessed programs and services throughout their lifespan to date for various different reasons. Given the sample demographic and background, it is likely they are fairly representative of mainstream Canadian society. This suggests we need support at many stages of our lives - acquiring a disability and/or chronic illness is just another reason for needed support programs and services. Contrasting this with attempting to access support services post MS will show a marked difference.

Self-Identity Post-Diagnosis with Multiple Sclerosis

Perception of Meaning of Terms “Disability” and “Chronic Illness”

General Confusion

The most salient theme of every interview was a consistent and somewhat frustrating confusion on the part of all participants in their attempts to articulate clearly their understanding of “disability” and “chronic illness.” This confusion reflected not participants’ lack of intellectual comprehension, but rather the ambiguities inherent in the terminology itself. Participants found themselves tripping over other terms, such as “impairment,” “symptom,” “effects,” and “disability” that could mean similar things. Different terms seem to reflect various medical or social foundations. Usually the participants began their explanations confidently, but rapidly found themselves getting a little muddled in choice of terminology. For example: “I need exercise and I’d really like to walk and swim because of the symptoms, and I don’t think of them as symptoms, that the ‘effects’ – whatever.”

One participant, although quite clear in her conceptualization, also referred to “episodes” she had had before she was diagnosed which were not then perceived as anything in particular as she had no label to attach to them:

Participant: Me being disabled means that physically I’m having troubles with uh, just day-to-day living and dealing with the environment.

Chronically ill means that I have a disease process called multiple sclerosis that I have been living with for over 20 years so...um, and and

um, so I don't think too much about the chronically ill part of who I am. So that is just in a real quick nutshell what I think about it.

Catherine: So if I understand correctly you see chronically ill as being something internal, the actual disease process, whereas disability is how you interact with your environment, is that what you said?

Participant: Well, just how I live day to day, so ya. So I can say that the disability that I experience isn't something that I have associated always with being chronically ill. Or with having a chronic illness. I see those as quite separate and different.

Catherine: I see. So you say although you have had a chronic illness ever since you were diagnosed you haven't always been disabled?

Participant: that's right. And in fact I probably had the chronic illness before I was diagnosed for many years before that, but I didn't realize it? So but only in doing the history going back and say "oh ya, that's what that other thing was before I had the diagnosis too", but even at the point of diagnosis I would not have uh, included me being disabled in that time frame. That wasn't part of it.

Catherine: It's kind of interesting. That other "Thing" you refer to what would that other thing have been?

Participant: Well, it was an episode that was not diagnosed as being part of MS in the beginning. It's only in hindsight you say, "Oh that's what it was."

This terminology confusion is also reflected in the literature and highlights for me the dilemma regarding applying terms to such variable and subjective experiences.

"Disability"

Social-political model Awareness

Half of the participants indicated that they had quite a well developed critical awareness of the social political model of disability. One participant with a considerable background in disability-related research articulated it thus:

It's just a matter of putting a sense of not fitting in or fitting the environment onto a person. It's really a lack of fit between the person and the environment.

All of the participants made reference at some point in their interview to the impact of environmental barriers, but only three described the impact of the environmental barriers in social political terms.

Functional / Limitation model

As interviews continued, all participants, including those with a social political awareness, responded that to some degree they also related “disability” to having permanent and visible “symptoms” or “impairments” which limited their functioning. Although two participants articulated “disability” as meaning “total” inability to “do anything,” others indicated that it wasn’t until their symptoms became significant, permanent, and visible to other people that they began to see it as “disability” (requiring “major adjustments,” assistance or “mechanical aid” in negotiating the environment). The following are samples of the comments:

Disability is connected to the amount of adjustments that you have to make in your life.

I think I have only viewed myself as disabled once I had permanent symptoms that interfered with my functioning.

I think the disabled person is more *profoundly* - that their way of life the things that they can perform for themselves without mechanical or other aids, is more profoundly altered than mine.

I guess I think the disabled person is paralyzed, possibly blind.

Dis-ability means totally unable to do anything.

These comments reflect a functional/limitation model which views disability as a wholly negative experience. The participants did not appear consciously aware of this connection as they contradicted themselves frequently. The role of their previous experiences likely impacted them significantly in this respect.

Disability = mobility and/or visual impairment

The participants also consistently indicated that “disability” is particularly related to mobility “symptoms” or “impairments” with one participant also specifying loss of vision:

Disability is linked in my mind to mobility.

Mobility is the primary thing.

It just impacts on all aspects of my life in terms of getting around physically.

I would have thought of a disabled person as somebody whose functioning was impaired, profoundly. That would have meant their eyesight.

Again, confusion and contradictions were frequent as even those who acknowledge the role of the environment in the disabling process identified disability with types of impairment.

“Invisible Impairments” are not Disabilities

Invisible symptoms/impairments, including sensory, bowel and bladder, mental health and cognitive symptoms/impairments and fatigue, were largely considered a “nuisance” or “inconvenience” as opposed to a “disability.” The participants indicated that hidden symptoms/impairments tended to slow them down but did not necessarily “...stop me doing things,” as a participant put it.

I didn't consider that disability, well because it didn't interfere when I was dragging my leg and stuff so it was a nuisance.

One participant outlined in detail the extent to which these hidden symptoms affected her day-to-day life. I have chosen to include the excerpt in its entirety to emphasize the subjectivity involved in determining what constitutes “severity.” It is a good example of the tendency shown by all participants to minimize their experience of ‘disability’. The ‘symptoms/impairments’ outlined below are all quite common features of MS:

I can walk; it's true my legs are often stiff, sometimes I can't walk well, sometimes I totter or move very spastically, but I can do it! Sure I don't mind some of them are a – (pause) uh, well, more...obvious ones, they're not obvious in that sense [to other people], they are big changes. I can't go to the washroom normally, a *lot* of trouble trying to be able to pee. I have to resort to a lot of “hoodoo-vooodoo” and incantations – run the water and rub my stomach and stand-up and sit down, [laugh] and knock three times, you know. It's *very* uncomfortable I feel the distention, but I don't feel the sensation that tells you “oop, I need to pee”. Until I can absolutely

taste it, and then I'll be so distended I know I can't go. I can squeeze it out, but I'll walk away and I will know I still need to go. It's very *uncomfortable*. It leads to um, well, I have a catheter I have been given, I am supposed to be using it but it seems like one of those things that brings risks of its own. You want to void properly so you don't get infections, but it's very easy to infect yourself with all the scratching. I was given this teeny catheter and I still can't insert the damn thing without scratching myself. I think "Great" I'll induce an infection. Plus it's a hassle, I'm a private person and, you know, so I have managed to avoid that still. And I just deal with that *inconvenience* [italics added] The others - I can't go number two without *massive* amounts of [laxative] and I do have to plan my life around the bloody [laxative]. When you haven't gone poo for five days you start to feel a sort of boulder like that, uh, wolf in the old fairy tale? And I have to think, well, do I have to give my partner a lift to work in the morning, cause if I do I can't take the laxative tonight so I just feel *Wooooou* for another day. And I have to think so many hours that I calculate that it will work. If you haven't calculated how many you should take, then you're trapped to the stupid "can" for the rest of the day. Going a little at a time and having alarms and false alarms all the time. It seems so stupid. But I actually uh, you know, you have to kind of drag the potty around basically coping with this thing ...and I also often can't get up early in the morning, but I have to cause I just feel literally ill and I just take it in the afternoon or evening and I just end up sleeping on the sofa because,

you know, *it disrupts your life. It's an unpleasantness.* [italics added]
...sometimes I think that, say I did have a job, how would I manage this darn thing? Live my life around my bowels? There's that. Then the other thing is the distorted sensation. It's gotten so that I can hardly stand to be touched at all. My partner and I sit on the sofa watching TV and he just affectionately likes to put his hand on my leg, or even if his hand happens to be resting near my leg, and it feels like a hot iron is against my skin. It feels scorched. And uh, I just have to remove his hand. Or my back, you know, so much of my body can't stand touch at all that its more and more affecting shall we say, the possibilities of an intimate life. It's one thing not to be able to feel sexual; it's another when you can't even just cuddle a person without them fighting the desire to just jump out of your embrace to the ceiling. These are the daily things."

Despite the considerable extent to which these hidden MS symptoms/impairments interfere in the day to day life of this participant, she did not consider this to be "disability":

I'd say "I am limited or I am inconvenienced by" or you know, "experience greater difficulty."

This could be attributed to her attachment of a negative perception to defining these symptoms/impairments as disability and defining herself in relation to people with visible permanent disabilities:

I just feel perhaps it would be - kind of, *malingering* of me to describe this as disability when in so many significant ways I function so...so um, at such a high level?

Her choice of the term “malingering” is interesting. Webster’s dictionary defines “malingering” as “to feign illness in order to avoid duty.” In this instance, she is implying that by defining these symptoms/impairments as “disability” she would be feigning or exaggerating disability. This despite the fact that she acknowledges the difficulty they cause her in her day to day life, and would cause her if she had a job. She commented later that she felt she would be “guilty of laziness or self-indulgence – self pity – by arrogating to myself some sort of right to special consideration that perhaps may not be justified in my case...”

Temporary Symptoms / Impairments are “disabling”, but do not constitute “disability”

Temporary symptoms/impairments which are “disabling” but did not connote “disability” are defined by the participants as visible symptoms / impairments that *did* stop participants from doing things but not *permanently*.

Two participants outlined their temporary ‘symptoms/impairments’:

The un-daily things like my hands shaking. If I get just a little bit tired, things are just *flying* out of my hands. My handwriting, it looks like a deranged chicken [laugh]. I feel like I’m doing some sort of high-wire act and things could fly out of my control anytime. My vision’s affected, my ability to focus. And I feel terribly weak a lot of the time, exhausted.

When I had relapsing-remitting and I'd have a couple of attacks a year, sometimes it would affect my functioning, but it was always temporary? So I didn't see that as disabled.

I think of it more as a transitory condition that doesn't kind of affect my essence.

The contradictions surrounding disability as an environmentally created experience versus an internal deficit are clearly evident through this dialogue as the participants struggled with what they considered less restrictive activities and impairments and whether they constituted 'disability.' Again, the highly variable and subjective nature of these decisions is clear.

Chronic Illness

Participant's perceptions of the meaning of "chronic illness" also ranged quite significantly and posed a considerable conundrum. Meanings ranged from "feeling under the weather" to "It's in you. It's you! It's you!"

Chronically ill means feeling under the weather, not "at par". If I feel this way I want to get "fixed" so I can function "at par."

Chronic illness I would have thought of as pain, uh, symptoms that affect your comfort.

