The Social Organization of Power in the Academy's Disability Policy:
Chronic Illness. Academic Accommodation and "Equity"

by

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTER OF ARTS

in the Department of Sociology and
Contemporary Social and Political Thought

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University of Victoria

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Abstract

Using an institutional ethnographic approach. I explore the everyday experience of women students who are disabled by chronic illness in order to discover how disability policies – which aim at improving accessibility and providing academic accommodation for disabled students – accomplish their purposes. Starting from women student's own accounts of their experiences. and tracing the practices of policy implementation, I analyse and explicate the social relations that structure the university's disability policy for accommodating disabled students. Normally understood as the university acting "in the interests of students with disabilities", I show that the disability policy intends an institutional course of action that accomplishes, accountably, the university's legal obligation not to discriminate against students with disabilities. I argue. however. that as students claim disability in order to gain access to needed assistance and services. they also become subjected to institutional processes that may (dis)organize their future student and graduate careers.

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Acknowledgements

My decision to return to university, after a fifteen year absence, was accompanied by considerable concern that I wouldn't be able to keep up with my younger, more energetic, peers. It is ironic, perhaps, that my most difficult course was also the most rewarding. In that first term, it was my good fortune to have taken a "Current Issues in Psychology" course with Charles Tolman. I may have struggled, but I was seduced by my introduction to social theory and philosophy, and I was inspired by Charles' depth of knowledge and his sense of social justice. Without his encouragement and support, I would never have considered the graduate course of study that has given me so much satisfaction over the last three years.

I am also grateful for the contributions made by each member of my thesis committee. As I shifted from psychology to sociology, Bill Carroll picked up where Charles Tolman left off. Bill provided me with some of my favourite, and most challenging, graduate courses. He has always been available to assist me articulate and clarify my ideas. I have made good use of his insights and his precise and elegant use of language: where I would use a page, Bill could give me a sentence that would say it all, and say it better. I thank Dorothy Smith for being willing to be on my thesis committee. Long distances and infrequent contact notwithstanding, her genuine interest and her generous reading of my work have been invaluable. Marie Campbell has been a wonderful mentor and example. She has constantly challenged me to be a better student and has always provided me with opportunities to present my work to a wider audience.

The six women who agreed to be interviewed for this piece of work also deserve special mention. Without their willingness to share what were often very sensitive and difficult experiences, I would never have been able to develop this analysis. My regret is that I could never fully do justice to the range and varieties of their experience. I only hope that the research will be useful to them in seeing how their experiences came to unfold as they did. Finally, I want to thank my children, Trevor and Lisa Clark. During their adolescent and young adult years, they have tirelessly listened to me trying out my ideas, they have humoured me, and they have rewarded me with their wonderful company. I have been fortunate indeed.

Introduction

Living with a body that is disabled by chronic illness does not merely involve the experience of contingency, lack and limitation in ordinary everyday living, it also inaugurates a stigmatized identity and consignment to a category of people in society that are typically excluded, marginalized, and discriminated against. Traditionally, the negative personal, social and economic consequences that follow from disability are attributed to the individual's impaired body which is then "treated" or "managed" by the professional practices of medicine, rehabilitation, nursing, social work, adjustment psychology, occupational therapy, and so on. More recently, disability rights activists have argued that the individualistic biomedical approach to disability is not only limited and ineffectual, it is also implicated in the oppression and discrimination experienced by disabled and chronically ill people (Lane 1998; Linton 1998; Lupton 1997; Oliver 1992; Williams 1998; Winzer 1998).

Instead, people with disabilities have argued for a more social model of disability; one which shifts the obligation for change from the body and activities of the person with a disability to the built environment and social arrangements which are all organized around norms of "able-bodiedness" (Barnes 1998; Davis 1998; Hales 1996; Oliver 1996; Shakespeare 1998; Swain et. al. 1993). From the perspective of the social model of disability, exclusion and marginalization are not consequences of an individual's impairment. Rather, they are the consequences of social discrimination (Barnes 1998; Davis 1998; Finkelstein 1998; Morris 1992; Oliver 1992; 1996). Likewise, disability does not refer to bodily impairments and limitations, it is the naming of the experience of oppression (Linton 1998).

This research begins from the success of the disability rights movement in having the demand for a social, rather than biomedical, model of disability constitute the basis

for "anti-discrimination" policies within the various social systems in Canada. For example. the Charter of Rights and Freedoms (1981) affords all Canadians the same protection from discrimination and the British Columbia Human Rights Act ((Section 3) 1992 amendment) provides equitable access for people with disabilities in all the systems and core services in which other members of Canadian society are entitled to participate. In our own local setting at the University of Victoria. the Policy on Providing Academic Accommodation for Students with a Disability (rev. 1997) ensures that students with disabilities are treated fairly and consistently. and are afforded genuine opportunities to access and participate in all aspects of university life.

In principle. people with disabilities – including chronically ill women – should have equal access to. and be able to participate fully in post-secondary educational opportunities. Post secondary education has been identified as an especially important social determinant of health in that it provides disabled individuals – particularly women. who are especially vulnerable to the downward mobility that accompanies the onset of chronic incurable illnesses – with opportunities to find more flexible. well-paid and professional employment. More importantly. it provides the means by which people with disabilities can eventually participate in the production of knowledge that reflects their own interests and experiences.

In this thesis. I use Smith's (1987) unique methodological approach. known as institutional ethnography. to explore how the university's disability policy is implemented in the concrete circumstances of the everyday lives of women who are disabled by chronic illness. In my analysis. I argue that while chronically ill women may depend crucially on some form of academic accommodation to remain engaged in their studies. the unfolding of the university's disability policy also subjects them to institutional processes that may (dis)organize their future graduate and career opportunities. Further. I show that even

though the policy enunciates a normative theme of social justice for people with disabilities. it intends an institutional course of action that accomplishes. accountably. the university's legal obligation not to discriminate against students with disabilities. I argue that the same rules and procedures that are integral to accountable administration and organizational decision-making. also subordinate the subjectivities of chronically ill students. and they distort the aims and goals of the disability policy as originally conceived. By illuminating how equity policies become bound up in relations of ruling. I hope to provide an analysis that is useful for chronically ill women. and for people with disabilities in general.

In Chapter One. I survey the literature and outline some of the main economic. social and personal consequences of becoming disabled and chronically ill. I also introduce the two main theoretical approaches to the problem of disability: in the more dominant biomedical model of disability. individuals are studied in their particularity. usually as objects of other's professional practices. In contrast. the social model of disability shifts attention to aspects of the built environment, social arrangements. discursive conventions. etc. that can be identified as discriminatory and that create barriers for people with disabilities. It is important to note that in spite of the influence of the disability rights movement. the established dominance of biomedical concerns and service delivery models have impeded the unqualified accedence of the social model of disability (Albrecht 1992: Lock 1998: Linton 1998). Biomedical understandings also persist because they engage directly with the experience of pain and suffering. a dimension often missing in the more political social model. I conclude Chapter One by suggesting that institutional ethnography provides a way to integrate these two areas of study — the "embodied experience" of illness and the systemic inequities that disability and illness can be seen to produce — into one project of research. I maintain that by starting with

chronically ill women's own accounts of their experiences in the academy. this type of analysis can shed light on the institutional processes and the complex of relations within which people with disabilities are embedded.

In Chapters Two and Three. I introduce Smith's sociology and the research strategy known as institutional ethnography. Chapter Two is primarily a theoretical discussion that highlights the social organization of knowledge. proposed and elaborated by Smith (1987: 1990a: 1990b: 1999). In this chapter I also introduce the academic field of inquiry that has come to be known as disability studies. Like the social organization of knowledge. this newly emerging area of study is situated within a constructivist paradigm and it problematizes the social relations of knowledge production in the academy. Scholars working within the field of disability studies focus broadly on relations of power. history. culture. literature. and aspects of discourse and meaning. Their overall aim is to place "disability in a political. social. and cultural context. that theorizes and historicizes ... disability in similarly complex ways to the way race. class and gender have been theorized" (Davis 1999:3). In this chapter. I argue that Smith's social organization of knowledge – and the research strategy that follows from it – can provide an analysis that is congruent with the overall aims of disability studies.

In Chapter Three I continue to explore many of the topics introduced in the previous chapter. but I focus specifically on institutional ethnography as a research strategy that investigates the way in which broader social, political. and economic relations organize. control and give shape to the local and particular experience. Smith's ontology of the social as "a concerting of activities that actually happens... in time and in actual local sites of people's bodily existence" (Smith 1999:97), directs the researcher's attention to the activities and routines of ordinary individuals in their everyday settings. Because their own activities are actively coordinated with, oriented to, and co-determined by the

activities of others. in multiple far-flung sites. it is possible to explicate the generalized bases of the individual's experience. including the experience of oppression.

There are two distinct directions that my own research has taken: in the first I have explored the work processes of chronically ill women as they go about obtaining a postsecondary education. In the second. I have explored the university's "disabilities apparatus" and I have problematised the notions of "accessibility" and "accommodation". These two different areas have required different data gathering techniques. The first relies on in-depth. open-ended interviews that were audio-taped and subsequently transcribed and analysed. The second involves both formal and informal interviews. textual analysis of the university's policies and regulations. and some archival research. The goal of my exploration of the university's disabilities apparatus was not to study it exhaustively. but to extend my own working knowledge of how the disability policy is implemented in the lives of chronically ill women. It is important to note that although institutional ethnography shares many of its data gathering techniques with other qualitative methods. there is a distinct difference in how the data is used. Experience is not the "object" of the research. Rather. it provides an entry point into an analysis of the social relations that penetrate and organize it.

In Chapters Four. Five and Six I present the results of my analysis. In Chapter Four I juxtapose the experiences of chronically ill women over and against the administrative regime of the university's disabilities apparatus. I also introduce and describe the Policy on Providing Accommodation for Students with a Disability (rev. 1997). By sketching in the background conditions of chronically ill women's lives alongside the objectified and institutional processes of the academy. I demonstrate the disjuncture between women's experience and the operations of the institution.

In Chapter Five. I take up the work processes and practical activities that are required of chronically ill women when they request accommodation. and I examine the way in which the university's disability policy unfolds in practice. I argue that when chronically ill students claim disability in order to gain access to needed assistance and services. they are also subjected to the broader dynamics that organize the disability policy in the first place. In my analysis I show how the policy is structured by the assumption that any modification to established practices of teaching and evaluation may inadvertently confer an unfair advantage for disabled students. This assumption. in turn. legitimates normative judgements that are particularly consequential for chronically ill students: physical symptoms that are not immediately visible may give weight to suspicions of fraud and malingering. In the process of determining whether or not a student is eligible for accommodation. I show how chronically ill students are further subjected to other diagnostic and prognostic assessments that may disorganize. or even foreclose. their future student opportunities. Finally. I argue that the individualization of accommodation according to each student's "unique needs" actually constitutes an onerous set of procedures that may be unfair. and even discriminatory for chronically ill women.

In Chapter Six. I conclude my analysis by turning my attention to the ideological procedures through which the work processes and practical activities of chronically ill students. faculty and administrative staff are all rendered accountable within the ideological schemata of the university. The work of the university's disabilities apparatus. I argue. consists mainly in articulating disabled students – in all their varieties and with all their differing "needs" – to the overall institutional function: it produces an institutional order out of the conflicts. disagreements and resistance that often characterize the work of providing accommodation.

This is not to imply that accommodation is not useful. Indeed. chronically ill women depend crucially on some form of accommodation (whether formal or informal) in order to remain engaged in their studies. Many faculty members are also deeply committed to ensuring that students with disabilities are afforded genuine opportunities to participate in university life. Some go to extraordinary lengths to encourage and support students with chronic illnesses. However. my aim in this analysis is to show how accommodation becomes a ruling activity. Despite their good intentions. both faculty and administrative staff come to know chronically ill students and what would be relevant action from within the discursive frame provided by the university's disability policy – which is part of ruling practice (Campbell 2000). By showing how apparently beneficial policies may turn out to have negative or unintended consequences. I hope to provide an opportunity for professionals. and those who are ordinarily objects of other's professional practices. to choose what kind of stance to take. what course of action to follow. and thus disorganize the "ruling project as originally conceived" (Campbell and Manicom 1995:11).

Chapter One

Of the sick body. Kleinman writes: "The fidelity of our bodies is so basic that we never think of it - it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental trust. We feel under siege: untrusting. resentful of uncertainty. lost. Life becomes a working out of sentiments that follow closely from this corporeal betrayal: confusion. shock. anger. jealousy. despair" (Kleinman 1988:44-45).

Introduction

As the grounds of our daily experience. the fidelity of our bodies appears to be an

essential precondition for venturing to the outside world to take advantage of

opportunities to extend our knowledge and skills. to contribute productively to our

communities and families. and to experience the trials and pleasures of intimacy and love.

Debilitating diseases. with the suffering and losses they entail. directly contradict the

commonsense qualifications for a productive and fulfilling life. Energy and vigour. self-

discipline and self-control. independence and autonomy. health and vitality offer the

selfsame opportunities that pain. fatigue. weakness. and dependence seem to deny. To

those who do not experience them. impairment and suffering are thought to be personal

struggles best kept private and hidden from the public everyday world. cared for in homes

and institutions. managed by charitable organisations and professionals. These are not

callous sentiments. Illness has long been thought of as an internal and private event. a

personal tragedy (Oliver 1996): one that involves a retreat from normal roles and

expectations (Parsons 1951). and recuperation, wherever possible. at home or in the safety

of a caring and insular environment (Matthews 1983). "[I]llness leaves no aspect of life

untouched" (Frank. A. 1991a: 6). Relationships. work. self-identity. goals and aspirations

are radically. and often permanently, altered (Charmaz 1999; Toombs et. al. 1996). The

consequences of chronic illnesses can be devastating; described as diseases that "ruin

rather than take life". chronic illnesses have the potential to disrupt intimate relationships.

limit or end labour force participation. and significantly diminish the life chances of the individual (Russell 1989:277). Yet. in spite of the overriding conviction that illness suspends ordinary. everyday life. illness does not detach the individual from everyday living. "Suffering and loss are not incompatible with life" (A. Frank 1991a:7) after all. and illness simply inaugurates another way of living in and experiencing the everyday world.

Living with the fundamental conditions of an ill body does not merely involve the experience of contingency. lack. and limitation in activity and role performance. it also inaugurates a stigmatized identity and consignment to a category that signifies disadvantage and oppression (Thomson 1998): those who are disabled. According to the widely used United Nations definition[1]. disability is grounded in the inability to perform personal. social or occupational activities. and it can result from genetic defects. accidents or the sequellae of chronic illness (Allbrecht 1992; Wendell 1996; Williams 1998). There is no precise or universally accepted definition of disability: defining disability is a practice of power wherein the category can be contracted or expanded in accordance with the vested interests of the definer (Albrecht 1992; Wendell 1996). For example. the definitions used to determine eligibility for income-replacement programs will differ from those employed in deciding suitability for rehabilitation or re-training and they. in turn. will be different from those that are used to decide type and amount of home support. In each case the same concept may be used. but it will be operationally defined in terms of each different professional's background and interests and in relation to the particular uses and purposes that are intended (Albrecht 1992). Disability. therefore. is not a homogeneous category. It includes people with physical. sensory and mental disabilities which may vary in terms of severity. longevity, cause and consequences. Despite the differences, however, all people with disabilities share common experiences of social,

economic and personal disadvantage that people without disabilities do not. Some of the experiences that are common for people with disabilities include discrimination. poverty. dependence and social stigma (Asch and Fine 1988: Davis 1998: Lane 1998: Shakespeare 1998: Wendell 1996).

It is important to note that people who are chronically ill often resist defining themselves as disabled. even where their limitations are evident and their losses – in terms of social and economic roles – are considerable (Gordon and Banishek 1996: Gordon and Feldman 1998: Russell 1989: Wendell 1996). The failure of people with chronic illnesses to identify with the interests of those who are visibly disabled may be due. in part. to symptoms that emerge slowly over time and disadvantages that accumulate progressively (Gadacz 1994). Alternately. this failure may signal the repression and avoidance of a stigmatized identity (Gadacz 1994). which is reinforced by the initial opposition in even disability rights groups to include people with illnesses as an "understandable desire to avoid the additional stigma of illness" (Wendell 1996:21). It is commonly accepted now. however. that people who are chronically ill are just one group of people with disabilities and. as such. they belong to one of the least advantaged groups in society.

There are reasons why. as a culture and society. we fail to acknowledge chronic illness. and there are reasons why this failure gives rise to such serious contradictions. With the exception of representations aimed at eliciting charitable contributions and apart from the occasional representation of "disabled heroes" (Hahn 1998: Hevey 1998; Wendell 1996: 1998). there is a virtual invisibility of chronically ill or disabled people in the media and other cultural representations (Kent 1988). The failure to acknowledge chronic illness is due. in part. to the cultural preoccupation with beauty. youth and health. The objectification and commodification of bodies. and women's bodies in particular. as a significant feature in consumption advertising and consumer culture (Turner 1997). do not

include the bodies of ill or disabled women. The female body. spoiled or made unacceptable by disease. forfeits visibility in a culture committed to the quest for physical perfection (Meekosha 1998). The celebration of difference stops just short of illness. which signifies lack and aversion rather than another difference to be embraced (Thomson 1998). In any case. cultural representations and advertising. fuelled by the commodity purchasing power of "the public". has had little impetus to include downwardly mobile. chronically ill women in their economic appeals (Hahn 1998: Hevey 1998).

Mirroring the neglect of chronic illness and disability in society. illness and disability are seldom. if ever. taken up in sociology[2] as problems of discrimination and oppression. or used as categories of social analysis[3] (Turner 1991): at best. disability may be simply added on in the recitation of the new "diversity agenda" that usually emphasizes other differences such as gender. race. ethnicity and class (Linton 1998: Morris 1992). Arthur Frank (1991b) argues that consignment of the sick or disabled body to a residual category. in social theory and in sociology in general. mirrors the way in which sick and disabled people are marginal and residual to society itself. People with illnesses and disabilities. as I go on to discuss below. are widely agreed by writers in academia. activist groups. policy analysis. and governmental organizations to be "a substantially numerous and substantially disadvantaged minority" (Gadacz 1994). Indeed. people with chronic diseases and disabilities are perhaps the largest disadvantaged group in Canada. with the 1991 Census showing that 15.5% of non-institutionalized Canadians reported some level of mental or physical disability due to chronic health conditions[4] (Gadacz 1994). Chronic disease conditions. which are typical of twentieth-century industrial society. are sufficiently prevalent to be described by writers in the field of medical sociology as the "new morbidity" (Russell 1989: Zola 1994). The idea that chronic illness and other disabling conditions are medical problems affecting a small proportion of the population,

therefore. is no longer sustainable (Barnes 1998). The silence in sociology about the consequences occasioned by differences grounded in chronic illness and disability. likewise. is no longer justifiable. This inquiry represents a small step towards remedying the infrequent engagement of sociology with illness and disability as problems of discrimination and oppression.

In this inquiry. I take up the everyday experiences of working age women who are chronically ill – who experience significant limitations in mobility and in role performance – as they go about accomplishing the daily activities of obtaining a post-secondary or university education. Education. which provides the means to well-paid. flexible. and more professional employment. has been identified as an especially important social determinant of health (Lippman 1998) and as a crucial component in resisting the accumulation of disadvantage and downward mobility that is common with the onset and progression of chronic. "incurable" illness[5] (Esdaile and Wilkins 1989: Lock 1998: Mithaug 1996). I am interested primarily in chronic illnesses such as rheumatoid arthritis or other arthritis-related conditions[6] which have an insidious onset. are marked by periodic remissions and exacerbations. are progressively debilitating and have uncertain outcomes (Russell 1989). Characterized by pain. fatigue. inflammation. limitation in mobility. and inability to perform the activities of daily living. these kinds of illnesses affect mainly women[7] and they are not always readily visible to and identifiable by others as disabilities.

In the remainder of this chapter. I lay the groundwork for a more thorough explanation of my research problem. First. I survey the main economic. social and personal consequences of chronic illness and disability. Next. I identify the two competing theoretical frameworks for understanding these consequences: i.e., the individualistic biomedical model of disability and the social model of disability. In each approach. I

review the relevant academic literature and discuss both their contributions to. and

limitations in. adequately reflecting the interests. aims and experiences of chronically ill

women. It is important to note that each analytic approach informs and underpins actual

professional. legal. and administrative processes and practices in the social world – i.e..

in identifying the source of the "problem" and in developing or applying "solutions" –

which. in turn. are consequential in the lives of people who are disabled or chronically ill.

I shall focus more on social measures designed to alleviate the consequences of disability.

especially as they relate to postsecondary education. My research problem. which is

situated within a constructivist paradigm – or social model of disability – aims at

exploring the "embodied experience" of chronic illness in relation to the institutional

processes and practices of the university.

Economic Consequences of Disability

All research. both scholarly and government. indicates that the socioeconomic

condition and life chances of people with disabilities are significantly worse than those of

people without disabilities (Asch and Fine 1988; Barnes 1998: Finkelstein 1998: Hahn

1998: Mithaug 1996; Osmond and Schrader 1979). In Canada. people with disabilities are

less likely to finish school. are less likely to receive a higher education, are more likely to

be unemployed. and tend. on the whole, to face serious economic hardships in their daily

lives with some of the highest rates of welfare dependency and poverty (Canada Pension

Plan Advisory Board 1994: Federal/Provincial/Territorial Ministers Responsible for

Social Services 1998: Fortin 1987; Roeher Institute 1995).

Disability pensions and social assistance benefits are always less than can be earned by

participating in the labour force. reflecting the belief that individuals must be "cajoled" or

forced into seeking and retaining employment, even where they are disabled (Jongbloed

and Crichton 1990: Wendell 1996). The actual income of people with disabilities is dependent on "whether they became disabled at work. in a car accident. had contributed to the Canada Pension Plan before becoming disabled. or are war veterans" (Jongbloed and Crichton 1990:35). The majority of people with disabilities are not eligible for these more generous income replacement programs and consequently are dependent on disability pensions that are set at the social minimum level (Jongbloed and Crichton 1990: Wendell 1996). Women with disabilities. in particular. experience even greater economic disadvantages: women with disabilities are less likely to be employed or have college educations than are disabled men: the disproportionate share of domestic responsibilities assumed by women continue to present significant barriers to labour force participation: and where women with disabilities are employed. their employment income is concentrated at the bottom of the employment income scale (Asch and Fine 1988: Federal/Provincial/Territorial Ministers Responsible for Social Services 1998: Quinn 1994).

Feminist critics argue that the culture of rehabilitation – with its focus on restoring masculine ideals of productivity and independence for war-wounded or work-injured men[8] – fails to recognize and value the unpaid labour that women perform outside the paid work force. and fails to provide quality training for competitive employment for women[9] (Quinn 1994: Russo and Jansen 1988). Disabled women who are retrained for employment tend to be channelled into traditionally female-dominated. low-status. low-wage service-sector positions. often in poor working conditions (Mudrick 1988; Russo and Jansen 1988) which. in combination with poor nutrition. inadequate medical care. and substandard living conditions. often exacerbate the existing physical condition. creating permanent disability and permanent unemployability[10] (Asch and Fine 1988). The statistics compiled by the recent Vision Paper on Disability Issues (see

Federal/Provincial/Territorial Ministers Responsible for Social Services 1998) provide
ample evidence of the "double-handicap" that women experience: on one hand. disability
due to chronic illness: on the other. gender. where women. regardless of health. are
"placed in a subordinate position with respect to economic. political. legal. and social
structures" (Sherwin 1998:2).

Social Consequences of Disability

While the income-earning opportunities of women with disabilities are severely
constrained. "[s]o too are their opportunities to be nurtured and to nurture. to be lovers
and be loved. to be mothers if they desire" (Asch and Fine 1998:241). Asch and Fine's
(1998: 1988) review of the academic literature reveals that attitudes towards both men and
women with disabilities are overwhelmingly negative. However. there are some important
differences[11] when gender is taken into account. For example. male disability tends to be
attributed to war. work injury or accident (Chubon 1994: Russo and Jansen 1988).
whereas women's disability is attributed to internal causes such as disease. Asch and Fine
(1988) argue that more negative attitudes towards women with disabilities are fostered by
the stimulation of fears about contagion. The fear that disabilities caused by disease are
more likely to be transmitted to future generations, in turn. underscores the rejection of
disabled women in "normal" roles as lovers, wives and mothers. Women with disabilities
also fail to match up to either the attractiveness or nurturance stereotypes which are
associated with women's eligibility for partnership (Asch and Fine 1998; 1988; Thomson
1998). In fact. interview and autobiographical data "corroborate the census data and the
stereotype of the disabled woman as alone" (Asch and Fine 1998:242). Although disabled
men also experience considerable apprehension about finding a mate and although
disabled men. too. experience separation and divorce. the rates for women with

disabilities are much higher (Asch and Fine 1998: Roeher Institute 1995). Disabled

women are more likely to be divorced and live alone, often heading households with

dependent children (Asch and Fine 88:16). Being alone creates problems of vulnerability

for women with disabilities: they are less likely to receive adequate medical and social

support, are more likely to encounter violence and abuse, and they are much more likely

to live in isolation and poverty (Asch and Fine 1998: Quinn 1994: Roeher Institute 1995).

Personal Consequences of Disability

Not only do disabilities lead to economic and social disadvantages, disability detracts

from the "complement of attributes felt to be ordinary and natural" for "normal" members

of society (Goffman 1963). Stigma, grounded in the social response to the dilemma of

difference – as a means of accounting for the experience of discomfort that an encounter

with someone "different" may provoke, as a way of rationalizing feelings of animosity, or

as an avenue for justifying and explaining away discriminatory behaviour – activates

stereotypes according to which "a wide range of imperfections may be imputed on the

basis of the original one" (Goffman 1963). For those who are disabled, stereotypes

foreclose the opportunity to be recognized as an individual (Coleman 1998). Instead,

people with disabilities, possessed of "spoiled" identities, must struggle to reconcile a

"special discrepancy between a virtual and actual social identity" that imputes a set of

stereotypes that are "deeply discrediting" in particular relational settings (Goffman 1963).

"Deeply discrediting" stereotypes, such as suspicions of fraud, malingering, and

unworthiness – especially in those cases where the disability is not immediately visible or

otherwise obvious – actually inform human rights law and legal decisions about eligibility

for disability insurance, social assistance, and other forms of assistance available to

people with disabilities (Bickenbach 1994), i.e., statutory protections are not intended to

cover those individuals who "fake" or "exaggerate" their limitations. It is not surprising then. as Goffman notes. that stigma arouses shame. self-doubt. self-derogation in its possessor and confers insecurity and uncertainty on every new encounter. The desire to be rid of stigma is evident in the extremes to which individuals will go. either to conceal the "defect" or to "cure" and otherwise "master" it (Goffman 1963). Indeed. the current literature on disability points out that in an effort to avoid stigma and stereotypes. people with disabilities often object to being labelled as "disabled" and struggle to find alternate. more acceptable. terms (Charmaz 1999: Finkelstein 1993a: Gadacz 1994: Gordon and Banishek 1996: Gordon and Feldman 1998; Linton 1998: Russell 1989: Wendell 1996).

Where disability occurs in mid-life. usual patterns of interpersonal interaction and activity are interrupted and well-established roles are disrupted without ready access to support from similarly disabled peers (Meyerowitz et. al. 1988: Quinn 1994). For individuals who become disabled as adults and who may themselves hold stereotypic and stigmatizing attitudes towards the disabled. the emotional impact of disease and disability may be intensified. leading to disavowal of disability. social withdrawal and failure to take advantage of potential legal rights and social support networks (Meyerowitz et. al. 1988: Watson 1998). In their exploration of the role of friendship and social support in the lives of disabled women. Fisher and Galler (1988) confirm that disabled people have fewer opportunities to make friends; are required − due to the effects of stigma − to carry an unfair share of the burden in social interactions with others; need to confront and often correct other's negative attributions and assumptions of people who are disabled; are often forced to ward off inappropriate gestures that non-disabled people extend as "help": and experience difficulty in maintaining the reciprocity that relationship-building requires due to pain. fatigue and limitations on their activities. Once again, the cost of having fewer friendships and less social interaction include social invisibility, isolation. progressive

withdrawal. and a paucity of intimate and affirming personal relationships (Fisher and Galler 1988: Meyerowitz et. al. 1988). Goffman's (1963) persuasive argument – that stigma effectively. if unwittingly. reduces the life chances of the individual – is patently manifest in the discrimination that people with disabilities experience at the economic. social and personal levels respectively.

The Biomedical and Social Models of Disability

The experience of chronic illness and the consequences of disability can be understood in terms of two different theoretical frameworks: the individualistic biomedical model of disability and the social model of disability. In the biomedical model. because the source of the disability is located in the individual's impaired body. the medical professions and other allied health care practitioners acquire a dominance in researching. treating. and imposing solutions upon those who are disabled or ill (Linton 1998: Lupton 1997: Oliver 1992: Williams 1998). In North America. up until the nineteenth century. and up until the shift from the belief in supernatural causes to scientific explanations of human variation (Winzer 1998). disability was accommodated in each community with varying degrees of acceptance and support depending on the nature of the disability. the status of the family. the type of community (whether rural or urban). the race. gender. class or personality of the individual. the skills of the disabled person or the kind of role they occupied. and so on[12] (Linton 1998:46). The emergence of scientific or biological explanations for disability paved the way for the dominance of the medical profession[13] (Albrecht 1992: Wendell 1996: Winzer 1998).

As the complex health care division of labour grew. especially in the first half of this century. "many health occupations were 'born' under medical control" (Coburn 1993:131). The field of rehabilitation medicine is just one of the new health occupations

that are integral to the "care industry" or "disability business". In recognition of the

complexity of disability, especially in its social consequences, the work of rehabilitation is

coordinated with the efforts of a vast array of other highly specialized disability experts:

including psychologists, counsellors, social workers, nurses, occupational therapists,

recreational therapists, and vocational experts who work with disabled individuals to

facilitate their reintegration into the "normal" community (Chubon 1994).

As deviations from the valued social norms of health and able-bodiedness, illness and

disability are assumed to require rehabilitation or adjustment in order to "fix", "cure" or

otherwise normalize the sick or disabled person (Chubon 1994). Appropriate adjustment,

indicative of rehabilitation success, involves two dimensions: the physical and the

psychological. Proper physical adjustment, which is assessed using various functional

indicators and measures of physical skill (Finkelstein 1998), requires the person with a

disability to pursue the highest possible level of independence in performing the activities

of daily living (Chubon 1994). Psychological adjustment, upon which successful physical

adjustment depends (Charmaz 1999), situates the responsibility of "adjustment" within

the chronically ill or disabled individual[14] (Chubon 1994; Howell 1994; Kendall and Buys

1998; Sidell 1997) and reinforces the belief that success or failure in adjusting to chronic

illness or disability turns on pre-existing personality traits or psychological attributes

(Davis 1998; Russell 1989). In this literature, it is reported that there is a growing body of

evidence that chronic medical illness is associated with an increased prevalence and

incidence of psychiatric and psychological disturbance (Gordon and Banishek 1996; Hill

et.al. 1992; Howell 1994; Sidell 1997). In other words, anxiety, depression, poor self-

concept or low self-esteem, and withdrawal from intimate or satisfying relationships and

social roles, are all attributed to the failure of the individual to "adjust" to the experience

of illness or disability. It is not surprising, therefore, that much of the psychological

literature on adjustment is oriented towards the practical application of adaptive rehabilitative techniques or professional counselling practice (for example. see Gordon and Banishek 1996: Gordon and Feldman 1998). Indeed. the research in this area allows professionals to more effectively and efficiently anticipate and "manage" the problems they encounter when providing services for people who are chronically ill (Lenny 1993).

