

**Defining Disability:
The Social Construction of an Illness Career**

by

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Abstract



Disability has been socially constructed through the institutions of medicine, education, work and welfare. Traditional theories concerning disability and people who have disabilities have been formulated from a mainstream (non-disabled) perspective, emphasizing a medical model, and personal accountability; personal limitations resulting from disability are cited as the main barriers experienced by people who have disabilities. This impacts negatively on people with disabilities, leading ultimately to stigmatization, a lack of personal rights and the development of a permanent "illness career". I contrast this traditional view with the "social" model of disability, in which the focus is on the social (rather than personal) barriers encountered by people who have disabilities. Medical standards that define normality and barriers in the areas of education, work and welfare systemically exclude people with disabilities from the opportunities which most Canadians take for granted.

I critically analyse the 1991 Health and Activity Limitations Survey, undertaken by Statistics Canada to develop an "official" picture of disability. Although it is a strong survey, tapping many important issues for people who have disabilities, people are still forced into pre-formed categories, with all those who do not fit simply being left out. Statistics Canada focuses on mainstream notions of what it means to be disabled, citing personal disability rather than social barriers as the greatest limitation.

In order to allow people with disabilities to enjoy full citizenship and personal rights we must challenge traditional social structures and re-theorize disability from the perspective of people who have disabilities. We must challenge dominant stereotypes in order to forge a more positive social and cultural identity for people who have disabilities.

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Introduction



Making a "comeback" to my former life is no longer really discussed. The code word now is maintenance.

– Personal Journal, November, 1996 –

There is a growing body of literature in which it is recognized that disability has been socially constructed in ways which lead to stigmatization and a negative self-identity for the person with disabilities, although few authors appear to analyze or deconstruct the social phenomenon of disability in any great detail. In an effort to fill this gap in the literature, I address the following questions: (1) How has disability been constructed by the social institutions of medicine, work, education and welfare? (2) Must disability lead inevitably to stigmatization and a negative self-identity for the person with disabilities? That is, is it inevitable that a person with disabilities will "choose" an "illness career"? (3) By re-theorizing disability, and grounding it in personal, everyday experiences, can we develop a form of political advocacy or awareness which will allow us to construct a new, positive (or at least neutral) identity of disability? In my thesis I discuss primarily people who have physical, mobility related disabilities. The terms "disability" and "disabled" will refer to people with physical disabilities, with the exception of Chapter 4, and other places, in which a wider perspective is taken.

I was very fortunate in the past six months to have the opportunity to attend meetings at the BC Coalition of People with Disabilities, located in Vancouver, British Columbia. This experience has added to my awareness of the impact that disability can have on the lives others. This text has been influenced by this interaction, as well as my own experiences with disability. These experiences are crucial to the development of my thinking on this subject, providing me

with new insights, not only into myself, but also into the medical, work, educational and welfare institutions in Canadian society. At the beginning of each chapter I have included an excerpt from my own personal journal. The purpose of these selections is to provide the reader with insights into my own experiences of disability, and how these relate to the topic at hand. I begin by briefly detailing my history with disability, focusing on the initial incidents which have led me to research in this area. This is followed by a review of the widely used definitions of impairment, disability and handicap as these have been laid out by the World Health Organization (1980). I also elaborate on my theoretical approach to the subject of disability, and explain how this has led to the methodology I have chosen. Finally, I provide an overview to the remaining chapters of this thesis.

A Personal Perspective

Early in 1992 I suffered a back injury. I was working full-time in an office, and received short term disability benefits from my employer until I was able to return to work two months later. My back, however, had not yet healed. A serious (and unrelated) illness in the summer of 1993 complicated my situation, requiring six weeks of bed rest. At the end of this time I was physically very weak. The responsibilities of my job became harder and harder for me to fulfill, and I made plans to leave my job and return to school full-time. I hoped that a more flexible schedule would provide me with the rest I needed in order to recover. In September 1993 however, I experienced the first real collapse due to my back, resulting in the use of crutches or a cane. In the three years since that time, I have frequently found it necessary to rely on some sort of support device for walking. Much of the time I have had to spend upwards of twenty hours a day lying down. I am frequently still unable to walk more than 20 metres, or sit, or stand for

more than half an hour, and find many of the activities of daily living very difficult, or even impossible to do. In short, I have become disabled.

I found that I began to detach myself emotionally from the non-working portions of my body. During consultations with various physicians my body was objectified, broken down into component parts and analysed. The 'surviving' part of myself was never taken into consideration: I was given no advice as to how I was to look after myself on an everyday basis. The basic elements of shopping, making food, doing housework, earning a living were not considered. Early in 1995, I was once released from the hospital emergency room at 2:30 in the morning, in spite of being unable to move my limbs or raise my head because of back pain. The one useful thing that came out of this event was that in response to my pleas, the doctor indicated that since my condition was chronic, and all I could be helped with was basic care, I did not belong in a hospital. Instead, he said, I should contact social services regarding home care. (The same doctor recommended that I take large daily doses of a sedating drug.) I had not known home care service was available. Unfortunately the doctor did not think it was necessary to keep me in the hospital until morning, when social services would be open. Nor did he think it was the role of the hospital to contact welfare for me.

I share a house with a number of long term friends, and the next day my housemates helped me to contact social services. It took some persuading to encourage them to make a home visit (I could not stand in line like everyone else), and about a week later, I began receiving help with some of the activities of everyday living. This was the beginning of a long relationship with welfare, a relationship which to me, has seemed demeaning and of minimal assistance. Although I was entitled to a "handicapped" benefit, which is greater than that received by 'regular' welfare recipients, I turned down the handicapped status. To accept was to agree to the requirement that

I was *permanently* disabled, and unable to work; that is, unable to work *forever*.¹ I was not willing to accept the status of being permanently "unemployable," and so was only allowed \$325/month for rent, and \$271/month for basic support. In addition, I received enough money for a bus pass, since I had more than one doctor's appointment each week (although I was unable to take the bus because of the extreme difficulty I had in walking, sitting and standing), and I received \$20/month to help cover non-prescription medications. Welfare paid for prescription medicines, but beyond what was covered by the basic medical services plan, they would not cover any costs for the ongoing physiotherapy, massage therapy, or chiropractic visits I needed in order to be able to function physically. In British Columbia, the basic medical services plan includes twelve visits to each of the above mentioned care givers; however, it is becoming increasingly common for these therapists to opt out of coverage by the B.C. Medical Services Plan, making it necessary for the user to cover the full costs. This can make it very difficult to receive the barest minimum of required care, even with 'official' sanction for the need for care. During this time I was attending a chronic pain rehabilitation clinic. This clinic sent letters to social services indicating that therapy with physio and massage therapists would enable me to return to productive employment. However, the management at the clinic also told me that in the six years they had been in operation, social services had not opted to supply additional coverage for a single patient. I was no exception to this disappointing trend. I had either to come up with an additional \$200-\$300 per month in order to cover the medical treatments I needed, or do without them.

I do not mean to undermine either the institutions of welfare or medicine. On the whole, I

¹ As a result of five years of lobbying, the BC Coalition of People With Disabilities was successful in having a new definition of "handicap" put into place in the BC legislation (related to GAIN) on January 1, 1996. The new definition takes into account the fact that for some people, disability is cyclical, and therefore, they may not be *permanently* unemployable. Please see Chapter 1 for further discussion.

have received excellent treatment from the majority of individuals in these fields with whom I have dealt. However, there were limitations in the help supplied by these institutions (along with my own financial limitations) which went a long way towards inhibiting my recovery. For example, without exception, every physician I have seen has recommended at one time or another that I stop attending school in order to rest. While permanent rest might decrease my levels of back pain, I believe that having to rely on welfare as a result would not. While in school I am eligible for loans, bursaries, and other forms of funding which give me greater spending power than I would receive from welfare. In addition, special grants, such as the Assistance Program for Students With Disabilities, or, the Special Opportunity Grant for Students With Permanent Disabilities are also available (Ministry of Education, Skills and Training, 1996/97), although there is a fair amount of competition for this funding, and receipt of a grant is by no means guaranteed. I was very reluctant to rely on welfare, as the subsidy provided by welfare is inadequate, and the social stigma attached to a welfare cheque is, at least for me, more stress-inducing than stress- and pain-relieving. Many times, during summer sessions away from school, and therefore away from funding, I was forced to search the house for refundable bottles that I could return for the deposit in order to supplement my welfare cheque. My housemates allowed me to return their 'empties,' as they knew this was the only way I could afford even part of the treatments I needed. Returning the bottles was very painful, and physically difficult, and as I would stand outside in the parking lot, sorting bottles and cans, I met many people who make their living scavenging in this way; I was entering an entirely different level of our culture. These experiences have pointed out to me that there are serious problems with our health and welfare systems. Many people are left alone and unaided, resulting in serious, and even life-threatening situations. Seemingly, those most affected are those who cannot afford to pay for the advanced

or intensive medical and rehabilitative help they need, bringing the element of social class into the purview of disability. I wish to point out that not all people with disabilities have ongoing medical needs. To assume that this is the case would be a grave misrepresentation.