Illness is always in you. Its you, its you! No one understands MS as much or as well as I do, because its in me.

Chronic illness comes with a medical diagnosis and is a constant. It is unrelated to disability.

Chronically ill means that I have a disease process called multiple sclerosis that I have been living with for over 20 years.

Chronic illness means you're never going to get better. They are never going to find a cure in my lifetime.

Those participants with more formal education, particularly in the medical field, defined chronic illness in clinical terms, whereas others focused more on the personal impact, such as identifying the internal focus and the lack of a cure. The distinction between disability and chronic illness at this point was clear for most of the participants, though became much more conflicted as they were asked to clarify the difference between the two as seen in the following sections.

"Chronic Illness" does not equal "Disability"

Most participants thought 'chronic illness' and 'disability' were very distinct categories as reflected by these statements:

Disability is not illness.

Disability is the way in which I function rather than an illness that has been described and diagnosed by a doctor.

The disability that I now experience isn't something that I have associated always with being chronically ill. I see those as quite separate and different. So I haven't always been disabled but I have had the chronic illness for 20 years...

Sometimes "Chronic Illness" might equal "Disability" maybe...

The participants recognized a confounding 'overlap' between the concepts, well-expressed by this participant:

I may get things a little blurred about the progression of the chronic illness versus the progression of the disability, I don't know...Only with increasing difficulty with day to day living and having difficulty with my environment have chronic illness and disability become linked.

One participant noted that MS as a chronic illness has disabling symptoms, but the external barriers are also disabling:

chronic illness is the underlying cause of my disabling symptoms, but external barriers in the environment are also disabling. MS is causing the physical symptoms. Now the restrictions that I face, the stairs, the lack of accessibility. All of those kind of things right.

She continues though, by discussing how she must adapt and accept things she can't do, as opposed to focusing on altering the environment to enable her to be

able to continue to do many of the things she did before the disabling symptoms occurred:

So the fundamental thing that's causing me to have these physical restrictions is the MS but the thing that is preventing me from doing the things I used to do and I like to do maybe - I've adapted, it's a constant process of adapting and accepting things you can't do anymore. I mean I want to go for a walk, you know, I need exercise and I'd really like to walk and swim because of the symptoms, and I don't think of them as symptoms, that the "effects" – whatever – that MS has caused so that my body won't do those things anymore. So the sort of underlying cause of that is the MS. Now at the same time there are a lot of other things that are disabling, which are the barriers out there. That you know the fact that the stairs, I mean not everywhere has an elevator there aren't always automatic door openers, I mean they're not major things. Sometimes they are but then they're not all major things. So those are the external barriers, so they're two different things.

This participant reflects most profoundly the struggle that all the participants indicated between whether disability was an interaction with their environment or whether their impairment experience factored significantly in the definition. The comment "it's a constant process of adapting and accepting things you can't do anymore" specifically raises the question who should be doing the adapting and accepting – the individual or society or both? And to what extent on each part?

Loss via disease process versus congenital disability or accident

There was recognition among participants of a difference between loss of ability as a result of multiple sclerosis and congenital disabilities, or losses incurred through accidents and other circumstances later in life. As one participant noted:

...one of the features of MS is that you lose something rather than being born with a disability and growing up with a disability.

Uncertainty and variability of experience

Participants also noted that some types of MS do not involve significant progression or loss of ability, and the uncertainty of an unpredictable future. People do not know what type of MS they have until after the fact.

It should get worse along the way but...not necessarily. MS can be so different... [from one person to the next]

At that time I thought MS meant I was going to become profoundly disabled – paralyzed, possibly blind – it looked like that is where it was going.

MS being an often progressive type of chronic illness, it has definitely changed. And didn't stay back as a non-disabling illness, but it has become a disabling illness.

When I was first diagnosed I felt as though I had been in an accident. It didn't feel like a disease or I didn't really I guess, qualify it as disability, but it felt like I had been in some horrific accident you know, where all of a sudden from one moment to the next everything had changed.

Here the subjectively and variability of the experience of disability and illness is most evident. The socio-emotional impact of the onset of sudden impairment is profoundly noted by the participants, comparing it to a severe accident. Again though, some experience a much more gradual onset of impairment with such huge variability, the common experience is only in the sense of variability and loss.

Perception of Self-Identity with terms 'Disability' and 'Chronic Illness'

It quickly became apparent that participants' self-identifications with "disability" and "chronic illness" also fluctuated considerably and for the most part, fairly frequently. Given the ambiguous nature of these terms, it is not surprising that participants felt considerable ambivalence about identifying with them.

At time of diagnosis

"Disability is totally incapacitating" correlated with disabling first 'episode' and negative previous exposure.

The participants who defined 'disability' with words such as "totally unable to do anything" or "profoundly unable to function" indicated that, upon diagnosis, they either initially identified with "being disabled" or focused on the anticipation of "being disabled". They also attached a deeply negative connotation to this

concept. These were participants who had disabling early symptoms. As one participant so eloquently put it

When I thought I didn't know how I was feeling or how I had to live, then this was going to be my lot for the rest of my born days. [italics added]

At that time I thought MS meant I was going to become profoundly disabled – paralyzed, possibly blind – it looked like that is where it was going. I guess I just imagined that it was going to get worse and *there would be nothing left*. But I didn't see myself as disabled, yet. [italics added]

I thought that, oh god, I will become disabled. It made me sad, it made me worse.

When I was first diagnosed I thought I was disabled. I looked at it that way.

They all attributed this to their heightened emotional state at the time:

I think I thought of myself as disabled then only because I was upset at the time.

Honestly, I don't know what I thought; the present was just so appalling.

At that point it was like some sort of a horror show. I thought of myself

maybe in kind of a twilight place then not knowing what would happen when I come out the other side, if there was another side to come out of?

Dual Identity – able bodied and chronically ill

Participants indicated that they continued to identify primarily as able-bodied before permanent visible symptoms developed, though they were aware they also "had a disease."

I was really not thinking of myself as disabled. I thought of myself as healing.

I don't know, that's a good question. I might have been more inclined to say "chronically ill", but probably my perception of myself would not have included that [either].

This participant indicated previously that she had not put a lot of thought into the two terms prior to her diagnosis

Present identification

Fluid and layered

The participants generally indicated they identified with both terms intermittently, depending on a number of factors. Most referred to their "chronic illness" and "disability" self-identities as something they could "take on and off" and/or "wear" simultaneously as necessary:

I supposed if you talked to me during some of the times I am using a cane I might feel more like ...um, and yet and yet, disability is almost like a - a -

a shawl I feel I can take off, you know? It isn't, I don't have an *identity*, and I haven't made an *identity* out of it. It's more like a condition that affects me sometimes.

If you were to ask me if I was disabled or chronically ill I would say both. It depends, on my situation and who I am talking to.

But you now, when things are going well, when I am at a party or something, I don't remember I am disabled – I don't remember that I am ill.

These comments indicate the utilitarian aspect of identity reflected also in the Charmaz study.

Tendency to prefer to identify as chronically ill.

To various extents, all participants indicated that they identified with the term "chronic illness." Participants generally seemed to feel it was less stigmatizing to identify as "chronically ill" than as "disabled," as their comments indicate:

I would refer to myself as chronically ill before disabled.

If asked if I am disabled or chronically ill, I'd say chronically ill. Cause that's the term that's associated with MS. That's how I was brought up. You're chronically ill if you have MS.

Over time, it was “your not disabled any longer, your chronically ill”

Another participant noted that getting the doctor’s note confirming her “illness” caused her less guilt and shame than when her doctor needed to confirm her “disabilities”:

The doctors note I actually do think, if it suggested illness I wouldn’t mind so much in a way, because its true I’m often feeling too ill. When its necessary that they have to say no I can’t walk more than so and so without keeling over without some sort of aid, sometimes its true, sometimes its not. So I feel dishonest.

Curiously the participant who made this statement had previously indicated that she identified as chronically ill, but didn’t think of herself as “sick.”

Here conflicts between self perceptions and the utilitarian need to present contrary to how one wants to is beginning to arise. As well, chronic illness being more acceptable than disability to these participants is notable.

Some illnesses are better than others

It was the perception of one participant that a hierarchy of illnesses exists, with neurological illness at the bottom. Thus, her preference was to identify with arthritis, seemingly a more acceptable illness:

Always I felt it was easier for employers to accept arthritis then it was to accept MS.

This theme would bare further exploration to see if others have similar perceptions.

Chronic Illness does not equal sick

Though participants tended to prefer to identify with chronic illness, they all indicated in one way or another that they did not see themselves as sick, unless they were undergoing treatment of some sort.

I have this chronic illness but I don't do anything about it as an illness.

Like I'm not - There's nothing, there's no treatment to cure this or anything like that, and I don't think of it in those terms.

I certainly don't walk around thinking of myself as – isn't that weird, I have a chronic illness but I don't think of myself as ill.

Now I always speak of having a chronic illness, although it's funny, I don't think of myself as sick.

I don't feel chronically ill although I have this illness which is sort of an overriding factor in my life. I have MS and all that leads to. Incontinence, bowel and bladder, clumsiness, pain, fatigue – terrible fatigue and depression, which seems to be connected somehow or other. But you know, when things are going well, when I am at a party or something, I don't remember I am disabled – I don't remember that I am ill. But if I have a bad spell of any of those things, then I want to get that "fixed".

This participant, who originally defined “disability” as a social construct, refers here to her temporary symptoms/impairments using a term meaning a bad “fit of illness.”

The connection of illness identity to activities related to treatment is notable, although some participants also noted that they identified as chronically ill regardless of treatment activities.

Visibility of symptoms/impairments leads to disability identity

Other participants referred to the need to access support (discussed further under the next major theme) and to influence other people’s reactions to their visible symptoms/impairments as factors contributing to their identification with “disability”:

To speak really rather boldly about it, that is the card I play. And the card that I have used to secure what support I have been able to [get].

I really only started to admit them [disabilities and chronic illness] when they became obvious to other people. I certainly didn’t feel disabled when I was “passing” as normal. I passed as normal for a long time.

I used just the power wheelchair. I didn’t like the way that made me feel about myself and I didn’t like the way it made me feel that other people were looking at me. The progression of the disability, I guess. Whereas maybe in the past I could ignore them.

Need for assistance = symbols of disability

The participants identified “disability” with the need for assistance or a technical aid, particularly to get around:

I looked at these things or thought about the advantages of these devices as *symbols of disability*. [italics added]

With disability – their life is more profoundly altered than mine – the things that they can perform for themselves without mechanical or other aids is much more limited than mine.

In this manner, the extent of disability identification was again attached to activities related to interacting with the outside world. Disability identity related to accessing disability supports, whereas illness identity related to medical treatment.