As critics of the literature on adjustment point out. adjustment to disability does not merely involve individual psychological adjustment to changes in bodily functioning. it also involves "changes in others' perceptions of the disabled person. in role expectations. in social positioning. in her or his place in family constellations. and in access to educational. economic. and social opportunities" (Linton 1998:98). The inevitability of these other kinds of social adjustments are often taken for granted in the adjustment literature (Linton 1998: Russell 1989). Central issues that might affect an individual's adjustment. such as the availability of accessible transportation. social opportunities. previous education and employment options. are simply not taken into account (Oliver 1991: 1996). Even where it is acknowledged that the severity of the consequences of chronic illness are dependent on a multitude of variables that include factors such as age. marital status. pre-illness fitness. ethnicity. and education (for example. see Sidell 1997). these kinds of material conditions and other social factors are not the focus of investigation. Resolved into psychological processes such as motivation. denial. attitude. learned helplessness. and locus of control. the social determinants of chronically ill women's experience remain understood as individual and idiosyncratic[15].

In the 1960's. the emerging disability rights movement called attention to the way in which disabled people were oppressed: not only were they denied access to education, employment and adequate housing, the manner in which they were "helped" by medical professionals was itself disabling (Finkelstein 1998; Williams 1998). The medicalization

critique[16]. arising initially in Marxist perspectives and the liberal humanism that underlay

the emergence of social movements in the late 1960's and 1970's, criticized the

professional dominance of the medical system that was taken-for-granted in much of

medical sociology (Lupton 1997: Turner 1987). Indeed, the failure of the biomedical

approach and the limitations of disease-based rehabilitation in "solving" the problems of

illness and disability, provided credibility to the demands of disabled people to be

included in describing their own experiences and in defining their own needs (Oliver

1996). The work of Erving Goffman (1963), especially on stigma, had significantly

changed the way in which disabilities were thought about. His work also provided

legitimacy to new ways of researching and writing about disability (Coleman 1998:

Williams 1998). Instead of the clinical, abstract and positivistic measures and needs

assessments (see Oliver 1992: 1996: Finkelstein 1998) that had prevailed previously,

social scientists laboured to qualitatively understand the meanings, social processes,

consequences and significance of illness, and focussed "on disability as an emergent

property of social relationships" (Williams 1998: 238: also see Charmaz 1994: 1999:

Frank, A. 1991a).

The experience of the chronically ill body features prominently in the qualitative and

interpretive research traditions in medical sociology. Chronic illness, understood as

"biographical disruption" (Bury 1982), offers an opportunity to explore the implications

and meanings of illness and the (re)negotiation of identity in the presence of a disordered

body[17] (Bury 1982: Charmaz 1994: 1999; Howell 1994). Extending beyond the

boundaries previously established by clinical categories, these qualitative analyses

concentrate on the subjective experience of illness, loss, changed roles, and stigma

(Charmaz 1999; Howell 1994). The notion of "embodied experience", here, is not the

same as the diseased or dysfunctional body at the centre of the biomedical paradigm:

studies in medical sociology argue for understandings of illness that "break up the reductionist medical model" (Charmaz 1999:9). Through the use of metaphor and narrative accounts. the focus is on the "symbolic and material interactions between the individual and society. and the interpretive processes whereby individuals construct meaning from their experiences" (Williams 1998:240).

While these kinds of analyses attempt "to define a sociological approach to illness liberated from the dominance of biomedicine" (Williams 1998:239). they are often produced expressly to inform health care reform and to support initiatives that promote "community care" over acute-care models (for example. see Charmaz 1999). This "social" understanding of illness in medical sociology is still implicitly structured by the relevances of medicine: i.e.. these studies still concentrate "on issues of importance to professionals and a professional service paradigm". they "assume a congruence of interest between the service provider and user and fail, consequently. to analyse opposing interests. inequality. and the distribution of power" (Rioux 1994:4). The focus on meanings – the cultural connotations. the symbols and significations – obscures the change (for the worse) in the material conditions of life that accompany chronic illness. as well as the broader social and economic relations in which people's lives are embedded (Dyck 1995; Watson 1998). While these kinds of analyses are a significant step in the direction of reflecting the realities of chronically ill and disabled people. the disability rights movement and writers in the field of disability studies go yet another step further.

With the emergence of the social model. the source of the disability shifts from the body to the social world; specifically. to "a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (Barnes 1998:73). Disability. therefore. is "all the things that impose restrictions on disabled people; ranging from

individual prejudice to institutional discrimination. from inaccessible public buildings to unusable public transport systems. from segregated education to excluding work arrangements. and so on" (Oliver 1996: 33: see also Swain et. al. 1993). If the built environment and social arrangements actually generate the barriers and problems associated with disability (see Davis 1998: Hales 1996: Oliver 1996: Shakespeare 1998). then the personal. social and economic consequences of disability are neither natural nor inevitable (Barnes 1998: Davis 1998: Finkelstein 1998: Morris 1992: Oliver 1992: 1996). Exclusion and marginalization are no longer consequences of an individual's impairment or the failure to adjust. Rather. they are the consequences of social discrimination.

From this more political perspective. the prescriptions of a "normalizing society and the whole range of professional activities which attempt to reinforce it" are rejected (Oliver 1996: 37). This includes rejecting the production of knowledge in the specialized applied fields. as well as the "solutions" proffered by the professional practices of rehabilitation and psychological adjustment (Lenny 1993: Morris 1992). Because disability is socially produced. the activities of researchers. professionals. policy makers. and indeed all of that which we consider to be "social" are implicated in the construction of illnesses and disabilities as "problems" (Morris 1992). As the disability studies critique points out. the specialized applied fields and the operations of the "disability industry" – including the whole host of "troubled" person professions, the schools and universities that train those professionals. voluntary fundraising organizations. sheltered workshops. the industries that develop and produce the technologies that disabled people use. and so on – all rely on the construction of disability as a social problem requiring the special expertise of professionals and the intervention of a trained community with special knowledge, facilities. extensive funding, and a dominant place in the medical. legal, and other social systems of the community (Lane 1998; Morris 1992). In other words, the

extensive material resources and the privileges of the "disability industry"depend on disabled people being defined as "in need" (Lane 1998:156).

Even the structure of the academic curriculum and the way in which "domains of knowledge [are] divided up or clustered" (Linton 1998: 76) play a constitutive role in the construction of partial or distorted understandings of disability. Just as the scientific study of "man" as a universal and standard category excludes women and people of different races. ethnicities and sexualities. most standard or mainstream inquiries assume ablebodiedness as a universal and standard category and fail to include people with disabilities (Linton 1998: Morris 1992). This means that if disability and disabled people are studied at all. they will tend to be studied in their particularity or as deviations from the norm. Disability studies scholars are particularly discouraged at the confinement of the subject of disability within the specialized applied fields: i.e.. rehabilitation medicine. special education. social work. nursing. adjustment psychology. and so on (Asch and Fine 1998: Finkelstein 1998: Linton 1998). The neglect of disability in the rest of the academy is particularly unfortunate. Linton argues, because the social sciences – including anthropology. economics. political science, sociology and history – "provide the research tools and theoretical material needed to shed light on disability as a social construct and on the manifestations and consequences of particular constructions" (Linton 1998:97).

In the specialized applied fields, researchers organize their activities according to constructed schemes of recognized professional practice that have developed socially and historically and specify exactly what constitutes the accepted methods, content and boundaries of their discipline (Danziger 1990): established techniques of eliciting information. the use of clinical categories, and measurements of "needs" and "functional capacities". pre-determine and structure. ahead of time. what can be known about people who are disabled and ill (Finkelstein 1998; Oliver 1992: Morris 1992). In other words, the

production of knowledge usually conforms to professional or academic interests and aims and not to the interests and aims of peoples with disabilities (Morris 1992: Oliver 1992). The failure to dislodge biomedical understandings of disability in the specialized applied fields is due. in part. to the infrequent opportunities for people who are chronically ill or disabled to occupy positions that allow them to influence or inform the disability research agenda (Meekosha 1998: Morris 1992): "limited educational opportunities. discrimination in hiring and promotion. and inadequate supports for disability scholarship" are just some of the reasons that disabled scholars find themselves unable to actively participate in research production (Linton 1998:73).

Refusing the construction of disability as a personal deficit or a social problem. disability studies scholars have also made inroads into arguing for the construction of disability as difference. Disability. in this conception. similar to other bodily based social identities such as gender. race and visible ethnicities. is the result of corporeal differences that are used to differentiate between and stigmatize particular individuals (Davis 1998: Hahn 1998: Lane 1998). In this variation of the social model of disability. discrimination and oppression are grounded in social invisibility or nonrecognition. unfairly biassed cultural norms. and disrespect that results from disparaging and stereotypic cultural representations[18]. Using an affirmative politics of positive identity. this movement uses the language of minority discourse. civil rights. equity and equal opportunity. The remedy to cultural injustice and social discrimination against people with disablities. they argue. require mainly cultural respect and legal protection from the majority (Lane 1998).

While the social model has challenged the prescriptions of a normalizing society and has illuminated the professional and academic interests and agendas that structure mainstream knowledge about illness and disability. it is not without its critics. Criticizing the social model from within. Mike Oliver (1992) acknowledges that the social model

does not necessarily connect with. or explain. the individual restrictions and individual impairments that people with disabilities experience. Indeed. the pragmatic attempt to "identify and address issues that can be changed through collective action". and the insistence that there is no necessary causal relationship between impairment and disability – which reflects the need to "break the link" between a person's body and a person's social situation – makes it difficult to incorporate and understand the personal experience of pain and impairment (Oliver 1996:38). Oliver notes that "to mention biology. to admit pain. to confront our impairments. has been to risk the oppressors seizing on evidence that disability is "really" about physical limitation after all" (quoting Shakespeare in Oliver 1996:38). Therefore. while environmental barriers and social attitudes are prominent features in the social model of disability. the subjective experience and personal meanings of illness and impairment are not (French 1993; Gadacz 1994; Oliver 1996).

The "minority model" of disability. according to which injustice is rooted in social invisibility and cultural disrespect. is similarly criticized by feminist disability scholars[19]. To claim that the disabled body – as a cultural text – merely requires reinterpretation as difference. they argue. neutralizes the subjective experience of pain and struggle and obscures the material and historical effects of differences grounded in disability. impairment. and even gender (Morris 1992; Thomson 1998; Wendell 1996). Cultural recognition. in this critique. is not sufficient to address the injustices wrought by illness and disability. The materiality of the disabled or chronically ill body requires measures that ensure the inclusion and participation of people with disabilities in economic arrangements and all the core services and systems of society in which people without disabilities are entitled to participate.

Another important criticism of the social model of disability. Oliver (1996) admits, is its failure to incorporate analyses of the experience of multiple oppressions. Social

differences, such as gender, sexuality, age, level of ability, race and ethnicity are only some of the "other" differences that complicate existing analyses of disability in the context of the social model (Morris 1992; 1993; 1996; Oliver 1996; Stuart 1993). In its insistence on scrutinizing and changing externally imposed restrictions in prevailing social structures and social arrangements, some connections are forced and others are obscured. For example, "mechanical changes", such as making buildings wheelchair accessible, formulating equity policies in workplaces and schools, providing sign language interpreters at public functions (Linton 1998) and so on, may create the false impression that inequities based on disability are not also intertwined with gender, race and class differences. Criticizing the ideological character of much of the writing produced in the context of the early phases of the social model of disability, disability studies scholars are increasingly taking up the issues of gender (Thomson 1998; Morris 1996; Wendell 1996), specific types of impairment (Davis 1998; Hale 1998), and race/ethnicity (Stuart 1993; Vernon 1996).

Social Measures to Alleviate Disadvantage and Discrimination:
Accessibility and Accommodation

The social model of disability and the political organization of disability rights activists have made significant inroads in changing the physical, social and political landscape for people with disabilities (Barnes 1998); features of the built environment, social arrangements, legislation, policy and public discourse identified as discriminatory have been challenged and gradually improved to address the "needs" and reflect the interests of people with disabilities. In Canada, the effort to eliminate systemic discrimination has prompted the review, revision and formulation of policies to provide equitable access for people with disabilities in all the systems and core services in which

other members of Canadian society are entitled to participate. Equity for people with

disabilities is grounded in the protections afforded by the Charter of Rights and Freedoms

(1981) and other human rights legislation (i.e.. the B.C. Human Rights Act (Section 3)

1992 amendment). Unlike equality, which involves ideas of equal treatment before the

law or the undifferentiating application of ordinary rules. equity requires going beyond the

practice of deciding what is "right" to deciding what is "fair" (Schaffer and Lamb 1981).

Because ordinary rules. by virtue of their necessarily general character. result in unfair

outcomes for people with disabilities. equity requires another set of rules or interventions

designed to promote a greater equality than would be realized in the course of the

application of the general rules. This other set of rules about "fairness". which is

enshrined in human rights legislation. requires institutions to eliminate or modify

practices. facilities and services that have discriminatory effects for people with

disabilities (Albrecht 1992: BCEADS 1996; Gadacz 1994).

Beyond policy and legislation. the public discourse about disability has changed as

well. In Canada. for example. the federal, provincial and territorial levels of government

recognize that people with disabilities. as one of the least advantaged groups in Canadian

society. are no longer to be deemed passive recipients of services. Rather, as full citizens.

people with disabilities are entitled

> "to participate and contribute to the systems and the 'core' services in which all
> Canadians can participate and to which most Canadians have access. These
> include schools. training programs, postsecondary education institutes. health
> care. workplaces. recreation facilities. cultural programs. transportation. parks
> and other forms of public space" (Federal/Provincial/Territorial Ministers
> Responsible for Social Services 1998:7).

In spite of the influence of the disability rights movement and disability scholarship –

along with the changes in policy. legislation and disability discourse – the established

dominance of biomedical concerns and service delivery models have impeded the

unqualified accedence of the more politicized social model of disability. In other words.

the social model of disability has not replaced the biomedical model of disability. Further.

even though activists. scholars and policy makers agree that the individualistic biomedical

model is a limited and partial way of understanding disability. it continues to be deferred

to as the ultimate authority in matters of illness and disease. especially in determining

eligibility for disability-related programs and assistance (Albrecht 1992: Lock 1998:

Linton 1998). Therefore. alongside a "disability industry" organized around medical

services and healthcare delivery. a more social **"disabilities apparatus"** organized

around concepts such as accessibility and accommodation has emerged to ensure the

elimination of barriers to the full inclusion of people with disabilities in the mainstream of

social life and. for this study in particular. in postsecondary education. **Accessibility**, in

the context of postsecondary education. refers to the institution's legal obligation to create

genuine opportunities for people with disabilities to participate in all aspects of university

life. The duty to **accommodate**. as one aspect of the duty not to discriminate. requires the

institution to take an active part in modifying those practices. facilities. or services that

prevent the inclusion and participation of otherwise qualified students who are disabled

(BCEADS 1996).

Improving accessibility in post-secondary education includes making changes in the

built environment (i.e.. ramps. elevators, improved signage. disabled parking). providing

specialized adaptive equipment to disabled students (assistive listening devices, laptop

computers. tape-recorders, voice synthesizers, reading material in braille). and providing

special support services that are designed to recognize the unique "needs" of people with

disabilities (i.e.. counselling services, full student loans for part-time attendance, and

dedicated offices and/or personnel who mediate on behalf of disabled students and raise

awareness of disability issues on campus). Accommodation. in the context of

postsecondary education. usually involves procedural changes (i.e.. extensions of time for

exams and assignments). modifications or substitutions in teaching and evaluation

practices (i.e.. alternate formats for exams and assignments. alternate locations for writing

exams). and substitutions or deletions in coursework or program requirements (i.e..

substituting or deleting field work or practica components). Exactly what constitutes an

accommodation is a matter of law: courts have the ultimate authority to define the

meaning of this term and the extent of the responsibility of the institution to provide it

(BCEADS 1996). In principle. the improvements in accessibility and the legal right to

accommodation should allow women who are chronically ill to fully access and equally

participate at all educational levels. including in obtaining a university degree.

Two questions arise here: the first question is whether or not the "disabilities

apparatus" – making improvements in accessibility and implementing policies on

providing accommodation – actually accomplishes what it sets out to do. Because

education has been identified as an important component of social functioning (Esdaile

and Wilkins 1989) and is fundamental to resisting the accumulation of disadvantage for

disabled women (Lock 1998). it is essential that policies providing accessibility and

accommodation be demonstrated to actually foster the inclusion. participation and the

success of women with disabilities and chronic illnesses in postsecondary education.

The second question that arises is how to assess the success of such policies in a way

that uses women's own accounts of their experience and concerns without losing sight of

the structures that make their experience take the shape that it does. This leads me to a

fuller explanation of my research problematic which aims at bridging the gulf between the

everyday experience of chronic illness and the way in which administrative. instructional,

and organizational processes of the university either facilitate. or undermine, the full

inclusion and equal participation of chronically ill women in the higher educational process.

The Research Problematic

The problem of staying politically engaged while "exploring the darker phenomenological waters of people's experiences"(Williams 1998:244) is a challenge that is identified in a number of critical analyses of the academic production of knowledge about illness and disability (Barnes 1998: Morris 1993: Thomson 1998). Depending on how "experience" is taken up and used, social processes, dimensions of experience, and interests or agendas can be either illuminated or obscured. For example, phenomenological or symbolic interactionist interpretations of the meanings of the experience of illness and disability tend to conceal the concrete material conditions of life and broader social and political practices on which such experience depends (for example, see Bury 1982: Charmaz 1994; 1999; Frank, A. 1991a; Howell 1994). Autobiographical or narrative accounts of experience (Driedger and Gray 1992; Matthews 1983; Morris 1996: Ricciutelli 1993; "Women's Education" 1996), while powerfully expressing the personal struggles of disabled and chronically ill women, and which are crucial in the construction of "counter-images" of disabled people (Gadacz 1994), confine analysis to the particular local setting and stay at the level of the individual (Meekosha 1998; Williams 1998). Objectivist interpretations of the experience of illness and disability produce analyses that conform to professional interests and are generally used to manage and control the problems that disabilities are seen to "cause" (for example, see Gordon and Banishek 1996; Gordon and Feldman 1998). Alternately, experience can be bracketed or ignored, as it is in many of the materialist analyses of disability, including much of the disability studies writing in the U.K.(Oliver 1996; and in Shakespeare 1998 see in

particular. Barnes 1998: Abberley 1998). Proceeding from a theoretical position. rather than an actual position anchored in the local setting and definite material conditions of the everyday world. these materialist accounts nonetheless provide compelling analyses of the "big picture" of disability. i.e.. analyses of the unequal relations of power that people with illnesses and disabilities encounter and live within.

Using the theoretical approach known as the social organization of knowledge. and the investigative method known as institutional ethnography – as proposed and elaborated by Dorothy E. Smith (1987: 1990a: 1990b: 1999) – this inquiry offers a way to integrate these two areas of study – the "embodied experience" of illness and the systemic inequities that disability and illness are seen to produce – into one project of research. The inquiry works through interviews and textual analysis to examine how chronically ill women themselves know and account for their experience of requesting and obtaining accommodation. and how ideals of equity for people with disabilities and policies relating to accessibility and academic accommodation are brought to bear. or are not brought to bear. on the everyday problem of chronic illness for women who are students. I will examine how women's ordinary everyday experience of being students. and what they know and say about their experience of living and coping with illness. are entwined with institutional processes – as organizational policies and procedures that exist beyond and prior to the individual's experience but which are also part of the individual's local setting (Campbell 1998) – and how these institutional processes actually 'produce' particular kinds of outcomes and experiences.

Smith (1987) notes that the word "problematic" is usually used to refer to matters at the level of theory rather than at the level of experience. The way in which Smith uses "problematic" is to indicate a procedure for developing a conceptual apparatus that "discloses and explicates" the properties of a particular social actuality (1987:91). A

research problematic is situated at the disjuncture between the ideological knowledge of a particular phenomenon and the local and particular experience of it. As an example, the following excerpts are taken from the interviews that I analyse later on in the thesis. They deal with just one small aspect of the process of requesting and obtaining accommodation: the reluctance of some chronically ill students to identify themselves as "disabled" and as needing assistance or accommodation:

Nicole: "*Definitely, there's a lot of guilt. Like, why would I need an extension? A lot of it, a lot of issues like feeling lazy came up. Like, did I really need it? Those [issues], and also just asking for it. . . A lot of it has to do with learning how to ask for help. I mean, I can think about what my needs are, but if I can't or don't communicate them then I won't know what kinds of opportunities are open – and they can't read my mind as to what I possibly might need and they might not know the first thing about my disease or my needs. But for me, it was also getting over the fear of asking.*"

Corina: "*Well, the first problem was that it took almost a year to finally get the diagnosis. So now that I've got a label, and [the doctor has] put me on medication and stuff. So, and given me a book on it, and like it scares the devil out of you. So you do what you need to do.*"

Anne: "*My policy is to never identify it until I really need to.*"

Jody: "*It changes any sense of self that you may have had. The reality is that it reduces any sense of entitlement you have – and you're in a box and that's a very tricky place to go – you know, it's hard to call yourself anything where you know that it comes with a whole package of oppressions.*"

Lee: "*I've always felt very reluctant to identify myself as having needs, and I've always felt much more comfortable securing accommodation in terms of emergencies. Once, when I was really not well and it was the end of the term, I had my doctor write me a note. I carried that note in my bag for a month – thinking, that if I have to, this is my passport to securing a formal academic accommodation. But then, I was also struggling to make sure that I didn't actually use it.*"

Coordinator for the Office for Students with a Disability: [speaking about the services the university has available and the Policy on Providing Accommodation for Students with a Disability, i.e., the "disabilities apparatus" on campus] "*The whole process is totally voluntary. So people don't have to disclose. They don't have to. Some people don't feel they need any specific type of accommodation – they're doing just fine – just perfectly okay. . . Depending on the disability, depending on where they're at with it. Or you have*

some people who have problems with denial, also with no visible disability and they don't want to be treated any differently. People are at different places in their lives, different levels of maturity, different levels of acceptance with what they can do, or cannot do, and so on. And by the end of the day, it's a personal choice.

The "disabilities apparatus" exists objectively as a set of definite institutional processes and services designed to ensure the inclusion and participation of people with disabilities on campus. The Policy on Providing Accommodation for Students with a Disability (rev. 1997) organizes the university's response to chronically ill or disabled students on condition they first identify themselves as "disabled" to the university (i.e., to the instructor or to the Office for Students with a Disablity). From the point of view of the university, this requirement seems to be straightforward and self-evident. From the student's excerpts, however, a whole other set of considerations come into view: students experience feelings of guilt and fear, they may not have a definite diagnosis, they may understand accommodation to be an option of last resort, they may want to maintain a "sense of self", they may worry about the oppression and disadvantage that the category of "disabled" signifies, and so on. These kinds of considerations or "troubles" are not reflected in either the Policy, or in the way that the Coordinator speaks about students who are reluctant to identify themselves as disabled. From the institutional framing of this "problem", the feelings, experiences and practices of reasoning of chronically ill women can be subsumed under explanations such as denial, immaturity, and the belief that those students who do not use the "disabilities apparatus" are "doing fine, just perfectly okay". In other words, there is a disjuncture between the administrative practice of providing accommodation and the locally situated, everyday experience of chronically ill women in requesting and obtaining the assistance and accommodation they need to participate in obtaining a university education.

Because the "social organization of the setting is not wholly available to us in its appearance" (Smith 1987:87). a research problematic seeks to make visible. or explicate. the social determinations of the particular and local experience. In other words. this inquiry aims at answering the question "how does it happen this way?" Instead of starting from the relevances. concepts and topics of sociological discourse or institutional understandings. this kind of research inquiry illuminates "the problematic of the everyday world" - as the people there know and live it. It offers the researcher the opportunity to see the activities. practices. material conditions. and possibilities of the local and particular before they pass into the prevailing objectified and ideological understandings of them. In the next chapters. I discuss in more detail the research paradigm and research strategy that I use.

Chapter Two

CONCEPTUAL FRAMEWORK

Introduction

In this chapter. I explain Smith's approach to the social organization of knowledge as I

have understood and used it. Although the social organization of knowledge and disability

studies are analytically and theoretically distinct. they share similar origins and insights.

As I proceed in my discussion of Smith's approach. I will indicate these areas of

convergence and agreement. I will also point to concepts and understandings that are of

particular importance in my own inquiry. I will conclude this chapter with a discussion of

the problem of exclusion and marginalization in the academy: especially as it relates to

the making and dissemination of knowledge that reflects the interests and experiences of

people who are disabled or chronically ill. My larger aim in this chapter is to demonstrate

how the theoretical approach known as the social organization of knowledge can provide

an analysis that is congruent with the prescriptions of the social model of disability (i.e..

focussing on social arrangements and the built environment. and not on chronically ill

women as a group). but which is also able to draw together both the subjective experience

of illness and the systemic inequities that institutional processes and practices can be seen

to produce. into one project of research.

Disability studies has only recently emerged as a specialized (and even autonomous)

discipline and has been farthest developed in the English-speaking countries. particularly

in Britain and the United States. British writers are mainly concerned with material factors

and political power. while their counterparts in the United States focus on history. culture.

literature and other aspects of discourse and meaning (Shakespeare 1998). In spite of their

differences. however. both the U.S. and U.K. approaches univocally reject the

individualistic biomedical model of disability and have embraced a social or constructivist

approach to disability instead[20]. This means that disability studies scholarship and the social organization of knowledge share similar interests and insights. For example. Smith's approach originates in the women's movement's discovery that. as women. they had been consciously and deliberately excluded from participating in the formation of the intellectual. cultural and political worlds that they were living in (Smith 1987). Disability studies. likewise. is both an area of political activity and an academic field of inquiry: contesting the oppression and exclusion of disabled people from the mainstream of social life including academia. and working to assemble a body of knowledge that reflects their own experiences. interests. and ways of knowing (see Davis 1998: Linton 1998: Morris 1991: Oliver 1996: Shakespeare 1998: Swain et. al 1993). Both feminism and the disability rights movement are part of the broad cultural struggles that emerged in the 1960's. and which provoked new sites of conflict in academia around issues of "difference" – such as gender. race, ethnicity. sexuality. class. disability. and so on. Similarly. the feminist and the disability studies critiques of the systematically developed knowledge in academia hold that scientific and objectivist approaches suppress and silence the voices of those who are marginalized and excluded and are integral to the reproduction of unequal relations of power.

Smith's distinctive social ontology and investigative approach. however. provide what I believe is a unique advantage: "a social ontology not of meaning but of a concerting of activities that actually happens" (Smith 1999:97). By always referring back to actual practices and experiences that are anchored in definite material conditions "in time and in actual local sites of people's bodily existence" (Smith 1999:97). the social organization of knowledge provides a way around the "'macro/micro split' persistently produced by ontologies that cannot maintain a continuity between what people are seen to do and the kind of understanding researchers call 'the big picture'" (McCoy 1999:27). Beginning in a

world of purposive and planned activity. individuals can be seen – in their temporally "concerted sequences of action". "performed by more than one and perhaps sometimes by a multiplicity of individuals not necessarily known to one another" (Smith 1987:167) – to actively bring into being the social organization of everyday life. This includes the social organization of the everyday lives of women who are chronically ill and who are in the process of obtaining a university education.

The Epistemological Use of "Everyday Life" as a Ground of Inquiry

In traditional sociology. Smith argues. the social world is known and explored through systematically developed concepts and categories that either discard or render invisible the "particularity of the individual. their actual situation and site of work. the ephemerality of the lived moment. and so on" (Smith 1996:174). In the social organization of knowledge. the knowing subject is embodied. located in her own life. situated in her local and particular actuality. her experience and activities happen in definite material conditions within constraints and under presuppositions over which she has little control (Smith 1999). The strategy of structuring inquiry from the standpoint of people begins in the ordinary comings and goings of living as people themselves know it. and can speak of it (Smith 1999:96). Based on the assumption that people are "experts" in their own lives (Campbell 1998). that they can speak authoritatively about their directly experienced worlds. the researcher takes up those experiences which arise as "conditions. occasions. objects. possibilities. relevances. presences. and so on." (Smith 1987:89) as they are understood and spoken by the knower. Here, the subjective experience of limitation and pain. and the individual woman's 'work'. in terms of time. energy and effort expended. are central to the inquiry (Smith 1987).

However. experience is not the object of the research: experience. in and of itself. is not treated as knowledge (Smith 1999). The experience provides a place to begin the inquiry: it provides an entry point into the social relations. as institutional practices and organizational processes that penetrate. organize and order chronically ill women's seemingly personal and idiosyncratic experience. The problem of how the "everyday world is put together in relations that are not wholly discoverable within the everyday world" (Smith 1987:47). locates the determinations of people's experiences outside and beyond their local settings in the "social relations that tie the local and particular into the generalized and generalizing relations that [also] determine the local and particular" (Smith 1990a:200). Beginning from the premise that individuals actively produce the social relations that they live. the exploration of people's everyday worlds can show that what they do. how they coordinate and plan their activities. actually contributes to and is articulated with the relations that overpower their lives (Smith 1990a:204). Recognizing that "local events are often controlled by forces beyond the purview of those acting at that site" (Linton 1998:35). people's everyday experience provides a way for the researcher to show "how power is exercised. in what official or unofficial activities. by whom and for what purposes" (Campbell 1998:96).

Smith uses the notion of "standpoint" to express the commitment to investigate and describe "those social. political and economic processes that organize and determine the actual bases of experience of those whose side we have taken" (Smith 1987:177). Taking sides. here. does not undermine the scientific objectivity of the research: rather. it conveys the intention to "create active linkages" with those activists working outside the academy. and to produce knowledge that reflects the concerns and interests of society's marginalized and exploited people (Smith 1999). Standpoint does not imply a common perspective or worldview. nor does it universalize a particular experience (Smith 1987).