As a result of the difficulties I have experienced trying maintain personal and financial independence, I have come to think critically about living in Canadian society with a disability. It seems sometimes that no amount of personal effort can bridge the gap between an able-bodied world and a disabled body; the barriers can seem huge and endless. My health problem is severe and atypical, particularly for a person of my age, and so I have frequently felt like I was falling through the cracks of our social system – no one could understand or name my problem, and no one knew what kind of help I needed. The struggle to prevent my disability from becoming a handicap, and my growing awareness that there are many people in society who face such a struggle has led me to question the social institutions of medicine, work, education and welfare. These institutions provide the major underpinning for determining a person's life chances. Facing a life of potentially limited opportunities it has become important to me to understand the way these institutions mediate the life chances of people who have disabilities.

Impairment, Disability, Handicap

Physical disability is primarily attributable to biological causes or accidents, neither of which may considered to be the fault of the individual her/himself. Supposedly, the biological and/or accidental origins of disability should enable those who are disabled to be both seen and treated by others with social tolerance. This line of thinking follows from Terry (1995: 137), who notes that biological explanations may also prove more forgiving than social ones for those who are "sexually deviant." Terry argues that many homosexuals seek biological explanations for

homosexuality: if homosexuality is a genetic (biological) trait, then one cannot be held to blame for being different, as the difference is perceived as being a matter of *fact* rather than *choice*. However, people with disabilities who are seen as “biologically defective” may be treated with even more derision than if their disability were seen as merely the result of an accident. A person whose disability is perceived as biological may be lumped into a category with other ‘defectives,’ and s/he may be treated as morally and mentally degenerate, as well as physically deficient. This treatment may well affect the way the disabled person thinks about her/himself.

Bury argues that becoming disabled has a major impact on all levels of an individual’s life. He describes “chronic illness as a major kind of disruptive experience” which undermines “the structures of everyday life and the forms of knowledge which underpin them” (Bury, 1982:169). In other words, people who *become* disabled (particularly as adults) find it necessary to rethink many of the assumptions they previously held, both about themselves, and about life in general. These changes may be highly personal, such as a reduced ability to maintain family responsibilities (for example, being unable to look after or play with children, or being unable to perform routine household chores), reduced ability to participate in group or personal social life (for example, being unable to attend social outings, or experiencing a reduction of capacity for sexual activities). Adaptations may also be required in terms of an individual’s working self. For example, someone who has become disabled may only be able to work part time hours, or may be unable to work at all, leading, perhaps, to a vast reduction both in earnings and self-esteem. Any or all of these changes may lead to crises for the individual, as s/he is forced to face a new reality. For the girl or boy, man or woman who was *born* with a disability, although s/he may not perceive this disability as any form of loss, s/he is still subjected to a societal perception of personal incapacity or inferiority.

The World Health Organization (1980) provides us with a clinical definition of disability. They state that disability is "any restriction or lack...of ability to perform an activity in the manner or within the range considered normal for a human being." This is different from an impairment, which is "any loss or abnormality of psychological, physiological, or anatomical structure or function" (ibid.). These definitions provide us with a description of the bare physical, or physiological, facts of disability. They do not, however, address the social consequences of disability or impairment. These social consequences may be found under the term "handicapped." The World Health Organization (WHO) tells us that a handicap is "a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors for that individual" (ibid.). Even though the WHO defines "handicapped" as a state that inhibits "the fulfillment of a role," they do so in very abstract terms that distance us from the realities faced by the person, the people who experience these limitations. In order to better understand the social consequences of disability or impairment, we must examine the ways in which "handicap" as a personal reality has been constructed.

Theoretical and Methodological Approach

In what follows I elaborate my theoretical standpoint, and explain how this relates to the methodology I have chosen. I begin with an overview of my theoretical perspective, and briefly relate this to the wider field of sociological theory. I outline a number of imperatives I feel are crucial if we are to re-theorize disability. Finally, I discuss the importance of individual experience, and argue that we must view the personal not only as political, but also as sociological if we are to remove the negative stereotype attached to disability (see Morris, 1996;

Campbell & Oliver, 1996).

Ritzer (1975, 1991) argues that we must integrate existing sociological paradigms in order to better explain social phenomena. He defines a paradigm as

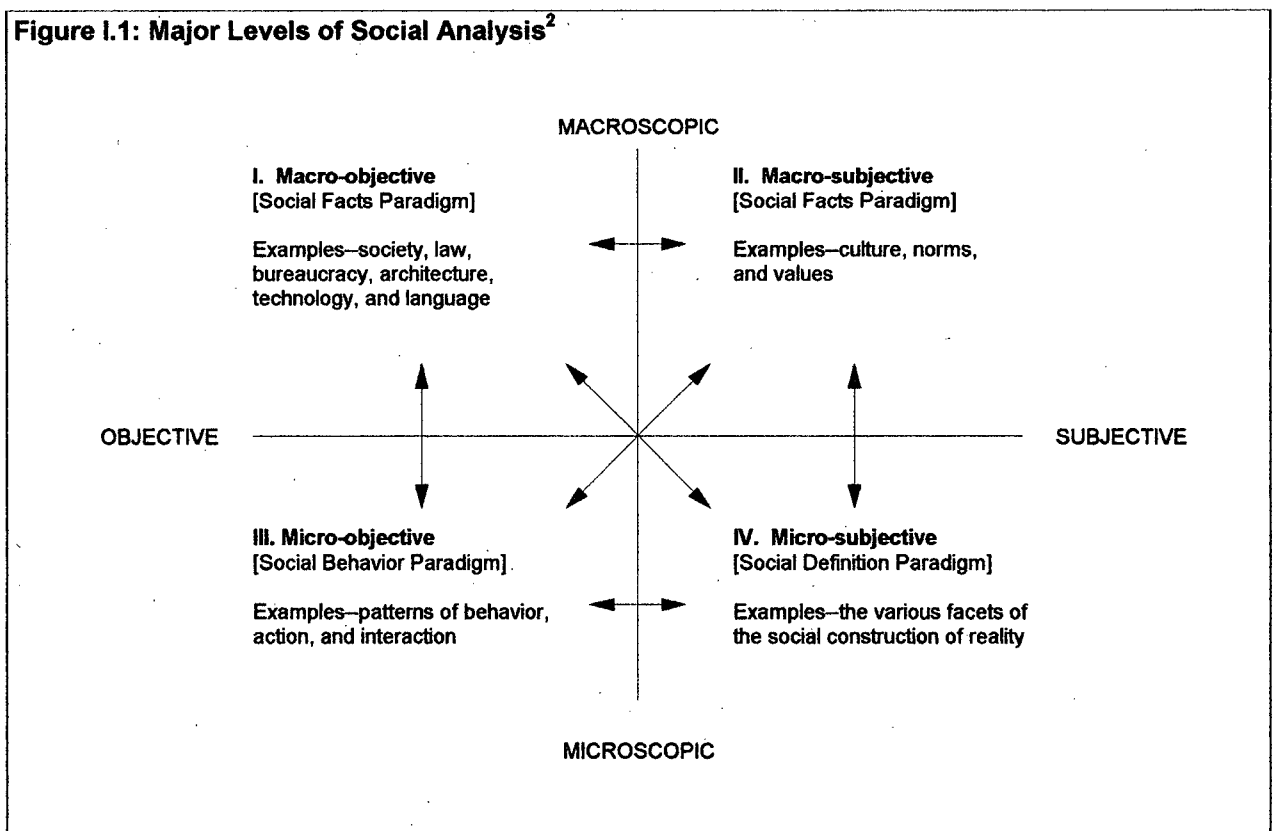
a fundamental image of the subject matter within a science. It serves to define what should be studied, what questions should be asked, how they should be asked, and what rules should be followed in interpreting the answer obtained. The paradigm is the broadest unit of consensus within a science and serves to differentiate one scientific community (or sub-community) from another. It subsumes, defines, and inter-relates the exemplars, theories, methods and instruments that exist within it (Ritzer, 1975: 157).