Disconnection between critical awareness and self identityTendency to “normalize”: conceal and minimize “disability”

All the participants indicated that they tended not to ‘admit’ disability or chronic illness until their symptoms /impairments became impossible to hide, or until they needed to access assistance of some kind. Even participants who reflected a clear understanding of the social model of disability did not share a sense of a positive disability identity. Thus, along with this tendency to “normalize” by concealing and minimizing disability and illness, participants seem to exhibit a disconnection between the critical awareness of the social political model of disability and the development of a “positive disability identity.”

Getting Help / “Disability Supports”

The programs and services discussed by the participants included the Canada Pension Plan – disability program (CPP); CPP vocational rehabilitation program; the Disability Tax Credit (DTC); the Manitoba Employment and Income Assistance Program (MEIA); Winnipeg Handi-Transit; Manitoba Disabled Parking Permit Program (MDPPP); Society For Manitobans with Disabilities (SMD); SMD Wheelchair Services; Manitoba Home Care Program; Vocational Rehabilitation for the Disabled Program (VRDP); Workplace Employee Benefits program; and Private Life Insurance.

Fitting into those Designer Labels

How severe is enough?

Difficulty in fitting into program criteria and how severe one needs to present were particularly true with regards to the federal government disability income maintenance program - the Canadian Pension Plan, Disability Pension. This program is essentially an insurance program based on contributions made over the course of one's career in the paid labour force. The Disability Tax Credit is a refundable federal tax credit intended to offset the added costs of disability for those who have high enough incomes. The Manitoba Employment and Income Assistance program is the provincial financial assistance program of last resort, and is needs tested. In general reference to her experience applying for help one participant explained:

I learned that you have to ask several times. I've learned over the years that you have to know your audience. But it's always a big hassle. And

part of the problem with MSers [those that have MS], is they like to minimize their disability and of course that doesn't help to determine attempts for help.

I didn't want to put myself in that category of having to meet...to say up front and out in the open and to myself I had a condition that was both severe and prolonged according to their definition and I always had a question in my head about well, ok, I can say I've got a condition that's prolonged, that's not a question, but how severe is severe? *You know, how severe is enough?* [Italics added]

Reluctance to apply

Another participant is in the process of preparing to apply for CPP. Her comments revealed that she had been hoping not to have to do so partly out of reluctance to having "to jump through more hoops." This participant had gone through a very difficult process in applying for the Disability Tax Credit (DTC).

I held back applying [for the DTC] for many years because I didn't want to face having to fill in their forms and having to fit their criteria and risk being rejected because I was deemed not disabled enough.

Well the Disability Tax Credit ...severe and prolonged and interferes significantly with activities of daily living...right. I haven't actually tried to apply. I mean I didn't fit the criteria, I could always walk too well. And I had to pay too much income tax.

Lack of Control

Whose definition is it anyway?

Participants questioned the relevance of eligibility criteria established by people unfamiliar with the reality of living with the range of symptoms/impairments that can characterize MS (among other chronic illnesses). Participants reported the feeling that such application processes, which are not based on the realities of applicants' lives and which take the control out of their hands, create a situation of learned helplessness. As one participant put it:

Helplessness is humiliating and painful. But you hug your chains because at least they give you some help.

Who's defining what it is to be disabled or to have a disability? The government definition of disability ...it seems unreasonable that they were defining what was disabled. If I considered these restrictions to be disabling, that should be enough.

It's difficult fitting into that box. It doesn't acknowledge the subtleties and the different types of the disease and the things that are realistically disabling. Like the whole invisible symptom thing. They don't accept that as a disability but if you're living it, the reality is that it is disabling, it is a disability. So ya, it is that lack of, sort of external...control? something like

control well, control and sort of judgement, assessment that is not based on the reality of peoples' lives.

They [Canada Pension Plan staff] are just a bunch of young people, they start off and they don't know anything. You don't want them to have MS but you want them to go through the symptoms, for any disease. I would like for them to know what it's like to walk around with 40 extra pounds on you. I dunno, get the numbness feeling in your legs all day long, and if it's not numbness it's tingling, and try walking with that. I mean you don't want them to get MS, but there are so many things you wish they could experience.

Doctor knows best?

Another theme arising in the interview data is the need for participants to cultivate a good relationship with their health-care providers, especially their general practitioner and their neurologist. Almost all application processes for "disability support" programs and services rely heavily, if not exclusively, on a report by the applicant's physician. As most doctors and neurologists are not trained in the application processes for disability related programs and services, all participants noted they had to make considerable efforts to educate themselves and their doctors in order to ensure that applications were being filled out appropriately. Doctors usually charge for this:

I wrote the letter stating what my limitations were and why I needed somebody [attendant for assistance traveling], and faxed it to her. She

just signed off on it. For ten bucks. I had to develop this relationship over years so that she trusts me. Then she retired and I had three willing doctors that all had to be educated.

[It was] my doctor who filled it in. You know, [I had to] make sure that he is filling it in correctly, what he needed to say on the application.

I'm going to just decide how to tell my neurologist how you should fill out the application.

One participant noted that the Social Assistance program in Manitoba requires people with disabilities to be reassessed fairly frequently:

Oh ya, every few years actually, you have to go back to your doctor and they have to assess you all over again. While its benevolently intended, you have to actually have some big you know, incredible health thing to access it.

with this [referring to disability income programs], now you have to prove something. *Like prove that what you are saying is true.* [Italics added]

Added costs of health care professional assessments

Although only one participant raised the added costs of assessments in order to receive services in their interview, (" She just signed off on it. For ten bucks") most doctors charge anywhere from \$10 -\$30 dollars to fill out

application forms for patients. Assessment costs can go into the thousands of dollars, depending on the impairment. In this instance, given that these participants basically did all the work, these charges represent little more than a fee for the doctor's signature.

"Getting my head around it"

Stress of process

All participants reported experiencing stress in obtaining help from services and programs to which they applied for support. They either did not receive assistance the first time they applied, or they had to do extensive research and preparation before applying. All the participants who were receiving CPP were forced to apply more than once. Two participants received CPP for a certain period, then lost it when they attempted to go back to work.

My first CPP application was denied, then I appealed and finally got it.

Then I tried the vocational rehabilitation program [whereby recipients can return to work on the understanding that if they "get sick" again before 3 months is up, they will be fast-tracked back on to CPP] But I got sick again after 14 months on the job and they wouldn't let me back on CPP. It took another year to get back on. It was supposed to be fast-tracked. I got fast-track denial.

I applied for it and I was successful on my second attempt. By that time I had gone back to work. They turned it on and then they turned it off for a while, even though I paid the full premium.

And with bureaucrats it really helps if you give them insight into the real world.

The difficulty of accessing programs tends to promote a sense of guilt: participants may worry that they are not “benefiting enough”, or they may feel guilty if circumstances arise which prevent them from taking advantage of the program:

I figured it's a limited resource and someone could use it more than me. And that I'd feel maybe guilty having it and not using it [power wheelchair].

This program would have taught me basic computer. It's really unfortunate that I started the program, but I was having problems with the MS, that were making it difficult for me to see. Also my eyes were just shifting, I couldn't see well, my health was bothering me. And I was exhausted all the time. I feel really bad about it, I wish I'd finished it. But I was getting nowhere. I also feel bad about driving people crazy. To ask for resources I don't take proper advantage of.

Forced Cognitive Dissonance: putting your worst face forward to get your needs met

When your self identity is attacked by others and you aren't willing to accept their judgement, you may be faced with what psychologists call *cognitive dissonance* – an inconsistency between two conflicting pieces of information, attitudes, or behaviour (Festinger, 1957). One participant described how the

necessity of fitting herself into externally defined categories with which she did not identify affected her and why she did it:

You feel about yourself the way you project. And I always try to project as good. But there are times when you only get what you want if you project as the worst possible case. And certainly you have to do that to stay on home care.

One participant referred to having considerable difficulty “getting her head around being in that category of disability that they are wanting me to be in,” but having no choice if she wanted to access the program.

I just felt like I was having to fit into this label of what degree of severity it was that the government needed to have in place in order for me to “fit” that category when in fact I didn’t feel that I was at that level but that I was making these changes in order to make you know, to be proactive and um, it was annoying that I had fill in that stuff. I had to fill that in so I had to get these as a medical expense. That was so annoying. Because I didn’t see myself that way! Period.

I was honest about it, I just couldn’t be optimistic about it. I often had to write things on the worst day, not how are they usually or how you want them to appear. [On being rejected from Canada Pension Plan - Disability] I had a colleague who said, “just apply again. And this time make it sound really bad” So I did. And I got it.

Skewered on the Horns of Contradiction: Am I worthy?

One of the most difficult stressors participants grappled with was feeling unjustified in requesting assistance. This matter is closely related to the eligibility criteria of programs and services.

There is a discrepancy between I guess my self-concept and ...what I've obviously... [been] deploying to live. Does that make me that I'm exploiting the system? And I have to admit to you that there is unease and distress, guilt or shame about – this sort of discomfort about this. I think to myself surely I could do more than I'm doing and yet the difficulties of dealing with the illness it's not like they don't affect how much you can do. I still feel ambivalent about it. When I'm getting steroid treatments I don't feel ambivalent, but when I'm doing better... you know as my capacities are more and more affected, I'm still not entirely 100% at ease.

Some participants noted a sense of discomfort in some of the requirements of the application processes that they had to ask their doctor to include:

When it's necessary that they have to say no I can't walk more than so and so without keeling over without some sort of aid, sometimes it's true, sometimes it's not. So I feel dishonest. So I feel the doctor and I in some way, he understands the situation so he is uh, helping me. Not that we are colluding exactly, but we are not really following the letter of the policy, and it makes you feel a little ashamed.

And even then, he filled it in a year after I was going to be applying for it, and I didn't apply for it for another year after that. Two years from when I ... originally was applying that I finally sent it in. A big part of it was my own headspace getting my own head around it. But once I did, actually it was one of the things that my doctor said that helped. He asked me how much money it was that I am not making now due to this chronic illness, trying to reason with me that you know because of this I am losing X number of dollars per year from what my earning potential could be plus all these expenses, and this program is there. So, sure I can't get my head around BUT I hopefully can see that because of this disability I'm uh, justified.

The participant receiving Social Assistance noted that as well as her identity struggles with disability and illness, she also deals with the label of "Welfare Recipient":

This is where I become skewered on the horns of contradictions because whether I see myself as disabled in terms of my self-concept or not, to speak really rather boldly about it, that is the card I play, and the card that I have used to to secure what support I have been able to. The label of welfare recipient. That's a painful thing. Even in an ideal society, people that, you know "From each according to his ability, to each according to his need"? People's differential abilities to function in a way that'll be able to secure for themselves the necessities of life, would be recognized and there would be some equalization made....