"A sociology beginning in people's everyday/everynight experience takes for granted that experiences are as various as people are. It does not seek to supersede this variety by constructing a version that overrides all others" (Smith 1999:97). Indeed differences in experience "arise in a matrix of everyday/everynight activities and through how they are entered into and coordinated with others' activities" (Smith 1999:97). By exploring this concerting and co-ordering of an individual's activities. "the relations that generate the varieties of lived experience" (Smith 1999:97) can be investigated also. The capacity to recognize the varieties of lived experience is especially important for this inquiry. Disability. after all. is complex: it does not exert an even influence over all individuals equally and there is no one to one relationship between physical and social disadvantages (Russell 1989). In fact. while disability is often theorized as though it constitutes a "master-category". disability interacts with other differences – such as gender. class. ethnicity/race. or type and severity of disability. among others – to produce complex and uneven results (Dyck 1995: Russell 1989). Exploring the relations that generate differences in the lived experience of chronically ill women. also illuminates these other dimensions of an individual's social experience.

The Development of Contemporary Forms of Organization

Smith. like Marx before her. insists on a definite. irreducibly material world in which actual individuals produce their material lives and make history. although not under conditions of their choosing (McLellan 1977:161). Following Marx. Smith understands social relations as "the actual coordinated activities of actual people in which the phenomena of political economy arise" (Smith 1990b:94). As sequences of action that no one individual completes. "generalized social relations are definite modes in which people's activities have come to be organized, and they are daily and nightly both

reproduced and changed as people's local activities articulate to, coordinate with, and are

determined by them" (Smith 1990a:202). These concerted and co-ordered practices and

activities, "in which many individuals unknown to one another may be active" (Smith

1987:133), take place "reflexively and recursively across space and time" (Smith, G.

1995:24), and they "coordinate and co-determine the worlds, activities, and experiences of

people entered into them at different points" (Smith 1987:134). These social relations

"knit" locally situated individuals to the state, the economy, systems of discourse, science,

mass media, large-scale organizations of all kinds, professional organization, and so on

(Smith 1999:91). These generalized social relations are what Smith calls relations of

ruling and they are both invested in, and mediated by, texts (Smith 1974; 1987; 1990a;

1990b; 1996; 1999). Smith writes that,

> [t]he phrase 'relations of ruling' designates the complex of extra-local relations
> that provide in contemporary society a specialization of organization, control
> and initiative. They are those forms that we know as bureaucracy,
> administration, management, professional organization and the media. They also
> include the complex of discourses, scientific, technical, and cultural, that
> intersect, interpenetrate, and coordinate the multiple sites of ruling" (Smith
> 1990b:6).

For Smith, relations of ruling is a concept that "grasps power, organization, direction and

regulation as more pervasively structured than can be expressed in traditional concepts

provided by the discourses of power" (1987:3).

Historically, the organization of the relations of ruling and their "dynamic expansion

are intimately linked to the dynamic progress of capital" (Smith 1987:5). Capitalism

creates "an extralocal medium of action constituted by a market process" that increasingly

takes the place of local governance, subjective decision-making and other "personally

mediated economic and social relations" (Smith 1987:5). Relations of dependence

between particular individuals in local settings increasingly give way to an impersonal,

abstracted and independent system of relations among people mediated by money and commodities (Smith 1990b). These same kinds of processes that Smith identifies in the development of contemporary forms of organization are also recognized by disabilities studies scholars who argue that more informal arrangements for accommodating disabled people within particular communities have given way to a complex of specialized. objectified and technical practices in the form of a "care industry" or "disability business" (Albrecht 1992; Linton 1998; Winzer 1998).

Extrapolating from Marx's materialist method. Smith argues that contemporary forms of organization and the emergence of a "social consciousness existing as differentiated practices and relations" (Smith 1990b:8). have followed from the "developed social relations of reasoning and knowledge externalized as textually mediated forms of organization and discourse" (Smith 1990b:7). These forms of social consciousness were present only nascently in Marx's time (1990b:160). but are analogous to the "functions of 'knowledge, judgment and will' that Marx saw as wrested from the original 'producer' and transferred to capital" (Smith 1999:77). Smith's investigation extends beyond the relations and organization of the economy to take up this new level of organization in which "the relations of consciousness and agency" are "extracted" from particular individuals in their local settings. and are subjected to "technological and technical specialization. elaboration. differentiation, and objectification" (Smith 1999:77). Today. "reason. knowledge. and concepts are more than merely attributes of individual consciousness. they are embedded in. organize. and are integral to social relations in which subjects act but which are not reducible to the acts of subjects" (Smith 1990b:160). Discourses and ideologies. as forms of social consciousness. for Smith. can also be investigated as actual social relations organized in and by the activities of actual people.

Text Mediated Relations of Ruling

Texts. for Smith. have a crucial and central role in the organization of the relations of ruling. They are "the mediators and bases of discourses and ruling relations that regulate and coordinate beyond the particular local setting of their reading or writing" (Smith 1999:80). The text. in its material aspect. is the "object that brings into actual contexts of reading a standardized form of words or images that can be and may be read/seen/heard in many other settings by many others at the same or other times" (Smith 1999:7). In contemporary society. texts are sufficiently ubiquitous to appear to have a perfectly ordinary existence. Yet. texts and text-mediated forms of knowledge organize. regulate. and coordinate the activities. and indeed. the lives. of people in their diverse local settings. Medical knowledge. social policies. and academic regulations are examples of text-based. text-mediated systems of knowledge. information. communication. regulation and control through which the local and particular are articulated to the relations of ruling.

Textual practices are forms of social organization that "externalize social consciousness in social practices. objectifying reasoning. knowledge, memory. decision-making. judgement. evaluation. etc.. as properties of formal organization or discourse rather than as properties of individuals" (Smith 1990b:211). Smith writes that

> "[a]n objectified world-in-common vested in texts is the essential coordinator of activities. decisions, policies, and plans produced by actual subjects as the acts. decisions. policies, and plans of large-scale organizations of various kinds. The primary mode of action and decision in the super-structures of business. governments. the professions, and the scientific. professional. literary and artistic discourses is symbolic and on paper or in computers" (Smith 1999:50).

Oriented to these "symbolically constructed virtual realities. accomplished in distinctive practices of reading and writing" (Smith 1999:50), decisions and actions "privilege the textual order of discourse and its textually constituted realities" (Smith 1999:61) over the order of the actual: "the schematic authority of a text" is preferred to the actuality it

describes. precisely because it transcends the "disorientation of the direct encounter" (Said 1979:93). Texts become the "prism" through which the actualities of social. economic and political processes are interpreted (Smith 1999:36): "a sphere of work and inquiry is created with its own internal logic. its agreed upon objects and categories. its recognized authorities and referents" (Smith 1999:36). As texts transmit their social organization into multiple sites. and as they regulate the local activities of increasing numbers of people. they acquire authority and legitimacy. A discursive world in common. "establishes canons of relevance and validity: reproduces judgments and values. and incorporates experiences and perceptions introduced by its participants as themes and topics that have become properties of discourse institutionalized in ruling relations" (Smith 1999:36).

Identifying the historical development of "forms of social consciousness that can no longer be adequately conceived as arising in the life conditions of actual individuals" (Smith 1999:78) is not unique to Smith. Althusser's ideologically constituted subject and Foucault's discourse as an intertextual process that displaces authorial intention are two examples of the shift in understanding consciousness as an attribute of individuals to understanding consciousness as the workings of objectifying organization and relations mediated by discourse. For Smith, 'discourse' refers to "an assemblage of 'statements' arising in an ongoing 'conversation.' mediated by texts. among speakers and hearers separated from one another in time and space" (Smith 1990a:161). Discourse includes all "forms of communication and interrelation that are mediated by texts - journals, magazines. newspapers. books, television, movies etc." (Smith 1990b:214). These are the distinctive contemporary forms of social organization which intersect with and coordinate the different sites of the ruling apparatus, and which intersect with and structure people's everyday worlds (Smith 1990b:1999). Smith's use of the term 'discourse' originates with

Foucault. but in order to avoid "reducing [the subject] to a mere bearer of systemic processes external to her" (Smith 1990b:161). Smith focusses on the way in which discourses are brought into being as actual communicative and interpretive practices: people routinely organize themselves in relation to various discourses. and they take up the forms of subjectivity and agency that these discourses provide (Smith 1999).

Conceptual and Ideological Practices

Through the practices of ruling. the social world is detached from the local and particular and is abstracted into a conceptual mode that can be managed and governed. The active "accomplishment" of the work of ruling depends on "distinctively organized ways of knowing those aspects of the world that are to be ruled" (Campbell and Manicom 1995:9). These distinctively organized ways of knowing the social world. including "the ways in which we think about ourselves and one another and about our society ... are given shape and distributed by the specialized work of people in universities and schools. in television. radio and newspapers. in advertising agencies. in book publishing and other organizations forming the 'ideological apparatuses' of the society" (Smith 1987:17). The educational system "that both produces and disseminates knowledge. culture and ideology" (Smith 1987:18) is central in the constitution of "a phenomenal world and a body of statements about it" (1990a:33). These "virtual realities" organize and order the expression of the local. particular, and directly known into forms concordant with the interests. aims and perspectives of the relations of ruling[21] (1987:56).

The established rules. conventions, and methods in the social sciences[22] are part of this ideological structure which creates "accounts of the world that treat it selectively in terms of a predetermined conceptual framework" (1990a:93). Ideological practices have a distinctive circularity within which what can be known is already structured by a

predetermined schema with its sanctioned concepts and categories. Data. or facts. culled from actual individuals and the everyday world. are then substituted as the reality intended by the schema. which then is also used to interpret and analyse them. "An inner coherence is established between the actuality thus presented and the statements that can be made about it. such that the actuality produced as "what actually happened/what is" can be seen to require its own descriptive categories and conceptual procedures" (1990a:78).

The disability studies critique draws a similar conclusion: positivistic and objectivist methods of inquiry characterized by clinical categories. "needs" assessments. and measures of "functional capacity" produce medicalized understandings of people who are disabled and ill which. in turn. legitimate and authorize the professional practices of the "disability business" or "care industry" (Finkelstein 1998: Oliver 1992). Knowledge. in both these views. is implicated through and through in relations of power (Oliver 1992) and practices of ruling (Smith 1975).

Ideological circles are not confined to academia: they are integral to people's everyday activities. where the actual is routinely "translated" into abstract conceptual forms and categories that render the local and the particular "actionable within bureaucratic. professional. or managerial modes" (Smith 1987:158). Ordinary people routinely participate in these ruling practices when they submit to organizational processes that make particular aspects of their bodies and everyday experiences visible. i.e.. in medical. psychological and social work records. in job applications. in applications for loans and admission to universities. and so on. All of these textual processes use a pre-determined schema to extract "particulars" from an indeterminate local actuality that are then "worked up to intend the categories and concepts through which they are entered into organizational courses of action" (Smith 1987:159). One of the distinctive properties of the ruling apparatus is "its capacity to organize the locally and inexhaustibly various

character of the actual into standard forms of organizational action" (Smith 1987:158). In the process of practical interchange between "an inexhaustibly messy and different and indefinite real world" and the bureaucratic. professional. academic. and other institutional contexts which control and act upon it. the appearance of "order" is produced.

Institutions

The interdependence of bureaucratic. professional. and managerial modes is expressed in Smith's notion of institution. "Institution" refers to "a complex of relations forming part of the ruling apparatus. organized around a distinctive function - education. health care. law." and so forth (Smith 1987:160). Institution. in contrast to bureaucracy. identifies the intersection and coordination of "more than one relational mode of the ruling apparatus" where "state agencies are tied in with professional forms of organization. and both are interpenetrated by relations of discourse of more than one order" (Smith 1987:160). For example. disability "is a linchpin in a complex web of social ideals. institutional structures. and government policies" (Linton 1998:10). Arising primarily in the institutional complex of medicine and the rehabilitation industry. the discourse of disability is conceptually linked to the institutional practices of law and education and is interpenetrated by the relevances of legislation. social policy. administrative decision-making processes, charitable fundraising. professional forms of organization. and so on. These discourses are not simply ways of understanding disability in various organizational contexts. they are brought into being as peoples' actual practices and they facilitate the ongoing coordination and articulation of various institutional sites.

Smooth institutional functioning depends on all members sharing the same vocabularies and work processes that accomplish the practices of ruling. i.e.. developing eligibility criteria for particular services, recognizing a legitimate case of "disability",

determining what constitutes an appropriate "accommodation", providing a properly authorized service, etc. Even women who are chronically ill typically organize themselves in relation to discourses of disability, and they take up the forms of subjectivity and agency they provide. For example, they may conform to prescribed medical regimens as "good" patients, they may "overcome" their illnesses by developing attitudes and coping mechanisms that promote "healthy adjustment", or they may define themselves as disabled in order to take advantage of legal protections and services for people with disabilities.

The coordination and interchange between different specialized institutions is dependent upon the systematic development of ideologies that provide categories and concepts that express the relation of local and personal courses of action to the institutional function (Smith 1987). These categories and concepts, as ways of "knowing", arise in the practical accomplishment of the institutional order and they provide procedures for subsuming the actualities of people's everyday lives. The actual activities and reasoning of chronically ill women in their local settings are "glossed" by institutional ideologies which substitute concepts and categories of a textually-mediated discourse for "actual relations, actual practices, work processes and organization, and the practical knowledge and reasoning of actual individuals" (Smith 1987:163). Typically, Smith notes, "work processes are reconstructed as social or psychological processes, depriving them of their necessary anchorage in an economy of material conditions, time and effort" (1987:163). For example, disabled student's difficulties at university may be attributed to the failure to "cope" by faculty, administrative staff, and disabled students themselves. "Coping mechanisms", which are part of the lexicon of adjustment psychology, however, may be more surely related to an individual's social situation, available resources, sources of support, familiarity with institutional processes, developed skills, and so on.

The Social Organization of Knowledge and Disability Studies

The problem of exclusion and discrimination as we experience it today, both in terms of the social organization of knowledge and disability studies, is "an integral aspect of the development of a capitalist mode of production" (Smith 1987:18). According to scholars in the field of disability studies, the social process of "disabling", as it exists now, is co-extant with industrialization (Abberley 1998; Davis 1998; Hahn 1998; Oliver 1991). The ranks of the disabled swelled, not only through direct causes such as poor health and accidents but through processes of standardization and practices of exclusion: i.e., the mechanization of production and the routinization of work excluded those who could not perform specific tasks (Hahn 1998); the standardization of the working day excluded those who could not keep pace with the 'average' worker (Barnes 1998; Davis 1998; Hahn 1998; Wendell 1996); and finally, the design of worksites and commodities to suit nondisabled workers and consumers excluded those who could not either access or use them (Hahn 1998; Roulstone 1998). "As a result, patterns of aversion and avoidance toward disabled persons were embedded in the construction of commodities, landscapes, and buildings that would remain for centuries" (Hahn 1998:177).

Exclusion, or discrimination, can be theorized from a number of different perspectives, i.e., from the point of view of class, gender, race, ethnicity, ability, and so on. In each case, even as particular groups are integral to the existence and functioning of a society, they may systematically be denied opportunities to fully and meaningfully participate in social production and reproduction. Even when they do contribute to the production or reproduction of social life, they are nonetheless excluded from "the work of producing the forms of thought and the images and symbols in which thought is expressed and ordered" (Smith 1987:18). In disability studies, much as in the social organization of knowledge, scholars take up the problem of the way in which particular kinds of exclusion are

continually reproduced in institutional practices and in way that particular kinds of people

are distributed in an educational system "that both reproduces and disseminates

knowledge, culture and ideology" (Smith 1987:18). Smith points out that even as women

have been excluded from positions of power in the various ideological apparatuses (i.e.,

the educational system, mass media, communications, etc.), they have nonetheless

participated in the making of knowledge and culture. In the same way, disability studies

scholars identify a long history of exceptional thinkers and artists who were either

chronically ill or disabled. For example, Davis asks,

> "How many people realize that included in the category of people with
> disabilities are: John Milton, Sir Joshua Reynolds, Alexander Pope, Harriet
> Martineau, John Keats, George Gordon Byron, Toulouse-Lautrec, James Joyce,
> Virginia Woolf, James Thurber, Dorothea Lange, Jose Luis Borges, John Ford,
> Raoul Walsh, Andre de Toth, Nicholas Ray, Tay Garnett, William Wyler, Chuck
> Close and many others?" (Davis 1998:4).

As Davis goes on to point out, none of these individuals is known for his or her disability.

He explains this phenomenon as a particular "erasure" of disability when other "stronger"

categories are present. This is similar to the "peculiar eclipsing" of women in the

dominant intellectual and artistic traditions which is accomplished by admitting

exceptional women to such circles "only by a special license granted to the [person] as an

individual and never as a representative of her sex" (Smith 1987:18). In the context of

disability studies, this "erasure" effectively reinforces the mistaken belief that people with

disabilities are unable to make significant contributions to traditions of learning and art, or

that people with disabilities are unable to participate fully in the social life of the

community.

The project to challenge and contest their exclusion from the making and

dissemination of knowledge and culture is not unique to disability studies. Indeed, the

words "diversity" or "multicultural" are just two of the terms used to denote various

curriculum endeavours that are designed to promote acceptance and inclusion by utilizing gender. race. ethnicity. sexuality. class and disability as analytic categories (Linton 1998: Thomson 1998). Of all these categories. disability is the most unstable category of all. As a category. disability is theoretically open to everyone: able-bodiedness is often. at best. a temporary condition. and "as populations age. disability becomes a more likely endpoint for any given individual" (Williams 1998:243). In spite of the inherent instability in the designation of this category. however. disability and chronic illness tend to be omitted from the "multicultural/diversity curriculum" in higher education (Linton 1998).

While the visibility of scholarship labelled as multicultural or diverse is increasing. there are very few genuine attempts to include and discuss the issue of disability (Meekosha 1998): most analyses are confined to the familiar recitation of gender. race and class. Even within the ranks of those who favour a more democratic curriculum – a curriculum that more accurately represents the perspectives and experiences of different. often excluded. groups – there is debate about whether or not disability is sufficiently central to the liberal arts or the social sciences to be integrated into the existing curriculum (Thomson 1998). Fears that the "diversity" agenda will become too inclusive "and will lose its potency if the category is too elastic" (Linton 1998:90). difficulty classifying in which fields and disciplines disability properly belongs. and "the persistent assumption that disability is a self-evident condition of bodily inadequacy and private misfortune whose politics concern only a limited minority" (Thomson 1998:282). all inhibit scholarly engagement with issues relating to illness and disability.

Even research in more marginal fields such as feminist studies. queer studies. cultural studies. and so on. have failed to recognize disability as a stigmatized social identity. and have failed to identify that the same logic that ranks people according to ability is also present in discussions about gender, ethnicity and race (Thomson 1998). For example,

even though "a large portion of the disability studies literature addresses women's issues. women's studies has been slow to recognize disabled women's issues and to integrate disability studies into its work" (Linton 1998:90). Given the dedication of feminist studies to challenge privileged discourses. feminist disability scholars note that it is disappointing that there is little. if any. engagement with disability as an axis of difference that is also related to the sexed body[23] (Asch and Fine 1998; Linton 1998; Thomson 1998; Wendell 1996). The failure to include disability within the women's studies' frame of reference is ascribed to the perception that feminists – who have struggled to prove that they can work as hard as or as competitively as men – are reluctant to retreat from the advancement of "powerful. competent. and appealing female icons" (Asch and Fine 1988:4). By dwelling on the body. feminists risk giving credence to explanations of difference that lead back to essentialism and biological reductionism (Meekosha 1998). Feminist disability scholars acknowledge that the demand for equality of opportunity may not accommodate the needs and capacities of women with disabilities. Chronically ill and disabled women cannot transcend their biology in the way that second wave feminism proposes (Asch and Fine 1998).

Although feminist thought has often ignored the suffering body. there are feminist disability scholars who argue that femininity and disability are inextricably intertwined in Western culture (Thomson 1998; Wendell 1996; 1998). Beginning with Aristotle's equation of women and disabled men. the female body – like the "disabled" body – has been represented as deviant and deficient. Just as the "Othering" of women's bodies is not an inevitable or natural outcome of biological difference. disadvantage does not necessarily follow from impairment. Rather. certain bodily configurations – those that do not match the norms represented as universal and general – become interpreted as deviant. These practices of interpretation – wherein features of an individual's appearance

or functioning are singled out and labelled as deviant or deficient – are social practices

that are embedded in broader social relations that "gender" and "disable" particular

individuals (Thomson 1998). This line of thinking amongst disabled feminists is

congruent with Smith's imperative to explore the multiple and sometimes contradictory

social relations that gender (or. in this case. disable) the particular local historical sites of

women's experience (1990b).

Conclusion

Smith's project is to demonstrate how. in the rational organization of ruling practice

and in the production of knowledge. unequal power relations become a built-in feature of

what appears to be "objectified. impersonal. claiming universality" (Smith 1987:4).

Where Smith points to a "gender subtext" in the ruling relations and in the production of

knowledge. disability studies scholars point to an "ablist subtext" that excludes people

with disabilities. Smith's contention is that by conforming to the systematically developed

concepts and categories. the established rules and procedures. and by adhering to the

standards that constitute competent and valid sociological research. the researcher

produces 'objective' knowledge that objectifies its subject matter – people – in ways that

make them "knowable" and. therefore, "manageable" for various professional

practitioners (Smith 1987:1996). Disability studies scholars agree: by using established

methods for collecting data and established conceptual procedures to interpret or analyse

it. even researchers committed to their 'client's' interests are led into producing accounts

that abstract the experience of disability from the social world in which it is produced. and

that reinforce the objectification of people with disabilities as "targets" of professional

practices. organizational processes. and social policies (Jongbloed and Crichton 1990;

Morris 1992; Oliver 1992). For disability studies scholars and the disability rights

movement. the efforts to "medicalize and psychologize the social and private realms" of the experience of disability are recognized for what they really are: "efforts to displace conflict. to neutralize and drain disabled individuals of all potential for protest. and to 'rehabilitate' bodies and minds to internalize a specific rationality upon which social and cultural reproduction is supposedly based" (Gadacz 1994:9).

While women. and chronically ill women in particular. have been "deprived of the means to participate in creating forms of thought relevant or adequate to express their own experience" (Smith 1987:18). they still need systematically developed thought and knowledge about the social world and about their disabilities and illnesses that reflects their own experiences. interests. and ways of knowing. Just as Smith writes about the importance of feminist scholarship. I would argue that women with disabilities need "a firmly grounded body of theory. of historical. psychological. biological and social scientific knowledge. of methods. of criticism and philosophical reasoning and critique" (Smith 1984:10). Chronically ill women need knowledge that "discloses connections and relations. makes the segregating barriers permeable and thin. forces the questions of humanity. of life. of caring. and of the unique person. to become the topics of public speech" (Smith 1984:12).

Developing a knowledge that reflects the experiences. interests and ways of knowing of people with disabilities. however. requires the researcher to start elsewhere than in the ideological understandings of chronic illness and disability as they exist in sociological or professional discourses. Smith proposes an enterprise to "make a sociology that will look back and talk back" (Smith 1987:8): to develop for people – and in this case for chronically ill women – "analyses, descriptions. and understandings of their situation, of their everyday world. and of its determinations in the larger socio-economic organization to which it is articulated" (Smith 1987:88). Institutional ethnography – proposed and

elaborated by Smith as part of this enterprise – is a research strategy that focusses on people's actual everyday activities and experiences. and which commits the researcher to explore. describe and analyse the complex of relations in which the subject is embedded. from their point of view. In the next chapter. I discuss the three main procedures entailed by institutional ethnography. and I explain how I have used them in my own research process.

Chapter Three

RESEARCH METHODOLOGY

Introduction

In this chapter. I discuss the research methodology that I use. Discovering the way in which broader social. political and economic relations organize. control and give shape to the local and particular experience is based on a research strategy known as institutional ethnography. Smith's ontology of the social as "a concerting of activities that actually happens...in time and in actual local sites of people's bodily existence" (Smith 1999:97) directs the researcher's attention towards the activities. experiences and routines of actual women in the everyday world. By concerting. Smith means that the activities of individuals in their own local settings are not only purposive and planned. they are also actively coordinated with. oriented to, and co-determined by the activities of others in multiple far-flung sites which. together. produce a world in common. Experience. as it is spoken. bears traces of the social relations and processes that generate the bases of our experience, i.e.. that organize and determine the conditions of our action and give form and shape to our purpose. The strategy of institutional analysis aims at explicating the generalized bases of the individual's experience. including the experience of oppression.

The work of exploring the social involves what Smith calls "explication". as the researcher is invited to explore and then make visible how sets of interlinked institutional relations generate "the everyday bases of actual experiences. in characteristic ways" (1987:176). Smith's aim is to "disclose the social process from within as it is lived" (1987:177). Explication revises the relations of knowing by always returning the analysis to a standpoint in the actualities of people's lives: providing a means by which "people's own good knowledge of the local practices and terrains of their everyday/everynight

living" is extended. "enlarging the scope of what becomes visible from that site. mapping the relations that connect one local site to others" (Smith 1996:188). Such an inquiry intends to be useful. By showing how the everyday world is put together. and how everyday activities and routines actively accomplish the institutional order and bring into being those generalizing social relations that stand over against us in a relation of dominance and authority. Smith's sociology provides "maps" that can be used to "reform the social terrain" or to "move successfully through the actual. physical world they represent" (McCoy 1999:38).

The work of tracing the social relations that organize and order the locally situated experience involves three main steps. Summarized briefly. they include:

1) Use of a generous notion of 'work' that enables the researcher to engage with the ways in which people are actually involved in the production of their everyday world. examined with respect to how that world sustains and is organized by the institutional process. It is these work processes that "ideology analyses. interprets. and hence renders accountable within the institutional process" (Smith 1987:166-167).

2) Analysis of the ideological procedures through which "work processes and other practical activities are rendered accountable within the ideological schemata of the institution" (Smith 1987:176). Ideological procedures are constituents of the social relations articulating the actual work processes of actual individuals to the institutional function (Smith 1987).

3) Lastly. the concept of social relation is used to analyse the coordinated sequences of local work processes that articulate to and are determined by the generalized and generalizing relations that bring into being the everyday world as we know it and live it. The individual's locally situated work "is articulated to such concerted sequences of

action. performed by more than one and perhaps sometimes by a multiplicity of

individuals not necessarily known to one another" (Smith 1987:167). I will take up each

of these three procedures. in turn. and explain how I understand and use them in what will

follow.

Institutional Ethnography: Procedures

The Generous Notion of 'Work'

Rather than starting in the professional or academic literature regarding chronic

illness. this inquiry begins in the work and practical reasoning of actual women as they go

about their studies. While "work" is considered in its usual taken for granted sense - as

the work of instructors. administrators and coordinators - Smith is especially conscious of

work "essential to the accomplishment of accountable order. that is not itself made

observable-reportable as work" (1987:165). Therefore, work and its observability is not

defined by the categories. concepts and functional boundaries of institutional ideology.

Instead. the concept of work "is extended here to what people do that requires some

effort. that they mean to do. and that involves some acquired competence. The notion of

work directs us to its anchorage in material conditions and means and that it is done in

'real time' - all of which are consequential for how the individual can proceed" (Smith

1987:165).

Practical reasoning is also work in the Smithian sense. Harold Garfinkel describes

"practical reasoning" as: the temporal concerting of activities: knowing "what to do

next": giving evidence of the grasp of "what anyone knows". or commonsense; being able

to demonstrate the way in which the indeterminate "actual situation" is reordered and

"written up" in order to ensure the objective, effective, consistent. completely, empirically

adequate. i.e.. "rational character" of the personal and organizational "use of the rules":

making visible the subject's "system of alternatives". "decision-methods". "information".

"choices"as constituents of the same practical circumstances wherein the work of inquiry

is being done (Garfinkel 1974:96-97). The concept of practical reasoning as work makes

use of what ethnomethodologists call "accountability". which identifies individual's

methods of accomplishing the intelligibility. meaning. and orderliness of their actions and

choices in particular institutional contexts. That is. accounting for one's actions and

experience can be seen as both reflecting and intending the categories and concepts of the

institutional ideology. Once again. the way in which individuals act. interpret or explain

their actions actually brings into being generalizing institutional processes and

accomplishes the institutional course of action in the local setting.

Analysis of Institutional Procedures and Ideological Practices

Smith uses the term "institutional" or "institution" to reference those processes of

administration. management. government and professional organization which "together

organize. coordinate. regulate. guide. and control contemporary societies"(1987:152). As

a "functional complex". "coordinating multiple strands of action and knitting local lives

and local settings to national and international social. economic and political processes".

institutional processes perform the work of ruling (Smith 1987:154). The coordination of

institutional processes is always mediated ideologically, i.e.. through the use of concepts

and categories which serve to organize and order the expression of the local, particular.

and directly known into forms concordant with the interests and aims of the institutional

function. Members routinely acquire these ideologies as methods of analysing their own

work and experience in order to make them recognizable within the institutional order.

Ideological categories and concepts. however. stipulate particular boundaries of

observability that take up and account for selective aspects of people's experience and

activity and discount or discard others. The local work process itself remains indivisible.

but only parts of it become "observable-reportable" within the institutional order (Smith

1987). The "categories and concepts of ideologies substitute for actual relations. actual

practices. work processes and organization. and the practical knowledge and reasoning of

actual individuals. the expressions of a textually mediated discourse" (Smith 1987:163).

In other words. institutional ideologies specifically obscure some of the work processes of

actual individuals. These work processes. Smith maintains. become reconstructed as

social or psychological processes. thus "depriving them of their necessary anchorage in an

economy of material conditions. time and effort" (1987:163).

Social Relations as Concerted Courses of Action

Social relations remind the researcher that it is not only "sensuous human activity"

that brings the everyday world into being. it is the concerting and coordination of those

activities. "or as Marx and Engels put it, the forms of cooperation" (Smith 1987:123). In

institutional ethnography. the notion of social relations is used in "a practical manner" as

a method of looking at how individuals organize themselves vis-à-vis one another (Smith,

G. 1995:24). The concept of social relations. as Smith uses it, expresses "a commitment

not to reduce the social to properties of individuals or to reconstitute it as a supra-

individual blob" (Smith 1999:7). Social relations, therefore. do not refer to relations of an

interpersonal variety. Neither do they ascribe causal agency to social structures or social

institutions. Social phenomena and circumstances do not "just happen"; they must be

actively brought into being through the concerted and coordinated activities of actual

individuals in their different local settings.

Because texts are "active constituents of social relations [and] can iterate the particular

configuration of their organization in different places and at different times. thereby

conceptually coordinating and temporally concerting a general form of social action"

(Smith. G. 1995:24). documents and texts are a particularly important resource in

institutional ethnography. Smith uses the metaphor of DNA as an illustration of the way

socially organized knowledge that is "invented in one site of ruling" is "packaged in

texts". and which then goes on to both transmit and replicate its social organization in

multiple far-flung sites, regulating local activities and organizing relations among

particular people (Smith 1999:93-94). Textual practices provide the means through which

the social and physical worlds are represented as the objects of administrative and

professional action (McCoy 1999). The conceptual frames used to construct particular

texts and the interpretive practices required to read and correctly understand them are

themselves constituents of social relations and can be investigated as such.