Ritzer identifies what he feels are the three major paradigms of sociology: the social facts paradigm, the social definition paradigm, and the social behaviour paradigm. Each of these covers a major aspect of sociological concern (see Figure I.1), and by combining them, we develop an approach which will allow us to consider both "micro" and "macro" sociology, as well as "objective" and "subjective" accounts. In outlining the definitions Ritzer associates with each of these paradigms, I also indicate the way they relate to my thesis.

"Social factists" acknowledge "the reality of such social facts as a group, a norm, an institution, or a social system. They focus on the study of these social facts and their coercive effect on the individual" (Ritzer, 1975: 159). To some extent, my research has been influenced by conflict theory, and the role social institutions of authority (those of medicine, work, education and welfare) play in defining and asserting the position people with disabilities hold in contemporary society. I focus on the overt and covert power exercised by these institutions in defining the (macro-objective) laws, legislature and language which define the (macro-subjective) norms and values to which people with disabilities believe they must conform. "Social definitionists tend to be interested in the mental process as well as the resulting action and interaction" (Ritzer, 1975: 161). In this vein my research has been influenced by symbolic

interactionism: how do people internalize (micro-subjectively) the social construction of disability? I also draw on action theory to outline a number of important qualifications that a theory of disability must meet, such as addressing issues faced by real people, and stipulating an agenda for social change. Finally, “[s]ocial behaviorists are interested in the relationship between the individual and his [or her] environment” (Ritzer, 1975: 162). Of primary concern to me are the “contingencies of reinforcement” (ibid.: 163) which cause people to make choices (micro-subjective) which reflect mainstream expectations for people who have disabilities. Exchange theory is useful here to help us understand the ways in which people with disabilities strive to meet their needs (personal, social, financial) in a society in which systemic exclusion and discrimination mark every avenue of life.

Figure 1.1: Major Levels of Social Analysis²



² Reproduced from Ritzer, 1991: 276.

I have mentioned a number of sociological theories which have been important in influencing my choice of methodology. My primary concern is not an in depth analysis of each of these theories. On the contrary, I wish to indicate that I have been influenced by a broad range of subject matter; I attempt only to give an indication of some of the background materials which have contributed to the perspective I take in this thesis. I must also say that my work has been influenced by feminism, particularly a feminist critique of scientific claims to "objectivity." I feel there are important parallels to be found in the attempt to form a diversified and multi-dimensional feminist theory, and the development of a theory of disability: in both cases, there are differences amongst women, amongst people with disabilities, which no 'universal' theory can ever capture. Some of these concerns are brought out by Harding and Nicholson. Harding states that "[i]t would be historically premature and delusionary for feminism to arrive at a 'master theory,' at a 'normal science' paradigm with conceptual and methodological assumptions that we think we all accept. Feminist analytical categories *should* be unstable at this point in history" (1986: 244, original emphasis). Nicholson points out that although feminists have challenged the "historical embeddedness of all theoretical perspectives," they have also "displayed a decided casualness about the specific historical content of their [own] claims." She goes on to note that many feminist arguments are the product of the theories and traditions of "teachers accustomed to the universalizing moves of modernism" (1992:93), and therefore, may be unaware of, or even unprepared for the differences between individual women.

The writings of some post-modernists may help us to develop a methodology which is feminist, and through which we may be sensitive to the differences between people, between groups. In our attempt to construct a postmodern feminist methodology, must we choose between feminism and science, privileging one type of account (objective) over another

(subjective)? Currie (1988 a,b) claims that this is a false choice. Feminists should not abandon “validity; reliability; generalizability; and demonstration of causality” (1988a:28). Rather, they might “differ...over existing rules and proscriptions for research methods dis/allowing these criteria to be met” (Ibid.). Seidman provides a useful summation of what we should try to avoid.

Sociological theory occurs exclusively in academe; it is a disciplinary creature. Indeed, it has become a specialty area with its own problems and disputes, its own languages and rhetorical conventions. It has its own status hierarchy. Sociological theorists are oriented primarily to internal disputes in their specialties. This drift towards the insularity of sociological theory is reinforced by a scientistic ideology that legitimates science by claiming to promote the growth of knowledge and human rationality. Sociological theory appears more and more as an expert culture, split off from the practical moral concerns of everyday life and the major public disputes of our time (1992:62).

I would like to outline a prescription for a feminist methodology which would fulfill the political and moral imperatives of “postmodernism,” at least as it is understood by the writers I have cited. To begin with, this methodology should minimize the “power differential between the researched and the researcher” (Weston, 1988:145; Currie, 1988a,b; Storrie, 1988). This will help to ensure that research “subjects” remain subjects, and do not become “objects.” It will also help us to analyse the power, class, and gender hierarchies so prevalent in modern science and social science, allowing us to see how a wider spectrum of people (not only those who are at the top) might participate in the formation of social policies and other decision making. Secondly, research should be undertaken “to change things” (Weston, 1988:145; Currie, 1988a,b; Ralph, 1988); “researchers should act explicitly and consciously as moral agents” (Storrie, 1988:126). As a wider range of perspectives becomes visible, the current emphasis on ‘what is important’ should not only change, but should also reflect the interests of those who are being researched; these individuals should experience some benefit from the research, and should, perhaps, have some control over the final research product. Third, research should begin with the experience of

people's "actual" lives. It should not be subsumed solely within an academic medium, and academic concerns (Currie, 1988a,b; Smith, 1989; Weston, 1988; Storrie, 1988). If research is buried within academic institutions, how can it be reflective of people who are not similarly submerged in academia? The concerns, and even the language used will not be reflective of the 'average' individual who is so often the 'subject' of study. Finally, the researcher must be aware of his or "her own beliefs and behaviors as s/he provides for the beliefs and behaviors of others" (Harding, 1986:83; Storrie, 1988). It is important that the researcher him/herself is also a part of the study. It is not possible to remove ourselves, as individuals, from the context of our own life, our own place in history. Instead, these elements of ourselves should be carefully examined, in order to gain an understanding of what our own personal preferences, biases, and beliefs might introduce into the research, and in turn, what impact and influence these might have upon those who are being researched. As Nicholson notes,

[f]eminist scholarship has, more and more, abandoned the attempt, common in its first ten years, to solve the puzzle of sexism in one insightful account. Rather, it has taken the very different route of encouraging attention to a multitude of problems, topics, cultures, and time periods, integrating the results when possible, but merely describing difference when not. It is a strategy conducive to both political and scholarly strength and one other politically concerned social theorists might very well emulate (1992:98).

Disability has traditionally been theorized from a mainstream perspective. From this standpoint, it is impossible *not* to see those who are disabled as deviant. I argue that disability in and of itself is not cause for deviance. The experiences of people with disabilities are normal, they are just normal for a different group of people. If, conversely, we were to theorize the able-bodied state from a disabled perspective, we might be equally likely to categorize this group as deviant, and equally likely to misunderstand their needs and abilities (see Davis, 1995 for an example of such a perspective within the Deaf community). This does not mean that only

disabled people can write about people with disabilities. It is simply that this 'deviant' perspective is indispensable to any critical evaluation of the mainstream construction of the disabled identity; that is, the role of the local narrative is to foster the critical interpretation and evaluation of "grand theory" in both sociological theory and social practice.

The above mentioned strategies suggest a sociological methodology which will be less hindered by the inequalities implicit in social categories. The reason these changes have not yet taken place, is perhaps, as Acker suggests, that current sociological paradigms are simply too successful. They are "supported by the system of universities, departments, associations, journals, and funding agencies...that organize the power to allot money, job security, and status" (1989:71). If this is the case, such principles may not be implemented until there has been either a significant transformation of the society in which we live, or the existing paradigms are proven to be inadequate for answering the pertinent questions posed by those in the positions of ruling. Another possibility is that as people with disabilities gain an awareness of and the determination to exercise their full social rights as citizens, a new, insider's voice will gain full expression in the formation of theories about disability. Viewing the literature which is currently being published on disability issues, this seems increasingly to be a real possibility.

While there will doubtless always be some system of power, some "relations of ruling" which will represent either the majority and/or those who have the most power, perhaps we can hope to arrive at a better, wider understanding of human society and human nature. Perhaps the impetus for change will not come from any great revolution of the masses, but from slow and subtle processes of change and transformation. Foucault argues that

power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations...In short, it is not the activity of

the subject of knowledge, useful or resistant to power, but power-knowledge, the process and struggles that traverse it and of which it is made up, that determines the forms and possible domains of knowledge (1977: 28).