The participants indicate here considerable socio-emotional stress related to struggles in accessing support services, contrasting markedly with their experience accessing services prior to their diagnosis. Determining whether they are 'disabled enough' or 'ill enough' created cognitive contradictions between their self identity and how they needed to present. The extent of their need for the support seemed to correlate with the extent of the cognitive dissonance experienced. For these reasons, participants noted they were reluctant to apply for needed supports, and actually held off applying for several years in one instance. The loss of control over their lives and self identity was noted universally and the socio-emotional impact of this is clearly evident in the statement 'helplessness is humiliating and painful.' The requirement to access health care professionals to confirm needs is a grudgingly accepted frustration, though most notably, clearly not necessary for these participants as most participants found they had to educate their doctors on the procedures. And for this, they had to pay their doctors. Stress was also experienced during the process of access the needed supports, as many participants noted they were initially rejected. These participants had the wherewithal to appeal these decisions, but it is likely that many do not. Upon appeal, the participants indicated they were ultimately successful, but in some cases it took many months, to years. These experiences undermined their sense of worthiness, leading to a sense of guilt for choosing to apply.

Organizational Involvement

I should do something

The participants indicated that they didn't consider getting involved with either the Manitoba League of Persons with Disabilities (MLPD) or the Multiple Sclerosis Society of Canada (MSSC) significantly until they had permanent visible symptoms/impairments. This also correlates with beginning to consider themselves disabled.

Sort of around the time when I thought ok, you know it just sort of seemed like this isn't going to go away, this is interfering with my life I should really pay attention to this, I should do something.

Except for the most recently diagnosed participant, who was not involved in either organization, the participants universal choice of group involvement was the MSSC over the MLPD. Only one participant had been an active member of the MLPD. That involvement came after her involvement with the MSSC and it ended unhappily. Two of the participants, though not members of the MLPD, had been active members with the sister organization of the MLPD, the Winnipeg Independent Living Resource Centre. Even so, they did not identify with the MLPD.

Relevance: What I could relate to

Though not moved to get involved with the organization, all participants indicated they appreciated the MLPD's efforts in advocating, particularly in the area of transportation issues; they did not seem to be aware of other advocacy

activities the MLPD was involved in. They reported thinking the organization was not relevant to them, certainly not to the extent that they would make getting involved with the MLPD a priority:

I was never involved with any projects at the MLPD. I used some of the results of their projects. Handi-Transit, I have had my battles with Handi-transit, so I certainly appreciate the efforts they have made in that area. I was just involved up to my eyeballs with ILRC and other organizations. It's hard to get to meetings and hard to get involved. Living outside the perimeter, I don't have a stake in political advocacy for an accessible Winnipeg. And because I was always in helping professions I was always more comfortable with one to one then class advocacy.

One participant had been quite involved in political advocacy in other contexts prior to becoming disabled. She too, indicated that it never occurred to her to get involved with the MLPD. She indicated that the MSSC made the best "starting point" for her as it was "... what I could relate to." Another participant, involved in advocacy work at the MSSC, stated:

I have nothing to say about [MLPD]. I'm glad they're there - they have a purpose. I don't know anything about their work, but I'm glad that advocacy organizations are here, and are available so that if people felt they needed to be in touch that they have some place and some organization that is set up for that. I don't really see what I would need advocating for. I'm involved in enough stuff. That's it. I don't perceive that I am searching for an organization such as that.

The participant that was an active member of MLPD indicated her experience was not a particularly positive one:

I am a member, I know them because of the issues we were dealing with Handi-Transit. So whenever they had a meeting on this issue I would go there. I went there a few times, 5 – 6 times. I would sit there, after I left there, nothing was accomplished. So After 5 or 6 times I said don't call me. What is the point in calling me if you are just going to talk about it and not do anything? I didn't have anything specific, but no one came up with any ideas of what to do, so I stopped going. If you have to do something you have to do something. You can't think about this person is going to not like it or whatever, or be affected. You're not going to hurt anyone.

The only other concern expressed regarding the MLPD was that there may be a perception in the community that the MLPD did not view chronic illnesses and hidden symptoms/impairments as being as legitimate as visible, permanent disabilities. The participant relating this then remarked, "But I can fit in cause I use a walker now." It should be noted though that this was related to the participant second hand, and was not her direct experience.

The MSSC was clearly seen as more relevant to the participants. All the participants noted the MSSC was very helpful as an information source, particularly when they were first diagnosed. Their involvement tended to begin there and develop further based on their interests:

I do volunteer because I like to be out. I don't like to stay home. I go to yoga, I do whatever I can do to keep busy.

I am a client, member. For about 14 years. I read a few books in their library. I access their website. I did fundraising and just moved on to bigger and better things. And joined Boards and committees and National meetings.

I got in touch with them way back when I first had the diagnosis and they mailed out information and so my family could all read it and get familiarized with it. I went to a member's conference and went to some self-help group. I've trained as a leader/facilitator of the Journey to Wellness program, a 10 week course that is offered to members to help them you know, get their head around living with MS and not have – and looking at wellness in their life in all aspects of it.

Only one participant noted that the information was not helpful, as she said she "didn't want to know the facts."

Rapport with Staff

There were no specific comments about staff at the MLPD, but interestingly, few participants found the staff at MSSC particularly helpful:

really not much help from staff. It was really more from the other people in the self-help groups.

Several participants indicated they felt the staff was not as cognizant of their needs as they should be:

It's not a consumer organization, there's a bit of a fight to make sure things are accessible, those sort of things, the need to educate staff. So there's that side of it too.

Although it has more resources and has less difficulty getting resources than MLPD or ILRC, the MSSC didn't suit my impression of how a disabled organization should be. The staff at the MS Society is constantly forgetting what it is like to have MS. They didn't seem to have a very realistic view of life in the trenches. And they have staff to do everything, not people with disabilities themselves, so that staff doesn't have an inherent rapport with disabilities. Like, I used to have a rapport with people with disabilities I worked with because I had one. I certainly never hid my disability to the patients. I think that is the way it should be. I think that is the way the MS Society should be. There should be more of a voice for people with disabilities. You know people with multiple sclerosis should be encouraged to be on the board.

Perceived Mandate Conflict at MSSC: Good Quality of Life not Good for

Fundraising

Three participants thought there was an inherent conflict between the two aspects of the MSSC mandate. The following mandate was adopted in 1992 and states: The mandate of the Multiple Sclerosis Society of Canada is "To find a cure for MS and enable people with MS to enhance their quality of life."

The role of the organization with regards to finding a cure for MS is primarily in the area of fundraising for the MS Research Foundation. As one participant put it:

if people are able to live fully with this disease, I mean that's not really good for fundraising, is it. That's the origin of the organization which is the whole thing about "gonna fix these people and make them whole" whatever, its all that mentality. Which is again at odds with the issue of enabling people to live, and acknowledging that they can live a full and productive life. Its not only at the MSSC where this conflict exists, although I think its very predominant, um, outlook? Mentality? Philosophy? The organization is very much focussed on finding a cure. Cause and cure. And [enabling people with MS to enhance their quality of life] is secondary. I don't mean to belittle people who are working there but it is the dominant side of the mission in terms of the philosophy of the organization I think.

It is interesting that none of the participants in this sample note a positive experience with MLPD, the local disability advocacy organization, although most notable, few indicated they were very familiar with the MLPD or what its mandate is. Given their self-identities tended to gravitate more towards chronic illness, it is not surprising they felt the MSSC generally was more relevant to them. It is also interesting that they tended to remain uninvolved until their impairments or disabilities became more obvious to others, correlating with disability and chronic illness identity development. Both organizations may need to address relevance

issues given the concerns expressed by participants regarding the mandate conflict and lack of rapport with staff at MSSC and lack of knowledge and identification with the MLPD. The lack of resources for public awareness campaigns at the MLPD may be a significant factor in the lack of awareness of the participants of the organization its activities and mandate.

Moving towards a positive identity, but is it a disability identity?

Symbols of Disability or Symbols of Freedom

One participant raised an example of a positive outcome of an identity struggle she had around using devices she saw as “symbols of disability.” Through a difficult experience struggling with a manual chair, and then finding that a walker allowed her more independence and freedom, she was able to attach a new meaning to these devices:

My thinking about these things or about the advantages of these devices changed, that’s interesting, that process, that change. In looking at these as symbols of disability, I know that’s where my head was at. But then looking at them as symbols of freedom, and the fact that ya they *might* be symbols of disability that’s true, but I can now look at any kind of a device that helps with getting around in a *whole different way* of looking at it and *feel* completely different about it and *feel* completely different about *myself* using it.

This participant went on to note that she had worked hard not to see herself as “disabled” by taking steps to make her environment more accessible to her.

Here the theme of personal control is also evident:

I made changes around here, my house, adapted my environment to make life easier for myself, not that I absolutely *needed* it but I'm sort of proactive and don't just do things when I absolutely *have to*. So I had about \$7,000 worth of expenses of adapting my place sort of anticipating, wanting to be comfortable and not dangerous and wanting to be able to um... *take care of myself I guess*, [italics added] and not slip crawling in and out of the bathtub that I was already struggling with and had done the bath bar on the side and all that kind of thing and I thought "I don't need this! You know, my life would be a whole lot easier and simpler if I didn't have a bathtub in there." So making the kinds of changes that allowed me to have a safer (laugh) experience in the bathroom and I have done all the work, I mean I had done all the research so it wasn't like I was "disabled"- someone else had to come and do it for me. Heck no, I went and did all the research myself and hired the contractor and laid out exactly what I wanted and had gone to 1010 Sinclair [transitional housing for people with disabilities] to look at their layout and see what kinds of stuff that they had and gone and got all the specs from Central Mortgage and Housing for their outside ramp and that kind of thing.

Another participant noted her approach to day to day life was as follows:

When you have a problem you learn how to deal with them. I never think that I may not be able to do it. You know that you have to do something, and if you can't do it that way, you can do it this way, you know? At least

that's me. Something that has to be done, I think of other ways of accomplishing it. And I just don't do the things I can't do. I don't vacuum because my balance is bad. I might fall and you know, hurt myself.

This seems like a very common sense approach to life. Within the medical/functional/limitation paradigm, however, when a person with a disability has a problem, s/he is not supposed to be able to just "deal with it." Rather, you go to a professional to get an assessment to determine your needs to identify the corrective therapy or equipment needed to allow you to do the task as other people do, or to cope with the emotional adjustment to not doing it.