Methodological Implications

Generalizability

The concept of social relations is crucial in bypassing one of the problems of

traditional ethnographies[24] which, while providing useful and fascinating accounts of

people's lived worlds. cannot "stand as general or typical statements about society and

social relations" (Smith 1987:157). Beginning with "the everyday world as problematic

bypasses this issue. The relation of the local and particular to generalized social relations

is not a conceptual or methodological issue, it is a property of social organization" (Smith

1987:157). The ordinary talk and ordinary descriptions that individuals use in accounting

for their actions and experience in their everyday lives. "trail along with them as a

property of the meaning of their terms. the extended social relations they name as

phenomena" (Smith 1987:157). Individuals routinely acquire and then use ideological

concepts and categories to account for their actions and experiences. and to accomplish.

for themselves. the orderliness and sense of local events and processes. "Insofar as the

informant is speaking with the terms and relevances of her own life. she brings into the

researcher's presence the actual social organization of that experience" (Campbell

1998:60). along with the generalized and generalizing social relations in which they are

embedded.

Validity

The methods of institutional ethnography are not confined to methods of observation

and interviewing. Because of the commitment to "an investigation and explication of how

'it' actually works. of actual practices and relations". methods include observation.

interviewing. recollection of work experience, informal conversations. use of personal

experience. use of archives and textual analysis (Smith 1987:160-161). Data collection. in

institutional ethnography, does not proceed on the basis of a standard protocol or a

preconceived research plan. Rather, data collection is designed to extend the researcher's

working knowledge of the subject's local setting and of those relations and processes that

penetrate and organize it. Because there is no "implication that a social reality is fixed or

final". issues of validity always involve "reference back to those processes themselves as

issues of 'does it indeed work that way?'" (Smith 1987:160). Instead of grappling with

issues at the level of "truth". the products of this kind of inquiry are assessed in terms of

whether or not they make sense, or whether or not they adequately account for the character of the organization and relations investigated (Smith 1987). Validity, for Smith, relies on the possibility that others could return to the object of inquiry and could either confirm that "yes, it does indeed work in that way", or "no, it does not work like that, but like this". In other words, validity means being able to conduct "an inquiry oriented by prospective questions from others" (Smith 1987:127): an account "that can be checked back to how it actually is." (Smith 1987:122).

Questions of Sampling

Smith's social ontology and research strategy, where the ongoing co-ordering of actual activities accomplished in definite local historical settings is the focus of attention, also bypass the traditional sociological problem of the representativeness of the sample. Smith argues that questions of sampling arise only "as issues of generalizing statements to a population" (Smith 1987:186). In other words, the "multiple perspectives of subjects, the multiple possible versions of the world arising in subjects' experience, create a problem for sociology only when our project is to establish a sociological version superseding theirs" (Smith 1987:141). Where established methodologies are concerned to construct a "third version out of contending versions and thus [constitute] the objectivity of the world as a product of inquiry" (Smith 1987:127), "the problematic of the everyday world arises precisely at the juncture of particular experience, with generalizing and abstracted forms of social relations organizing a division of labour in society at large" (Smith 1987:157). Experience, as the point of entry into larger social and economic processes, shifts the researcher's concern from the "case" to the "actual social relations as these arise in the articulation of work processes and work organization in one setting to those of others"

(Smith 1987:175). It is *not* the goal of institutional ethnography to uncover generalizing concepts. to make general statements about society. or to describe the "typical" features of a population. etc. (Smith 1987:157-158). The intent of an institutional ethnography is to uncover the ordinary invisible determinations of the everyday world in relations that generalize and are generalized.

While institutional ethnography investigates and explores the complex of social relations beyond the scope of any one individual's experience. it does not aim at disclosing these in their entirety. Such a project is beyond the scope of any one researcher or research project. The boundaries of the inquiry are to be recognized as artificial boundaries of convenience (McCoy 1999), allowing the researcher to focus on particular relevant work processes and not on others. In this inquiry. I focus more narrowly on the processes involved in requesting and obtaining academic accommodation for students who are diagnosed with chronic illnesses such as rheumatoid arthritis. Ideally. Smith notes. an institutional ethnography is not intended to be "a solitary pursuit or a single fieldwork enterprise" (1987:177): instead. it is far better to take up a number of different viewpoints "from which the workings of a whole complex of relational processes come into view" (1987:177).

The Research Problematic

Using an institutional ethnographic approach – by working through interviews and textual analysis – this study explores the way in which the institutional practices and processes of the university. especially the Policy on Providing Accommodation for Students with a Disability (rev. 1997). regulate and organize the individual woman's personal experience of being chronically ill as a student. I have chosen to focus on the

problem of accommodation because it is the official organizational basis from which accessible and inclusive post-secondary education for people with disabilities is intended to proceed. As a complex of practices and decisions that are enacted by particular individuals in the organizational setting of the university. the formal policies and procedures for providing accommodation intervene in and organize the lives of women who are chronically ill. The success or failure of these policies and procedures are consequential. Denying or extending accommodation can make the difference between "dropping out" and succumbing to the accumulation of disadvantage that disability entails. or obtaining an education that can provide opportunities for flexible. professional. and well-paid employment. Participating in post-secondary education also provides the means by which chronically ill women can ultimately participate in the production of knowledge that reflects their own interests. experiences and ways of knowing.

There are two distinct directions that this inquiry has taken. The first involves discovering the actual work processes of women who are chronically ill as they go about obtaining a university education. In the second, I have explored the "disabilities apparatus" at the University of Victoria: problematizing the notion of "accessibility" and "accommodation": discovering the actual activities that led to the review and revision of the Policy on Providing Accommodation for Students with a Disability; examining the policy: and discovering the range of services that the university provides for disabled students. These two aspects of the inquiry are qualitatively different and have required different data gathering techniques. The first aspect relies on in-depth, open-ended and reflexive interviews, informal conversations, observation. and reflection on personal experience. The second aspect involves some archival research. textual analysis of the policies and procedures of the university, and some interviewing.

Although these data-gathering techniques are shared with other qualitative research strategies that seek to capture experiences that cannot be meaningfully expressed with numbers. institutional ethnography is significantly different. Unlike phenomenology. ethnographic fieldwork. participant-observation and other informal research techniques. collecting accounts of informants' own lives and their personal experiences is not the "object" of the research. Observational and interview data merely provide an entry point into an analysis of the social relations that organize. regulate and determine the everyday life of the informant. Instead of the "customary sociological interest in studying groups of people". institutional ethnography focuses on "institutions as functional clusters of extended relations"(McCoy 1999:42). People, themselves. are not the object of the research. Also. those people who talk with the researcher. or show how things are done. stand in relation to the research as "knowledgeable informants". Campbell writes that "the key assumptions within institutional ethnography are that people are experts in their own lives. are located in different places (social locations) in society and that external forces (e.g.. government mandates, organizational rules) enter and influence how one's life is lived and known" (Campbell 1998:96).

Starting in the Everyday Lives of Women

Working with an "insider's standpoint" is one of the key features in Smith's sociological enterprise. Here. women are "experts" in their own lives and the everyday world is the world that they experience directly (Campbell 1998; Smith 1987). In the methodical telling of their experiences, chronically ill women disclose an "organizing 'logic'[that] is located elsewhere than in [their] own activity and experience" (Smith 1987:96). That is. their talk "expresses" the social organization and the relations of the

university setting. To the institutional ethnographer, the personal account reveals the way in which the chronically ill individual's choices and courses of action become bound up in and shaped by the organizational practices and wider social relations that regulate and organize the experience of illness and disability.

Speaking from experience is "a method of speaking that is not pre-appropriated by the discourses of the relations of ruling" (Smith 1997:394). For Smith, talk is saturated not only with meaning but with social relations: "how people talk, the categories they use, the relations implicitly posited among them, and so forth, and in what is taken for granted in their talk, as well as in what they can talk about", gives direct access to the necessarily social character of people's worlds (Smith 1997:394). Smith argues that "the way terms are used in their original context, including their syntactic arrangements, is 'controlled' or 'governed' by its social organization and that the same social organization is present as an ordering procedure in how people tell others about that original setting" (Smith 1987:188). In institutional ethnography, the researcher's analysis depends on the understanding that competent practitioners know the order of talk required and are able to "make sense" in referencing the social organization of which they are a part.

The Research Process

This research project had three phases. Phases, here, refers more to a way of conceptualizing the research process, rather than to discrete stages or sequential steps that are anticipated ahead of time. Summarized briefly, the first phase started in the "everyday" world of women with chronic illnesses as they go about the "work" of obtaining a university education. This process involved in-depth, open-ended, and

reflexive interviews wherein the research participants talk about their lives. their experiences. their troubles. and their activities.

In the second phase of the research. the transcribed interviews were analysed to discover work processes that chronically ill women routinely engage in. and the "organizing 'logic'[that] is located elsewhere than in an individual's own activity and experience" (Smith 1987:96). In other words. the talk and actions of women with chronic illnesses "are conditioned" by the actual social organization of their experiences. thereby providing an "entry point" into the social relations in which their experiences are embedded (Campbell 1998). The work processes that were discovered and followed provided the direction for the final phase of the research process.

In the third and final phase of the research. the various organizational practices and processes of the university – especially the operations of the Office for Students with a Disability and the Policy for Providing Accommodation to Students with a Disablity (rev. 1997) – were analysed and explicated. Because the goal of this exploration. as George Smith has written. is to "extend my working knowledge of [the university as] a regime" (1995:31). this phase of the research involved textual analysis of the institutional policies and interviews with instructors, administrators, and resource personnel who provide assistance to people with chronic illnesses and disabilities. In this phase. I conducted three formal interviews (with the Coordinator for the Office for Students with a Disability. a service-provider for the OSD, and the Ombudsperson) that were tape-recorded and subsequently transcribed. and I compiled notes from innumerable informal conversations with instructors and administrative staff. The interviews conducted here were qualitatively different from those with chronically ill women: they were oriented to extending my own knowledge of "how" the university's disability policy is organized,

how its administrative processes unfold. and how policies and regulations are brought to bear on particular kinds of problems. I also examined the various reports. audits and assessments performed by the university during its review and revision of the Policy on Providing Accommodation for Students with a Disability (rev. 1997). It is in this phase that the institutional procedures and ideological practices of the university. as part of the university's "disability apparatus". can be analysed to show how chronically ill women's actions actually accomplish and bring into being the institutional order. My analysis demonstrates how the "order" that is explicated here is that which the research participants know and live. and how it is the same "order" that is referenced and expressed in their stories and talk.

Interviewing and Transcribing

The overall intention of in-depth interviewing[25] was to elicit accounts of chronically ill women's routine work processes and experiences of university life. The interviews were open-ended and lasted from sixty to ninety minutes. With the interview informants' permission. the interviews were tape-recorded and subsequently transcribed. The point of entry to the interview itself was focussed around the experience and work of being a student: how the work of being a student is practically accomplished; how the informant "knows" and "understands" what is relevant to her particular case; what the student must do to coordinate her action to the temporal sequence of activities at the university; what kinds of difficulties arise for the student and how these are addressed. While the interviews were structured around a narrative account of a typical university term, the informants explored the meanings of their illnesses, they provided historical accounts of their entry into the university, they talked about the material conditions of their lives, their

available resources (sources of financial. material and emotional support) and they recounted and described their "troubles".

In the analysis of these interviews. I resist interpreting the relative success of particular students. as opposed to the more labourious struggles of others. in terms of their personal attributes and individual competencies. Following Smith. I seek the objective correlates of their private experiences. For example. instead of interpreting the pervasive experience of anxiety as evidence of psychological disturbance. I look for the work processes that chronically ill women are engaged in, i.e.. that are necessarily anchored "in an economy of material conditions, time and effort" (Smith 1987:163) and which proceed under conditions and presuppositions over which chronically ill women do not have control.

All of the formal in-depth interviews were tape recorded and subsequently transcribed verbatim[26]. Informal interviews and conversations were recorded much more informally in handwritten note form. Liza McCoy (1999) notes in her review of institutional ethnographic research. that interview material is used in two different and distinctive ways. In the first. the understanding of the institutional process gained through the interview informs the researcher's writing but the interview informant does not "'speak' directly in the analytic text" (McCoy 1999:46). In the second. excerpts from the interview transcripts are incorporated into the written analysis, allowing interview informants to "speak" for themselves. In my use of interview data, I have used both of these practices. For the most part. interview informants have enriched my understanding and knowledge about the experience of chronically ill women who are students. As I proceed with the research analysis in the next chapters, I use and incorporate this understanding and knowledge directly in my writing. There are times, however. when the voice of the informant, "speaking" in the text[27]. is more effective in communicating a particular point.

I have been less concerned to "distribute" the excerpts equally amongst the informants than I have been to choose those "stretches of talk" that reference particular social relations that organize and coordinate the everyday experience of chronically ill women. Quotes. or excerpts. are not intended to "illustrate" the points that I make or to convey idiosyncratic details of particular events: they are intended to reflect women's tacit knowledge of the organization of the relations that provide them with accessible education and reasonable accommodation. These stretches of talk bring into view the disjuncture between the locally situated and reflexive knowledge of accessibility and accommodation as women themselves experience and can speak about it, and the objectified and ideological knowledge of accessibility and accommodation as it is contained in the official policies and procedures of the university.

Textual Analysis

"Experience. as spoken. is always social and always bears its social organization" (Smith 1999:96). Institutional ethnography starts in the everyday world of experience but explores beyond it (Smith 1999). "Beyond it". refers to the social relations and organization of consciousness. externalized and objectified in texts. Integral to *both* the ruling apparatus and to the accomplishment of order and intelligibility in our own everyday lives. these textually vested forms of communication and action have a "curious capacity to reproduce [their] order in the same way in an indefinite variety of actual local contexts" (Smith 1990b:2). For Smith. texts refer to any representation that is relatively stable or fixed and that can be reproduced. i.e.. printed verbal or visual material on paper, on computers screens and printouts. television, and so on.

The text is not a dialogue in the ordinary sense of the term. While the text. like a

dialogue. presupposes an essentially social act between a speaker/writer and a

reader/hearer using "the virtual space of a world recognized and known in common"

(Smith 1999:128). the text is – more or less – fixed and infinitely replicable. and thus

capable of constituting social relations amongst people not necessarily known to one

another. across time and space. Detached from the local historicity and activity of its

making. separated from locally situated speakers and writers. the text nonetheless

becomes a dialogue in which it "speaks" to us and we respond. albeit at different times

and in different places. The materiality of the text. its reproducibility. and the organized

practices of its distribution are fundamental to the coordination of social courses of action

though which institutional order. and the relations of ruling. are organized and

accomplished (Smith 1990b).

The notion of a text-reader conversation is therefore central to textual analysis,

instructing the researcher to direct attention both to the text and the conceptual frames

used in its construction. and also to the skills and competencies that it requires of the

reader. i.e.. the activity of producing the text and the activity of reading it. "Reading is

not entirely in the text, for at the point of reading. the reader both activates the text and is

responding to it" (Smith 1999:145).

Textual analysis requires the researcher to look for the structure or organization

underlying the form of words that the text contains (Smith 1999). This means looking

beyond the fixity or artifice of the text to make visible the socially organized activities

that produced it: to look for and at the practical organization of the ideas. concepts,

symbols. vocabularies, and images that it employs as a means for us to think about and

understand our world (Smith 1987:54). These aspects of language, contained within texts,

have a central and crucial role in the organization of the relations of ruling. They act as the "carriers of inter-individual organization of consciousness" (Smith 1999:144). and can be investigated "as socially organized practices...taking place in real time and in real places. and using definite material means under definite material conditions" (Smith 1999:49). Smith's understanding of ideology as practical organization. means that through the text we can "examine who produces what for whom. [and] where the social forms of consciousness come from" (Smith 1987:54).

Properly activating or "operating" the text requires that the reader bring particular competencies to the text in order to understand or analyse it. The text is produced to intend the particular interpretive practices and specific usages of its reading. In other words. the text sets an agenda that provides instructions on how to read it and it reorganizes or subsumes our prior knowledge. The interest in texts may be various. but textual analysis as Smith uses it "must explain how the text as petrified meaning structures the reader's interpretation[28]" (Smith 1990b:223) and how its meaning organizes the reader's subsequent actions. Asking questions such as: Who it the text written for? What does the text do? Who else might read it? Where will it go?. reminds the researcher that the text is active. that it is entered into particular sequences of action.

Conclusion

In summary: I have described and discussed the research strategy of institutional ethnography as I have understood and used it to explicate the social determinations of the particular and local experience of chronically ill women who are students. In the next chapter. I set the stage for my analysis by discussing the emergence of "accessibility" as a problem in postsecondary education. by describing the administrative apparatus of the

University of Victoria that manages the "needs" of disabled students. and by introducing

the research informants themselves. Following this. I present my findings and my analysis

of this investigation. My work of enquiry. insofar as possible. has been structured by

Smith's prescription - to investigate the social relations and ideological procedures as

actual practices of concrete individuals. Taking the everyday world as my problematic. I

have sought out "the 'inner' organization generating its ordinary features. its orders and

disorders. its contingencies and condition. and [I have looked] for that inner organization

in the externalized and abstracted relations of economic processes and of the ruling

apparatus in general" (Smith 1987:99).

Chapter Four

THE ORGANIZATION OF THE "DISABILITIES APPARATUS" OF THE UNIVERSITY OF VICTORIA

Introduction

In this chapter – corresponding to the two directions that the inquiry has taken – I discuss some of the common characteristics of the research informants and I describe the social organization of the disabilities apparatus of the University of Victoria. My intention. in this chapter. is to begin an analysis that juxtaposes the local and particular experience of chronically ill students over and against the objectified and institutional processes of the academy. By the conclusion of this chapter. I will have acquainted the reader with the various social situations of the research informants and I will have described in detail the disabilities apparatus of the University of Victoria. More importantly. I hope to bring to the reader's attention the disjuncture between women's experience and the operations of the institution, and to call into question the commonsense understandings of "accessibility" and "accommodation" in use by students, faculty. and administrative staff.

While my primary research interest is in chronically ill women's experiences of accessing the disabilities apparatus of the university, in this chapter I want to sketch in, very briefly. the background conditions of their lives and the varieties of their social situations. In general terms. while their specific circumstances and resource conditions are unique. the women I interviewed also share many of the defining features of the experience of disability. i.e.. in societal relations predicated on the capacities and needs of the "ablebodied". physical impairment predisposes very different women, from disparate backgrounds. to experience the similar economic disadvantages, social constraints and negative personal consequences that are associated with disability. My aim in this

introduction. however. is not to scrutinize chronically ill women as a group. but to pay

attention to those struggles and troubles that chronic illnesses give rise to. especially as

they relate to the experience of pursuing postsecondary education.

To provide the context for the development of a disabilities apparatus as part of the

administrative regime of the university. I present an historical overview of the emergence

of accessibility as a problem for postsecondary education in Canada. The initial

institutional interest in accessibility was prompted by the recognition that in spite of the

growth and increase in numbers of students enrolled in postsecondary education, some

groups – women and people with disabilities amongst them – continued to be under-

represented in the university system. Accessibility is the frame used by policy makers to

formulate various "solutions" to problems of exclusion and discrimination experienced by

particular groups of people. i.e.. aboriginals. women. visible minorities. and the disabled.

Currently. equitable access to education and the right to accommodation are protected by

the B.C. Human Rights Act (Section 3) (1992 amendment) and the Canadian Charter of

Rights and Freedoms (1981). In this chapter, I discuss the disabilities apparatus which has

been instituted as the University of Victoria's organized response to its new legal duty to

ensure that people with disabilities are afforded genuine opportunities to participate in all

aspects of university life. Specifically, I outline the services and resources provided

through the Office for Students with a Disability and the Resource Centre for Students

with a Disability. and describe, in detail, the Policy on Providing Accommodation for

Students with a Disability (rev. 1997). Here, I use the data that I gathered to "sketch in"

my own knowledge of the social organization of the university as a "politico-

administrative regime" (Smith, G. 1995): I draw on the university's academic regulations,

the Policy on Providing Accommodation for Students with a Disability, the numerous

audits. reports and studies conducted by the university's Interim Committee on Disability

Issues. and the interviews with the Coordinator for the Office for Students with a

Disability. the Ombudsperson. and the Equity Officer.

The Research Informants — Women Students with Chronic Illnesses

After obtaining approval from the University of Victoria's Ethical Review Committee.

six women with chronic illnesses were interviewed. The women were selected, not as

representatives of all women who are chronically ill students but as knowledgeable

informants who could tell me about their experiences as students in relation to the

instructional and administrative operations of the university. In this inquiry, my point of

entry was the everyday work that chronically ill women must do in order to obtain a

university education. Structured loosely around an account of a typical university term.

the informants talked freely about their experiences. activities and troubles. Each woman

recounted multiple experiences with requesting and obtaining accommodation; some

good and some bad. some through formal channels and others through more informal

ones. Indeed. one of the informants had never submitted to the formal institutional

policies and procedures for receiving accommodation and one informant had only

occasionally and informally approached particular instructors or administrators when

assistance or accommodation was deemed absolutely necessary. While each informant

had her own particular understanding of the aims and uses of the Policy for Providing

Accommodation for Students with a Disablity (rev. 1997). and while each had

experienced accommodation in completely different ways, they nonetheless all depended

on some form of accommodation to remain engaged in their studies and they all

referenced the university's policies and procedures in their ordinary talk about their experiences at the university.

As they talked about their experiences. the informants touched on all the familiar themes and topics that arise in the academic literature about people with chronic illnesses and disabilities: living with the fundamental conditions of an impaired body and the accompanying restrictions in ordinary role performance irrevocably altered their relationships. work. self-identity. goals and aspirations. Although these changes were usually spoken about as losses. the informants also insisted that chronic illness leads to opportunities for change. The decision to pursue postsecondary education was foundational to this sense of opportunity. While all the research informants shared a similar sense of positive anticipation with regard to postsecondary education. their experiences differed considerably. Some of the women experienced a certain qualified success in their chosen courses of study, reporting confidently about their achievements and competencies. Others were more circumspect: learning through trial and error and persisting through difficult times and succeeding in better times. Still others told about their frustrations. struggles and failures. Three students were working on their second and even third degrees. two had graduated with their Bachelor's degrees. and one was still working her way towards her first degree.

The commonalities in the experiences of chronically ill women were that they all reported the experience of struggle: they suffer from unrelenting fatigue and pain throughout the course of the day; their educations take years longer than the "average" student; they struggle with sitting for long periods, taking notes. typing, walking across campus. and from class to class; they cannot bend or kneel when doing research in the library; completing assignments and courses requires marshalling extraordinary resources

of time and energy and usually results in the exacerbation of the disease process afterwards; they experience feelings of social invisibility; they are often lonely and isolated because they do not have the time or energy to make the same social connections and friendships on campus as do other students.

In addition to the ordinary everyday work of being a student they also had to perform the peculiar work entailed by being chronically ill: keeping regular physiotherapy, acupuncture, counselling, and other various appointments: learning about their bodies' limitations: learning to relinquish familiar roles and control over the course of events in their lives: attending to medication regimes that require "shutting down" for a portion of the day; doing exercises to stay flexible and maintain their mobility; and finally, but most importantly, observing a strict economy of time and effort where rest is central in preventing the exacerbation of the disease process and in maintaining the overall well-being of their bodies.

The process of obtaining a definite diagnosis for most of the informants, was in and of itself, an intensive work process: of self-education. seeking medical assistance, finding the best treatment modalities, and so on. The excerpts below outline some of the work processes entailed by becoming chronically ill below:

Anne: "*It happened quite suddenly, not knowing what it was. diagnosis took a while...it seemed like a combination, so diagnosis was a big deal for me. not fitting any of the boxes real well, treatment, not sure if it was working but gradually improving over the years... When I realized that things were not getting to where I thought they should - that things didn't feel right, didn't fit, and I needed better answers. I went into a great amount of research on my own and had a lot of contact with the medical system and had a fantastic doctor who fed me to all the right people to talk to, and go through research, and do some tests. So I've been quite involved and have had incredible success because of that extra work that I did. Finding out that, yes, the majority of people fit into the boxes but then there are all these other results and those are real people, real cases. And what do you know? Looks like I'm one of those. And that took a lot of work and a lot of time away from my degree... and I can see that I was looking healthy and being treated with a*

lot of skepticism by the doctor. And then I realized that I was being compared to, for the large part, probably a very elderly population that was coming through the door. Things like, well, you're my best patient, you're doing great. And then finally when it comes down to pushing the point, that I can't walk to that corner, there's something very wrong here. So yes, those kinds of issues definitely played themselves out, the whole doctor-patient relationship, which has consequences in itself. So I went along for a long time thinking that I was doing great because I was told that I was. And that meant that I didn't have to panic quite so much...because you want to reduce that fear so much..."

Corina: *"Well I started my course two years ago in September. So that was in 1998 that I started the course. And I had problems with my hands then. So it was July before that, that I started having problems. So in September, my forearms were really sore, and they thought it might be tendonitis ...I was seeing a G.P. and she sent me to the hand therapy clinic and that was basically a waste of time. So then I went to another doctor who sent me to another GP. I changed because I didn't like what she was telling me. So the new one sent me to the Rehab and that was a waste of time because my hands never changed. So I quit doing that then I went to a sports medicine doctor and she sent me for all kinds of tests. I got X-rays on my hands and blood tests, and all the stuff they do, and they did the dye test, and she figured it was some form of arthritis and... Because I did the test, the strength test to see how much strength I had, and I didn't have any. And she couldn't believe that I would have that little strength in my hands and that's when she figured there was something wrong. So she sent me to a specialist. Of course I had to wait 6 months to see him. ...So, my hands started hurting me in September, it was the next July that I finally got a diagnosis. So almost a year to get the diagnosis...now we have a label and now we know and he's put me on medications and stuff. So and given me a book on it, and stuff, and like it scares the devil out of you. So you do what you need to do."*

Leslie: *"the way I was diagnosed was as totally unprofessional as it could possibly get....somebody who did the blood test, stuck my blood in the refrigerator in the university hospital....and the rheumatologist went off on holiday for 3 weeks. So I didn't know what was going on. I didn't know if I was going to drop dead the next day, or there would be nothing wrong. So after several phone calls to the hospital, I discovered.... finally I asked what was going on, and why was it taking so long, so then through this process of events, they found that they had somehow stashed away this sample. Needless to say, I was getting to the point of being really irate, and I felt totally abandoned. You know, I was really scared... So with this diagnosis, and being treated the way I was, and one thing that just clicked in for me that was just so totally, it was like someone gave me the right set of keys for the door that was to open... I took it upon myself to say -- hey, this is your opportunity, girl, go to it. Find out everything and anything alternative, whatever works. So in keeping well, I had to think, I made myself a list of all the different alternative therapies and I tried a bunch of them."*

Jody: "*I was 29 when I had my first symptoms. and in the year that I turned 32 I left my job... and that was the beginning of a 5-7 year cycle that was very difficult for me physically, and also emotionally and spiritually. I was not well most of the time, my disease was not well controlled. And every time I saw a rheumatologist it was "let's give you another drug". And I really hated that. Part of it because I didn't like the idea of eating a lot of drugs but also because it was expensive. And of course. I have to put in time and energy to take care of my health, right, so that's a whole other topic. What's not factored into the material conditions of living with a disability is the actual time and energy it takes so that I can keep doing what it is that I want to do, right*"

All but one of the women I interviewed applied for admission to university during or after the onset of illness. All but one returned as "mature" students: in their mid to late twenties. thirties and forties: times where most women expect to be independent and productively engaged in paid employment, childrearing. household management, or a combination of all three. Two of the women lived at home with parents, one was married. one lived with a partner but had spent the majority of her student life alone. and two of the women lived alone. The women who lived at home did so out of necessity rather than choice. and were aware that while living with parents reduced their isolation and allowed them a more comfortable standard of living, they had forfeited their privacy and sense of independence or autonomy. For the women living with partners. social isolation and poverty are similarly mitigated. but a whole new dimension of negotiation of roles - especially gendered roles - and the actual 'work' required to sustain a relationship are added to the work of being a student. The experience of living alone, for the remaining two women. was characterized by frequent expressions of loneliness and worries about money. and gave evidence of a much more labourious struggle through university as well.

The onset and course of illness. for all of the women interviewed, disrupted their participation in the paid labour force: none of the research informants was engaged in regular. full-time. paid work. All of the research informants. however, performed modified work of some kind. Three were working in practicum or co-operative education

placements as part of their chosen courses of study. Two were engaged in paid-work on a casual or part-time basis, and one research informant worked infrequently as a part-time volunteer. Because these alternate forms of labour-force participation do not lead to financial self-sufficiency, all of the research informants relied on supplemental or alternate sources of income. One research informant depended wholly on student loans for financial support. One depended primarily on spousal support. Another informant received a combination of social assistance benefits and parental support. Three received disability pension benefits[29]. It is important to note that disability pension benefits are calculated on the basis on years in employment and level of income at the time of exit from the paid workforce. Women whose labour force participation has been interrupted by childcare responsibilities, or whose illnesses have prevented full-time employment around the time of transition from participating in the paid workforce to unemployment, are seldom eligible for disability pension benefits over and above subsistence level social assistance benefits. Grants from the Vocational Rehabilitation program (with the Ministry of Skills, Labour and Training) were obtained on an occasional basis by four of the informants for expenses such as tuition, books and equipment: three of the informants had been awarded scholarships based on their academic achievement; and one informant was the recipient of a disability-related scholarship. For all of these women the experience of chronic illness either occasioned their return to university and/or influenced their chosen course of study. Most were engaged in studies within the traditional occupational and professional fields for women.

All of the research informants participated in the research interview voluntarily; although almost all expressed fears and anxieties that they would be inadvertently identified in the write-up of the research findings. Ironically, the same incidents that the

research informants, alone and individually. believe to be unique to themselves and their own experience are shared. albeit in a variety of different ways and configurations, with each of the other informants. This is an important point: chronically ill women express ambivalence about disclosing their disabilities and submitting to the scrutiny that disclosure entails. They know that being defined as "disabled". and judged as properly eligible for accommodation in the institutional context. has ambiguous and contradictory consequences. On one hand. it provides the proper basis for receiving needed assistance and accommodation. On the other hand, they know that in the course of the original judgement other types of assessment may slip in. The consequences of these other types of assessment may be highly stigmatizing, and may result in them being "seen" differently: for example. as lucky recipients of particular academic advantages; as less competent. less organized, and less intelligent; as a drain or waste of scarce educational resources given that their future ability to participate fully in the paid labour force may be uncertain. and so on. I return to this important dilemma in the analysis chapters following: first to explicate how it happens this way; and second. to trace through to the source of the dilemma in the construction of the policy itself.

Accessibility and Postsecondary Education

Women and students with disabilities are just two of the designated groups that have been targeted for special attention in relation to educational and employment equity. This is partially due to measures designed to alleviate discrimination against particular groups of people. eg. the Employment Equity Act and Federal Contractor's program which were both adopted in 1986 (Jean 1991). In part, it is the result of a focus on growth and accessibility that fuelled the extraordinary expansion of Canada's system of post-

secondary education starting in the 1960's (Bellamy and Guppy 1991: Fortin 1987). This

expansion was based on a convergence of economic and social policy which proceeded

on three different levels: first. the evidence in the economic and sociological literature

suggesting that economic growth and greater social and political equality are dependent

on higher levels of schooling and the democratization of access: second. the willingness

of the federal and provincial governments. like governments of other western nations. to

make education a top priority: and third. the increase in the demand for higher education

and public support for extensive spending in the educational sector (Fortin 1987).