The growth and elaboration of feminist theory, and the development of a theory of disability which contains the voices of people with disabilities, implies that there may already have been a subtle shift in power, and in knowledge. Such subtle and continuous shifts may be more lasting in the long run than any revolution. Power "is not acquired once and for all by a new control of the apparatuses or by a new functioning or a destruction of institutions" (Foucault in Rabinow, 1984: 174). It comes instead through a careful and meticulous attention to detail. It is this notion which leads me to consider disability as a political phenomenon, in which the importance and experience of everyday actors, as well as the institutions which construct the social meaning of disability must be considered. In order to understand not only the details, the "micro," or "subjective" accounts of people with disabilities, but also the "macro" or "objective" forces which have gone into constructing a disabled identity, we must view the personal experiences of people with disabilities as political.

Mills identifies "'the personal troubles of milieu' and 'the public issues of social structure'" (1959: 8) as one of the most important distinctions to be made in sociology. "*Troubles*", he states, "occur within the character of the individual and within the range of his [or her] immediate relations with others; they have to do with his [or her] self and with those limited areas of social life of which [s/]he is directly and personally aware...A trouble is a private matter: values cherished by an individual are felt by him [or her] to be threatened" (ibid.) "*Issues*", on the other hand "have to do with matters that transcend these local environments of the individual and the range of his [or her] inner life. They have to do with the organization of many such milieux into the institutions of an historical society as a whole, with the ways in

which various milieux overlap and interpenetrate to form the larger structure of social and historical life. An issue is a public matter: some value cherished by publics is felt to be threatened" (ibid.).

To engage the personal as political has, potentially, more than one meaning for disability activists. There are those who argue that in order to remove the negative stereotype associated with disability, the notion of tragedy must be removed from disability (Campbell & Oliver, 1996). On the other hand, Morris notes that "there was a concern amongst some disabled women that the way our experience was being politicised didn't leave much room for acknowledging the experience of our bodies; that too often there wasn't room for talking about the experience of impairment" (1996: 13; see also Crow, 1996). I argue that there must be a blend of these two representations: tragedy should not be confused with difficulty, and difficulty should not be overlooked if we hope to change existing social structures. In order to provide us with the necessary insights to change existing structures, I feel we must hear, at last, from the people whose concerns are to be represented. As Mills argues, we must accept the idea that "the individual can understand his [or her] own experience and gauge his [or her] own fate only by locating himself[herself] within his [or her] period, that [s/]he can know his [or her] own chances in life only by becoming aware of those of all individuals in his [or her] circumstances" (1959: 5). I turn now to an elaboration of how the chapters to follow attempt to foster this vision of the sociological imagination with respect to people with disabilities.

Preview

In the first section of Chapter 1, I examine some of the language which is used to define disability. The development of, and the present social meaning of words such as: "able, able-

bodied, disable, disabled, impair, cripple, handicap, and handicapped” is explored. I argue that the medical profession has had a profound influence in defining not only the language, but the inherent value (the social meaning) of terms used to describe a person’s physical and/or mental state. I discuss the prestige enjoyed by the ‘scientific’ field of medicine, and articulate the medical model which has traditionally been used to describe disability. In the second section I discuss the medicalization of society, and the development of the notions of normalcy and deviance through the birth and propagation of medical statistics. The impact of medical statistics on the eugenics movement is also discussed. In the final section of Chapter 1, I discuss both the professionalization and the internalization of the discourse surrounding disability. Included here is an analysis of the relationship of social class to both medicine and illness. Dorothy Smith’s (1990) discussion of the actuality-data-theory circuit is reproduced and analyzed to illustrate the cyclical nature of the production of knowledge; beginning with the everyday experiences of people, moving through a professional interpretation of those experiences, the production of a formalized account, the organization of accounts into theoretical or conceptual schemata, the application of these schemata to define the experiences of real people, and finally, the internalization of formal definitions at the level of every day experience/knowledge. The internalization of professionalized discourse, definitions, and values is essential in the formation of an “illness career.” It is by internalizing these beliefs that people with disabilities come to doubt their own abilities and rights.

In the first section of Chapter 2, I examine the relationship between disability, work, and education. I begin by reviewing functionalist, human capital, and Marxist explanations of the relationship between work and education, paying special attention to the ideology of rational choice. I elaborate my own viewpoint on this relationship, stating that although educational level

(from a functionalist and human capital view), and parent's social status (from a Marxist view) may be related to occupational attainment (status and income), the relationship is not as simple as expressed in these traditional theories. I argue that educational level (quantity), educational content (subject matter), educational quality and social class are *all* important factors in understanding an individual's occupational potential. In addition, when we consider the case of people with disabilities, we must also recognize both the social and physical barriers which preclude equal access to an equal quality of education. In the second section I discuss the relationship between disability and work: despite the fact that many people with disabilities want to work, there are very real physical and social barriers which prevent many from doing so. I argue that we must examine this relationship from both a political economy perspective, as well as from one which focuses on human need. Under the former, I explore both the demand and supply sides of labour. The demand for labour is influenced by the *perceived* productivity of workers, as well as the receptiveness of the market to goods and/or services produced by workers. The issue of discrimination will be explored from a number of angles. The supply side of labour is studied in terms of the training, or educational "choices" people with disabilities make in their preparation for entering the labour force. I examine a number of different factors which may influence able-bodied people and people with disabilities in different ways. Finally, I discuss the relationship of disability and employment from a needs based approach. Crucial here is how we understand and interpret the personal needs of the person with a disability which must be met in order for her/him to "choose" employment over unemployment (welfare).

In Chapter 3, I discuss the relationship between disability and welfare, beginning with some basic tenets of the welfare state, and articulate how Canadian welfare policies do or do not meet the needs of the population of people with disabilities in Canada. I argue that welfare

policies play a large role in influencing the “choices” people with disabilities perceive as being open to them. In the second section, I articulate a model based on Foucault’s theory of power/knowledge. The purpose of this model is to explore the role that the institution of welfare plays in *increasing* the levels of *dependence* experienced by people with disabilities. I examine the role that medical practitioners play in categorizing disability according to scientific principles, and how these categories are utilized and enforced through the processes of surveillance (observation, normalizing judgment, and the examination). I conclude that the welfare system has provided the permanent problem of disability in society with only temporary solutions. As a result, although many people with disabilities are helped at many levels, a substantial portion of this population is left with no choice but to adopt illness as a career.

Chapter 4 marks a departure from the earlier chapters. Rather than focusing on strictly theoretical and empirical material, I examine disability in Canada as it is represented through the lens of “official” government statistics: the 1991 Health and Activity Limitations Survey (HALS), conducted by the federal government through Statistics Canada. I explore the definitions used to define disability in this survey, and discuss their relevance to the population being studied. A selection of results related to the areas of work, education and welfare are presented, and these are linked to the theoretical discussions in Chapters 1-3. This discussion follows the logic of Smith’s (1990) actuality-data-theory circuit, as articulated in Chapter 1. My intention here is not to blindly use these data to support my theories. On the contrary, I critically examine these data in order to understand what has been revealed and what remains obscured. This contrast helps to highlight which areas are of “official” concern, and which are not. In other words, it helps to clarify the hidden power inherent behind definitions of disability.

Finally, in my conclusion I briefly summarize the earlier arguments. I discuss the tensions

and conflicts inherent in constructing a new identity of disability, and propose ways in which this may be done from the perspective of people who have a disability. I provide a model outlining the social response to disability, and explain how we might use this model to find a new way to politicize the personal problems experienced by people with disabilities.

Chapter 1

Deconstructing the Disabled Identity in a Medicalized Society



Dr. — and I decided that there would be no more injections, at least for the time being. I am so relieved. I live in horror of those things, and what they do to me.

— Personal Journal, January, 1996 —

The Language of Disability

My goal in this thesis is to examine those elements which go into the construction of a disabled identity. In order to do this, it is crucial to understand not only the language which defines disability, but also the process by which this language is created. The medical profession plays a profound role, not only in defining disability, but also in perpetuating and propagating a clear distinction between those who are able-bodied and those who are not (or, in sociological terms, those who are normal vs. those who are deviant). Through the medicalization of society, and the employment of medical and social statistics, norms have been established which lead not only to a negative identity for people with disabilities, but in turn, lead people with disabilities to internalize this identity, leading them to develop an “illness career” (Goffman, 1961, 1963). In this chapter I will focus on the language used to describe disability, and the ways in which this language is created and perpetuated by a medicalized society. I also review the medical model traditionally used to understand the process of becoming disabled. This is followed by a discussion of normalcy and deviance, and the ways in which a deviant self-identity is internalized by those who are physically disabled, leading for some, to a life-long illness career.