Yet another participant undertook the project of starting up a major recreational organization upon leaving the paid labour force. She chose to remain as active as she could, making accommodations as necessary to make it happen. This appeared to be her general approach to life, before and after MS.

This theme indicates some significant questions for the disability rights movement and disability studies surrounding the issue of positive disability identity. These participants indicate through their daily activities and problem solving approach to obstacles, they are developing what they consider positive identities, despite having a fairly negative view of disability. Their general lack of involvement in the local disability rights organization though is significant, and bares further exploration.

Discussion

A 'disability identity' was not perceived positively by these participants. People with MS in today's social-political climate are strongly influenced to deny, conceal, minimize and normalize their disability /chronic illness identities as much as possible. But in order to access disability supports, they must do the exact opposite – portray their disability / chronic illness as being severely debilitating. These findings seem to suggest that many people with disabilities and chronic illnesses may not be receiving the supports they need, and may also be experiencing significant cognitive dissonance in attempting to do so. Given this reality, it is hardly surprising that people with MS are not flocking to disability rights organizations, but identify rather with disease-specific health agencies that reinforce this juxtaposition of identities through conflicting mandates of encouraging quality of life issues while promoting the "pity me" image for fundraising purposes. Prior experience with disability and chronic illness also seems to play a significant role in influencing present self-identity for these participants.

Experience Prior to MS

Experiences prior to becoming disabled/chronically ill did seem to inform participants' current perceptions of disability and chronic illness, particularly in relation to their self-identification. The more negative their previous connotation was to disability and/or chronic illness, the greater their reluctance to see themselves in those terms.

The participants related pre-diagnosis experiences which only reinforced the prevailing medical/ functional/limitation paradigm of disability and illness as negative deviations from the societal norm of healthy, White, male, heterosexual, middle class and able-bodied. In congruence with the literature (Goffman, 1963; Derksen, 1980; Enns, 1981; Longmore, 1987; Kirschbaum, 1991; Zola, 1993a), nothing of value was attached to the experiences; the prevailing associations to disability/chronic illness were of patronization or ridicule, or denial and concealment wherever possible. None of the participants related an experience with or any type of exposure to a person with a disability that challenged those associations. As well, none of the participants reported having actually thought much about the concepts of illness and disability prior to their own diagnosis, excepting of course, the participant whose mother had MS.

Although one participant had had a "friend" with a disability, he still treated this friend as 'less than' in a significant way, referring to considerable teasing and lack of awareness of the need to accommodate the friend's difficulty climbing stairs. The participant whose mother had MS touched on a circumstance which, for her, must have occasioned profound contradictions: the need to rely on her mother while at the same time being aware of the societal view of people with disabilities/illnesses as totally incapable and also of seeing her mother's considerable and growing need for assistance. This is a common experience for children growing up with a parent with MS, and places major stresses on the family (for further discussion see Lois C. Peters and Lillian M. Esses "Family Environment as Perceived by Children with a Chronically Ill Parent", 1985).

Self-Identity Post MS

As all participants indicated these were not issues they had put a lot of thought into prior to this study, it was not surprising that their accounts of their personal identification with and perceptions of the definitions of disability and chronic illness involved considerable variation, confusion, and discomfort. This variation is also reflected in the disability studies literature (Hahn, 1995). As in the Charmaz study, participants' individual self-identities (described as "identity goals" in Charmaz, 1995) changed frequently. I found identity perceptions seemed to be fluid and layered depending on a number of factors. This "layered" quality was revealed in that several reported simultaneously thinking of themselves as chronically ill and able-bodied when they were not being treated or experiencing symptoms/impairments which were visible or troublesome enough to interfere significantly with their functioning.

For these participants, "disability identity" seems to be situated in the process by which symptoms /impairments transition to the 'permanent and visible' category. The dynamics of this process are highly interrelated with past experiences and social-political influences, particularly the disability supports system. The participants defined "symptoms/impairments" as "disabling" only if they visibly interfere, particularly in terms of their control over day-to-day life activities, but still did not see themselves as "disabled" until it was clear that the symptoms/impairments were staying permanently. Similarly, the participants felt that 'symptoms/impairments' only meant "sickness" if one were undergoing medical treatment to alleviate them; otherwise they viewed these either as

“nuisances” or as temporary disabling interference’s in their lives, until such time as they, too, become permanent.

These attitudes seem to coincide with current disability policy perspectives and strategies. Most people with invisible or non-apparent disabilities have great difficulty being perceived by disability policy program administrators as eligible for programs and services. If people with ‘invisible’ symptoms/impairments themselves are reluctant to identify as experiencing anything more serious than “nuisances” due to the stigma attached to “disability” and social-political pressures to “normalize” or “pass” for as long as possible, questions arise as to unmet needs. The contradiction between the participants’ critical awareness of the need to accommodate other people with invisible symptoms/impairments and their unwillingness to recognize that right in themselves is problematic and points to cognitive dissonance created by the current bio-medical policy climate.

Based on the findings in this study, participants’ choice of identification between disability and chronic illness seems to be a function of the interaction between the following factors:

1. past experiences with disability and chronic illness, which were universally influenced by the prevailing societal medical/functional/limitation model, and thus negative;
2. “chronic illness disease process” (or stability) and whether participants were involved with the medical sector (actively seeking or receiving treatment) and/or a disease specific voluntary health agency.

3. disability (in this study, a term having negative connotations), defined either as difficulty interacting with the environment, the need for assistance and/or the visibility of their impairment to other people; and
4. how participants were required to present at the time in order to have their needs met. This factor involves the dissonance inducing effects of meeting presentation demands/expectations to receive programs and services that contradicted self perceptions.

Each factor seemed to play a significant role in participants' self identification, but the last factor appeared to have the greatest impact, particularly as impairments increased. This corresponds with the disability studies identity development literature to date, although seemingly more comprehensive than either Charmaz or Admi in the inclusion of past experiences, the current social political environment and interaction with disability support services and disability organizations. This bears further investigation, particularly the impact of ongoing forced cognitive dissonance produced by contradictions inherent in policy and programs with eligibility criteria which do not match self-definitions.

Accessing Disability Supports

As noted in the literature review, there has been considerable documentation in disability studies and the DRM of the fragmentation of the disability policy environment (Enns, 1981; Roeher Institute, 1993; Bickenbach, 1993; Batavia, 1993; Wendell, 1996). This study replicated previous studies documenting aspects of the experience of people with disabilities in accessing disability supports: 1) the loss of control over one's life, 2) the requirement to

'justify' needs through health care professionals who often have little or no understanding of the day-to-day realities of them, 3) the requirement to accept externally imposed labels contrary to ones self concept, 4) the added costs of assessments, 5) stress of navigating difficult and often convoluted application and appeal procedures, and 6) feelings of guilt and shame if applicants perceive themselves as not benefiting or utilizing the services and programs they have been allotted in the manner they perceive they should be.

Resolving the cognitive dissonance involved in applying for support takes a considerable toll. At the same time, as noted in Anspach (1979) and Hahn (1995), as it leads to the adoption of a 'disability identity' - even if negatively perceived - this may be the first step towards ultimately identifying with others as disabled. The necessity of consistently presenting negatively in order to receive required support while seeing oneself in a more positive light has been described as more emotionally challenging to cope with than the disease/disability itself. As well, simply navigating the complicated, convoluted and sometimes costly processes is also noted by participants as taxing to the extent that they may avoid accessing needed supports.

Participants' experience in accessing supports post-diagnosis contrasts markedly with their experiences accessing programs and services prior to acquiring MS. These experiences were generally described as "pretty routine." The fact that participants accessed programs and services throughout their lives is noteworthy in that it emphasizes the universality of the human experience and our interdependence throughout our lives. It also highlights the irony of it

becoming more difficult to access supports when, arguably, one needs them most.

Organizational Involvement

The participants in this study indicated that they did not consider involvement with either the MSSC or the MLPD, (beyond relatively cursory information requests), until their 'disease process' or 'disability' became visible and permanent, which correlated with their beginning to see themselves as disabled. They indicated that while they perceived the local disability advocacy organization as having some limited global impact on them, they perceived it as having had little or no relevancy to their lives personally. This judgment was based on very little knowledge of the organization. The one participant who had briefly become involved on an MLPD committee expressed considerable frustration with the organization's perceived inaction on issues of concern to her. Several participants indicated they weren't interested in 'class advocacy' enough to get involved with the MLPD, although several of these same participants were or had been involved with class advocacy through the MSSC.

Interestingly, the participant who had been politicized into the women's movement prior to her diagnosis chose to focus her advocacy interests within the MSSC rather than within the DRM. She indicated she only became aware of the activities of the DRM after getting involved with the MSSC. She did not see a connection between her political awareness in the context of leftist feminist politics and with a political awareness in a disability context. Nor did she see any inherent conflict between the fundamental model of the MSSC and her previous

involvement in identity politics. Clearly, this highlights some significant deficits in awareness of the role and purpose of the DRM and the role of the MLPD, the local disability rights organization.

The fact that several participants involved themselves in advocacy through the MSSC rather than through the MLPD suggests that the issue is not one of lack of interest nor of a perceived lack of relevance in disability rights advocacy in general (as suggested by some participants), but more a matter of lack of identification with a cross disability organization. This bears further investigation.

The MSSC seems to play a significant and valued role in the lives of most of the participants. Most of the benefits noted were of an informational and intra-personal nature (e.g. self-help groups and programs such as 'Journey to Wellness'). The major issues raised in relation to the MSSC had to do with a perceived conflict of interest related to its fundraising role for bio-medical research, its support for quality-of-life issues, and a lack of rapport or identification with staff. Several participants pointed to a direct conflict between the two goals of the organization, specifically noting that the quality-of-life objective of the organization seemed to take a back seat to the fundraising for bio-medical research. As none of the participants anticipated a cure in their lifetime, nor were actively seeking treatment, this priority had little relevance in their lives. One participant particularly noted how "hard" it was for her attending MS conferences where the focus was solely on research and treatment options. It may be an erroneous assumption that this is what people with MS want the focus to be at these conferences.

The participants indicated they received the most help from other people with MS connected with the organization (non-staff), as opposed to the MSSC staff. This fact was attributed to the lack of people with MS on staff (although in fact some staff members may have invisible symptoms/impairments) and/or the staff's demonstrated lack of awareness of their needs as people with MS. Given this finding, the MS Society could move more actively towards being a consumer directed organization and put greater emphasis on the quality-of-life goal of the organization in order to enhance the organization's relevancy to their clients/members.