Federally. the Charter of Rights and Freedoms. enacted in the 1980's. enshrined the notion

of "equitable access" and "right to accommodation" for specific groups of people,

including those with disabilities. The Employment Equity Act of 1986, and the

subsequent development of a framework by the Government of Canada to ensure the

equitable management of human resources for institutions under its jurisdiction further

encouraged universities to implement employment and educational equity programs

(Carrière 1991: Jongbloed and Crichton 1990). The legacy of the expansion of Canada's

post-secondary education system can be seen in the enactment of more flexible

admissions policies and the development of short-term programmes. night courses,

satellite campuses. and distance education facilities.

While the efforts to increase post-secondary opportunities have been. in the main,

successful. there have also been some marked limitations. As early as 1982, in a speech to

a conference organized by the Council of Ministers of Education, the Honourable Bette

Stephensen (then Ontario's Minister of Colleges and Universities) pointed out that

> "while we have dramatically increased the number of students attending
> post-secondary institutions. access to post-secondary education remains
> far from equal across all social and economic groups in Canada....

Accessibility can also be further improved for native peoples. part-time
students. the handicapped. women and those who live a long distance
from any post-secondary institution" (quoted in Fortin 1987:4).

In reviews of accessibility to and participation in postsecondary education. researchers

and analysts note that despite the development of opportunities for alternate forms of

involvement in post-secondary education there continue to be disparities in the

distribution and use of these alternatives (Guppy 1984). These disparities, they argue, may

have an opposite effect of accentuating differences between social groups rather than

reducing them. For example. part-time enrolment. which is an important option that has

increased opportunities to pursue post-secondary education. tends to be less accepted in

prestigious institutions or in prestigious programs (Fortin 1987). Further, while the

community college system has enabled an increasing number of people with disabilities,

mature women. part-time students and people from less-privileged backgrounds to pursue

post-secondary education. their concentration in the college system, as opposed to the

university system. reveals that community colleges play a limited role in the

democratization of higher education (Fortin 1987).

The distinction between academically versus vocationally oriented education creates

other social inequities for those enrolled in community colleges and institute-based

programs of vocational and technical education and training: most notably, the

reorganization of vocational and technical education to be more flexible and responsive to

the "needs" of the labour market have resulted in "more narrow, short-term, instrumental

educational objectives" that may actually limit, rather than expand. an individual's

opportunities at work (Jackson 1991:357). The emphasis on "flexibility and

responsiveness to industry", Jackson writes, "produces an organization of vocational

training which fails to satisfy the legitimate needs of workers and addresses only the most

short-sighted interests of employers" (Jackson 1991:365). Instead of workers with the technical expertise to ensure their long-term employment in a competitive labour market, vocational training is more likely to produce workers "whose purchase on an employment future will be through a continuous recycling of disposable skills" (Jackson 1991:364). Ironically, because community colleges and institute-based programs of technical and vocational education and training operate with more direction from the provincial government than do universities, and because they receive funding from Adult Special Education grants for disability services, they have led the way in developing access policies and in creating more inclusive environments for people with disabilities (BCEADS 1996). Universities, unfortunately, function more autonomously and have generally lagged behind, making the inclusion of disadvantaged or previously excluded groups – such as women with disabilities – that much more difficult.

It is also important to understand the context in which postsecondary education is delivered. Since the economic crisis of the 1980's there has been a reduction in government revenues along with a reordering of social and economic priorities (Bellamy and Guppy 1991). In the context of new 'economic realities', where resources and budgets for postsecondary education are more restricted, there are also perceived limits to the objectives of openness and accessibility. Critics of the more "liberal" educational system have questioned the usefulness and necessity of a policy of openness and accessibility when, at the same time that the cost of maintaining the current system continues to rise, benefits to its graduates can be seen to decline (Bellamy and Guppy 1991). "[R]ather than gaining social mobility, [graduates] often find themselves underemployed or even unemployed" (Fortin 1987:11). In the face of shrinking resources and the restructuring of education along the lines of the market system, productivity and

accountability have more weight than openness and accessibility. In the current

'economic reality'. the legal obligation to promote equitable access is seen by many

members of the university community as inherently incompatible with maintaining a

"quality" of education that emphasizes such ideals as excellence. competition. and

selection (Fortin 1987). Organized in relation to the merit principle. these 'ideals' are

achieved through the application of increasingly stringent academic entrance criteria.

higher standards of evaluation. and the imposition of quotas which. for the most part. fail

to recognize any concomitant responsibilities to disadvantaged people (Hanen 1991).

Universities. as with all other post-secondary education institutes in British Columbia,

must be able to demonstrate compliance with both the Charter of Rights and Freedoms

and the B.C. Human Rights Act. However, as universities are required to formulate and

implement policies. procedures and other initiatives aimed at fostering the inclusion of

particular disadvantaged groups. and as instructors are required to provide reasonable

accommodation on the pain of creating legal liability for the university, there is a

concomitant rise in resistance to the changes that such initiatives entail (Breslauer 1991;

Tancred 1991). While the abstract criteria of social justice may be embraced. there are

contradictions and difficulties that arise wherever such "ideals" must be implemented as a

coherent set of tasks and practices within the concrete situations of people's everyday

lives. Making education more accessible and including previously excluded groups in

higher education stand to disrupt the existing institutional order of the university. The

resistance to improving accessibility and inclusiveness is connected to what feminist and

anti-racist critiques call the "backlash" discourse that seeks to protect the status quo and

the social organization of the academy.

There are a variety of ways in which this backlash discourse or resistance to inclusiveness and diversity can be framed. For example, the changes and initiatives entailed by policies on providing academic accommodation can be seen as the encroachment of political and administrative concerns into a domain usually reserved for academics (Blackburn 1991); in other words, diminishing faculty's previous autonomy and control over the content of curricula and methods of evaluation in their various disciplines. Epithets such as "politically correct" are often used to disparage the active implementation of particular initiatives, and arguments about the problem of censorship and the freedom to teach as one sees fit may be used to resist legislated or juridically imposed remedies (Blackburn 1991; Hanen 1991; Tancred 1991). Questions about "standards" in canons of scholarship may be raised (Blackburn 1991; Hanen 1991; Tancred 1991), reflecting the assumption that procedural changes required to accommodate disabled students may inadvertently confer particular "unfair advantages" for them. Increasingly fierce competition amongst students for limited funding and enrolment restrictions in particular courses of study, give weight to the argument that unethical students may claim to be "disabled" in order to gain "unfair advantages" over fellow students.

The resistance of faculty to the inclusion of previously excluded groups itself increases the disadvantages associated with disability. As Nancy Fraser (1997) points out, affirmative remedies that seek to correct and compensate for past failures of institutions to foster the equal access and full participation of particular excluded and disadvantaged groups, usually succeed only in calling attention to and supporting group differentiation. That is, they mark a particular disadvantaged group "as inherently deficient and insatiable", as "recipients of special treatment and undeserved largesse" (Fraser 1997:25).

While policies and procedures that provide services. assistance and accommodation for people with disabilities aim at correcting inequitable outcomes of social arrangements. the process of accommodation itself – i.e.. repeated reallocations of "scarce" resources and providing special "exceptions" to the ordinary rules – also singles out disabled people as targets of resentment. Where many students generally struggle financially. academically and physically to complete their programs of study. procedural changes and "exceptions" to the ordinary rules for one group of students may be interpreted as unfair to those students who do not have similar recourse.

This means that for women who are chronically ill and who are pursuing an education. material disadvantage will be experienced in combination with social stigma based on the perception that disabled students are inherently different from "ordinary" students: that they pose an unnecessary burden on scarce educational resources and are intrinsically needy and flawed. It is within this climate that the measures adopted by the University of Victoria. to ensure the fair and consistent treatment of people with disabilities, must be understood.

The University of Victoria – Services, Policies, and Procedures

The University of Victoria's response to students with disabilities was reviewed and subsequently revised during the years of 1994-1997. While the previous policy upheld disabled students' legal right to "reasonable assistance". it did not spell out clear eligibility criteria, there were no clear procedural guidelines for arranging the accommodation. and a process for appealing decisions was not laid out. As part of the process of review, the university's interim Advisory Committee on Issues Affecting Students with Disabilities conducted surveys and assessments of disabled student's

"needs" in July 1994. performed "physical access audits" of the University of Victoria's

facilities on campus in 1996. provided legal seminars to faculty and instructors on the

legal rights and liabilities of teaching people with disabilities during April 1996. and they

compiled an inventory of policies relating to accessibility and accommodation from

universities across Canada. The review process. itself. followed soon after two important

legal decisions – the *University of British Columbia v. Berg* decision in the Supreme

Court of Canada[30] (1993) and the *Howard v. University of British Columbia* ruling before

the British Columbia Council of Human Rights[31] (1993) – that upheld the rights of

disabled students not to be denied services or facilities customarily available to the public

because of either physical or mental disability[32]. In addition to demonstrating that

universities are not immune from the operation of the B.C. Human Rights Act[33]. and that

students constitute "the public" whom the Act is intended to protect. these two legal

decisions also provided both the impetus and direction for the University of Victoria in

drafting a Policy Statement and a set of Procedural Guidelines for accommodating

students with disabilities in the academic setting. In June 1997. the policy and procedural

guidelines were ratified by the University of Victoria Board of Governors as the Policy

for Providing Accommodation for Students with a Disability (hereafter the Policy).

As stated in the preamble to the Policy, the University of Victoria recognizes its

"moral and legal duty to provide academic accommodation" and has put in place services,

resources. policies. procedures and systems of appeal that are designed to ensure the fair

and consistent treatment of people with disabilities. enabling their participation in all

aspects of university life. The official university policy is situated within a legal

framework (provided by The Canadian Charter of Rights and Freedoms, Section 15 (1),

and the B.C. Human Rights Act, SBC 1984 c. 22) and it lays out a system of mutual

obligations. responsibilities and procedures (for both the "university" and the student) designed to provide "otherwise qualified" disabled students with "reasonable" opportunities to access and participate as members of the university community, at the same time that it protects the university itself from unreasonable expense or "undue hardship" and from compromising or lowering academic standards.

Just as legislation provides the framework for the Policy. the definitions of "otherwise qualified student". "disability". "undue hardship" and "reasonable accommodation" are similarly derived from the meanings and uses of these terms in juridical contexts[34]. An otherwise qualified student – one who has already met the relevant prerequisites for registration as a student at the University – must be able to demonstrate "acquisition of the body of knowledge or the skill normally required for passing a course and/or completing an academic program" (UVic Policy. Section 4.1). A disability is institutionally recognizable only if it results in problems of access, requires modifications in regular teaching and evaluation practices, and is medically verifiable (UVic Policy. Section 4.2). Academic accommodation, which consists in "reasonable measures", is defined as "a modification or extension of university resources, or of teaching or evaluation procedures. which is designed to accommodate the particular needs of an otherwise qualified student with a disability" (UVic Policy. Section 4.3). Accommodations themselves can be accomplished through activities of adapting, modifying. substituting. or deleting components of a particular course, assignment or examination that would otherwise be discriminatory on the basis of disability, only as long as the student meets established institutional standards in accordance with course requirements. Alternately the university may provide access to material resources of equipment (i.e.. computer software, tape recorders, etc.) or extra time in order to

compensate disabled students for the difficulties and limitations that their disabilities entail. In all situations, regardless of the type or degree of disability, accommodations are intended to conform to academic principles without causing the university "undue hardship".

Both the concepts of "undue hardship" and "reasonableness" are intended to preserve essential course requirements, maintain academic standards, and limit accommodation to those activities which do not fundamentally diminish the operations of a program or pose a financial burden sufficient to seriously undermine the existence of a program or service (UVic Policy, Section 4.4). Undue hardship is always defined from the institutional point of view and it constitutes the technical means – i.e., evidence or proof of the "undue" effort or cost prohibiting the provision of accommodation – by which the university protects itself from legal liability for failure to accommodate: the university is legally obligated to accommodate the disabled student up to, but not beyond, the point of undue hardship.

The Responsibilities and Obligations of Students

The provision of services and the extension of academic accommodation are not one-way transactions in which students with disabilities unproblematically receive services and concessions from the university. In order to receive accommodation, students carry significant responsibilities. Most importantly, students are responsible for identifying themselves as disabled to the appropriate personnel in a timely manner. Timeliness, which is not an absolute or essential requirement for obtaining accommodation, nonetheless requires that students provide both the instructor and the university with advance notice in order to plan and arrange services and accommodation. Rather than

struggle alone to "keep up" with a class, the prompt – or timely – disclosure of a

disability is also intended to facilitate the implementation of strategies or measures aimed

at the full and equal participation of the student in the class from the outset of the term.

Timeliness can be accomplished in a number of different ways: by indicating the presence

of a disability on the University of Victoria's Application for Admission form: by

contacting the Office for Students with a Disability before registration: by discussing the

disability and the anticipated problems it may cause with the instructor at or before the

beginning of the term: by notifying the Office for Students with a Disability of a need for

any alternate testing arrangements at least 4 weeks prior to the scheduled date of the

examination (UVic Policy, Sections 7.1 & 7.2).

Self identification of disability, in and of itself, is not sufficient to justify the extension

of special services and concessions. To be acceptable to the university, self-identification

must be accompanied by appropriate medical documentation submitted for review to the

Office for Students with a Disability (hereafter, OSD). Students with chronic illnesses

would be required to provide a detailed report, obtained from a physician properly

licensed to practice in the medical profession, that "outlines the nature of the disability"

as well as a "detailed explanation of the functional impact of the disability on the pursuit

of a post-secondary education" (UVic Policy, Section 8.3). The documentation would

also be expected to provide "explicit recommendations for remedial and/or coping

strategies" (UVic Policy, Section 8.3) to assist the student and the university in

determining the appropriate accommodation to extend. Students with disabilities are also

obliged to "receive or be receiving appropriate treatment for, or remediation of, his or her

disability" (UVic Policy, Section 5.1.(c)). Proper documentation is also required to be

current. This means that the lapse of time from the initial clinical assessment to the

request for accommodation can be of no longer than two years duration. Also, where the student experiences significant changes in his or her medical condition, either improving or deteriorating, and thus significantly changing the type, degree or frequency of accommodation requested over the course of their studies, further medical information would be requested and required at the student's expense. These responsibilities assume that disabled students are, or should be, in the constant care of an authorized medical practitioner.

While the university's policies and procedures recognize the student's right to privacy and confidentiality, they also reserve the right to verify or confirm the documentation that the student provides, even to the point of the university incurring expenses for further opinions and consultations (UVic Policy, Section 9.1 (a)). Regardless of the findings, the university is not bound by any of the recommendations formulated by the various professionals that provide the required documentation. Where documentation or requested accommodations are found to be inadequate or inappropriate, the student has the option of appealing any decisions to the Senate Committee on Appeals.

The Accommodation Process

Where documentation and requested accommodation are deemed acceptable, the OSD provides the instructor with sufficient information, in accordance with Freedom of Information regulations, to confirm that the OSD is in receipt of appropriate medical documentation and that the anticipated request for accommodation is deemed reasonable. The instructor then has the options of implementing the requested accommodation, requesting the assistance of the OSD representative to more fully discuss the accommodation, or presenting the reasons for disagreeing with the requested

accommodation to the student. Disagreements may be taken to the Chair or Director of the instructor's academic unit for review and recommendations. Where either the student or the instructor is dissatisfied with the recommendations of the Chair or Director, the Dean of the Faculty reviews the Chair or Director's recommendation and makes a decision. Unless appealed, the decision of the Dean of the Faculty stands. Once implemented, the student is required to observe any "conditions that are attached to the provision of a reasonable accommodation" (UVic Policy, Section 5.1 (d)).

The Office for Students with a Disability

While the Policy on Providing Accommodation for Students with a Disability is the textual means through which the university demonstrates compliance with its legal and human rights obligations, the OSD is the physical locus of the "disabilities apparatus" on campus that disseminates the policy and coordinates the various student, administrative and instructional activities required for its enactment. Physically, the OSD is a small office (with 2.5 employees) that is coordinated from the Office of Student and Ancillary Services, and that operates the Resource Centre for Students with a Disability.

For students with disabilities, the OSD provides assistance in arranging accommodations, information on special programs and services available on campus, access to specialized adaptive equipment and software, and other assistance with specific problems or concerns related to a disabled student's studies (see UVic Calendar 1999-2000. Uvic Handbook for Persons with a Disability 1999). The OSD also performs a number of important functions for the university: distributing the Handbook for Persons with a Disability which is designed to acquaint students and faculty with the facilities, services and policies relevant to the issues of disability and accommodation; referring

disabled students to existing services and departments on campus. i.e., Student Financial

Aid Services, the Student Employment Centre, and Counselling Services; acting as an

educational resource for the rest of the university by providing presentations about

disability and accommodation issues to faculty in various departments; and, finally,

working towards the elimination of any environmental or physical barriers to accessibility

by conducting "physical access audits" of the university and prioritizing them in terms of

a five year plan.

The OSD also operates the government Work/Study Program, Students-Helping-

Students (hereafter SHS), which provides eligible disabled students with a maximum of

75 hours per term of assistance in doing library research, invigilating separate

examinations, and other services more relevant to visually impaired students (i.e., reading

materials onto audiotapes and scanning materials for use by blind students). Student

assistants receive minimal training beyond an orientation workshop, but they provide

services in those areas in which they have some experience or wherever they are willing

to contribute. In general, student assistance programs tend to have limited budgets and

provision of services is dependent on government and other funding being available. At

the University of Victoria, for example, because note-taking assistance takes up so many

hours, the SHS program provides note-taking services only where announcements or

requests made by the instructor fail to solicit and secure volunteer note-takers in the same

class as the student requesting note-taking services.

Leaving aside the processes of appeal and the various services and types of assistance

offered by the OSD, the main procedures involved in requesting and obtaining

accommodation for students can be summarized as: 1) self-identifying as disabled, 2)

supplying the appropriate documentation, and 3) negotiating and arranging the actual

accommodation with the instructor. Each of these three procedures is fundamental to any type of accommodation. regardless of whether or not it proceeds as part of the formal organizational process as outlined in the official university Policy or as an informal arrangement between the student and instructor. The first procedure. self-identifying as disabled. sets the Policy in motion. The next procedure. supplying appropriate documentation. provides the means by which the university ensures that only properly eligible students with medically verifiable disabilities be accommodated or provided with assistance and/or other services. The third and final procedure. negotiating and arranging the actual accommodation with each individual instructor. allows the student and the faculty member to "individualize" the accommodation to suit the student's "distinct needs... in a manner consistent with academic principles" (Uvic Policy, Preamble). The responsibility of disabled students to actively arrange and negotiate accommodation intersects with the university's responsibility to maintain academic standards. preserve essential course requirements and limit accommodation within the available resources of the university to provide them. In other words. the student provides suggestions and alternatives for accommodation which may be modified to the extent that they contravene academic principles. I will return to these three procedures in the chapters that follow to show how they are particularly consequential for chronically ill women, and how they stand to organize their future experiences in significant. and sometimes undesirable, ways.

The Disjuncture: Everyday Experience and the Disabilities Apparatus

Taken together. the university's policies, procedures and resources constitute an administrative disabilities apparatus that manages the "needs" and "problems"

encountered by students with disabilities, usually by providing some form of service or accommodation. The services and accommodations provided through the disabilities apparatus are intended to foster the full inclusion and equal participation of students with disabilities in all aspects of university life, in accordance with human rights legislation. The rules and procedures of the Policy are also designed to ensure that academic standards are upheld, that the competitive conditions for academic achievement are preserved, and that the operations of the academy are not undermined. In other words, the Policy lays out a set of procedures – i.e., self-identification of disability, supplying appropriate documentation, and negotiating accommodations with individual instructors – which are intended to reconcile the interests and relevances of the law with the interests and relevances of the academy.

Even by simply juxtaposing the locally situated, everyday understandings and experiences of chronically ill women over against the objective, official understandings and processes of the disabilities apparatus, an epistemological line of fault comes into view – there is a disjuncture in how disability and accommodation are understood from the organizational and personal points of view, respectively.

Summarized in general terms, the OSD and the Policy are organized as a supplemental resource for a disabled student's education; dispensing organizational services, providing referrals to other services and departments on campus, and arranging procedural modifications which are added onto the disabled student's overall educational experience. However, for chronically ill women, disability does not simply require accommodation as a sort of "supplement" to the educational process; the experience of disability is interwoven with every single aspect of both their educations and everyday lives.

The rules and procedures of accommodation are created by the institution and are distinct and separate from the needs and requirements of chronically ill and disabled students. Even though the Policy exists to maximize the opportunities of disabled students to fully and equally participate in postsecondary education, it is also designed to reinforce and maintain the organizational operations of the university, i.e., to protect the university from legal liability and to maintain the integrity of academic standards. Academic standards – which are organized around practices of competition amongst students for hierarchically ranked grades, positions in programs with limited enrolment, scarce funding, and which are crucial in the credentialing of labour power – require students to demonstrate mastery of the same body of knowledge under the same kinds of conditions. At best, modifications to established practices of evaluation or conditions of testing are perceived as a lowering of academic standards; at worst, they are perceived as unfair. For chronically ill women, therefore, ongoing participation in postsecondary education hinges on practices understood to be incompatible with standards of excellence, selection and competition in the academy.

For the university, accommodation is comprised of an objective and definite set of institutional practices that link up with and are designed to actively accomplish the legal duty to accommodate as it is contained within human rights legislation. From even a cursory description of chronically ill women's experiences, the process of accommodation is not confined within the boundaries of the officially sanctioned organizational process: accommodation, as it is understood and spoken by chronically ill women, has a much more contingent, uncertain, informal and personal character than is stipulated by the Policy. Recalling the example in the first chapter, for the university, self-identification of disability constitutes the first organizationally recognizable step in the

process of accessing the university's "disabilities apparatus": for chronically ill students, self-identification of disability is just one possible end-result in a process of practical reasoning. i.e.. weighing the relative advantages and disadvantages of identifying oneself as disabled in the institutional context and considering alternatives to engaging the formal and official process. In other words. while the university is driven by legal and administrative concerns. chronically ill students are driven by personal and situational necessity.

Conclusion

In this chapter. I have described the social situations of the research informants and I have traced out the social relations that have given rise to the concepts of accessibility and accommodation in Canada's postsecondary educational system. The contrast between the organizational and personal understandings of accommodation signals a disjuncture. Accommodation is experienced differently depending on "who knows" and "how one knows". I explore this disjuncture further in the chapters that follow.

Specifically. in chapter five I take up the work processes and practical activities that are required to obtain accommodation for chronically ill women in order to explore some of the ways in which the Policy stands to (dis)organize their activities, experiences and future opportunities. In the final chapter. chapter six. I analyse the ideological procedures through which the work processes and other practical activities of chronically ill students are rendered accountable within the ideological schemata of the university as instances accessibility and accommodation. I will argue that. in the process of providing needed assistance and services to students with disabilities, the Policy also serves to organize and order chronically ill women's locally situated and directly known experience into forms

concordant with the interests and aims of the institutional function for the purpose of

actively accomplishing the institutional course of action in the local setting.

Chapter 5

THE EVERYDAY EXPERIENCE OF REQUESTING AND OBTAINING ACCOMMODATION

Introduction

Having discussed and described the common characteristics of the research

informants and the key features of the university's disabilities apparatus. I now turn to

focus more specifically on the everyday experience of chronically ill women who are

pursuing a postsecondary education. Specifically. I take up the "work" that the

informants do in order to access and obtain academic accommodation.

Accommodation. as it is spoken and experienced by chronically ill students, I will

argue. is not a standardized institutional "item" provided to disabled students; it is an

institutional category under which a complex organization of work processes takes

place. These work processes include. but also extend beyond. the three official

institutionally recognized procedures required to obtain accommodation (i.e.. self-

identifying as disabled. supplying appropriate documentation. and arranging the

accommodation with the instructor). and they are especially consequential in the lives

of chronically ill women. In this chapter, I turn my attention to how the Policy unfolds

in practice in order to explore the processes that go on beneath the circumscribed,

textually mediated organizational process of accommodation.

I argue that in the process of requesting and obtaining accommodation, chronically

ill students do not only gain access to much needed services and privileges, they are

also subjected to the broader dynamics – or social relations – that organize the

university's Policy in the first place. Specifically. in this chapter. I focus on the way in

which the Policy activates the assumption that accommodation may confer "unfair

advantages" for disabled students; I show how the individualization of the

accommodation according to each student's "needs" actually constitutes an onerous

set of procedures that may be unfair. and even discriminatory. for chronically ill women: and. finally. I show how. in the course of determining whether or not chronically ill women are properly disabled within the mandate of the Policy – and whether or not accommodation should be provided – other normative. diagnostic and prognostic judgements and assessments slip in to accompany the unfolding of the original judgement. Taken together. the procedures required by the Policy and the actual unfolding of the Policy itself can be seen to undermine full inclusion and equal participation for chronically ill students in the educational process.

While it may be tempting to attribute these negative consequences to improper use of the Policy. or to the intentions or personalities of particular individuals. I will argue that they are "built in" features of Policy. Even where accommodation proceeds informally. outside of the organizationally sanctioned process. I show that the social relations that organize the Policy – along with the interests and relevances that underpin and structure it – are routinely expressed in how chronically ill women speak about the experience of requesting and obtaining accommodation. In other words, regardless of what chronically ill women do. or fail to do. the social relations of accessibility and accommodation organize and give shape to their experiences, practical reasoning and understandings.

Accommodation as 'Unfair Advantage'

In contrast to the objective set of institutional items that constitute accommodation in the official Policy for Providing Accommodation for Students with a Disability (rev. 1997). the way in which chronically ill students speak about accommodation brings into view some of their unique requirements and the range of their problem-solving strategies: audiotaping assignments; videotaping assignments; obtaining

assistance from the OSD for special grants for computers and other equipment; using the services of note-takers and transcribers; dividing examinations to take in two separate time periods; having portions of an exam deleted (i.e.. doing two instead of three essay questions); taking exams in rooms that have facilities for the student to lie down or rest during them; salvaging portions of course work completed in one term for submission at a later date; requesting disbursement of scholarship funds in a way that makes the least possible impact on long term disability pension benefits; tape-recording lectures instead of taking notes; requesting that field work courses or practica be replaced with theory courses or other electives; requesting extensions of time; and part-time enrollment in full-time programs of study.

There are other less obvious forms of "self" accommodation upon which students also depend. For example. in order to conserve energy and remain engaged in their studies. most of the interview informants report a process of withdrawing from. or limiting social relationships. Renegotiating the performance of household tasks – such as cooking. cleaning. shopping – was another strategy commonly discussed. Some informants talked about the need to be willing to sacrifice health and well-being in the short term in order to complete an assignment or course. These gains would then be "paid for" in periods of recuperation and rest during the breaks between terms or semesters. In each case. these accommodations take place in particular contexts, within definite material conditions. The "costs" of these accommodations, therefore, vary according to whether or not the informant has a secure social network, whether or not they live alone or with others, and whether or not they can afford to take a term off or are able to recuperate within the requisite amount of time.

Seeking accommodation is not confined to the activities of students; in the interviews with the informants, faculty members were also instrumental in creatively

assisting chronically ill students continue in their studies. Some instructors personally arranged workplace modifications on behalf of students in practicum or field experience placements. Others assisted students in gaining financial support and entrance into particular programs of study. In a couple of cases, faculty even provided students with forms of sheltered employment. While these various types of accommodation overlap, I focus on those that can be considered "academic" in character.

In the excerpts below, the informants talk about the experience of requesting accommodation:

Jody: "So first of all, I went to the Grad Advisor and appealed to her on the basis of my disability. What I said was – I have a chronic illness. I'm older than most of the other students. I have a disability of pace, and I need you to recognize that and treat me equitably. And what I got back was a line about – well, we need to create a level playing field for all of the students. And I said to her – when you live with a disability, there is no level playing field, most of the time we're not even on the field – and I said – I don't want fairness, I want equity. And she didn't understand the difference. She kept falling back on – we have to treat everyone the same, we have to be fair to the other students as well.

Corina: "The problem was that I was having a hard time typing... So the only thing I could come up with was taping, for me to tape my assignments... And that worked for one course... And then I came up against the next professor who just said, flat out - No! No to the taping. It's not fair to the other students."

Nicole: "There are some teachers who are really fair, and then there are others that aren't. And they constantly use the rhetoric of having to do what is fair for the other students. You know, they keep saying that. And I would say – well, those other students don't have a disability, and those other students don't face this whole mess, you know. And they still come back to the same issue of fairness, you know. They just don't understand, the awareness isn't there."

Lee: "The problem of getting accommodation always seems to be weighed against the need to instill competitiveness and toughness in the students. And the nagging suspicion that accommodations somehow undermine the quality of education, like you're getting something for nothing"

In each of these excerpts. the informants provide a glimpse of those social relations which organize the Policy on Providing Accommodation for Students with a Disability. The most striking feature of their talk is the recurrent notion of "unfair advantage": the belief that accommodation may result in an "unfair advantage" for the disabled student: that accommodation may thwart efforts to maintain a "level playing field" for all students: and, finally, that accommodation may lower academic standards. These reasons for refusing particular types of accommodation are not arbitrarily invented or imagined by chronically ill women. Indeed, they are methodically referring to the ongoing resistance of faculty to the encroachment of legal and administrative concerns into the academic domain. My analysis discloses how in their talk. 'pieces' of the social organization of the university around practices of competition can be seen.

The preoccupations with avoiding unfair advantages. and maintaining a "level playing field". which are repeated in all of my interviews and informal conversations with instructors and administrative staff providing university-related services, reflect the organization of academic achievement in terms of competitiveness and comparison among students in the same course of study. Here, skill. speed, logic, calculation. mastery of a particular body of knowledge, and other competencies need to be "measured" or evaluated in the same conditions, and at the same time, in order to produce verifiable results that can be ranked hierarchically, and that can be used to reliably infer the level of achievement of the students enrolled in a particular course.

Meeting institutional standards and demonstrating academic achievement or individual merit is fundamental to processes of evaluation through which decisions about scholarships or allocation of financial resources and eligibility for entrance into particular programs are made. Institutional standards also confer legitimacy and

authority to a student's credential. Because many students generally struggle financially, academically and physically to complete their programs of study, procedural changes and "exceptions" to the ordinary rules for one group of students – especially those whose disabilities may not be visible or otherwise obvious – may call into question both the fairness of the accommodation and the legitimacy of the student's claim.

The Coordinator of the OSD spoke about this explicitly:

"Any non-visible disability is more of a problem. That's true. And, I guess somebody comes in and - well, you know - that person looks perfectly normal and a lot of people will be surprised. And the person comes in and says - I have a disability, I can't put my paper in on time. And from the point of view of the professors who are thinking - okay, they'd like to trust you but they would like a bit more evidence or something like that. There's always the issue of fairness to the other students that comes into play. And unfortunately, people are there who are (laughs) cheating, in terms of trying to play the system. But, it's not a perfect world so you will always have people who are trying to take advantage of the system."