The role language plays in defining individuals, qualities, or states of being, is crucial in the construction of personal identity. For example, in her book *Sexual Politics*, Kate Millett

(1970) shows us that in interpreting a text, we must not only be aware of the words, but also of the power relations in and between the words. She keys us into the power underlying the use of language (both positive and negative), drawing our attention to who is speaking, and who has the power in the social relations. By establishing whose voice is speaking, we may begin to perceive whose conventions, ideas or values are being represented. The narrator's words, or dominant voice in any story provides clues to the reader as to how to interpret the text.

If we look first at fictional texts, we see that novels are based on structures which are normative, representing what are perceived to be universal traits "of the central character whose normativity encourages us to identify with him or her...This normativity in narrative will by definition create the abnormal, the Other, the disabled, the native, the colonized subject, and so on" (Davis, 1995: 41-42). Identifying with the normative aspects of the major character may be problematic, in that it encourages us to adopt the beliefs and values represented by, or within that character. Thus, with respect to disability, we see that

If disability appears in a novel, it is rarely centrally represented. It is unusual for a *main character* to be a person with disabilities...On the other hand, as sufficient research has shown, more often than not *villains* tend to be physically abnormal: scarred, deformed or mutilated (Davis, 1995: 41, my emphases).

This type of representation is based on categories and social values that already exist in society. However, when we read these social relations as they have been translated into text, we further internalize that which is represented; texts, whether "official" (factual), or "unofficial" (fictional), confirm our beliefs regarding what the positive and negative attributes of characters, of people, really are. For example, if we are continuously exposed to images of the hero as physically "normal," or even superior, and images of the "villain" as someone who is both physically and morally deficient, we may become inclined to make these same associations in every day life: healthy people are good and moral, and disabled people are physically and

morally lacking.

This type of analysis should not be limited to fictional materials. Both Millett (1970) and Davis (1995) open the door to a revolutionary way of thinking about the power structures behind language, and although their analyses refer to literary materials, the same type of criticism should be applied to the power structures represented in the language of both scientific and social scientific enquiries. Ritzer outlines the conflict theory of Dahrendorf, stating that "Authority does not reside in individuals, but in positions. Thus societal positions and the differential distribution of power among them should be the concern of sociologists...The first task of conflict analysis, to Dahrendorf, is identification of various authority roles within society" (Ritzer, 1975: 160). Looking first at science, we see that the importance of language in science is stressed by Feigl (1969), who notes that it is crucial to develop a unified language with which to impart meaningfulness to scientific statements, concepts, or theories. A common language allows individuals to share their experiences with one another, leading to greater unity and understanding (Bryant, 1985). In the natural sciences, there has been some endeavour to make this common language the language of mathematics. And yet, even the language of mathematics is not without a significant "social history" and power hierarchy (Harding, 1986: 48; Starr, 1989: 20).

In terms of the social sciences, particularly sociology, Mills (1959) stresses the importance of language as it relates to the development of grand theory. He argues that

grand theorists are so preoccupied by syntactic meanings and so unimaginative about semantic references, they are so rigidly confined to such high levels of abstraction that the 'typologies' they make up – and the work they do to make them up – seem more often an arid game of Concepts than an effort to define systematically – which is to say, in a clear and orderly way – the problems at hand, and to guide our efforts to solve them (Mills, 1959: 34).

Semantics, according to Mills, refer to "what a word stands for," whereas when we concern

ourselves with syntax we are interested in words “in relation to other words” (1959: 33). I argue that social theorists who are primarily concerned with syntax overlook not only the social meaning, but also the power structures embodied in words as they are used in everyday language. By approaching language semantically we come to understand how certain terms have evolved, and which, if any, power structures are reflected in this evolution. In this vein, Storrie states that

modern knowledge is created by specialists in different disciplines who lift the daily experiences of people...and translate them into abstract concepts and impersonal language which carry enormous authority and legitimacy. This is because in this form, knowledge appears to be neutral and “objective”, supported by supposedly scientific procedures (1988: 124).

This “neutral,” and “objective” voice serves to hide the social history of science, this history dictating not only the language, metaphors, and vocabulary which are used, but also the research agendas and allocation of available funds.³

In the social sciences this type of exclusion comes about by the use of language which is overly reflective of members of certain social categories – usually upper class, highly educated, white males (Harding, 1986). This language, Mills argues, is often obscure, exclusionary, and perhaps, “not readily understandable; the suspicion is that it may not be altogether intelligible” (1959: 26). This unintelligibility – or use of what I will call advanced language – serves to distance social theories from the everyday level, advancing them to an academic, or elite level. By making the language of knowledge also the language of authority, “[t]hose in authority attempt to justify their rule over institutions by linking it, as if it were a necessary consequence, with widely believed-in moral symbols, sacred emblems, legal formulae” (Mills, 1959: 36). The “moral symbols” in question here are the language, vocabulary, and metaphors with which this “authority” is represented. We must deconstruct these symbols to see how advanced or scientific

³ Although it is outside the scope of this thesis, Carol Cohn (1987) provides a fascinating discussion of the role of specialized language within the realm of military defense intellectuals.

language becomes the language of knowledge, and how this in turn provides support for power and authority.

Brown argues that we should use a discursive approach when analyzing the dominant meanings that structure society. He states that "The metaphor of society as discourse also suggests that social structures can be understood as structures of language and that these structures are invented through acts of speech" (1992: 227). Following Brown, and building upon the semantic approach discussed above, I argue that language is "a system of signification," and not just a "system of communication." By viewing language as a system of signification, we become concerned primarily with the sign: signs are used as symbols which enable "speech performances [to] express and embody different worlds of meaning that are ordered hierarchically in society. Such symbol systems are realizations and regulators not only of speech performances but also of the structure of social relationships" (Brown, 1992: 228; see also Smith, 1989, 1990; Seidman, 1992; Harding 1986), with the most obvious example being differential forms of address. In simpler terms, this means that language consists of widely agreed upon symbols which represent and mediate a hierarchy of social values. We must concern ourselves with the social meaning of words, how they have developed and according to whom, rather than study what one word means in relation to another word. If we understand the ways in which a word is used, and how it came to its present meaning, then we begin to reveal the power structures behind the composition of these words, and the ways in which they help to organize both a social hierarchy and a social contract (Brown, 1992: 236-237). The key points here, are that language has widespread social meaning, and this social meaning is reflective of, and helps to organize the beliefs and values of a select group within society. In order to apply this analysis to the social construction of disability, we must examine the language which has been used both

historically and in contemporary society to define disability. We must ask ourselves: Who has constructed these terms? What is their social value? What position do they hold in a social hierarchy? and, How do they impact upon the group to whom they apply? In seeking to answer these questions we must remember that it is not just the language of everyday life which defines disability – although this language is present too – it is also a specialized, scientific, medical language which defines disability. The power of this language lies in its perceived authority and exclusionary force which alienates those being described from the process of description itself.

That language is exclusive is by no means a new idea. It is a reality faced by those who are not, or who have not been in social positions which allow them the power of defining terms. Smith states that “The constitutional theories of sociology have provided methods of writing society into texts. The conventions established construct an objectified standpoint situating their readers and writers in the relations of ruling and subduing particular local positions, perspectives, and experiences. This is *an organization of relations* that we enter in reading” (1989: 43). More concretely, Smith (1990) argues that this has been, and still is a problem faced by women. It is not a problem which exists only on an everyday level, but to the contrary, it is a problem which is augmented when every day experiences are translated by others into technical, or scientific terms; those making observations from outside a particular perspective may claim to be “objective,” but in reality, their accounts are ultimately incomplete.

Women have recognized the alienating effects of our participation in language that does not express our experience. The issue goes beyond that of *entering* women’s experience *into* the language. When we begin from women’s standpoint in the actualities of our everyday/everynight world, we confront a sociology that is written from, and writes, a standpoint *outside* experience. Sociological methods of thinking and research *write over and interpret* the site of experience. This alienation is more than in the relation *between* women’s experience and sociological utterance; it is also in how that speaking and writing *transposes and displaces* a speaking and writing grounded in experience. Sociological methods of analyzing experience and of writing society produce an objectified version that subsumes people’s actual speech and what they have to tell about themselves; its

statements eliminate the presence of subjects as agents in sociological texts; it converts people from subjects to objects of investigation (Smith, 1990: 31; my emphases).