CHAPTER FOUR - IMPLICATIONS

Social Work

Given the foundation of our profession in the "Charity Organizations," and Mary Richmond's medical-model framework for casework of the late 19th - early 20th century (Heinonen & Spearman, 2001) Social Workers must understand the dissonance producing effects of 'normalization' and the impact of disability support programs and services based in the functional / limitation model on the identity development process. Understanding and supporting the need for control, problem solving and decision-making in the lives of people with chronic illnesses and disabilities is extremely important in maintaining a positive sense of self. The role of developing a collective identity in the context of community is also a vital factor for social work, as is supported by Disability Studies and the Population Health literature.

An interdisciplinary connection between Disability Studies and Social Work is reinforced by Ernest Boyer's report "Scholarship Reconsidered" (cited in Fuchs, 2000). Boyer's report is a call to rebalance four equally important aspects of scholarship: discovery (research), integration, application and teaching. This approach has been integrated into the central characteristics of the soon to be implemented Master's In Disability Studies Program at the University of Manitoba (Fuchs, 2000).

Disability Studies

The feminist disability discourse presents a very strong argument for joining disciplinary approaches in the evolution of the social model of disability. I suggest we explore a "social model of disability, feminism and social well being" incorporating not only feminist discourse, but also Population Health and the Social Well-being proposal of the Roeher Institute. Combining the minoritizing approach, via the minority group model and feminist standpoint theory with a universalizing model such as Sedgwick proposes may lead towards the development of a model with which more people with chronic illnesses can identify. Acknowledgement and accommodation of difference is vital, but a collective societal commitment to equality is also necessary (Watson, 1994).

What follows is a discussion of some issues that have come up in the course of this study:

- 1) Given the dynamic within Feminist Disability discourse of "conflicting and always complex dual aims of politicizing the materiality of bodies while rewriting the category of woman," are these not exactly the kinds of inquiries

being addressed in the questions regarding a more inclusive social model of disability, the material reality of the body with disability in environment, and the rewriting of the category of 'impairment'? In the hypothetical fully accessible environment, are we not still impaired and does that not still have meaning and inform who we are? The lived experiences of disability and chronic illness do not seem to be as interchangeable as the literature has historically noted and as policies, such as the ADA in the USA would suggests. Nor is the lived experience of illness/ impairment and disability as mutually exclusive as the social model suggests.

2) What should be considered a "positive" post-diagnosis identity with a chronic illness such as MS? The need for control in problem solving and decision-making in the lives of people with chronic illnesses/ disabilities seems key in maintaining a positive sense of self. From a social-political paradigm, a positive disability identity is described as finding value in the characteristic that makes your body different, and a positive collective disability identity is connecting with others on the basis of that difference. The development of Disability Pride and a disability culture are examples of such positive identities. When it comes to chronic illness however, it becomes somewhat more difficult to imagine someone saying "Say it long and loud, I have MS and I'm Proud!" ... Or does it? Wendell (2001) raises the possibility that there may be some redeeming virtue or value in acquiring a sometimes devastating illness such as multiple sclerosis. This idea bears further study, and may relate directly to a revised

definition of “health” and what it means to be “healthy,” congruent with a population health and social well-being paradigm.

None of the participants in this study identified any aspect of their illness or disability in a positive light, but some did refer to positive experiences related to their disability / illness experience, such as identifying previously stigmatized equipment, (e.g., walker or wheelchair), as sources of freedom rather than sources of stigma. Others simply found taking control of their lives, focusing on problem solving and doing whatever they can, however they can, positive and self-affirming experiences in and of themselves, and took a fairly neutral stance towards the illness itself.

The Disability Rights Movement

It is clear that even between oppressed groups we are subject to the influence of the societal values of sameness and deviance. Ultimately, we need an understanding of disability that does not support a paradigm of humanity as young, healthy, white, middle class, male, and heterosexual.

Class advocacy initiatives at the MSSC are a relatively new development, having emerged over the last decade. Comparatively speaking, a very small percentage of the organization’s resources are devoted to these activities (approximately 5% compared to 77.5 % to research, MS Clinics and services according to the MS Society of Canada, annual report, 1994). The focus of the class advocacy work at the MSSC in the first few years of the program, tended to prioritize funding access to new drug treatments and treatment therapies. The focus has since become more disability policy access based. People with

disabilities who have been politicized into the disability rights movement are adamantly opposed to many bio-medical developments because of the eugenicist basis of the technologies and their real and potential discriminatory consequences.

One of the reasons for the rise in patient's rights groups may be that people who identify as ill do not see themselves reflected in the DRM, nor are they satisfied with the amount of control they can exert within disease-specific voluntary health agencies. Another reason for this proliferation may be that a number of pharmaceutical companies have been instrumental in the development of patients' networks such as "The Canadian MS Network," sponsored by Teva Marion Partners².

Both the MSSC and the MLPD have noted concerns regarding their low membership numbers. Without a full understanding of the influences and variables that affect the movement of people with chronic illnesses and disabilities towards the disability community as a culturally appropriate response, a strategy to support this cannot be crafted.

Weeber (2000) contends that having an awareness of/ embracing disability "identity politics" is of great importance in the initial steps towards developing a personal disability identity. A positive identification with the disability community, whatever shape that takes, has been shown to be the starting point of personal transformation for individual disabled people. Weeber's next point leads toward the possible reason why people with chronic illnesses do

² Teva Marion Partners are Teva Pharmaceutical Industries Ltd. and Hoechst Marion Roussel Pharmaceutical Industries Ltd.

not identify with disability identity politics. She states that “the very concept of disability as a collective minority reality, versus an individual medical problem, allows disabled people to begin to understand the effects of medical oppression in their lives and enables them to begin to “decolonize” their minds and bodies of the domination of that worldview (hooks, 1989).” Although I concur with her reference to “medical oppression,” there are many of us who cannot separate ourselves from that system. Until such time as the social-political model of disability can be modified to a *social-political model of disability, feminism and well being*, people with chronic illnesses are unlikely to identify in large numbers with the disability rights movement. As chronic illness affects more women than men, a higher percentage of this alienated group will be women (Crow, 1996; Wendell, 2001).

It seems that disabled people must first radically shift paradigms to see their own struggles as of equal value with those of other minority groups before they can begin to develop a critical consciousness that will shape their own identity development and struggle for liberation. The political elements of this identity-development process are ongoing, as the public struggle for civil rights continues to be intricately linked to individual intra-personal liberation. A strategic process to nurture such identity development will need to be developed by the disability community, in much the same way as the First Nations and Aboriginal community has taken up the task in order to educate and nurture the development of both individual and community identities. Such an education

agenda can only emerge from a research foundation built on the community's knowledge of its own needs.

Disability Policy Development

It was found that resolving the cognitive dissonance involved in applying for disability supports (based in the functional/limitation paradigm) takes a considerable toll on the self-concept of participants. Participants reported a sense of 'attack' on their self-concepts in their interactions with this disability support system. In requiring the acceptance of restrictive labels, this system also demands that the participants withdraw from anything that suggests that the individual can participate actively in society or exert control over their own lives. This dilemma is clearly illustrated by the participant who went to considerable lengths to be "proactive" in preparation for the disabling effects of MS, and her concomitant struggle to feel justified in applying for various supports, despite her need.

Restrictive definitions, needs testing and the requirement to exhaust all other resources before being considered eligible for services also reflects the Hobbesian/ Benthamist belief that positive functions of the state should be kept to the barest minimum to ensure that 'unfettered capitalism' is not diminished by support transfers, characterized as disincentives to work (Macpherson, 1973; Nagase, 1995). Disability Studies literature tends to refer to the fragmentation of programming and ties of supports to income programs as 'disincentives' to employment as well (Albrecht, 1992; Hahn, 1993). The findings of this study indicate that the implications of functional/ limitation and Hobbesian-inspired

disability policy go beyond disincentives to employment to undermining the self-concept of participants.

Policy based in a social political, feminist and well being paradigm

The lived experiences of the participants clearly indicate that forced acceptance of restrictive labels marginalizes and stigmatizes them, and is counterproductive to social participation. If societal agreement can be reached that the goal of disability policy must change from one of 'normalization/employability' to one of diverse social participation, then development of a policy tool to test existing and new policies based on restrictiveness vs. inclusiveness and enabling components vs. disabling components could be valuable in making incremental policy changes. By moving towards a universalizing social model of disability, feminism, and well-being, we could evaluate policies on how effectively they facilitate social and economic well-being, environmental sustainability and security for all Canadians. Recognizing the problem as societally- rather than individually-based is the first and vital step (Batavia, 1993; Hahn, 1993; Watson, 1993; Zola, 1993b).

Implications for Further Research

As Weeber (2001) emphasizes, the work that must be done now is to develop a knowledge base that truly reflects the disability identity development process. Without the knowledge of how that process actually unfolds, effective strategies cannot be developed to nurture its development. Weeber contends that it is embracing and celebrating one's unique way of being-in-the-world that makes it possible to experience unity with others. And it is in understanding how

this particular diverse population comes to that place of embracing and celebrating its uniqueness that it will be possible to nurture its capacity to embrace and celebrate its commonality with all humanity.

The investigation of some combination of the social political model of disability and the population health approach may allow for the incorporation of health policy into the disability policy environment without risking a re-medicalization of disability. This in turn may encourage more people with chronic illnesses to get involved in the DRM and thus create greater collective identification for people with chronic illnesses within the DRM.

Discarding the archaic definition of health as “the absence of disease or injury” and expanding it to mean “social well being” is a very important step. The “Social Well Being Framework” proposed by the Roeher Institute (1993) may be an avenue to explore in concert with the Population Health and Social Model. The “Social Well Being Framework” is described as addressing the needs for interdependence and coordination between social, economic and environmental policy through elements entitled Security, Citizenship and Democracy. This approach coincides with the ‘universalizing’ view of difference put forward by Eve Sedwick. Much as feminist standpoint theory allows for the recognition of difference within feminism, analysis of these frameworks in the context of disability and chronic illness may result in a more universalized model while still recognizing the unique lived experiences of diverse community members.

With regard to future clinical social work applications, it would also be interesting to find out which, if any, of the participants received social work

intervention when they were diagnosed and thereafter. Information about what therapeutic interventions and strategic approaches were used and the participant's perception of how those interventions influenced them would be useful towards developing more effective strategies based in a social-political paradigm of disability, feminism and well-being. Strengths-based (Saleeby, 1992) and structural social work theories (Mullaly, 1997) may be particularly applicable within this context.

Participants noted a lack of rapport with staff that did not relate personally to disability or chronic illness. The role of personal experience with disability as a mechanism to inform professional practice and foster rapport with clients with disabilities is a matter which merits further investigation.