In the excerpt above, the Coordinator of the OSD takes for granted the assumption that accommodation provides an advantage for the student and that it lowers the academic standard to which other students, without disabilities, are held. Further, in his talk, he shows how less obvious, or "invisible", disabilities are more likely to activate the assumption that students may fraudulently claim disability in order to "take advantage of the system" and thus gain access to the advantages that accommodation is believed to confer. This suspicion is structured into the Policy's requirement that students who identify themselves as disabled must also submit appropriate medical documentation in order to "prove" the disability and legitimately request and obtain accommodation.

The "fact" that students may cheat means that instructors and administrators must assume what Zimmerman calls "an investigative stance" in which "being 'sceptical' is a way of displaying a hard-headed commitment to establishing the 'facts of the

matter (as against the [individual's] mere *claims*)" (Zimmerman 1969:331). The

Coordinator of the OSD understands that the process of inquiring further may turn up

information that runs counter to the student's own account of the situation. Fierce

competition for grades. scarce funding, positions in programs with limited enrolments

all increase the likelihood that students may attempt to gain an advantage over their

peers. Claiming disability is one way that students may extend deadlines. be allotted

additional time to write an exam. be permitted to use particular types of equipment.

and so on. This understanding justifies displaying the "active assumptions of the

investigative stance" as evidence of "a recognizably adequate" process for ensuring

the fairness of the requested accommodation to other students. and the conformity of

the accommodation to academic principles. Regardless of whether or not the

assumptions made by the OSD – or instructor – are proven to be mistaken, the

"investigative stance" is always relevant because it is established and reasserted in the

daily. routine practice of deciding who is eligible for accommodation. and what kinds

of accommodation should be provided.

This sceptical stance is especially salient for women who are chronically ill.

Unpredictable periods of exacerbation and remission and the experience of pain and

fatigue – all characteristics of chronic health conditions such as rheumatoid arthritis –

are difficult to gauge and measure objectively. Changing symptoms disrupt the more

commonsense understanding of disability as a fixed, or constant. physical condition.

Chronically ill women often appear to others as "perfectly normal". For example,

when asked to talk about the most difficult aspect of being chronically ill, these

informants explained:

Anne: "*I think the whole issue around understanding the change of it, how it changes all the time. The volatility of symptoms makes it so different today than the next day. You know, when I hear comments – Well, do you really need those crutches? Because*

yesterday, you weren't using any: so are you sure you need those? Those kinds of things to me a lack of understanding, in general, of the complexity of it, in terms of the lengths people with chronic illness must go to: to manage everyday."

Lee: "I actually found myself wishing that my wrists would just swell up, be bright red and swollen, so that there could be no suspicion that I was unable to meet the deadline because of laziness, or failing to schedule my time properly. When I was experiencing a "flare-up" years ago (the physical symptoms were so much more dramatic. Your all I have is the permanent damage to my wrists. They hurt, especially when I push myself, but no-one sees it anymore."

Leslie: "Being constantly ill like this is very unpredictable. You know, you may start out all healthy and gangbusters and then part way through you find your energy bottoming out ... and then you're flat on your back sleeping 10 or 15 hours a day. Unless you look very closely, I look very healthy, and why would I need to get an extension, or why would I ever need to use any of the services for disabled students."

Here, informants talk about how a visibly damaged or disordered body is more likely to "stand in" as incontrovertible proof of disability. Without such immediate "evidence", they reason, there are always grounds for doubting their "deservingness" of accommodation. Doubt, in turn, provides the grounds for subjecting people with chronic illnesses to further scrutiny: determining whether or not the claim of disability is legitimate and judging whether or not the accommodation is warranted.

The practice of assessing the legitimacy of a disability claim is not unique to the academy. Just as the duty to accommodate follows from human rights legislation, the practice of determining the legitimacy of a disability claim must conform to the precedents set within the juridical process.

"Unfair Advantage": Human Rights Legislation and the Juridical System

Just as suspicion is not a characteristic of a misguided or uninformed individual – but is a "built-in" feature of the university's Policy – suspicion and skepticism are structured into the procedures used to guide the interpretation of human rights codes. Not all physical attributes and conditions upon which unfair treatment may be based

are included in human rights legislation. Protection covers only those physical attributes or conditions which cannot be changed and which – with due accommodation – would not be relevant to the individual's overall functioning (Bickenbach 1994). The assumption of what Bickenbach calls voluntarism holds that there can be no discrimination where the social response to the physical attribute or condition is not unwarranted. irrational, and unfair. Bickenbach characterizes "the moral and political foundation of social policy for people with disabilities" as a matter of determining when the disadvantages a person with a disability experiences are socially produced handicaps and when they are "unavoidable concomitants of disability that fall outside the range of misfortunes to which society has an obligation to respond" (Bickenbach 1994:114).

Where an individual is seen to have control over the disability. or where the disability is not seen to be immutable. the social obligation to satisfy those needs is diminished. Indeed. as the reasoning from this assumption follows. to satisfy the needs of those who are malingering. fraudulent, undeserving. or who have brought particular conditions upon themselves. is to "dilute or pervert the benefits provided by anti-discrimination legislation" and to trivialize the human rights protections for those who are "truly disabled. but genuinely capable" (Bickenbach 1994:119). As an example, human rights cases in both the U.S. and Canada have held that people fired or denied jobs or promotions due to obesity "will have no remedy unless they can show that their condition is the result of an illness or other medical condition over which they have no control" (Bickenbach 1994:115). U.S. veterans with alcohol or drug induced disorders have similarly been denied benefits.

The preoccupation with "capturing the true 'target population' – those whose conditions of dysfunctioning are biomedically verifiable and 'substantial' enough to

disqualify the fraudulent and malingering" (Bickenbach 1994:120) – within the juridical system. also organizes how the Policy is activated and implemented for chronically ill students in the educational system. Suspicion and scepticism. therefore, are not characteristics of unenlightened or biassed individuals. but are "built-in" features of the institutional practice of providing accommodation. Further. not only are the activities and reasoning of institutional actors – faculty and administrators – thus organized. so too are the activities and reasoning of chronically ill women.

Where chronically ill students reflect on the concept of "unfair advantage", they recognize the flawed logic that produces it: they point to the selective way it treats the material conditions of their lives and the way it conflates accommodation with actual benefits and advantages. The informants also speculate about the "causes" of people holding this mistaken assumption: i.e.. an instructor may be unable to differentiate between fairness and equity. preferences or biases of particular instructors. lack of awareness of disability issues. and so on. Even though chronically ill women explicitly identify the faulty logic behind this reasoning. the notion of "unfair advantage" nonetheless still finds its way into the talk of chronically ill women who use this same concept to interpret their own experiences and activities. For example:

Corina: *"Well procrastination is a big problem for me anyway, and sometimes I find myself wondering if I'm just using this as an excuse, if I have a legitimate reason to procrastinate now."*

Leslie: *"A lot of times during my B.A.. there was a lot of guilt. Like, why would I need an extension. A lot of it. a lot of issues like feeling lazy came up. Like, did I really need it? ...Having come from a family that, you know - we've worked hard for where we're at. So these are really confusing times, too. Like even now, I guess it's been diagnosed for about 7 years and it's still difficult, there's still denial in that. There's part of me that doesn't want to use those concessions unless it's absolutely necessary."*

Lee: *"I do this thing, you know, where I'm always asking myself – Could I have gotten up earlier? Could I have stayed up typing longer? Am I really that tired?*

Anne: *"I think when I was receiving support and getting assistance, there was this constant feeling of, okay, should I be doing this? You know, those kinds of guilt issues where you're not doing anything out of the ordinary, you're certainly not taking advantage, but you're feeling that your life is not your own right now. I think that was an issue for me. And it wasn't worth it."*

The excerpts above show the way in which chronically ill women organize themselves in relation to the concept of accommodation as "unfair advantage". Not only do the informants express feelings of guilt and anxiety over using any form of assistance or accommodation, they also scrutinize their motives and activities to ensure that they are aligned with the intentions of the Policy. Even as they talk about the disadvantages they face in the classroom and on campus, these informants can be seen to actively take up a sceptical stance in relation to themselves and, as a result, they can be seen to actively limit their use of accommodation in the academic context. In other words, even the directly known experience of chronic illness – along with the experience of pain, struggle, and limitation that it entails – is subordinated to the way in which disability can be known in the institutional context. When they speak about accommodation, the informants take up a subject position from within the ruling relations of the university: one that invariably limits their use of the Policy and which undermines their full participation in the academy.

"Work" and the Individualization of Accommodation

Where chronically ill students identify themselves as disabled and present the appropriate documentation or "proof" of disability, they must still perform the work of individually planning, arranging, and implementing the accommodation, usually in each course and with each instructor. While these processes are not ordinarily considered to be either observable or reportable as 'work' in the organizational context, these tasks often take time, effort and even expertise. While providing

documentation and the individualization of accommodation are understood – from the institutional point of view – as a means of providing an accommodation that addresses each disabled student's unique "needs". I will show that these work processes actually serve to protect the institution from the wear and tear of making continual adjustments and readjustments. In other words, while accommodation appears as an instance of the institution acting in the interests of the individual, the rules and procedures of requesting and obtaining accommodation also conserve and maintain the institution.

The issue of documentation is both complex and contentious because, while it is required by the university as a basic precondition for accessing services and obtaining accommodation, it is experienced by disabled students as a violation of the right to privacy, and as an unnecessary burden of time, effort and money (BCEADS 1995). Further, it is premised on the suspicion of student dishonesty. In part, providing medical documentation is seen to resolve the problem of the "unfair advantage" discussed earlier. Here, supplying the appropriate documentation gives evidence of the genuineness of the individual's claim, and hence, their "deservingness" for accommodation. The documentation "stands in" for the student's actual embodied experience, and verifies, through the activities of other professional "experts", the objective existence of the disability.

It also represents the student's part of the mutual obligation in working towards reaching an acceptable accommodation: the activity of obtaining documentation is a simultaneously the fulfilment of the student's responsibility to act, and a test of their "actual need". Submitting to a physical examination, and justifying and explaining a request for accommodation – both to a physician and to the instructor or Coordinator of the OSD – involve a sacrifice of privacy and the dedication of actual resources of

time and energy which. as a "test" of the individual's need for accommodation. has

the appearance of an "ordeal". As Foucault uses it. the regulated mechanism of the

ordeal sets forth a "physical challenge that must define the truth" (Foucault 1977:41).

Extending the metaphor of the "ordeal" to the problem of disability and the obligation

to supply the appropriate documentation: if the student is not "truly" disabled. then the

inconvenience. the wasted time and effort. the loss of privacy. and the process of

supplication are not unjust: "but it is also a mark of exculpation" if the student "truly"

is disabled (Foucault 1977:41).

Once documentation has been supplied and the need for accommodation deemed

reasonable. the student must still negotiate and arrange the accommodation with each

individual instructor:

Nicole: *"I did have to request accommodation, and it's interesting how each teacher was so individual... one of the things that I found was that if there was someone who was disabled in the class before you, then your teacher automatically assumed that you required the same accommodations that the other person did. So, sometimes that would work very. very well. but no two people with arthritis are the same. just as no two people are the same with MS. And if you had a teacher who really couldn't process that you weren't the same as that person, then you ran into conflict, you ran into this big barrier because you had to try and educate as you were going along and also trying to be seen as an individual and not this other person who might have been brighter. or more creative (laughs). or a talker. or whatever. but not you..."*

Leslie: *"So with some instructors I've found that I can do assignments in different media. and I could videotape with a classmate one of my assignments. With another class I audiotaped them. Those are really new composition strategies for me. and they do take time and they do take patience. I've had some instructors say - no way. there's no negotiation here. it's against policy. we don't know how to mark it, because it doesn't follow the typical university strategies and policies. And they were not helpful at all."*

Corina : *"What really struck me as odd is the fact that other people must have the same problem with finding the right kind of accommodation. You know, where it works for the student and doesn't mess things up with the professor. I know other people must have the same problem and yet there's no communicating it. It's like everyone keeps to themselves with that knowledge."*

Anne: *"I usually came up with a plan myself, not expecting people to come and cater to my needs, and they were very accommodating."*

Jody: *"I've learned, you know. I wouldn't have gone in as a part-time student, I'd get in and then deal with it. I'd get in as a full-time student and then I'd deal with it. Now, I've become quite politically savvy in terms of, you know, manoeuvring myself around all this bureaucratic crap... And I must say, they've been genuinely accommodating to me, personally, on the basis of my disability. They've made it easier for me to just concentrate on what's the most important thing, which is getting into my studies"*

Although each informant provides a different explanation for the experience, all refer to a similar exchange between the individual and the institution: where the student, as an applicant, presents her wants or "needs" for the items and privileges of the university's services. Typically, the individual is disaggregated into program terms as a set of referrals to be made or equipment to be provided. The simple precept that similar cases be treated similarly, however, stops being simple at the point of institutional action. As the excerpts above show, the routine implementation of the rules and procedures of accommodation have different material outcomes for different students: some are rewarded, others are penalized.

For the informant in the first excerpt, the "individuality" of each instructor appears as the cause of the unending struggle to find an acceptable accommodation. For the second, the problem consists in the instructor's lack of familiarity with evaluating coursework in an alternate medium. The third assumes that she has not yet discovered the correct or proper kind of accommodation. The fourth attributes her success to her own competency in "coming up with a plan". Finally, the fifth informant has become "organizationally literate[35]": she is able to use her knowledge of how the university works to present her own "needs" and wants in a way that conforms to the interests and agenda of the university. In each instance, chronically ill students are engaged in actual work processes, i.e., of education, learning to work in alternate media, seeking

better types of accommodation. "coming up with a plan" for accommodation. and "manoeuvring through the bureaucracy".

The success of the institutional encounter does not hinge solely on the personal characteristics or skills of the applicant. Rather. it depends on the social position of the applicant. the viable alternatives available to the applicant. and the degree of complementarity between the "needs" of the individual and the services and privileges offered by the institution. Those individuals whose interests and agendas most closely coincide with those of the institution are accommodated successfully. Alternately. those individuals who have other resources, or who are able to adapt their own skills and capacities. will also eventually reach agreement on accommodation. As "work", the negotiation of an accommodation is anchored in definite material conditions. It takes place in "real time". Student's resource conditions are especially consequential for the success of the institutional encounter. Those students whose resource conditions were limited tended to be less successful than those with abundant resources. Indeed. during times when the disease process was exacerbated. informants supported by spouses or parents were able to retake courses. take terms off. forego grants. or drop out of their studies mid-term without experiencing serious financial consequences. Informants dependent on student loans or fixed incomes were not so fortunate.

It is important to remember that public policy, of any kind, represents the commitment of important resources, not as single "moment of decision" but, in a continuing pattern or network of distributions and allocations that must be sustained over time (Schaffer and Lamb 1981:8). The limits of organizational resources to provide services and accommodation are already anticipated in the concept of "undue hardship". The decision to accommodate proceeds mainly on the basis of precedence

where the university is familiar with, or has already encountered, the numbers and kinds of accommodations that students with disabilities might request. As they negotiate and arrange accommodation with individual instructors in their particular courses, the actual requirements and "needs" of chronically ill students are subordinated to the kinds of accommodations and services to which the institution or the instructor is already habituated. As such, the Policy and the practices of accommodation are intended to be responsive to the "needs" and requirements of disabled students, but only insofar as the resources and established practices of the university allow.

The problem for chronically ill students arises as their "needs" and wants are seen to differ from the institutional items and privileges that can be routinely offered. Unlike students whose disabilities can be accommodated through a one-time expenditure of funds (i.e., students who simply need access to a building, or who require a piece of specialized adaptive equipment), chronically ill students require accommodations that disrupt the smooth organizational flow of the university. The institutional barriers to inclusion and participation are less physical and more organizational in character. Thus, for chronically ill students, accommodation also requires ongoing interaction with institutional actors (i.e., faculty and administrative staff) in order to continually adapt the item or service being offered.

Depending on the differences between students, and the way in which each individual instructor takes up and uses the institutionally organized concepts and categories, the Policy is activated and unfolds with varying degrees of success or usefulness. The lack of "fit" between chronic illness and the organizational framing of disability gives rise to the extra "work" that is needed to negotiate and arrange reasonable or acceptable accommodation in every course and with each instructor.

These work processes are understood by the university as the "individualization" of accommodation to suit each disabled student's "unique needs". In practice, however, this individualization appears more as means of shifting the responsibility for change from the university to the student.

For Foucault, "individualization appears as the ultimate aim of a precisely adapted code" (1977:99). The individualization of accommodation effectively compartmentalizes decisions about academic accommodation to particular situations and specific students and instructors. Therefore, the more difficult procedural changes entailed by academic accommodation are never "shared" amongst the disabled student population or among faculty in the way that physical changes to the landscape, or the acquisition of specialized adaptive equipment can be used by many disabled students.

The individualization of accommodation also forecloses the setting of general institutional rules of precedence. Compartmentalized to specific students or situations, general procedural changes and modifications to teaching and evaluation practices are unlikely to become widely accepted or taken for granted as ordinary everyday practices. In other words, individualization omits academic accommodation from the established institutional agenda. Without general familiarity as to what "counts" as reasonable or acceptable, both students and faculty embark on an institutional encounter that is novel and uncertain. This is why, in the excerpts above, students talk about being denied accommodations previously deemed acceptable and vice versa.

Because institutional decision-making tends to proceed on the basis of rules of precedence and established institutional agendas, individualization is also a means of preventing "loopholes" and avoiding the unnecessary expenditure of institutional resources. By performing the "work" of putting forward suggestions for accommodation, providing alternatives, and actively negotiating the accommodation

students are required to continually adapt themselves to the institutional items and services. Likewise. faculty also perform the "work" of engaging with the students. considering the student's suggestions. and perhaps even modifying or changing their own teaching and evaluation practices. Together. the coordination of the work of students and faculty protect the university. as an institution. from the "critical impact of the wear and tear" of continual adjustment and readjustment (Schaffer and Lamb 1981:8). Where students must adapt themselves to the institutional items and services, the existing social organization of the university is preserved and maintained.

At the same time that individualization of accommodation requires students to 'work' — i.e.. the work of petitioning the instructor. negotiating and securing an acceptable and reasonable accommodation, providing education on issues relating to illness. and enduring the heightened visibility of their bodies or coursework — it also reinforces and brings into being the institutional order. in compliance with the university's legal obligation to accommodate students with disabilities. By simply requesting accommodation. regardless of whether or not the accommodation is useful, or whether the individual subsequently drops the request. or develops ways or "games" for handling them. the chronically ill student is always participating in the realization of an institutional course of action that "counts" on behalf of the university's public display of good citizenship.

Chronic Illness And "Other" Judgements And Assessments

I have already shown that the Policy is structured around the assumption that accommodation may provide an "unfair advantage" for some students, and that unscrupulous students may fraudulently claim disability in order to "take advantage of the system". In this section of my analysis, I pick up from this discussion to point to

the other ways in which the Policy may stand to (dis)organize the experiences. activities and future opportunities of chronically ill women in particular. often undesirable. ways.

Taken together. the fulfilment of the mutual responsibilities of the university and the students in relation to the Policy also set in motion a whole set of assessing. diagnostic. prognostic and normative judgements of the individual who has identified as disabled. These other judgements. which "slip in" to accompany the unfolding of the Policy. include assessments of the disabled individual's "deservingness" of accommodation. valuations of the severity and implications of the visible symptoms of the disease. predictions of whether or not chronically ill women will be capable of productive or full employment in the future. and appraisals of chronically ill women's suitability for their chosen professions. These kinds of assessments and judgements are not intended to be part of the provision of services and accommodation and they generally proceed either unintentionally or covertly on the basis of the experience. practical reasoning. and understandings of the assessor rather than those of chronically ill women.

The politics of requesting accommodation – of being an applicant – are very significant here. The practice of application or requesting accommodation is highly regulated within the context of the Policy. There are formal rules and processes that must be followed. However, even where the request for accommodation proceeds in a less formal and more personal way. the applicant must still demonstrate or identify herself as a member of a group that is institutionally defined. The applicant "can find [her] self allocated in effect to a stereotyped group like [disabled] or [chronically ill] which suffers from the imposition of prejudice but which is inescapable to the very extent that application and access are worthwhile" (Schaffer and Lamb 1981:107).

While the informants depend on some form of accommodation to remain enrolled and engaged in their studies. the process of requesting and obtaining that accommodation makes them peculiarly visible in unanticipated ways:

Corina: *"I know I don't look like I need it. and in class. I know that the professor really watched me. you know. to see if I could write. or how much I wrote. which made it really awkward for me. And then he marked me really hard too. so I got a really low mark in that course and that didn't help matters"* [and later] *"Well. I guess how I approach professors has changed somewhat. Actually. I had to do my practicum and I didn't know then if I was going to be able to do it. how I was going to manage it. But I didn't tell them. ahead of time. that I had a health problem. And I didn't really need any special accommodations. just extra time and help with the typing"*

In this first excerpt. the informant learns that by insisting on a particular type of accommodation. she has made both herself and her work more visible to the instructor. While she must master the rules and conventions of a new medium in which to present her coursework and assignments, she is also aware that her claim of disability is treated with scepticism and suspicion.

The informant then goes on to explain how, subsequent to this original experience, her approach to accommodation has changed. She no longer identifies herself as having physical difficulties ahead of time. Without the visibility involved in self-identifying as disabled. she makes arrangements for help more informally. In her practicum. for example. while she still receives an extension of time and the actual physical assistance of a transcriber. these activities do not proceed within the authorized organizational procedures of accommodation. She is no longer being scrutinized or judged. The cost of proceeding in such a contingent way, however. becomes evident later in the interview: with deteriorating health. the informant must weigh the relative disadvantage of disclosing her disability against the possibility that poor work performance might be interpreted as a problem of competency.

For the next informant:

Anne: *In terms of labelling. I think again. I've been careful when I say that I have a disability. I wait until I really need to. And I have used that term because it makes sense. And it also conveys the need. In some ways if I have done that, then sometimes I get this puzzled look, you know, not sure if I'm straight up, or if I'm trying to pull one over. It wasn't an issue when my health was a lot worse, but it's more of a problem now.*

This excerpt shows the informant's reluctance to identify herself as a member of the institutionally defined group: she waits until the situation warrants the disclosure. She also reveals the way in which others' reactions to her claim of disability are organized by how closely she approximates the concept of "normal". Her previously severe limitations in mobility and her previously extensive accommodations were not questioned. However, like the previous informant, the unpredictability of her disease, and the relative invisibility of her symptoms, now legitimate a sceptical stance towards her claim of disability. The underlying disability has not disappeared – she continues to live with the conditions of an ill body – but with virtually invisible symptoms, the informant knows that normative judgements about her "deservingness" of accommodation are more likely to be a "problem". This excerpt, and the one previous to it, show how the problem of chronic illness consists largely in its unpredictability. Periods of remission and periods of exacerbation disrupt the institutional framing of disability as a fixed and constant category and come to constitute the grounds for suspicion and doubt as to the student's deservingness of special consideration.

Nicole: *"I was in my third year and I had darn good grades. I was pulling A's and A minuses, and the only reason I'm mentioning this is because I missed school, when my arthritis was bad, you know, I didn't have stellar attendance. And usually, when you miss so much you don't get top grades, right? So, I didn't think too much about it but I was actually, not asked, but told, that I had to go and see the Acting Dean of my department. I went in to see her and was totally dumbfounded. I thought - oh my god, I must have totally bombed a test, or something had gone wrong. She proceeded to ask why I thought I would make a good [professional in my field]. And for 15 minutes*

she grilled me... And it was - how do you think you're going to cope? Do you really think you can do this job? You have arthritis... And I really question whether or not anybody else got that kind of treatment. "

Jody: *"When I applied for grad school, and I got to the interview stage, I had this distinct impression that he'd made the decision before I got in the door, that I would get in, because I just felt so comfortable and I basically sat there and talked about my life... Anyway, he revealed at one point - much later - that he had wondered whether or not I was physically up to being a graduate student and had some serious doubts about my ability to complete the program because of that. "*

The above excerpts give evidence of the vulnerability of chronically ill women to

practices of scrutiny, evaluation and judgement that go beyond the original

determination of disability. In the first instance, the informant's disability is

interpreted as a contraindication to her future professional goals. In the second, the

informant talks about how a prognosis of her health – made by her graduate supervisor

– almost foreclosed her educational opportunities. While the original judgement

about whether or not the student meets the institutional definition of disability always

take place in accordance with strict rules (i.e., the rules and procedures of the Policy),

these other types of diagnostic and prognostic assessments and judgements do not.

And while they are not intended to be punitive, these kinds of assessments and

judgements are the practices in which discrimination and exclusion are grounded. A

diagnosis, here, is not simply consignment to a stigmatized or stereotyped identity, it

represents a definite and concrete set of organizational courses of action, where on the

basis of "knowing" the diagnosis, the informant's eligibility and future progress in

academia are called into question. While it is generally accepted that medical

practitioners should be accorded greater authority in recognizing and describing the

condition and limitations of the student's body, here faculty and administrative staff

themselves can be seen to believe that they too have diagnostic and prognostic

authority over students disabled by chronic illness.

Chronically ill students. themselves. are aware of the possible consequences of the

documentation of their disabilities in their student records. For example:

Anne: *I had a university scholarship. and one or two scholarships related to disability issues. And I also had some funding when needed through a programme. the vocational rehab programme...* (and later. in regard to the setting up of ˜˜accommodations˜˜ in her co-op work placements) *[the staff in the department] were proactive in setting up my co-ops. they'd send a letter to co-ops saying we have this student. and I got a great letter back saying. yes. we'll make special accommodations!˜˜*

Interviewer: ˜˜*Were you ever concerned about. when they did the co-op. about being identified as a student with a disability?*˜˜

Anne: ˜˜*Yes. I have actually. In terms of contacting someone. say when you're applying for jobs at a later stage. and if they see something that triggers a rejection of some kind. I suppose I do wonder about that, and I do have concern about keeping that trail of records about those things, Yeah. for sure. yeah. Sometimes I feel very paranoid. very cautious about all that documentation being out there. I mean. if the mobility problem becomes particularly bad. and obviously visible. then worrying about the documentation is pointless. The disability is obvious. But when things are on the mend.... I've actually asked for advice around that in terms of seeking work, and my general policy is to never identify it until I've had a chance to tell them what matters about the decision being made*˜˜

While special accommodations arranged in her coop work placement and

disability-related scholarships have fostered this informant's participation in her

program of study. they have also left a ˜˜paper trail˜˜ that leads back to her medical

history. This student worries that the documentation ˜˜out there˜˜ may ˜˜trigger a

rejection of some kind˜˜ when she applies for employment in the future.

The university recognizes that while identifying oneself as disabled is voluntary,

the process also has the potential to be intrusive and stigmatizing. Consequently, there

are steps taken to ensure the confidentiality of disabled students documentation.

Coordinator of the OSD: ˜˜*When a student has a concern around their documentation, we also put a note in the letter* [to the instructor] *saying - please remember, all this information is to be kept confidential, and so forth. We're dealing with professionals, too. on the other hand, and I think faculty also have had training about student's files and what student's files in the department are used for, and they're probably kept under lock and key... And if someone phones me (laughs) asking me information about*

this and this student. I don't do that over the phone. I'll wait and ask the student to sign a release of information form. so there's a fairly stringent policy around that. "

Interviewer: *"Are students cautious about releasing different kinds of information?"*

Coordinator of the OSD: *"It varies. Some of them couldn't care less (laughs). And others are very, very cautious. They might say - I don't want my information to be distributed - or - I don't want you to write a letter to my prof, I'll talk with him if necessary. That's fine with me. But sometimes you get a concern about that, professors phone me back and would really like to know a bit more... Well, we also have people with chronic illnesses - AIDS or Hep C - and they really don't feel comfortable with having that around. "*

Here. although the Coordinator says that some students "couldn't care less" about the confidentiality of their documentation. it becomes apparent later on in the interview that these students are those whose disabilities are visible and obvious. For student's whose disabilities are less visible. or are highly stigmatizing. as in the case of psychological or emotional difficulties. AIDS and Hepatitis C, confidentiality becomes crucial. These students. as the Coordinator of the OSD discloses, actively make use of the protections in place to protect their privacy. However, there is a troubling assumption that is made in this excerpt, i.e., that faculty and staff are all professionals and will always make sure that they protect the confidentiality of the documentation of the student. An interview with another informant shows the limits of such understandings of professionalism.

Past Service-Provider in the OSD: *"Not all professionals are bound by the same ethics... It's not a problem in the counselling department, it's lock and key. But once it's sent out to the departments. who keeps that? Who sees that? What are their rules about sharing information amongst themselves? ...I told you about the instructor who asked the class whether or not they thought it fair that one student was getting all these accommodations. And my supervisor's response was - well that was just one professor, that's an anomaly. That was the only one we heard about. And that's unconscionable. because some of that information may have real consequences for students. "*

While the work practices of professionals such as counsellors are organized around and governed by the concept of "confidentiality". the work practices of other

professionals. such as instructors and administrative staff. are not. The assumption that all professionals will be bound by the same ethic ignores the way in which concepts such as privacy or confidentiality have different meanings and different uses in different organizational contexts. While the concept of confidentiality cuts across any number of disciplines and professional practices in the context of the organization of the university. its precise meaning in each of these contexts can only be determined in relation to what particular individuals, as practitioners. can be seen to do with it.

Signing a confidentiality agreement is little protection against the inadvertent sharing of interesting or unusual information. and it doesn't prevent what is known in one professional or organizational context being used to make decisions in others. These decisions. as to who is eligible for admission to a particular programme, who should receive scholarships or other funding, and who receives a letter of recommendation. or the like, may all be structured by prior knowledge of. or information about. students' disabilities. Especially where disabilities are believed to make a student's full-time and consistent involvement in a particular programme, course of study. or employment opportunity uncertain. or where requirements to provide accommodation may be seen as onerous, it is impossible to ensure that such knowledge is either suspended. or not taken into account in decision-making processes.

Conclusion

In chapter four. I explained the disjuncture between the personal and organizational understandings of accessibility and accommodation, respectively. In this chapter. I have explored the work processes – including those that are not observable or reportable as student's "work" – that are required to obtain

accommodation. I have also pointed to some of the unintended consequences of using the Policy that are experienced by chronically ill students.

Specifically. I have shown how the university's need to determine the eligibility of disabled students for accommodation legitimizes a sceptical or investigative stance towards them. Because chronic illness is characterized by unpredictability. varying symptoms. and uncertain course. this scepticism and the assumption that students may be trying to cheat are especially salient for students with chronic illness. I have also argued that the individualization of accommodation may actually constitute an unfair, onerous. and even discriminatory process that undermines the full inclusion and equal participation of chronically ill students in the postsecondary educational process. Finally. I have argued that in the course of the original judgment about whether or not an individual is properly eligible for accommodation, other kinds of diagnostic. prognostic and normative assessments and judgements are inadvertently made. These practices of assessing and judging. I have argued, organize the experiences and future opportunities of chronically ill women in particular. often undesirable, ways and they can be seen an integral part of those practices which actively accomplish the discrimination and disadvantage experienced by people with disabilities in general.