People with disabilities also experience alienation from creating the terms which define them and their existence. Until very recently – and still, even now – people with disabilities have been overstudied, objectified, marginalized, and largely, not treated as masters of their own destiny. The language describing both disabilities and the people who “suffer” from them has been constructed by able-bodied people, who are themselves outsiders to this experience. It is for this reason that I will examine a number of specific terms in order to analyze who is speaking, the assumptions which are being made, and the power relations which are being represented.

Several terms are important to this discussion, the standard definitions of them are discussed below.⁴

able (1a) having sufficient power, skill, or resources to accomplish an object, (b) susceptible to action or treatment (2) marked by intelligence, knowledge, skill, or competence

able-bodied having a sound strong body

The terms “able,” and “able-bodied” have a positive signification, describing a person who *is* skillful, resourceful, competent and intelligent. If we examine “disable,” “disabled,” “impair,” and “cripple,” we see striking differences in social meaning, reflecting a perceived lack of social rights and personal attributes.

disable (1) to deprive of legal right, qualification, or capacity (2) to make incapable or ineffective; *esp[ecially]*: to deprive of physical, moral, or intellectual strength: cripple

disabled incapacitated by illness, injury or wounds

impair to make worse...to damage or make worse by or as if by diminishing some material respect

cripple (1) a lame or partly disabled person or animal (2) something flawed or imperfect

⁴ All definitions have been taken from *Webster's Ninth New Collegiate Dictionary*, 1983.

To “disable” means *to remove* the rights of, *to render* incapable, *to take away* “physical, moral or intellectual strength,” *to cripple*. To be “disabled” is *to be incapacitated*. To “impair” is *to diminish*, to be crippled is *to be flawed*. Immediately we see that the subject has become the object: a person who is able or able-bodied is someone who is *capable of action*; a person who is disabled is someone who has had something *happen to her/him*. There is no mention in these definitions, no hint that to be disabled is merely to take a different approach to life, to require different means to reach the same, or perhaps even different goals.

The positive associations which are widely linked with the terms “able,” and “able-bodied,” and the negative meanings associated with “disable,” “disabled,” “impair,” or “cripple” reflect a social norm assumed by able-bodied people, most of whom have no personal experience with disability, and who also, perhaps, greatly fear a disabled state of being. Put another way, these terms are strictly negative, and do not take into account the experiences or standpoint of people with disabilities themselves. As Liz Crow argues,

the perception of impairment as personal tragedy is merely a social construction; it is not an inevitable way of thinking about impairment. Recognising the importance of impairment for us [people with disabilities] does not mean that we have to take on the non-disabled world’s ways of interpreting our experience of our bodies. In fact, impairment, at its most basic level, is a purely objective concept which carries no intrinsic meaning. Impairment simply means that aspects of a person’s body do not function or they function with difficulty. Frequently this is taken a stage further to imply that the person’s body, and ultimately the person, is inferior. However, the first is fact; the second is interpretation. If these interpretations are socially created then they are not fixed or inevitable and it is possible to replace them with alternative interpretations based on our own experience of impairment rather than what our impairments mean to non-disabled people (1996:211).

Disability does not become a personal tragedy until it is made so by an able-bodied world (see also Campbell & Oliver, 1996). We cannot ignore the social definitions and barriers that contribute to the isolation, and oftentimes, the incapacity of those who have disabilities. When

we consider whose values are reflected in the definitions surrounding disability we begin to understand the social relations which inform the language of disability, and where these relations are found in a social hierarchy. The terms and definitions used to describe disability reflect the beliefs, prejudices and fears of those who are not disabled; they reflect the normative beliefs of the mainstream population, and the social expectation that anyone who is disabled is also disadvantaged.

Before moving on, we must discuss one final term: “handicapped.” As discussed in the introduction to this thesis, the World Health Organization (1980), defines handicap as “a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal, depending on age, sex, and social and cultural factors for that individual.” In other words, “handicap” describes the *social consequences* of disability for the person who has disabilities. This word, however, has not always held this meaning (also see Davis, 1995). Webster traces the evolution of the word handicap from 1660, at which time it was used to describe the holding of forfeits in a cap (hand in cap) during a game or contest.

¹**handicap** [obs. E *handicap* (a game in which forfeits were held in a cap), fr. *hand in cap*] (1660)

During the 1840s the term acquired a new meaning: a handicap was a physical limitation or other disadvantage that could be imposed on someone or something in order give all contestants an equal chance of winning a contest or competition. In this sense, a handicap was used to make opponents more equal, by imposing a disadvantage on the stronger.

²**handicap** (1841) (1a) to give a handicap to (b) to assess the relative winning chances of (contestants) or the likely winner of (a contest) (2) to put at a disadvantage

It was not until early in the 20th century that “handicapped” came to take on its present meaning,

describing a person possessing a physical or mental disability.

handicapped (1915) having a physical or mental disability that substantially limits activity esp. in relation to employment or education

Webster defines handicap as a disability, particularly a disability limiting an individual's activities in the areas of employment or education. The importance of this definition lies in its relation to an individual's ability to be a productive worker, as it is through this state that s/he gains social value (Turner, 1987), and it is her/his contrast to this productivity that causes the disabled individual to be seen negatively, as unproductive and dependent (see Illich, 1977). Further, this definition focuses on the impairment or disability as the *cause* of personal limitations; social barriers are overlooked.

Recently, positive changes were made to the definition of the term handicapped, as this term is used in the BC legislation pertaining to the Guaranteed Annual Income for Need (GAIN) – welfare for the handicapped. An Ad Hoc group, consisting of the BC Association for Community Living, the BC Coalition of People with Disabilities, and the Canadian Mental Health Association (BC Division) began in 1991 to lobby the provincial government to change the GAIN definition of “handicapped.” The previously existing GAIN definition was as follows

... “handicapped person” means an individual age 18 years or older who, at the discretion of the director, has been designated as handicapped due to the individual being mentally ill or mentally retarded as defined in section 1 of the Provincial *Mental Health Act*, or due to the individual having a physical injury, amputation or physical malfunction of the body. Such designation shall be made only after a qualified medical practitioner has confirmed that the disability is apparently permanent and that there is no remedial therapy available for the individual to significantly lessen the disability, and provided the disability is sufficiently severe that

- a) the individual requires extensive assistance or supervision to manage normal daily functioning, or
- b) as a direct result of the disability the individual requires unusual and continuous monthly expenditures for transportation or for special diets or for other unusual but essential and continuous needs.

For purposes of these regulations, the foregoing definition excludes an individual who, regardless of any physical or mental disability, has not tried nor completed

all possible training or retraining for employment and has not tried nor completed all possible remedial treatment to overcome the disability. The definition also excludes an individual whose reason for being unemployable is due primarily to causes other than those stated in the first paragraph of this definition...(cited in, Ad Hoc '93: Appendix 1).

The negative aspects of this definition become apparent when we consider the application form a person applying for GAIN had to fill out prior to January, 1996.⁵ In Figure 1.1 I have reproduced the introductory paragraphs from the medical form that accompanied my GAIN application of May, 1995 (identical to the application I filled out in 1994). If we analyse the content of this form, we can see the way that disability is mediated by the formal discourse of the welfare institution.

Figure 1.1: Introductory Portion of Medical Form Accompanying GAIN for Handicapped Application, 1995

Dear _____,

I understand that you believe you are suffering from a medical condition which renders you temporarily or permanently incapable of accepting or maintaining permanent employment. You have therefore requested Income Assistance benefits as an "Unemployable Person."

To consider your request, the Ministry requires the bottom half of this form to be completed by your physician. When you return the completed form to me, I will then be in a position to make a decision on your request. Please note that the Ministry of Social Services will not provide a payment to your physician for this information. Any question of payment will be a matter between yourself and your physician.