Participant's prior experience with disability and illness clearly impacted their present concepts of disability and illness. It would be interesting to further explore, how people with disabilities and illnesses perceive their pre-disability/illness experiences from their present perspective. Asking "If you knew then what you know now, how do you think the experience might have been different?" may lead to information that could help develop effective education campaigns.

Self Reflections on Results and Implications

"How close should a researcher be to a research topic before they are too close?" is a question for further discussion. I was aware that I related to many of the identity struggles of the participants, in some ways more so. I have so internalized the concept of normalization (having grown up with it) that I was not

aware of the extent to which I am still influenced by it. From this process I have learned the vital importance of self-interviews and debriefing to ensure a high level of self-awareness throughout a research project one feels quite close to.

In developing the ethics protocol, I ensured the incorporation of a safety net for the participants in the event the subject matter triggered issues for them. By sharing a list of counseling resources with participants, I prepared for that possibility. Unfortunately, I didn't adequately prepare for the possibility that I myself might be triggered by the subject matter. This seems to be an "occupational hazard" of "researching from where you are." Despite close to 20 years of membership in the disability rights movement, I found that the closer I got to this work, the louder my personal "cognitive-dissonance" became as I fluctuated between seeing myself as able-bodied, disabled or chronically ill. In speculating about why I hadn't yet resolved this dilemma, I wonder if it may have been because I always felt on the 'fringe' of the movement, never sure if I represented a legitimate member. I also realized that my attempt to create distance from my research subject by choosing a disease context different from my own did not, in-fact, make much difference at all. In this context, 'disease' is an artificial medicalized notion of difference. The personal and social impact of the disease of MS had enough similarities with my own experience, I found I did not have the emotional distance I thought I would.

The primary difference between my own experience of the issues and that of the participants is that I have lived my entire life in the "gray area" between illness, disability and relative "normality," whereas these participants began to

address these issues from the perspective of people with disabilities/ chronic illness as adults. I believe this is a significant difference, and it was important for me to be aware that my perceptions on certain issues might be different than the participants'. In fact, I believe I was more deeply impacted by some issues than the participants, particularly issues related to "invisible symptoms /impairments." This caused serious delays as I found I was often re-triggered on different levels when I returned to the work. During this period I re-negotiated time lines, to the best of my ability, with a number of systems I was connected with:

- 1) the advisory committee,
- 2) my thesis advisor and committee,
- 3) the institutional structures I was working within, including the university graduate studies time frames and
- 4) the time frame identified by the granting agency I received funding from (as I received a small grant to work on the project from the Canadian Centre on Disability Studies).

Although I am sure that frustration was also experienced on the part of all of these systems, they were all remarkably accommodating, particularly my thesis advisor. In retrospect, I wish I had been able to recognize my need for flexibility and broader time frames before the fact, as I would have been able to communicate those needs better. In the end, this has been a profound learning experience for me, in every sense of the word. In future, when embarking on work to which I feel very close, I will better know to prepare both those connected

with the work and myself for the possibility of personal triggers. This has also been an empowering experience for me, in many ways.

Reflections on the Research Process

I posed questions similar to those Barton (1994) asked:

1. What right have I to undertake this work?

As a person living the experience of disability from several perspectives – a person with relatively invisible symptoms/impairments, a person with a quasi-chronic illness (albeit diagnosis and prognosis unclear), and a person who has been a member of the DRM and worked within a DSVHA, I believe I have a right to undertake this work, as long as I place myself within the work in an unbiased manner, recognizing that my experience is not necessarily the same as others.'

2. What responsibilities arise from the privileges I have as a result of my social position?

As a Masters in Social Work female student from a White middle class family with mild to moderate disability, I recognized that I had opportunities and privileges not afforded some of my participants. I recognized the need to accommodate whatever needs arose, such as any financial expenses they might incur, any equipment they might need in order to participate, travel costs, etc. Pacing and flexibility needed to be incorporated into the process. I also emphasized as much as possible that although confidentiality was paramount, this was a shared project. Even though, as the primary researcher, I was a major stakeholder in that I was completing this study as an aspect of my degree

process, it was important that participants felt that their input was what the research hinged on and that their guidance would direct the project.

3. *How can I use my knowledge and skills to challenge the forms of oppression disabled people and people with chronic illnesses experience and thereby help to empower them?*

By using a participatory methodology based on principles of empowerment, I hope to raise the awareness of the participants in terms of where they place themselves in relation to the social model of disability and chronic illness. It is my hope that through the completion of the project, the final report can act as a basis for further research, advocacy and policy development. I plan, with the guidance of the advisory committee, to develop dissemination strategies that will ensure the report is a living document, rather than just another report.

4. *Does my writing and speaking reproduce a system of domination or challenge that system?*

By returning to the participants and asking this question and making revisions based on their feedback, I will ensure the report does not reproduce a system of domination but challenges that system. Findings from the report may also challenge the systems presently in place at the MSSC and the MLPD to look at how responsive they are to their target membership.

5. *Have I shown respect to the people I have worked with?*

I did have concerns regarding the perception of the delays I experienced in the research process due to my own disability related issues. I do not believe the participants experienced the delays in the research process as lack of respect. I

was concerned about the impression the delays left with the funding agency and my thesis committee as well. In retrospect, better communication would have been helpful. I believe I was still working through issues of cognitive dissonance with respect to feeling the need to normalize and conceal as much as possible.

Throughout both my own process and the research process I maintained a journal as a way of identifying and reflecting on my own experience and understanding of the issues, vis-à-vis the process and content of the research process. I particularly found the iterative use of Griemas' Semiotic Square with constant comparative analysis an excellent way of keeping myself both grounded in the participant's experiences and reflecting on and challenging both the literature and my own experience base. For these reasons, it seems like a very appropriate methodology for use within a social political model of disability.

Reflections on substantive issues arising in literature review.

The prevalence of focus on visible, permanent disability within the social model of disability discourse was very apparent (Hahn, 1985) and reflected my experience within the disability rights movement. In reading articles related to identity development, I saw myself reflected quite vividly, particularly in the Anspach (1979) article. This is clearly a seminal article in disability studies discourse, considering how often it was cited in other work. Even though Anspach did not discuss identity management issues of "passing," the very dismissal of the subject by way of a minor footnote emphasized the "invisibility" I felt within the DRM as well as in society in general. Conversely, the role of identity politics in providing some sense of community was also reflected in the

literature on the social model of disability. The medical model literature review triggered memories of my own sense of being medicalized, problematized and identified as a 'disease.' I had spent so many years concealing that I had repressed the memories very successfully, and was surprised at the virulence with which they resurfaced.

One question I grappled with while reading the material was whether membership in the disability community was mandatory for the development of a positive identity vis-à-vis disability and illness. Through the processes I have gone through doing this research and the therapeutic approaches I involved myself in, I believe I have come out the "other end" with what I would describe as a positive disability identity. I recognize that my unique experiences both within my body and through interaction with society have significantly informed who I am and I am very glad to be who I am today. If offered the opportunity to be 'cured' I would not take it. I like who I am, and who I am is important as I am. This is an awareness I did not develop while involved in the DRM, though I perceived it in others. I believe this was because I did not personally identify with others in the movement beyond the sense of shared alienation, as reflected in the literature.

The feminist disability discourse came the closest to reflecting my experience, particularly Driedger (1999), Wendell (1996, 2002), and Crow (1996). They all articulated the importance of the impact of impairment on the disability experience. I found it difficult again, however, as I don't identify all that closely with chronic illness either, since my experience with it was characterized more by

the sense of 'malingering' mentioned by one of the participants in relation to disability. I didn't feel sick, so why did I spend so much time in the hospital under investigation for having a disease? Sometimes I do feel sick, perhaps more than the average person does, but so does my neighbour with high cholesterol and low iron. And yet she is not identified as having a 'disease.'

Reflections on substantive issues arising in data analysis

Surprisingly for myself, as someone who has spent a lot of my life grappling with these issues, all participants indicated that these were not something they had put a lot of thought into prior to this study. This is possibly due to their development of disability in adulthood and my disability being from childhood.

The pre-MS experiences which the participants related were interesting in that I realized at this point how different our lifetime experience of disability was. As children, they could have been some of the people who made me feel "less than," "the problem" and "not trying hard enough." One of the participants had even been a nurse, and I remembered some very uncomfortable experiences with nurses. This was jarring, as in the present day context I see them as more oppressed than myself. This was an interesting 'turnabout', which led me to wish I had asked them how their current experience informs their memories of past experiences before MS.

The current issues the participants struggled with related more directly to their interaction with the disability support systems and the labels imposed on them. I found I related to a degree, as during the research project I had similar

experiences applying for income support after taking medical leave from the MS Society. As well, as a child and adolescent, I experienced the exclusion and lack of accommodation some of them referred to, although surprisingly the participants did not raise this much, referring to needing to adapt and accept things they cannot do. Initially, I found it difficult to understand why the participants with invisible symptoms impairments felt they were just 'inconveniences' and 'nuisances', when later they stated that policy definitions should include such impairments as disabilities.

Reflections on issues arising in Discussion

"We are spiritual beings learning to be human"

So the question remains, What is a positive identity post MS? Is chronic illness an 'illness' or a 'disability'? Does it really matter? Is either the ultimate evil? Is it only acute illness? Can some redeeming virtues be drawn from the experience, as disability activists insist there are in disability? As Wendell notes, many people who are or have been ill testify that it has changed them for the better.

In synthesizing the information from the literature review and the participants' responses, it seems to me that at the core of this study is the essential question - fundamental to today's technological society – *what does it mean to be human?* Our society today is profoundly technological and body-focused and becoming more so. The definition of the "ideal norm" seems to be in the hands of the media, and anyone who deviates from that norm is strongly encouraged to change. To mainstream ways of thinking, it is a novel, almost

preposterous idea that someone with a disability may actually enjoy life. It is even a novel idea that someone who is overweight may enjoy life, just as they are. In this climate, we face biotechnologies that will eliminate disability in the womb, clone the 'ideal people' and identify the 'deviants'. It is a very frightening time to be 'non-perfect,' never mind disabled.

CONCLUSIONS

In a society where 'normal' is defined as a White, heterosexual, young, able-bodied, middle class and male, deviance is rather hard to avoid. Eugenically based advances in biotechnology reinforce this standard and underwrite the medical/ functional/limitation model and normalization goal of rehabilitation by creating an undercurrent of fear about being the "other." In such a highly charged 'perfect' body conscious social political climate, people with chronic illnesses and disabilities, the majority of whom are women, are strongly influenced to deny, conceal, minimize and normalize their self-identity. It is hardly surprising, then, that this study's findings indicate that even where a critical awareness of social political concepts of disability and the existence of a disability rights movement are known a disability identity is still viewed as a very negative thing. Despite the Disability Rights Movements' 30 years of work to create a subculture to counter society's negative view of disability, people with chronic illnesses interviewed in this study are not seeing the relevance of the movement to their lives.