In the next. and final. chapter, I will show that accommodation is what Smith calls "ideological practice" and I will argue that the disabilities apparatus, itself – of which the Policy on accommodation is a central feature – is part of the administrative regime of the university and it operates primarily to articulate students with disabilities – in all their varieties and with all their different "needs" – to the overall institutional function for the purpose of accomplishing the university's legal obligation to be "inclusive" and *not* to discriminate against students with disabilities.

Chapter Six

ACCOMMODATION AS IDEOLOGICAL PRACTICE:
THE DISABILITIES APPARATUS

Introduction

In this final chapter. I conclude my analysis by showing how accommodation works as an ideological practice. In the previous chapter I started with the experience of the everyday – as it is known and spoken by students disabled by chronic illness – in order to explicate the assumptions and social relations that structure and organize the Policy. In this chapter. I turn my attention to the ideological procedures through which the work processes and practical activities of chronically ill students. faculty and administrative staff are rendered accountable within the ideological schemata of the university.

Specifically. I will show how the disabilities apparatus. through the Office for Students with a Disability (OSD). constructs both disability and accommodation as textual products of administrative practices. First by producing disabled students' "needs" out of the surveys. assessments and physical access audits conducted by the university. Then by providing students and faculty with an interpretive schema through which legitimate instances of disability and accommodation can be recognized. The Coordinator and administrative staff who work in the OSD may be committed to assisting disabled students remain engaged in their studies. They are also professionals who clearly think of themselves as providers of a caring service to the students who approach their office. Accommodation. itself. is a crucial process that allows chronically ill students to participate in postsecondary education. My aim in this analysis. however. is to show how accommodation becomes a ruling activity. Despite their good intentions. both faculty and administrative staff come to know

chronically ill students and what would be "relevant" action from within the discursive frame provided by the Policy – which is part of a ruling practice (Campbell 2000).

The work of the OSD, I argue, consists mainly in articulating disabled students – in all their varieties and with all their differing "needs" – to the overall institutional function. It produces an institutional order out of the conflicts, disagreements and resistance that characterize the work of providing accommodation. The Policy – as a textually mediated relation of ruling – also coordinates the activities and decision-making processes of the university with the activities and decision making processes of the medical system. It is this latter process that contradicts the taken for granted assumption that a "social" disabilities apparatus constitutes a genuine alternative to the dominant biomedical model of disability.

The Ideological Practice of Accommodation

The concept of "disability" is a lynchpin in a complex web of institutional definitions, though which eligibility for social assistance, disability pension benefits, accommodation, and so on, are made (Linton 1998). In other words, the concept of disability is a constituent of a complex of relations articulating people with disabilities to the specialized functions of the ruling apparatus (Smith 1987). Disability and accommodation, as organizational categories appearing in university policies and regulations, are not categories of a natural kind; that is, the experienced phenomena are not the same as the organizational categories. Rather, these categories are the means by which an idiosyncratic and personal experience of bodily impairment can be articulated to the administrative and bureaucratic relevances of the university for the purpose of activating an organizational course of action (Smith 1974:1987). It is through the work of the OSD – as the physical locus of the university's disabilities

apparatus – that specific discrete "needs" of disabled students are identified in order to plan and coordinate the various student. administrative and instructional activities required for the Policy's enactment.
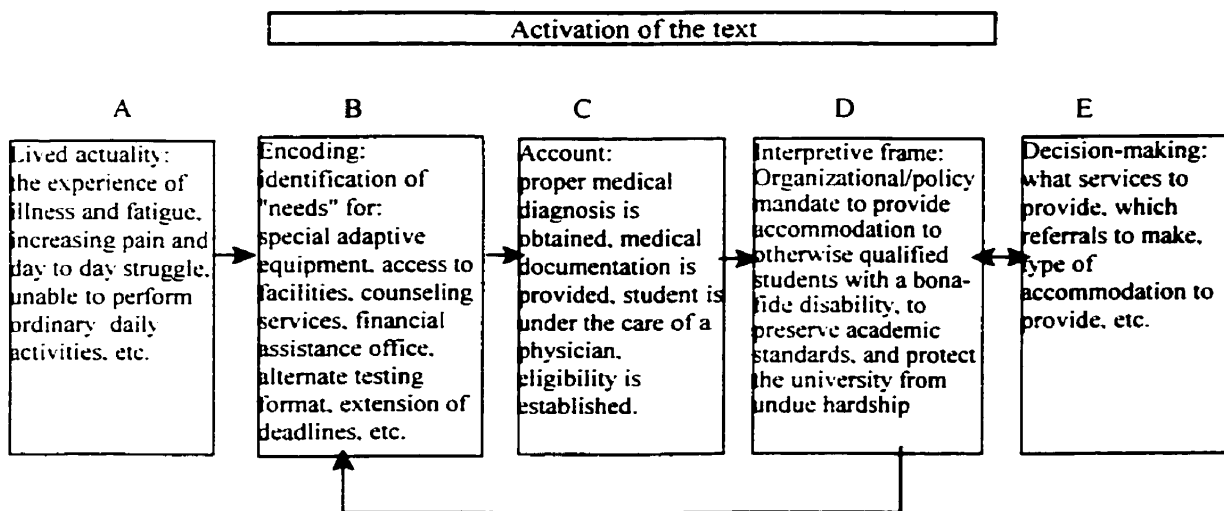
Disability and "Needs"

During the period of time that the old disability policy was reviewed and a new one was drafted (between 1994-1997). the University of Victoria's interim Advisory Committee on Issues Affecting Students with Disabilities conducted surveys and assessments of disabled student's "needs". systematically collected and evaluated disability policies from other universities across Canada. and performed physical access audits of the University of Victoria's facilities on campus. While this process is normally taken for granted as a process of identifying disabled students' "needs". it is analytically an administrative project of disaggregating a disabled student's actuality into manageable parts. The resources of the university – including the services and forms of assistance to which it was already habituated – provided a schema for "discovering" disabled students' "needs". For example. only established students who were already participating in postsecondary education were involved in the survey. This means that the "needs" of individuals unable to access or remain engaged in postsecondary education were effectively excluded.

Canvassing disability policies from other Canadian universities ensured that the institutional categories and concepts used by the University of Victoria in its new disability policy would be aligned with the categories and concepts used by other Canadian universities. The process of harmonizing the University of Victoria's new disability policy with disability policies at other Canadian universities is not simply a means of benefiting from the experiences of actors in other organizational sites, it also

provides a glimpse into how rules. routines and ordinary everyday work processes in one local setting become coordinated and standardized across different institutional sites. The physical access audits were of particular importance because they provided a means by which the university could demonstrate immediate compliance with its duty to accommodate. Through a one-time expenditure of funds – used to make changes to the built environment such as building ramps. improving signage. making washrooms wheelchair accessible. acquiring specialized adaptive equipment. and so on – the university is able to provide concrete accommodation to not just one. but potentially many students with disabilities.

Below is a schema. adapted from Smith (1990a:152). that will help me show how students' lived actualities are transliterated into an account for organizational action (i.e.. arrows A-B-C-D). The lower arrow from D to B suggests how categories of "need" arise in relation to the interpretive frame that the Policy provides.

Activation of the text				
A	**B**	**C**	**D**	**E**
Lived actuality: the experience of illness and fatigue. increasing pain and day to day struggle. unable to perform ordinary daily activities. etc.	Encoding: identification of "needs" for: special adaptive equipment access to facilities. counseling services. financial assistance office. alternate testing format. extension of deadlines. etc.	Account: proper medical diagnosis is obtained. medical documentation is provided. student is under the care of a physician. eligibility is established.	Interpretive frame: Organizational/policy mandate to provide accommodation to otherwise qualified students with a bona-fide disability, to preserve academic standards. and protect the university from undue hardship	Decision-making: what services to provide. which referrals to make. type of accommodation to provide. etc.

A: is the student's actuality. B: provides the "codes" or "needs" that are selectively taken up from that lived actuality and which are necessary for determining the student's eligibility for accommodation, at C. The student's "needs" are formally

recognized through the interpretive schema that the Policy provides (at **D**), and they form the basis of the decision about what organizational course of action will be selected at **E**.

It is important to note the circularity of the university's ideological practice of meeting disabled students' "needs". The decision to review and revise the disability policy followed closely from two important legal decisions that both upheld the rights of disabled students to obtain reasonable accommodation[36]. Thus, legal necessity provided both the rationale and the framework for identifying disabled students "needs" in the first place. During the time that the university collected and interpreted its survey data, it was actually selectively treating disabled students' lived actualities in terms of a predetermined framework, by transposing them into the institution's categories and concepts. The data, thus ordered, became the administrative and constructed reality intended by the schema and the schema interpreted the data (Smith 1990a).

Because the university's process of providing accommodation draws on students lived experience, the Policy can be said to incorporate the interests of students with disabilities. When disabled students become applicants for the items and services of the university, however, their actual conditions of life and their differing resources, capabilities, alternative choices, and social realities are ignored and rewritten. The subjectivity of the student is cancelled as she takes up a discursively organized subject position as an applicant. The Policy helps to construct a set of institutionally defined "needs" that may or may not correspond to the student's actual demands. For example, in one situation, an informant was awarded a disability related scholarship for a period of a year. Due to the exacerbation of her illness, she was required to take a leave of absence during the second term of her studies. Because there were no provisions to

defer the scholarship. she was required to forego the remainder of the scholarship funds. The actual demands and requirements of this student were thus subordinated to the rules and procedures that governed the disbursement of scholarship funds.

Articulating the Individual to the Institutional Function

Physically. the OSD is a small office (with 2.5 employees) and it depends crucially on existing services and departments in the university such as Student Financial Aid Services. the Student Employment Centre, and Counselling Services:

Coordinator of the OSD: *"We try to work as much as possible with the existing departments. I don't believe in recreating our own little financial aid office, and such, for students with disabilities. What is nice, is that under Student Services you have all these other departments: you have Financial Aid, you have student counselling, employment office. the learning centre - we're in the same building... We're a small office physically, but I also think that it's the best model where you work with the other people in the other departments and bring their awareness up"*

The OSD not only performs the work of recognizing particular discrete "needs" of the disabled student. it also refers. or articulates, them to those services and programmes that they are seen to require. While the outcomes of such work processes as "assessing the needs of students with disabilities" appear to address the unique circumstances of each student's individual situation. such "needs" assessments are already organized by the availability of specific existing services and programs that the university offers. Outcomes of assessments are always directly linked to the "problems" that can be identified and are elaborated within the official organizational processes. "Solutions" are always directly linked to the services and programs that the university can already provide. These services and programmes, themselves. are organized around the identified needs and requirements of the general student population.

Once again. there is a peculiar circularity, and also a contradiction, that arises in the work of the OSD in referring disabled students to other university services and

programmes. Rather than meeting the unique "needs" of disabled students. the activities of the OSD can be seen as working in two distinct directions: in one direction it isolates and names some of the particular "problems" and "needs" – financial. employment. or psychological problems – of that part of the student population who are defined as disabled: in the other. it authorizes particular services and programmes to be the holders of the "solutions" to these problems. There is "an inner coherence" between the problem of disability thus represented. and the solutions that can be applied to it. "such that the actuality. produced as 'what actually happened/what is.' can be seen to require its own descriptive categories and conceptual procedures" (Smith 1990a:78).

While the OSD intends to maximize the learning opportunities of disabled students. it can only ever do so in terms set by the organization of existing services and programs. which are themselves organized around the concept of the average, and not disabled. student. Hence. the OSD can only attend selectively to the problems that may be encountered in the everyday lives of students with disabilities. However, in their work of facilitating the absorption of particular disabled students into the overall organizational structure of the university, the OSD can be seen as accomplishing the accessibility and inclusiveness of the university. in compliance with legislation and other juridical processes. without actually requiring any significant overall organizational change.

A telling example of how this process of articulation happens – i.e., how identified "needs" suggest their own solutions – can be seen in the close working relationship between the OSD and the counselling centre:

Coordinator of the OSD: "*I have a background in counselling, but I am not a trained counsellor. But I know very well when I'm talking with students and I can see that, I don't know, they have a problem with stress, or personal problems, I will refer them to one of the counsellors. And it's nice being in the same office. I can actually walk them*

over there and introduce them. " [and later in the interview] *"depending on the
disability, depending on where you are with it – or you have some people who have
problems with denial – people are in different places in their lives, different levels of
maturity, different levels of acceptance with what you can do or cannot do, and so on.
By the end of the day, it's a personal choice"*

The close relationship between the OSD and Counselling Services, and the

frequency with which the Coordinator of the OSD talked about the importance of

being able to refer disabled students for personal counselling, may also point to the

way in which the work processes of chronically ill students become "reconstructed as

social or psychological processes, depriving them of their necessary anchorage in an

economy of material conditions, time and effort " (Smith 1987:163). Here, the

distress, anxiety, frustration, and fear experienced by disabled students are seen by the

Coordinator to be more surely related to their psychological attributes and emotional

characteristics than they are to their objectively existing difficulties and strained

resources.

The importance of personal psychological counselling was also echoed by the

research informants: all but one accessed some form of counselling, i.e., at the

university's Counselling Services, private counselling, or counselling provided

through the Arthritis Centre:

Jody: *When I started to see a counsellor, I would leave with these huge insights and
was beginning to see myself differently... I think I was starting to mature and also to
deal with what I had to deal with around my losses..."*

Corina: *"And going [for counselling] helped too. I saw [the counsellor] individually
and went through a stress management course, and I went to the educational
workshops too. And some of it was helpful. "*

Leslie: *"And my [physician] actually said – well things like this are usually connected
to something else – and because it started early, there's a chance of it progressing or
not, and if you work on your emotional stuff, it could be gone in five years. So I keep
making a point of working on that and being assertive..."*

Lee: *"One of the things I that I certainly experienced at the university, and that I know other people did, was when I first started going there, I accessed Counselling Services. It was a whole new environment, a new adventure for me, it was new, the whole thing. I was scared. I had just gotten a lot better and I wanted to sort of get some basis for where I was and where I was going, you know, that sort of thing. And you know, there wasn't any understanding about the issues that I was contending with. There wasn't any at all."*

The close relationship between the OSD and Counselling Services is a socially organized relation where the different services play complementary roles: the OSD attends to the accessibility of the physical environment and the accommodation of the disability, and Counselling Services takes up the "problems" that are left over. While these problems may result from the mismatch between the students "needs" and the university's "solutions", they become interpreted – as demonstrated in the excerpt from the Coordinator of the OSD above – as "personal problems", and the failure to properly manage stress. More importantly, the central role of counselling locates the responsibility for change within the individual. Counselling can only ever take up those issues that are already situated within its frame of reference; and counselling is seldom political. Through the practice of referring students with "problems" on to counselling, the "problem" remains located in the individual, and the social determinants of the experience of distress remain invisible.

The Conceptual Framing of Disability and Accommodation

The Coordinator for the OSD also indicates that it is the OSD's goal to "bring up the awareness" of other people in other departments. Accordingly, the Coordinator of the OSD, along with the Equity Officer, also provide educational presentations about disability and accommodation issues to faculty in various departments. These presentations clarify for faculty the kinds of difficulties and issues that disability

entails and the limits and extent of their legal obligation to provide reasonable

accommodation.

Coordinator of the OSD: *"Every department has their own culture, their own ways of conducting business, but they are all subject to the same university policies. So when it comes to providing accommodation, there is no choice. Well, for a lot of departments it has to do. I guess, with attitudes, beliefs, with education... So when we go to the faculty meetings and we present an hour, or one and a half hours on accommodations, not only for students but also for staff - because we have an aging faculty (laughs), you know, it brings it home a bit closer to them. We have a lot of them, like me, who wear eye glasses, sense of hearing is becoming a problem, or people who are starting to use scooters, or find that the stairs are becoming a bit more difficult to go through so the elevator becomes more of a necessity... But for students, I've found that having a policy, and I mean clear guidelines as to what is the way to proceed now, quite often solves any problems right away."*

Here, the Resource Centre "teaches" faculty about accommodation as it is textually

mediated through the conceptually organized rules and procedures of the university.

These educational seminars can be seen as drawing all the various "players" of the

university into the same "ideological circuit": where the legal obligation of the

university provides an interpretive schema through which the actual "problems" that

its members - as administrators, instructors and support staff - might encounter with

disabled students can be "shaped up" to "fit the various bureaucratic responses" of the

university (Smith 1990a). Being able to properly implement the rules and procedures

for providing accommodation depends on all of the participants using the same

terminologies, methods and procedures for recognizing, describing and acting upon

the student's situated and embodied experience of disability.

The "clear guidelines", or proper interpretive schema, assists faculty,

administrators and students alike to properly recognize and attend to what is relevant

in the institutional context, in order to realize a particular institutional course of

action. By transposing the actuality as it is experienced into the categories and

concepts that the institutional processes provide, in accordance with the rules and

procedures of the Policy, the compliance of the university with provincial and federal human rights legislation is also actively accomplished. The intentions of particular departments and particular professors may differ, as indeed they do. However, by attending to the same categories of persons, and by conforming to the same rules and procedures for providing accommodation, each department and each instructor actively bring into being the institutional order of the university.

There is another point to be noted in the above excerpt. Because concepts and categories depend on shared understandings and shared vocabularies, the commonality of the experience of physical or bodily vulnerability (i.e., the aging process) can be called upon and used to show faculty how to recognize what disability is and what it entails. Arguably, as disability studies writers point out, such "ease of intuitive knowledge is really another aspect of discrimination against people with disabilities" (Davis 1998:2). The over-extension of the category of disability – that everyone can imagine what it is like to be disabled "because everyone has some limitations or imperfections" – may lead to the underestimation of the struggles of people with disabilities who have not only their physical conditions to contend with, but also the many "socially constructed obstacles in their lives" as well (Wendell 1996:66).

Yet, from the institutional point of view, encouraging its members to draw upon their own commonsense understandings of bodily limitation as a means of imagining the experience of disability, also fosters the development of a template for practice that has the administrative or professional point of view built-in to it. Faculty and administrative staff may experience the aging process, physical limitations and even disabilities but, by virtue of their positions as paid and, therefore, protected members of the organization, they do not share the same vulnerabilities, the same disadvantages, or the same restricted life possibilities of most disabled students.

Policies as Coordinators of Activities: Ruling Practices

The Policy on Providing Accommodation for Students with a Disability is a structured framework which links up with. and realizes the legal obligations of the university and the state to disabled people as they are expressed in the Charter of Rights and Freedoms and the B.C. Human Rights Act. The various rules and procedures that characterize the university's policy on accommodation are an organizationally structured sequence of distinctive processes that only loosely correspond to the actuality of people's everyday experience of requesting and obtaining accommodation. They impose an organizational order on what would otherwise be a discontinuous and contingent flow of everyday activities. decisions, and practices of reasoning. However. these policies and procedures cannot simply be understood as constituents of organizational processes. they are also concrete organizers and coordinators of people's everyday activities:

Ombudsperson: "*The university gets all of its authority from legislation. The University of Victoria. like every other university in the province, gets its authority from the University Act. which is a piece of provincial legislation. So whatever authority the university has. has to be somehow founded in some section of that Act. It also must be consistent with provincial legislation... Similarly. once you get into the University itself. we have a structure which is basically a bi-party kind of split: we have a Board of Governance which is essentially responsible for anything to do with money and a Senate which covers anything to do with academics. Now that's really simplistic. but that's the split. So let's say for example that either the Senate or the Board of Governors develops a policy, that policy does govern every unit on campus, in theory. But. I mean. to actually make it work, you have to have cooperation from each of those different units.* "

Coordinator of the OSD: "*In the book there is a detailed version of the Policy. But from experience (laughs) I know that people hate to read the policy document, so we've prepared a kind of handout that we give to the students and it explains the policy in a nutshell. I find that this is quite useful for students and faculty. So quite often we send it to faculty. In September we'll do a major mail-out to everybody so people are at least aware of what the process is. So you see. it's both for faculty and students... Whenever there is a request for academic accommodation, say for extra*

*time on an exam or a need to write the exam in a quiet location...we always write a
letter to the instructor, explaining that this student has a disability, that they've
registered with this office, that they've presented documentation, and I encourage
students to get a copy of it and present it to the prof themselves, while I make it clear
that we will send a copy as well in the in-house mail... so we need about a week in
advance, at least, notification. The professor has to sign a release form for the student
so that we get the exam. There is a fair amount of coordination here. But sometimes, it
is true, I get a call from a professor saying - you know, I'm not comfortable with your
request. I believe it is compromising the integrity of the curriculum. And that's where
the policy has helped a lot, has made a difference, because I say - you know, there's a
process in place here, if you're not comfortable with the request... first of all you have
to talk to the student and explain your concerns. That is the first step. If the student is
not happy, or does not accept your reason, they also have to appeal the decision... and
so on.*

In the excerpts above, the organizing capacities of legislation, the institutional

functioning of the educational system, the organization and social construction of

university rules and procedures, their enactment at the level of the department, the way

in which they are taken up at the level of the individual faculty member, and

consequences for the individual student all come into view. Each level is characterized

by activities and decisions of actual individuals, each in their own local settings which

are anchored in definite material conditions. At the same time, these decisions and

activities do not come about as the personal and idiosyncratic preferences and actions

of individuals working within the institutional complex, but are enacted by them as

features of the social organization of the university setting. As such, the decisions and

activities of actual individuals actively accomplish the "ruling practices" of the

institutional complex regardless of whether or not they agree with each other, or share

similar intentions and motivations. The university's policies and procedures are

intentionally designed to produce an institutional order out of the conflicts,

disagreements and resistance that characterize the work of providing accommodation.

This is especially apparent in how the responsibilities of the "university" are

characterized in the Policy. Where policies and procedures refer to "the university", all

individuals involved in the provision of university-related services are included. i.e..

faculty. administrators. counsellors. or other support staff (Policy on Providing

Accommodation for Students with a Disability. Section 6.1). Yet. "the university"

implies a cohesiveness within the category that does not actually exist. In the system

of appeals. which provides a mechanism through which to "settle" disagreements

about accommodation between instructors and students. the differences between the

relevances of administration and the relevances of instruction become more apparent.

While the provision of accommodation ostensibly takes place in the classroom and in

the processes and practices of teaching and/or evaluation. the "legal and moral" duty

to provide accommodation lies with the university as an institution. The activities of

both students and faculty. therefore. are coordinated and organized by the

administrative relevances of the Policy which are designed to produce an institutional

order.

For example. even where a student has satisfied the conditions of the Policy – that

is, the student has identified herself as disabled, her documentation is determined to be

acceptable. and the requested accommodations appear to be reasonable and

appropriate in relation to the student's chosen program of study – the instructor may

not have participated in planning or approving the proposed accommodation, and may

not wish to. There are practical reasons for these kinds of responses. While some

instructors regard the provision of accommodation as an opportunity to refine and

improve the overall quality of their practices of instruction and evaluation, others may

resent interference in their established methods of teaching and evaluating (Young

1996). Some report that the work of planning alternate strategies of evaluation or

working with unfamiliar media to be an onerous and time-consuming process. Many

are unaware of disability-related issues. Still others find that increased class sizes

severely curtail the amount of time that can be spent on each individual student. making students with disabilities a drain on their scarce resources of time and energy. These institutional constraints within which faculty must provide accommodation are also consequential for chronically ill students.

However. regardless of whether or not faculty are amenable or resistant to providing accommodation for students with disabilities. and regardless of whether or not students find such accommodations to be useful, by adhering to the organizational procedures as outlined in the official policies. the proper institutional course of action, i.e.. providing reasonable accommodation. is realized and the university actively fulfils its legal duty to accommodate. Further, by securing reasonable accommodation through the Policy on Providing Accommodation for Students with a Disability, the activities and tasks of the student. the student's physician. the administrative and support staff in the OSD. the instructor, and whoever else comes to be involved in the process. are all coordinated and concerted through the realization of the institutional course of action in the local setting.

This particular coordination of knowledge and action – by individuals not necessarily known to each other. not sharing the same expertise, and not situated in the same local setting – simultaneously makes disabled students' "needs" manageable and fulfils the university's legal duty not to discriminate against students with disabilities. As an ideological practice. the Policy does away with the organization's capacity to interact with the chronically ill student as an individual. She becomes an aggregate of "needs" to be satisfied through the services and privileges that the university has to offer. Depending on the student's actual demands or the way in which the faculty member "takes them up". the accommodation can be genuinely useful or it may be

ineffective. Regardless of the outcome. however. the student is understood to have been "accommodated".

Conclusion

The study presented here uses institutional ethnography to close the gap between analyses of the "embodied experience" of illness and analyses of the systemic inequities that disability can be seen to produce. Using the everyday experiences of chronically ill women who are postsecondary students in this particular university. I have attempted to explicate some of the broader societal processes which penetrate the local setting and which stand to disadvantage chronically ill students. My initial interest in this subject matter was kindled by the discrepancy I observed between the struggles of chronically ill students to remain engaged in their studies and the widely-held assumption that the university's new disability policy not only "solved" the problem of equity for disabled students, it also conferred advantages and benefits that were unfair for other students (Young 1996).

My decision to focus on women was prompted by the call in disabilities studies for analyses that disrupt the homogeneity of the category of "disability" by including other axes of difference. i.e., of gender. race, type of disability. and so on (Morris 1991; Wendell 1996). Women are more likely than are men to be affected by chronic health conditions (Morris 1991) and they are less likely – due to childcare responsibilities or working in traditionally female-dominated, low- status, low-wage service sector positions – to receive disability pension benefits above subsistence level social assistance benefits (Asch and Fine 1988; Quinn 1994). For women, therefore, disability is often complicated by poverty. This means that postsecondary education – with the opportunities for more professional, flexible and well-paid employment it

provides – is especially important for women. Even though I have chosen to start from the experiences of women, much of my analysis will be relevant for chronically ill men.

In the first chapter, I introduced the two main theoretical approaches to the problem of disability. In the more dominant biomedical model of disability, disabled individuals are studied in their particularity, usually as objects of other's professional practices. The social model of disability, which argues that the biomedical approach is intertwined with and part of the discrimination and oppression experienced by disabled individuals, shifts the obligation for change from the body and activities of the disabled person to the built environment and social arrangements which are all organized around norms of "able-bodiedness".

As I pointed out, the disability rights movement has been successful in having the social, rather than biomedical, model of disability adopted as the basis for anti-discrimination policies within Canada's legal, educational, healthcare, economic and other social systems. The Policy on Providing Accommodation for Students with a Disability (rev. 1997), developed by the University of Victoria, is typically considered to be part of this more social response to the exclusion and discrimination experienced by disabled people. However, while the Policy enunciates a normative theme of social justice for people with disabilities, the concrete tasks and practices it entails – especially the medical criteria for eligibility – reinforce and sustain individualistic biomedical understandings of disability as well. Even though it is intended as a social solution to the problem of exclusion and discrimination, the Policy also explicitly replicates the social relations of medicine within the local site of the academy. This is not simply a matter of the university "borrowing" concepts and categories from medical discourse. By requiring students with disabilities – especially those with less

obvious or "invisible" disabilities – to provide appropriate medical documentation, the institutional processes of education are coordinated with and made dependent upon the institutional processes of medicine.

For people with disabilities, medicine is part of the "ruling apparatus". Both medical knowledge and medical practices are structured through and through by ruling relevances. Through the implementation of the Policy, the social relations that characterize the professional practice of medicine – where the physician is the "expert" knower and the patient is the object of knowledge – are reproduced in the academy. Thus, the embodied, directly-known experience of chronic illness is subordinated and subdued to the categories, coding procedures, and conceptual order of medicine.

This coordination of the academy and the medical system is particularly consequential for chronically ill women. Women are more likely than men to be affected by chronic illness and within the context of healthcare, women and women's health care needs are often discounted or ignored (Lock 1998). Because pain and fatigue – the most common symptoms of chronic illnesses such as rheumatoid arthritis – cannot be objectively measured, these kinds of complaints are often disregarded or are subordinated to "visible" evidence that the physician can observe. "[T]he subjective experience of illness does not stand in a one to one relationship with measurable pathology" (Lock 1998:56), and the process of diagnosis is often protracted and complex. It is therefore troubling that at the heart of a "social" response to the problem of discrimination, medical practitioners can still be seen to have authority over the bodies, understandings, and experiences of chronically ill women. As my analysis discloses, far from moving away from a biomedical approach to disability, the policies and procedures actually reinforce and sustain the resiliency of

medical ways of knowing. Indeed, the university's policy depends for its very legitimacy and authority on the objective knowledge of medicine and its individualistic biomedical understandings of disability.

In chapters two and three. I introduced Smith's sociology and the research strategy known as institutional ethnography. My intention was to show how Smith's approach could provide an analysis congruent with the prescriptions of the social model of disability, while at the same time combining two usually separate areas of study – analyses of individuals in their local settings and analyses of institutional relations – into one project of research. Rather than objectify women disabled by chronic illness, or to study them in their particularity as deviations from the "norm", my aim was to shed light on some of the institutional processes in the academy that may disadvantage chronically ill women and (dis)organize their future opportunities and student careers. In its broadest sense. my analysis discloses – for chronically ill students – how their own locally situated experience is inextricably bound to regimes of ruling (Smith, G. 1995).

Smith's approach is especially useful in providing an analysis that adequately accounts for the differences in outcomes that people with disabilities experience. As I discussed in the first two chapters, disability does not exert an even influence over all individuals equally and there is no one to one correspondence between physical and social disadvantages. By exploring how differences in experience arise – i.e., through how students' everyday activities are entered into and coordinated with the activities of others – other dimensions of an individual's social experience were also illuminated. For example, by exploring the "work" processes of chronically ill women. particularly those activities not ordinarily observable or reportable as their work. it was necessary to take their material circumstances and resource conditions

into account. Instead of resolving the differences in material outcomes into the psychological characteristics of the informants, it was possible to explore the relations that generate differences in the lived experience of chronically ill women.

Smith's approach provides a unique way to investigate what she calls "the relations of ruling". For Smith, texts and text-mediated forms of knowledge organize, regulate and coordinate the activities of people in their diverse local settings across space and time. The University of Victoria's Policy on Providing Accommodation for Students with a Disability (rev. 1997) is a good example of a textually mediated ruling relation that organizes, regulates and coordinates the activities of students, faculty, administrative staff, physicians, lawyers, policy makers, and so on. Designed to reconcile the relevances of human rights legislation with the interests and relevances of the academy, the policy can be seen to produce an institutional order out of the conflicts, disagreements and resistances that characterize the process of providing accommodation. By activating the Policy, the work processes and activities of students, faculty and staff all actively accomplish the university's legal obligation not to discriminate against students with disabilities. The provision of "accessible and accommodating postsecondary education", I argued, is a text based and ideological practice. That is, the subjective and everyday actualities of chronically ill applicants' lives were transposed into the ruling categories and relevances of the Policy. That process accomplishes the ruling enterprise of "no discrimination" for the university, but as an account it departs from what the informants know about their own experiences and the workings of their lives.