Sincerely,

Financial Assistance Worker

In what follows I examine the text in Figure 1.1. The opening salutation on this form is in itself depersonalizing: "Dear _____." The person applying for benefits is not

⁵ I have been unable to obtain a copy of the form in present use, and so am unable to discuss any changes to this form which may have resulted from the change in the definition of "handicapped."

addressed as an individual, but as a case among many other cases, waiting for official categorization. Although it may be necessary for large bureaucratic organizations to have stock forms which can simply be photocopied, and re-used over and over, it is a very impersonal way to begin a request for sensitive, personal information. In the next line, "I understand that you believe you are suffering from a medical condition," the "medical condition" is referred to as existing in the mind of the one who is "suffering;" its reality and legitimacy is subject to doubt, a doubt which has not, and will not be dispelled until its existence is verified by a physician. In the second line of paragraph 1, we learn that the applicant has been rendered either "temporarily or permanently incapable of accepting or maintaining permanent employment." "Incapable," synonymous with incompetent, implies that the applicant lacks in ability or qualifications. By the last line of paragraph 1, the applicant has become an "Unemployable Person," organized under an official institutional category, as is the "Financial Assistance Worker."

In the second paragraph, we are informed of the power of the Financial Assistance Worker, who is "in a position to make a decision" regarding the Unemployable Person's request for help. It is implied that the application is a matter concerning only the Financial Assistance Worker, the physician (who must verify the condition), and the Unemployable Person. As a representative of the Ministry of Social Services, the Financial Assistance Worker *appears* to have been granted the power of deciding whether or not the Unemployable Person may receive welfare. This decision may ultimately be the responsibility of the *Ministry*, and the Unemployable Person may have the right to appeal this decision, but this information is not explicitly specified on the application form. Finally, the Unemployable Person is warned that the Ministry of Social Services will not pay any charges the physician may make for completing the application form. (In my experience, this fee ranges between free, and \$25, depending on the

doctor.) It is not only the onus of the Unemployable Person to have this condition certified by a physician, but, the Unemployable Person who is so broke that s/he is applying for Income Assistance must also front any funds required to obtain this certification.

An Ad Hoc group, representing a cross-disability perspective, lobbied the provincial government to change the conditions of employability, and retraining/remedial therapy/rehabilitation required for a person to become eligible for GAIN for the handicapped. In terms of employability, it was felt that "this criterion is particularly misguided because it brands the individuals with a very stigmatizing label that is not necessary to establish either the presence of a disability or the individual's need for income assistance" (Ad Hoc '93). In order to meet the remedial therapy/retraining/rehabilitation requirement, the Ad Hoc '93 group argued that "These requirements become disincentives for people. The very financial support required to complete a program of retraining or rehabilitation is not available until a person has 'failed' these programs." Instead, they argued that "If employability is not a requirement, there will no longer be a need to exhaust retraining or rehabilitation" (ibid.). The proposed definition was to address the issues of impairment, severity and duration, as follows:

1. "Ad Hoc '93 recommends that the description of a disabling condition recognize any loss or abnormality of psychological, physiological or anatomical structure or function. This description is broad enough to cover both physical and mental disabilities. This description will be called impairment."
2. "Ad Hoc '93 recommends that severity of condition be based solely on an assessment of functional abilities as they relate to the social, psychological, physical and developmental impact of a disabling condition."
3. "Ad Hoc '93 recommends that an applicant be required to demonstrate that the disability is likely to remain for at least 12 months or likely to reoccur within 24 months." This criterion takes into account the fact that some people with disabilities may experience periods of remission.

The Ad Hoc committee was successful in its lobby, and on January 1, 1996, a new definition was admitted into the GAIN legislation. The new definition of "handicapped" (BC Coalition of

People with Disabilities, 1996a: 7) is as follows:

“handicapped person” means an individual who

- a) is 18 years of age or older.
- b) as a direct result of a severe mental or physical impairment
 - (i) requires extensive assistance or supervision in order to perform daily living tasks within a reasonable period of time, or
 - (ii) requires unusual and continuous monthly expenditures for transportation or for special diets or for other unusual but essential and continuous needs, and
- c) has obtained confirmation from a medical practitioner that the impairment referred to in paragraph [sic]
- d) exists and
 - (i) is likely to continue for at least 2 years, or
 - (ii) is likely to continue for at least one year and is likely to reoccur.

In spite of this victory however, there remain many negative associations with the term “handicapped,” not only as it is perceived by people with disabilities, but also as it is measured by the community at large. Why is this so?

The Institution of Medicine, and the Birth of Medical Statistics: Normalcy vs. Deviance

To date, the major power behind existing definitions of disability is the medical profession. Disability as a personal state has long been defined according to a medical model (Figure 1.2), which focuses on the functional limitations which arise as a result of disability (see Bury 1979; Crow 1996). According to the precepts of this model, “functional limitations (impairments) are the root cause of any disadvantages experienced and these disadvantages can therefore only be rectified by treatment or cure” (Crow, 1996: 208). No mention is made here of the social limitations which lead to disadvantages for people with disabilities. Bury (1979: 35) provides us with an illustration and expansion of this traditional model (Figure 1.3), indicating the placement of clinical medical intervention, and replacing the purely medical terms (etiology, pathology and manifestation) with those discussed earlier in this thesis (disease, impairment,

disability and handicap). As mentioned above, the latter terms are of specific relevance to this thesis, as these are the terms widely used both in medicine and in everyday language to describe both disability and the disabled. The medical model itself is important in that “[c]urrently, the treatment available is dominated by the medical model’s individualistic interpretation of impairment as tragic and problematic and the sole cause of disadvantage and difficulty. This leads policy-makers and professionals to seek a ‘solution’ through the removal of impairment” (Crow, 1996: 213). But how, we must ask, did the medical model, medical practitioners, gain the power to define disability? What are the social consequences for those who are disabled when we follow the path of treatment and cure outlined in the expanded medical model?

Figure 1.2: Traditional Medical Model



Figure 1.3: Expanded Medical Model



Our society has become highly medicalized through the development of a specialized medical knowledge, a standardized medical education, and the evolution of a specific medical language (Turner, 1987). Individuals who possess these things hold a privileged position in our society, and have the power to define what is considered normal. Their definitions are supported by “scientific” evidence, that is, by medical statistics. The medicalization of society is itself a strategy of social control (O’Neill, 1995:28-29); we, as individuals, are supposed to conform to medical norms, and to the advice of our doctors. This is especially problematic for those who are disabled, as they are expected to fulfill both healthy and unhealthy norms.⁶ By this, I mean that people with disabilities are constantly compared with able-bodied people (for example, in terms

⁶ I am indebted to Colleen Brown for clearly emphasizing this point.

of job performance, appearance, marital status, etc.), and yet, they are also supposed to conform to their doctor's orders to rest, and to a social expectation that they are "feeble," or dependent. Who makes this comparison? both able-bodied and disabled people alike. Goffman discusses this problem with reference to the origin of the term stigma.

The Greeks, who were apparently strong on visual aids, originated the term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places. Later, in Christian times, two layers of metaphor were added to the term: the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin; the second, a medical allusion to this religious allusion, referred to bodily signs of physical disorder. Today the term is widely used in something like the original sense, but is applied more to the disgrace itself than to the bodily evidence of it (1963:1-2).

In addition to being an attribute identifiable by others, I would argue that stigmatization is also the process by which individuals internalize a negative self-image based on their differences from the norm. Stigmatization is the consequence for those who do not conform to expected norms.

The stigmatized individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a "normal person," a human being like anyone else, a person, therefore, who deserves a fair chance and a fair break... Yet he may perceive, usually quite correctly, that whatever others profess, they do not really "accept" him and are not ready to make contact with him on "equal grounds." Further, the standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility, arising from the individual's perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing (Goffman, 1963:7).

It is for reasons of shame, Wendell (1996) argues, that many people with disabilities would like to distinguish disability from illness, especially serious (and stigmatizing) illnesses, such as AIDS or cancer. The worry is that including these illnesses as disabilities will increase the

negative attitudes with which disability is already perceived.

Science, particularly medical science, holds a great deal of power over us as individuals, and it is through the medical and statistical sciences that we have developed the notion of normalcy. Davis traces the evolution of the word “normal” as it is currently used in the English language.

The word ‘normal’ as ‘constituting, conforming to, not deviating or differing from, the common type or standard, regular, usual’ only enters the English language around 1840. (Previously, the word had meant ‘perpendicular’; the carpenter’s square, called a ‘norm,’ provided the root meaning.) Likewise, the word ‘norm,’ in the modern sense, has only been in use since around 1855, and ‘normality’ and ‘normalcy’ appeared in 1849 and 1857 respectively. If the lexicographical information is relevant, it is possible to date the coming into consciousness in English of an idea of ‘the norm’ over the period 1840-1869 (1995:24).

Davis⁷ argues that this use of the word normal arose with the development and propagation of statistics, the first purpose of which was to determine and record characteristics of the population at large in order inform state policy (see also Starr, 1989).