Even so, a picture of a dynamic interactive identity-development process is emerging to counter the traditional view of people with chronic illnesses and disabilities on a one-way street of passively receiving social stigmatization. For these participants with MS, it would be inaccurate to describe that identity as a disability identity. These participants struggle daily to fight pressures to accept labels they feel do not fit their positive though fluid and layered self-identities.

They choose rather to simply get on with the act of living, problem solving and proactively preparing for the uncertainty that is MS. Dealing with the stressors inherent in the lack of control, hurdles and labels of the present disability support system are obstacles to get around in order to get what they need.

A clearer, more accurate picture of disability and chronic illness identity processes will be gained through recognition of the interaction between intra-personal identity development and social-political identity influences. Intra-personal identity development is strongly influenced by past experience viewing chronic illness and disability through the filter of an able-bodied person, and by present involvement with the medical system. Stability vs. exacerbation, visibility vs. invisibility, permanence vs. fugacity of symptoms are key dimensions impacting self-identity. Social-political identity influences include interaction with a functional/limitation based disability support system, which forces cognitive dissonance through restrictive definitions of disability. Disease-specific volunteer health agencies which send mixed messages regarding the devastation of disease and quality of life with disease by conflating "pity" and "the need for a cure" with "enabling people to live life fully" could also promote dissonance affects among their members. Disability rights organizations that do not take strong action on issues nor expressly indicate acceptance and accommodation of chronic illness issues, particularly those with invisible disabilities may not be viewed as relevant to the lives of many with chronic illnesses – who, again, are primarily women.

Thus to build a bridge between these realities, it would seem there is a need to explore a more universalizing social-political model of disability, one that would embrace feminist disability discourse and population health/well-being theories. Through interdisciplinary cooperation incorporating Boyer's call to rebalance four equally important aspects of scholarship – discovery (research), integration, application and teaching - the social-political model of disability can continue to evolve, embracing more universal identities, while still honouring individual standpoints.

The issues of disability and chronic illness provide an opportunity to raise serious questions about the nature of our present society and the kind of society we desire or hope for (Barton, 1994). Macpherson contends that our society is based on the proposition that the purpose of Mankind is to use and develop our uniquely human attributes enabling us to make the best of ourselves (1973). By addressing the need for a more inclusive social model of disability, feminism and social-well being, we may expand our societal concept of 'normal,' providing society as a whole with answers to the questions, "What are our 'uniquely human attributes?'" and "When is a life not valuable, if ever?" With the remarkable advancements taking place in biotechnology and eugenically based pressures to eliminate defects and deviants, these are questions not just for a minority, but for all of us.

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APPENDICES

Research Advisory committee members:

People with MS:

Roger Laurencelle; Carole Miles Redwin, Ph.D. (OT/PT/Community Health Sciences); Sharon Segal, MA (History); Sandy Popham, BN/PHN.

Partnering Organizations:

MS Society:

Sharon Segal, Social Action Coordinator

Manitoba League of People with Disabilities:

Carol Polson, Provincial Coordinator.

Consent Form

Dear potential participant:

My name is Catherine McGowan and I am a Masters in Social Work student at the University of Manitoba. Towards the completion of my degree, I am undertaking a research project in partnership with the Manitoba League of Persons with Disabilities and the MS Society of Canada, Manitoba Division. I am exploring how our view of ourselves is affected by accessing (or trying to access) programs, services and organizations after a diagnosis of multiple sclerosis. Although I do not have MS, I have struggled with similar issues, which is why I am interested in finding out from you how you identify yourself today, based on these experiences, versus how you identified yourself before your diagnosis. This research will help to determine how supportive and inclusive a social political climate people with disabilities and people with chronic illness are in today.

I would like to ask for your consent to participate in this research project by allowing me to interview you. I would like to hear your story in your own words. The interview is likely to be at least one hour in length and can be done in two sessions if necessary. There may be a follow up interview to clarify themes that are developing. The interviews will be taped and transcribed, and can be conducted wherever you are most comfortable. I will ensure your confidentiality to the greatest extent possible by changing all identifying information in the transcript and the final report. If you choose to, you will have the opportunity to read the transcript of your interview and the final report draft to

ensure you are comfortable with the confidentiality and accuracy of your story.

The interview will be taped, but only my thesis advisor and myself will have access to the tape. The tape and the transcript will be destroyed upon completion of the research project. Despite these efforts towards confidentiality, it is possible that identification may occur due to the small disability community in Winnipeg. As well, I am bound by legal obligations to report disclosures which involve breaking the law, such as child or domestic abuse.

Your decision to participate or not participate will in no way affect your ability to access services or participate with either the MS Society or the Manitoba League of Persons with Disabilities. I am on Leave of Absence from the MS Society. As such, I am no longer an active employee. I am also on leave from the Council of the Manitoba League of Person's with Disabilities, and therefore am no longer an active Council member. Only information shared during this interview will be incorporated into this research project.

If the interview stirs up issues for you that you would like to address through counseling, I will have a list of resources available at the interview. This study has been approved by the Joint-Faculty Research Ethics Board, University of Manitoba. Any complaints or concerns regarding a procedure may be reported to the Human Ethics Secretariat :

If you have any further questions you can contact myself at and/or my thesis advisor, Don Fuchs, Dean of Social Work

Sincerely,

Catherine McGowan, BA/BSW

My signature here indicates I have read and understand the research project objectives and expectations. I consent to being interviewed for this project and I understand that my confidentiality will be assured to the best of the researcher's ability. I understand I will have the opportunity to read the transcript and report drafts to ensure my comfort level with how my identifying information has been disguised and that the accuracy has been maintained.

Semi -structured interview questions:

“What does it mean to you to be disabled? To be chronically ill?”

“What do you see as the difference between being disabled and being chronically ill?”

“If asked whether you are disabled or chronically ill, what would you be more inclined to say? Why? Has this changed since your diagnosis? Why?”

“Thinking back to before you were diagnosed, what were your perceptions of chronic illness and disability? Have they changed since then? Can you talk about that?”

“Please tell me about some of your experiences since your diagnosis with MS in accessing any technical aid, service, organization or government program where your eligibility was an issue or where you weren’t satisfied with the result,

Probing questions: If you were not satisfied, what recourse did you have? Have you had any difficulty access or receiving the needed services? Have these experiences changed over the years? If so, could you describe when and why? How did these experiences make you feel?

“Do you think these experiences impacted on how you felt about yourself?
Did you feel they impacted how others felt about you? In what ways”

“Do you think these experiences impacted on how you identify/ied yourself? If so
how?”

"How do these experiences compare to accessing any programs or services
before you were diagnosed?"

Probing question: did you have to deal with issues re: eligibility? How were
they the same? Different? Where you usually satisfied with the results? If not
what recourse did you have?

MLPD is a consumer driven advocacy organization by and for people with
disabilities. The constitution of the MLPD stipulates that people who self identify
as having a disability direct the organization and what it does. The MS Society of
Manitoba is a traditional charity based disease specific voluntary health agency
whose mandate is “finding a cure for MS and enabling people with MS to
enhance their quality of life”. The constitution of the MS Society does not
mention a need for people with MS to be directly involved in directing the
organization and what it does.

“Are you familiar with the Manitoba League of Persons with Disabilities? If so, can you describe your relationship with that organization? If you are familiar but not involved in any way, why did you choose not to get involved? Is there anything preventing you from getting involved with this organization?”

“Are you familiar with the Multiple Sclerosis Society of Canada, Manitoba Division? If so, can you describe your relationship with that organization? If you are familiar but not involved in any way, why did you choose not to get involved? Is there anything preventing you from getting involved with this organization?”

“So that I can get a demographic profile of my participants, I would like to ask you the following questions. Again, this information will only be used in the aggregate. All identifying information will be disguised in the final report:

Are you in the paid labour force?

If not, were you ever?

When did you leave it?

What profession or job are/were you in?

What is your present source of income?

What is your age?

Marital status?

Ancestry?

Do you have children?

How many?

When were you diagnosed?

Do you know what type of MS you

have?

Example of the use of Greimas' Semiotic Square

Binary category dilemma: The transcripts note a primarily negative view of disability, but positive identity development post MS still seems to be occurring. The literature from disability studies on identity politics suggests a positive identity needs to view disability as a positive thing in ones life.

<u>Starting position</u>	<u>It's contrary</u>
Positive identity development post MS means viewing disability as a positive thing ('identity politics'/social model view).	Positive identity post MS means viewing disability as a negative thing ('normalization' view).
<u>It's implication (neither 1 nor 2)</u>	<u>It's contradiction (both 1 and 2)</u>
Positive identity development post MS involves dimensions other than how disability is viewed.	Positive and negative views of disability are both aspects of positive identity development post MS.

Through this process, the possibility of other significant dimensions is raised impacting on the development of a 'positive identity' with disability and illness, as opposed to strictly a positive *disability or chronic illness* identity.

Example of Coding Memos

Coding memo	Transcript quote
<p>Self Identity Post MS is fluid and layered</p> <p>- depends on visibility and current needs</p>	<p>Participant 3: "When I was first diagnosed I thought I was disabled. But over time it was, you're not disabled any longer, you're chronically ill." (line 84)</p> <p>Participant 4: "They [terms disability and chronically ill] both apply part of the time but neither apply fully all of the time." ((line 48)</p> <p>Participant 4: "When things are going well, I don't remember I am disabled...I don't remember that I am ill."(line 39)</p> <p>Participant 1: "I don't have an identity, I haven't made an identity out of it. It's more like a condition that affects me sometimes." (line 53)</p>
<p>Preference to view self as chronically ill over disabled</p> <p>- prior experience of disability before diagnosis.</p>	<p>Participant 2: "You might have the illness, but you might still be able to do things. I would refer to myself as 'chronically ill' before disabled." (line 92)</p> <p>Participant 1: "...I was not thinking of myself as disabled. I thought of myself as healing." (line 228)</p> <p>"I don't think of myself as disabled" "I always speak of having a chronic illness (line 7 – 13)</p> <p>Participant 3:" I'd say I was chronically ill. That's how I was brought up."(line 63)</p> <p>Participant 3:"When I was a kid, my dad's friend's son was disabled, but we just laughed at him..."(line 109)</p> <p>Participant 2:"Prior to my diagnosis, I never thought about disability or chronic illness. In my country, disability was a shame..." (line 108)</p>