This is not to say that accommodation never operates in the interests of disabled students. Chronically ill students depend crucially on some form of accommodation to access and participate in postsecondary education. Yet in spite of the good intentions

of policy-makers. faculty and administrative staff. accommodation depends on objective administrative – or ideological – practices that subdue the subjectivities of chronically ill women to the institutional accounts that "stand in" for them. The same procedures that are integral to accountable administration and organizational decision-making. also operate to subordinate what chronically ill women might know or say about their own experiences. My analysis exposes and describes "built in" flaws arising from the conceptualization of accommodation as a text mediated ruling practice.

The argument that disadvantage and discrimination may be consequences of institutional measures designed to produce fairness for particular disadvantaged groups contradicts the taken for granted assumptions that lofty ideals can be legislated and that good rules will always have good effects. Yet the abstract criterion of social justice must always be understood as a set of coherent tasks and goals that are enacted in the actual local settings and circumstances of people's everyday lives. Even though they are organized and implemented in the interest of producing fairness for excluded and disadvantaged groups. equity policies (such as the Policy on Providing Accommodation for Students with a Disability) are necessarily bound up in relations of ruling. By interrogating the inadequacies of these policies. and showing how apparently beneficial practices may turn out to have negative or unintended consequences. researchers provide a place to begin to engage in oppositional work. They allow professionals. and those who are ordinarily objects of other's professional practices, to choose what kind of stance to take. and what course of action to follow, and thus disorganize the "ruling project as originally conceived" (Campbell and Manicom 1995:11).

AFTERWORD – TO ACCOMMODATE OR NOT TO ACCOMMODATE

In the telling of their experiences, chronically ill students reveal the way in which identifying as disabled and requesting accommodation may stand to (dis)organize their activities, experiences and future opportunities. Indeed, the implementation of the rules of accommodation do not necessarily operate in the interests of chronically ill women. Informants who secured accommodation on a more contingent and informal basis tended to have more success: they were not scrutinized or subjected to the same assessments and judgements that characterized the experience of those who became formal applicants. Students who avoided formal institutional encounters also minimized the "work" required to stay engaged in their studies.

While the practical implementation of the Policy can be seen to produce inequities for students who are chronically ill, it does not necessarily follow that chronically ill students should be advised *not* to use the services of the OSD. The problem of chronic illness as a disability is already largely invisible in the organizational context of the university. For example, while there was no shortage of informants with chronic illnesses, the interviews with institutional members (i.e., faculty and administrative staff) failed to yield even one example of students with chronic health conditions such as rheumatoid arthritis. Instead, they used examples of learning disabilities or emotional and psychological disabilities to parallel the problem of invisibility. To illustrate the problem that absences and unpredictability might cause, they used examples of accommodation for religious observances. For examples of stigma and concerns about confidentiality, the experiences of students with AIDS and Hepatitis C were used. Chronic illness, in other words, failed to fit the institutional framing of disability. If chronically ill students continue to choose *not* to identify themselves as disabled, they contribute to their social invisibility and they reinforce the notion that

chronically ill women have little of significance to offer the academy. Acknowledging the participation and achievements of chronically ill students is important. However, it is questionable whether or not these broad aims might be accomplished through attention to the university's disability policy.

While the university's Policy enunciates a normative theme that is intended to realize the ideology of human rights. it relies on a logic of rules. procedures. standards. and actions to do so. Where outcomes are demonstrated to be inequitable. the emphasis is usually placed on the quality of the process. As already discussed in previous chapters. the process of requesting and obtaining accommodation usually produces ambivalent results for chronically ill women. Thus. improving the quality of the process would tend to strengthen the same standards. rules and procedures that do not operate in the best interests of chronically ill students. This means that all efforts to improve and streamline the implementation of the Policy. including strengthening systems of appeal in order to reform and improve accessibility. will tend to reinforce procedural remedies. which are themselves determinants of inequitable outcomes. In any case. chronically ill students seldom have the requisite resources of time and energy to be able to consider appeal a reasonable option. Even the activities of the university's Ombudsperson – as an "insider" that can initiate action from within the institution without requiring the mobilization of the chronically ill student – are still confined to monitoring and "policing" the existing policies and procedures of the university. Unless the underlying assumptions and social relations that structure the Policy are challenged and transformed. all efforts at streamlining and simplifying the process will strengthen the same administrative approach to "managing" chronically ill students' "needs".

Genuine measures to improve equity for chronically ill students would seem to consist in changing the fundamental position of chronically ill and disabled people themselves. On a general societal level, this would involve scrutinizing the social relations which structure the allocation of social positions. i.e.. improving income replacement programs that are calculated below social subsistence levels. changing "all or nothing" disability pension rules that penalize modified forms of labour force participation. and so on.

In the context of postsecondary education. improving the position of chronically ill women would entail a focus on measures that improve opportunities for disabled and chronically ill women to participate. After all, postsecondary education – which provides the means to well-paid, flexible. and more professional employment – is an especially important social determinant of health. It is also a crucial component in resisting the accumulation of disadvantage and downward mobility that usually accompanies the onset of chronic illness and disability. More importantly, chronically ill women should have the opportunity to participate in the production of a body of knowledge that reflects their own experiences, interests. and ways of knowing. Accommodation. as it is currently framed in the context of the university, consists mainly in meeting disabled students' institutionally defined "needs". To accomplish the goal of improving the position of chronically ill women and foster their participation in the academy, accommodation would need to remove the obstacles that stand in the way of chronically ill women being able to negotiate their own demands.

1. The United Nations definitions of impairment, disability, and handicap (UN 1983: l.c. 6-7): *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 an 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 fulfilment of a role that is normal, depending on age, sex social and cultural factors, for that individual".

2. Apart from anthropological analyses of the way in which the body functions as a surface upon which "the marks of social status, family position, tribal affiliation, age, gender and religious condition can easily and publicly be displayed" (Turner 1991:6), and apart from the use of the body as a metaphor for the body politic or for social systems, and illness and disease as a metaphor for disorder and dysfunction, the body and the experience of disability have remained marginal in social theory and in sociology overall (Turner 1991).

3. The one notable exception to the absence of illness and disability in social theory, prior to the 1960's, is Talcott Parsons' theorizing about the "sick role" (Parsons 1951). Briefly, Parsons' structural functionalist model provided a framework for understanding illness and disability as evidence of instability or disharmony in the overall functioning of society (Turner 1997). However, while the "sick role" exempts the individual from the obligation of fulfilling "normal" social roles and absolves the patient of responsibility for his or her condition, the "sick role" also enshrines the authority of the physician and the medical system by requiring the patient to follow only medically authorized pathways to healing (Turner 1987). In this paradigm the patient is subordinated to the ultimate authority of the medical system and must accept an obligation to become well by complying with an authorized therapeutic regime. The importance of Parsons is that he introduced into social theory and social analysis a phenomenon that had previously been limited to the domain of medicine. The concept of the "sick role", as a particular social role, provided a "powerful instrument for the analysis of culture" (Turner 1987:58), and brought into the foreground the whole question of responsibility for illness and the social response to disability.

4. The 1980's ushered in at least two different epidemiological shifts of profound significance. Not only was the general population aging and becoming more susceptible to illness and disability, but "[e]very study, no matter what the measure, showed tremendous increases in both the general rates of disability and the specific rates of disability-related chronic disease conditions" (Zola 1994:59). These increases do not indicate a simplistic rise in "organically based disturbances" of the body's structures and processes. Rather, because "the biological and the social are interactive in creating disability"(Wendell 1996:35) the increase in disability also reflects social factors such as accidents; injuries; lack of prenatal care; dangerous or inadequate obstetrical practices; the deprivations of poverty; poorly enforced occupational safety standards; environmental degradation and contamination; and the changes in expectations of performance or increases in the "pace of life" that exclude people unable to meet expectations of "normal" performance (Wendell 1996).

5. Rheumatoid arthritis has an uncertain origin, is unable to be predicted with any accuracy, and is also difficult for professionals and medicine to control. In spite of medical advances in patient treatment and care, there are no known cures for rheumatoid arthritis and many other arthritis-related conditions. As well, doctors, with the help of pharmaceutical and other medical researchers, focus attention "on cures and imminent cures, on successful life-saving

medical interventions" (Wendell 1998:269): they take little interest in, and are relatively unequipped to help patients with the less glamourous, more persistent chronic conditions that cannot be eliminated or "cured".

6. This would include juvenile rheumatoid arthritis, lupus, scleroderma, and myalgic encephalomyelitis.

7. Roughly seventy-five percent of those affected with rheumatoid arthritis are women (Arthroscope 1995).

8. Because the meaning of disability for men challenges all that is seen as synonymous with the traditionally masculine ideal, i.e., being virile, strong, physically able and independent, rehabilitative efforts were initially directed primarily towards restoring the masculine ideal for men. For disabled women, where the feminine ideal was deemed to include such attributes as passivity and dependence, the effort to promote women's productivity and independence was deemed unnecessary and redundant (Asch and Fine 1988; Russo and Jansen 1988). Rehabilitation, therefore, is not only structured by a clinical biomedical orientation, it also has what Smith would call a "gendered subtext", which has developed historically and has become a "built-in" feature of its operations.

9. While medical and rehabilitative interventions have improved the overall quality of life for many people with chronic illnesses and disabilities, its effects have not been uniformly positive. The "culture of rehabilitation" may actively ignore or deny the benefits of adjustment that take place outside of the sphere of their professional expertise and influence (G. Frank 1988). "Successful" adjustment is usually equated with attempts to more closely approximate the "normal" population, or is equated with using the prostheses and appliances supplied by rehabilitation or occupational therapists regardless of whether or not these are useful for the disabled person (G. Frank 1988; Linton 1998).

10. For women who are chronically ill, and who are unable to work a full complement of hours in any case, there has been, and continues to be, little incentive for participating in vocational training or returning to modified work (Canada Pension Plan 1994).

11. There is evidence that disabled women are much more likely to internalize negative attitudes, feelings of inferiority, and stereotypes, seeing themselves as burdensome and unwanted (Asch and Fine 1998). Once economically and physically dependent, disabled women are also thought more likely to be emotionally unstable, emotionally needy and bitter (Kent 1988). While many able-bodied women complain about the sexual objectification of their bodies and the oppression inherent in the traditionally "feminine" role as nurturers for husbands, lovers and children, women with disabilities face a "rolelessness" and social invisibility as sexual beings and nurturers (Asch and Fine 1988; Quinn 1994; Thomson 1998). Women with disabilities are described as internalizing societal projections of themselves as dependent, unproductive, passive, and needy to the point that they remain at home with parents, even as adults. As Asch and Fine point out, however, research indicates that while disabled boys are encouraged to go out and meet the world, disabled girls are often sheltered and protected from it, undermining their capacity for independence and autonomy later on (Asch and Fine 1988:8). Further, the alternatives to living at home with parents often include debt, substandard housing, extreme poverty, and social isolation (Asch and Fine 1988: 1998)

12. The social meanings attributed to different disabilities are by no means constant or static: they vary over time and across different cultures depending on the roles that are available for people with disabilities and illnesses (Winzer 1998). Reasons for institutionalization have changed too: in the early Christian era many disabled people were cloistered as objects of piety and good works. while in the seventeenth century institutionalization served "to protect society from the physically. intellectually. and socially deviant and dependent persons in its midst" (Winzer 1998:99).

13. The dominance of the medical profession in matters concerning illness and health. however. was an active accomplishment that occurred only towards the end of the last century (Coburn 1993). In Canada. medicine was granted direct or indirect control over the context of care and over other health occupations. In effect this created a "monopoly for medicine" (Coburn 1993) where the medical profession acted on behalf of the state to control health care. Later. this monopoly for medicine was reinforced through the restriction of the activities of other occupations and of the public. i.e.. "through the all-inclusive definition of medicine in the Medical Act. through making certain drugs only available through prescription by a physician. through restricting the role of public health institutions etc." (Coburn 1993:130). As the complex "health care division of labour grew. mainly in the hospital. many health occupations were 'born' under medical control" (Coburn 1993:131).

14. Psychological adjustment requires the person with a disability to develop values, beliefs, behaviours and goals that promote optimal functioning in maintaining a sense of control, modifying daily routines. dealing with role changes. maintaining a positive self-concept. handling physical discomfort. complying with prescribed regimens. dealing with social stigma. grieving losses. adjusting to altered social relationships. and maintaining hope and a sense of normalcy despite an uncertain future (Chubon 1994:156).

15. Further. the attribution of success or failure to the disabled or chronically ill individual, adds the burden and stigma of psychological failure to women already compromised by physical impairments and limitations and restrictions on their activities (G. Frank 1988).

16. The shift in sociology away from the biomedical model was further fuelled by the impact of Foucault on social science in general (Turner 1997). Challenging the Marxist conceptualization of power as a macro-structure, Foucault saw power as exercised between two limits: "a right of sovereignty and a mechanism of discipline" (Foucault 1980:106). Intertwined with knowledge. power engenders apparatuses of knowledge and a multiplicity of new domains of understanding which exercises its coercive force in terms of disciplinary techniques. The knowledge/power relation is productive: for example. the common denominator in the proliferation of the forms of knowledge and institutions that characterize what we know as the "social problems" apparatus today (i.e.. psychologists, social workers, and so on) is the discourse of medicine, which in its circulation has produced new categories of persons - the insane. the criminal, the sick - who subsequently become subject to various "disciplinary techniques" (Foucault 1980). Hence, power becomes "dispersed, heteromorphous, localized" (Foucault 1980:142), and operates on the bodies of individuals in the conduct of everyday life. Discursive practices, "embodied in technical processes, in institutions. in patterns for general behaviour, in forms for transmission and diffusion, and in pedagogical forms which. at once, impose and maintain them" (Foucault, quoted in Fox 1997:36). exist independently of any authorial intention or human agency, and they can never be reduced to particular texts or practices.

Foucault's interest in "local techniques and strategies of power", which focus on the "interrelation between the imperatives of bodily management expressed at the institutional level and ways that individuals engage in the conduct of everyday life" (Lupton 1997:103), provides an ideal terrain to explore the problems of the"disordered" body in relation to institutions and power. However, while Foucault's analyses of discourse, power and governance have informed both medical sociology and the "tentative emergence of the sociology of the body" (Turner 1997: ix), there has been little attention to the problems of chronic illness and disability (i.e., see Featherstone, Hepworth and Turner 1991; Petersen and Bunton 1997). With the exception of writing identified explicitly as disability studies scholarship, the use of illness or disability as categories of social analysis in this sociological literature remain unusual, if not rare (for exception, see A. Frank 1990b).

17. One of the important features of this literature is that it takes up the experience of pain and suffering and acknowledges an important, yet often invisible, dimension of the experience of chronic illness; it provides a vocabulary in which the experience of living with impairment and uncertainty can be expressed.

18. See Nancy Fraser's (1997) essay "From Redistribution to Recognition: Dilemmas of Justice in a 'Postsocialist' Age" for insightful commentary on the limits of identity-based claims that become disconnected from claims for distributive justice.

19. Feminist disability scholars point out that the minority model of disability fits better with impairments where there is no intrinsic deficit and where a strong cultural tradition organized around that difference thrives (Thomson 1998; Wendell 1996), i.e., the experience of deafness, in and of itself, does not involve pain or suffering of any kind, and American Sign Language provides deaf people with a language and culture as rich and diverse as any other linguistic minority (Lane 1998). They also point out that like other political movements, the disability rights movement is dominated by men - both as theoreticians and as holders of important organizational posts (Morris 1991). Disabled men, they note, are less likely to suffer from chronic health conditions and more likely to have impairments - such as spinal cord injuries - that are not accompanied by chronic symptoms of suffering and pain

20. Like the social model of disability, and similar to the postmodern and poststructural critiques of more mainstream social analysis, the approach known as the social organization of knowledge "stands on the fundamental premise that the social world has no existence independent of the activities and understandings of social actors, including the understanding and activities of researchers" (Jackson 1991). This means that disability "cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it" (Oliver 1992:101). Because disability is socially produced, the activities of researchers, professionals, policy makers, and indeed all of that which we consider to be "social" are implicated in the construction of illnesses and disabilities as "problems" (Morris 1992). The conventions of objectivity, Smith argues, that is, "the theories, concepts, and methods of the discourses in which we participate as intellectuals constitute the objectified standpoints through which we are related to the world as if we stood outside it" (Smith 1996:173). By assuming a discursively constructed position outside time and space, unproblematically using the systematically developed categories and concepts for understanding the social world, sociology "subdues all forms of consciousness to its own dominating system of interpretation" (Smith 1999:98).

21. Research that is done using the established objectivist methods of inquiry, commits the researcher, from the outset, to a determinate social relation - i.e.. that of professional and client - which is structured by the relevances of the social scientific and professional discourses that produce it (Smith 1975). Here, the researcher, as the "expert", defines, categorizes and scrutinizes the object of study in ways that conform to professional or academic interests and aims. Unequal relations of power between the researcher and the researched characterize much of the work in medical sociology, adjustment psychology, rehabilitation, nursing, social work, and so on (Jongbloed and Crichton 1990; Morris 1992; Oliver 1992).

Because researchers organize their activities according to constructed schemes of recognized professional practice that have developed socially and historically and that specify exactly what constitutes the accepted methods, content and boundaries of their disciplines (Danziger 1990), the knowledge that they produce is never neutral: it is always produced with particular actionable ends in mind (Smith 1975). The emphasis on objectivity obscures the vested interests and biases of the researcher, and is just one way of sidestepping the necessarily social character of research and the knowledge it produces (Oliver 1992). Oliver (1992) argues that most knowledge about illness and disability is produced in the interests of professional practice for the purpose of managing and otherwise controlling disabled and chronically ill individuals.

22. Within an objectivist research paradigm, the researcher usually seeks to identify and explain universal laws of causation by using a "scientific" method which is "understood as a universal procedure involving the testing of theories by reference to 'facts'" (Morrow 1994:37). Within a constructivist paradigm, on the other hand, the social world is not governed by universal laws, but by social organization. Natural order, or "realities" of a systematic kind, do not lie waiting to be discovered through inquiry and investigation; such "realities" are constructed as a condition of human existence (Outhwaite 1996:91) and are continually brought into being and sustained by people's ongoing everyday talk and activities (Shotter 1993). In sociology, as Smith (1975) explains, the "facts" and factual accounts which are constitutive of sociology as a science, are social constructions. Empirical data are produced through activities of observing, counting, note-taking, measuring, recording, and so on. Analysis is then actively accomplished through the application of conceptual procedures - imposing a temporal organization, and assigning descriptive categories and a conceptual structure, as an interpretive schema - upon "what actually happens" (Smith 1975:258). All of these activities depend on socially organized processes that are mediated by language, technology and previously established knowledge as to what counts as being observable, measurable and relevant (Smith 1975). These other more fluid, indeterminate, and contingent social processes that underpin the practices of research, however, disappear in the final presentation of the "facts". Mainstream disability research, for the most part, has proceeded in the same way: techniques and technologies of eliciting information, the use of clinical categories, and measurements of "needs" and "functional capacities", pre-determine and structure, ahead of time, what can be known about people who are disabled and ill (Finkelstein 1998; Oliver 1992; Morris 1992). In the applied fields of study, disability becomes a "causal" agent or a predictor variable that leads to the study of disability in a deterministic manner (Linton 1998).

23. Just as the social category of "woman" turns on a particular bodily configuration and functioning, so too does the social category of "disability" (Thomson 1998). While the disabled body cannot be conflated with the female body, Thomson (1998) argues that in

theorizing gender. feminism offers insights and lessons for theorizing disability:

"Both feminism and the interrogation of disability I am undertaking challenge existing social relations: both resist the interpretations of certain bodily configurations and functioning as deviant: both question the ways that particularity or difference is invested with meaning: both examine the enforcement of universalizing norms: both interrogate the politics of appearance: both explore the politics of naming: and both participate in positive identity politics " (Thomson 1998:281).

In terms of feminist issues. the interests of women with disabilities are aligned with those of feminists in struggles "for comparable worth. to an end to job segregation by sex. and for an end to tying disability. pensions and [other] social security benefits exclusively to earnings" (Fine and Asch 1998:254). For disabled women, equal access to education. to employment, and to economic security depend on work with both disability rights and feminist groups (Asch and Fine 1998:254).

24. I reiterate here the ways in which an institutional ethnography is different from a traditional ethnography. In anthropology and sociology. a traditional ethnography remains a fieldwork enterprise that confines the researcher to the local setting under investigation. Traditional ethnography focuses mainly on description and interpretation that is able to convey an understanding of the language, practices, concepts. categories, rules, beliefs, etc., of the local setting (Van Maanen 1988). The continuous flow of events. activities and interactions that characterize the local setting become reordered into the concepts and categories that ethnographers typically employ for the purpose of rendering the account reportable as an ethnography. Likewise. the realism. or naturalness. of the traditional ethnography is accomplished by employing particular writing conventions that intend the production of the ethnography as a natural, authoritative and reportable account. Even where there is agreement that the ethnography is faithful to the culture. institution, or situation that it reports about. questions of generalizability to other local settings and other populations remain. In contrast. an institutional ethnography is not confined to the local setting, it does not impose a particular preconceived order on the data. and it does not aim to discover typical features of a particular population or local setting.

25.It is important to note here that interviewing, in the context of this study, means *reflexive* interviewing. This kind of interview process is similar to the qualitative interview process that is explained by Steiner Kvale. He writes that in a qualitative research interview the researcher "attempts to understand the world from the subjects' point of view, to unfold the meaning of peoples' experiences. to uncover their lived world prior to scientific explanations" (Kvale 1996:1). This notion of interviewing is also similar to accounts of interviewing techniques that are typically deployed in phenomenological analyses of experience, although an institutional ethnographic interview is less concerned with the informant's intrapsychic processes and issues of meaning than it is with what the informant actually does and the practical reasoning that informs those actions.

My study of various constructivist approaches to interviewing and developing interview questions has been useful in elaborating a more adequate understanding of how to go about doing a *reflexive* interview. A reflexive interview typically proceeds like a normal conversation but has a specific purpose and structure, organized around a specific theme of mutual interest (Kvale 1996). A context for the interview is provided by means of a briefing before and a debriefing afterward. The quality of reflexivity implies that the questions involved in the research should have personal meaning and significance for the researcher as well as the research informant. Personal experience, from this point of view, "is a rich and

relevant source from which to derive. and in terms of which to argue. [sociological] issues" (Bannister 1981:195). Not only should reflexive interviews be democratic and cooperative. they should draw on. and make explicit. the personal experiences of the researcher as well as the personal experiences of the research subject. Bannister explains that reflexivity "points intransigently toward the need for [researchers] to see their [research] as part of life and part of society. and thereby to acknowledge and make explicit its moral and political significance" (Bannister 1981:195). A reflexive interview is characterized by mutuality and a shared commitment to understanding.

Massarik explains a similar kind of interview. a phenomenal interview. that permits a more free-form mode of communication that allows iterative opportunities for review and clarification (Massarik 1981:203). In a phenomenal interview. he writes. "while an important emphasis remains with explication... of the interviewee's world. the dynamics of the interviewer are explicitly part of the process" (Masserik 1981:204). Further. the product of this kind of interview becomes "a document revelatory of both interviewer and interviewee, chronicling the process and content of their evolving exploration....[it] shows the ups and downs. detours. interruptions. apparent irrelevancies. etc. with substantial fidelity" (Massarik 1981:204). While the institutional ethnographic interview is not used in the same way as a phenomenological interview. both types of interview attempt to get at the actuality of the everyday. given in direct and immediate experience, independent of and prior to explanations that transpose the actuality into the pre-givens of a theoretically designed discourse. Both interview processes also proceed in similar ways: aiming to produce knowledge "which is itself in and of the social" (Smith 1999:97).

26. It is important to note that transcripts are not "the" solid empirical data of the research, they are constructions produced in the translation from an oral to a written mode of communication. Transcription from one context to another "involves a series of judgements and decisions" (Kvale 1996:163) where the rules of spoken language no longer appear coherent or conform to accepted language use in the written form. Kvale makes the valuable observation that the intended use of the transcripts should govern the degree of detail used in transcribing the interviews and the amount of effort used in transforming the conversation into a literary form. Accordingly, for this research, interviews were transcribed verbatim including false starts. abandoned sentences, and laughter, but without attention to the length of pauses, tonal variation, fillers such as "you know", "ums" and "ers" or any literary reconstruction. As a reflexive interview, where the dialogue is a mutual and shared production. both the questions and answers were fully transcribed.

27. Here, the reader should be aware that the interview excerpts are intended to be heard rather than read: frozen and fixated as text, the words may seen disjointed or may take on a solidity not intended in the ongoing flow of a conversation. I have addressed this problem, and protected the confidentiality of the informants, by making slight stylistic revisions and by omitting any identifying information from the excerpt.

28. Investigating interpretive practices, as properties of social relations, requires methods of textual analysis which "explicate the active power of the text as it is realized or activated by the competent reader" (Smith 1990b:223). By invoking a particular method of reading, and by knowing how to make such a reading, the text "unites reader and writer as practitioners of an extended social relation" (Smith 1990b:223). A competent reader knows the correct interpretive practices and schemata relevant to the reading of the text. These too are built into social relations and can be made visible for analysis. The researcher, likewise, as a competent

reader must draw on her "insider's knowledge" of the relations of which the text is a part. I use my own "insider's knowledge" as a student, and my previous professional, administrative and personal experience as a resource for this inquiry. I have also had to learn, through interviews and reading, how to operate the relevant conceptual practices that characterize the university as an institution, with which I was not familiar.

29. Receiving disability pension benefits adds an important dimension to the experiences of chronically ill women. Because working – even on a volunteer or part-time basis – may contravene the rules of eligibility and disqualify disability pension recipients from receipt of continued benefits, those informants receiving such benefits admitted reluctance in reporting their work and educational activities to their private insurers or government administered income replacement programmes (i.e., Canada Pension Plan). Likewise, because scholarships and monetary awards may be seen as taxable income and, hence, as warrantable grounds for reducing benefits, informants also reported hesitation in fully disclosing their additional income. Receiving both benefits and income, as the informants themselves explain it, creates a dilemma: on one hand, the inability to independently financially support themselves makes continued receipt of benefits crucial for day to day economic survival; on the other hand, because these benefits are set at the social minimum, they also depend on extra income to alleviate the effects of poverty. Further, they report that they also depend on the sense of achievement and accomplishment that usually accompanies the performance of meaningful work. Because not reporting income or work-related activities may be interpreted as a criminal offense, deciding whether or not to report additional income or work-related activities provoked considerable guilt, anxiety and fear for those informants receiving disability pension benefits. Anxiety and guilt were not confined to disability pension recipients, all informants receiving any kind of assistance report worry and anxiety over whether or not they were perceived as sufficiently "deserving" of disability-related grants and scholarships.

30. In *University of British Columbia v. Berg* (1993), Berg, who suffered from depression, was accepted to a graduate program in nutritional science. Based on her mental condition and behaviour, she was denied a key to the faculty building and a rating sheet; both customarily available to other graduate students in the program. A rating sheet, completed by faculty on behalf of the student, was required for consideration for a Canadian Dietetic Association hospital internship. Berg was denied entry into the dietetic internship program. The B.C. Human Rights Council found that the decision to refuse entrance to the internship program was based on the university's refusal to provide a rating sheet when it was first requested. This is an example of direct discrimination on the basis of mental disability.

31. In *Howard v. University of British Columbia* (1993), Howard was a deaf student with a degree in Psychology who wished to obtain a graduate level degree. Prior to commencing he informed the university of his need for a sign interpreter. No funds were available through the Vocational Rehabilitation program which only provides funding to assist students obtaining a first degree. The university did not provide either the funds or the interpreter services that Howard required to complete his graduate degree. Howard, therefore, discontinued his studies. The B.C. Human Rights Council found that sign interpreters are an accommodation required by deaf students to enable them to use the university's services. Failure to provide an interpreter places a burden on deaf students not placed on others, and has an adverse effect on their opportunities to become educated. The council concluded that the university had

failed to provide accommodation to the point of undue hardship.

32. These two legal decisions also provided illustrations of the two types of discrimination that are recognized under the B.C. Human Rights Act: direct discrimination and adverse effect discrimination. Direct discrimination results from the application of any university policy, rule, or decision that treats the disabled person in a discriminatory way, based on his or her disability (eg., *University of British Columbia v. Berg*, 1993). Adverse effect discrimination involves university policies, rules or decisions that appear to be neutral, but have adverse effects on disabled students (eg., *Howard v. University of British Columbia*).

33. The B.C. Human Rights Council awarded *Berg* $2000 for the humiliation and indignity she suffered. As a result of the *Howard* ruling, the University of British Columbia was ordered to provide accommodation to the point of undue hardship (in this case, employing a sign interpreter at a cost of $40000 per year), and to refrain from committing the same or similar violations of the B.C. Human Rights Act in the future.

34. For example, in the *Central Alberta Dairy Pool* case, the Supreme Court of Canada enumerated factors that can be considered in deciding "undue hardship" in accommodation: financial costs of the accommodation, morale problems amongst other employees, interchangeability of work force and facilities, size of the employer's operation, and safety concerns.

Because the issue of accommodation has not been analysed in Canada with respect to academic requirements and academic standards, legislation and legal cases from the U.S. are used to provide guidance in deciding the limits of accommodation in the academic context. The comprehensive legislation in the *Americans with Disabilities Act* allows two defences: a) where the accommodation would fundamentally alter the measurement of the skill or knowledge being tested, and b) create an undue burden for the provider of the service.

In the *Wynne v. Tufts University School of Medicine*, the First Circuit Court acknowledged the deference due to academic institutions, i.e., they stated "when judges are asked to review the substance of a genuinely academic decision... they should show great respect for the faculty's professional judgement." The court also laid out a test through which the institution might prove that it conscientiously carried out its obligation to accommodate the student: i.e., "if the institution submits undisputed facts demonstrating that the relevant officials within the institution considered alternative means, their feasibility, cost and effect on the academic program, and came to a rationally justifiable conclusion that the available alternatives would result either in lowering academic standards or requiring substantial program alteration, the court could rule as a matter of law that the institution had met its duty of seeking reasonable accommodation".

(The above is taken from the summary notes provided as part of the legal seminar "Accommodating the Disabled Student" by Patrick Gilligan-Hackett and Judith Macfarlane at the University of Victoria, April 11 and 12, 1996).

35. Organizational literacy or "dominant literacy" (Darville 1989) refer to the way that information is managed, regulated and controlled within the organizational context. "Written up" instead of "written down", organizational accounts are abstract and disorganized, they employ unfamiliar organizational categories and they redefine experience in a way that permits it to be acted on organizationally. Without competencies anchored in organizational processes and conventions, students are at a disadvantage.

36. For a discussion of these two legal decisions. see chapter four. p. 12.

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