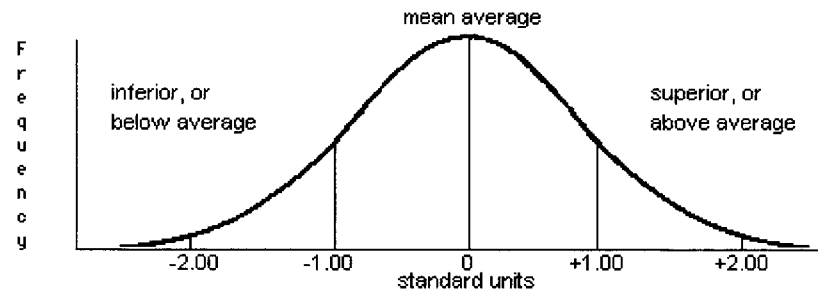
The word *statistik* was first used in 1749 by Gottfried Achenwall, in the context of compiling information about the state. The concept migrated somewhat from the state to the body when Bisset Hawkins defined medical statistics in 1829 as ‘the application of numbers to illustrate the natural history of health and disease’ (cited in Porter, 1986, 24). In France, statistics were mainly used in the area of public health in the early nineteenth century (Davis, 1995: 26).

The use and propagation of medical statistics led to the notion of the “average man,” which in turn gave rise to the belief that the “norm” was an ideal not only to be striven for, but one which could actually be attained by “the majority of the population.” The “norm” was not a norm, but rather an elite basis for comparison (Illich, 1976). The concept of the “average man” (“*l’homme moyen*”) provided the justification for a new hegemony of the middle classes (“*classes moyennes*”). “The social implications of this idea are central...With bourgeois hegemony comes

⁷ Citing Theodore Porter’s (1986) *The Rise of Statistical Thinking 1820-1900*.

scientific justifications for moderation and middle-class ideology” (Davis, 1995: 26; Wallerstein, 1991; Turner, 1987). This established a “norm” to which all would be compared (Starr, 1989), including those who were on the lowest end of any scale of measurement (including economic, intelligence, or health).

Figure 1.4: The Normal Curve



Statistics are based on the normal curve, which is basically any curve or distribution in which the greatest number of cases lie on the mean average, and the mean average divides the distribution (the frequency) of all cases into two equal halves (see Figure 1.4). Approximately 68% of all cases (people) will fall between -1.00 and +1.00 standard units on either side of the mean average, and approximately 95% of cases will fall between -2.00 and +2.00 standard units of the mean average. The problem of the normal curve is that it presents a central norm with two deviant poles. However, for many human characteristics, what is perceived to be a socially more desirable extreme accompanies the less desirable one; for example, intelligence and height are seen as being more desirable than lack of intelligence, or shortness. This leads to a system of statistical ranking, whereby those falling on the high side of the average are believed to be superior, and those falling on the low side of average are seen as inferior.

Thus, closely related to the notion of the norm is deviance: “Any bell curve will always have at its extremities those characteristics that deviate from the norm” (Davis, 1995: 29). Not

surprisingly then, coinciding with the development of statistics, was the birth of the eugenics movement. Eugenicists, influenced by Darwin's theory of evolution, believed in the perfection of the human race by "the elimination of 'defectives,' a category which included the 'feeble-minded,' the deaf, the blind, the physically defective, and so on" (Davis, 1995: 31). This desire in many cases led to the sterilization of those who were seen to be "defective" (Davis, 1995: 38), and also to what is termed the new eugenics movement in Britain (Bailey, 1996). The new eugenics movement is informed by the medical model; pregnant women are "now routinely offered one or more prenatal screening tests...If any test indicates that the potential child would have an impairment, the mother is offered an abortion" (Bailey, 1996: 143). Bailey also points out that criteria used to determine which illnesses are tested for, and whether or not abortion is recommended are based solely on the discretion of those in the medical profession.

Taken together, these points illustrate that the notion of suffering used by the medical profession includes physical pain and distress intrinsic to a particular medical condition, but also the psychological impact and social reaction to that impairment for both the potential child and the mother. There is also some evidence that this notion of suffering is extended still further, to include the impact of impairment on society (Bailey, 1996: 147).

By aborting disabled fetuses, medical practitioners play the privileged role of intervening in lives they feel would be limited by pain and suffering; they also intervene between the potentially disabled person and society, protecting society at large from "unnecessary" social and financial burdens. In other words, in this case, clinical intervention takes the form of curing the ill by killing the patient. In order to assist in this process, the British government passed abortion laws (as of 1990) which differentiate between healthy and "unhealthy" fetuses, such that abortion of "seriously" handicapped fetuses was available up to the full term of pregnancy⁸. As Bailey points out, however,

⁸ See Bailey, 1996: 143-167 for a more complete discussion.

There was little attempt during the course of the [House of Lords Select] Committee's deliberations to ascertain which impairments, if any, prohibited a 'meaningful life' or the broader consequences of allowing abortion to term. They seemed rather to accept their own apparent horror of impairment and consequently wished to facilitate its prevention wherever possible (Bailey, 1996: 159).

The notion that we can determine the nature or degree of impairment which will prohibit a "meaningful life," particularly before a foetus is born is highly problematic. And yet, is there any way to prevent the definition of "meaningful life" from merely reflecting our perceptions of health and ability? We may find an answer to this question if we further examine the way disability, both mental and physical, has been constructed by the medical profession.

The Professionalization and Internalization of the Discourse of Disability: The Illness Career

In *Madness and Civilization*, Foucault (1965) documents the process by which madness became mental illness. This is the story of the medicalization of madness, which led to the social stigmatization of the man or woman who was mentally ill, and to his or her own internalization of the definition "mentally ill." The medicalization of the knowledge of mental illness served to remove it further and further from those who experienced it firsthand, with patients becoming mere categories, objects for classification and treatment. At the same time, the practitioners of medicine and science gained in prestige. The result of this was that the mad were no longer owners of their own experiences; these had been reserved for the knowledge and vocabulary of the doctors. "In the patient's eyes, the doctor becomes a thaumaturge; the authority he has borrowed from order, morality, and the family now seems to derive from himself; it is because he is a doctor that he is believed to possess these powers" (Foucault, 1965:275). The consequent development of psychiatric science only served to further objectify the woman or man who was

now called the “mentally ill” patient. And yet, this “progress” of knowledge, this supposedly “objective” study of mental illness, did not free the patient from stigmatizing social and moral associations. If anything, it only further entrenched the position of the mentally ill man or woman as a social deviant by causing them to *internalize* their identity as such. “Madness was not what one believed, nor what it believed itself to be; it was infinitely less than itself: a combination of persuasion and mystification” (Foucault, 1965: 276).

It is not only in the field of mental illness that medicine has played so crucial a role, but also in the formation of our notions of physical illness. The development of a unified, scientific field of medicine predicated the beginning of a specialized practice which served to further objectify the human body and experience through scientific norms.

Medicine must no longer be confined to a body of techniques for curing ills and the knowledge that they require; it will also embrace a knowledge of *healthy man*, that is, a study of *non-sick* man and a definition of the *model* man. In the ordering of human existence it assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate the standard for physical and moral relations of the individual and of the society in which he lives (Foucault, 1973:34).

By studying both wellness and illness, medical practitioners gained power not only as “givers of cures,” but also as intermediaries between normal and pathological, and between life and death. This practice was established when the moral and traditional taboos preventing dissection of the human body (diseased or otherwise) were finally lifted. Illness became a “spectacle,” and the ill person became an object for scientific learning, still replete with basic human rights, but otherwise depersonified. This was especially the case for the poor, who were commonly hospitalized in what would today be considered barbaric institutions.

Social class had entered upon the medical stage, creating a pattern of differential treatment for rich and poor. Foucault notes that a hierarchy of medical practitioners evolved:

those for the poor (“officers of health”), and those for the rich (doctors). The former were not required to possess the same degree or type of training, as it was widely “accepted that the labouring classes, especially those in the country, led a more simple, moral, and healthy life than others” (Foucault, 1973: 81). These same poor individuals were also made to feel indebted to the rich, and had little choice but to enter willingly into this type of social contract. Turner documents the importance of the issue of class in terms of “the evolution of the modern medical science” (1987:161-62). By practicing upon the poor, doctors were able to gain expertise and professionalize their practice. Improvements in hospital sanitation, “the emergence of a middle-class clientele and the discovery of psychosomatic medicine” also led to increasing patronage of hospitals by those of the middle and upper classes. These changes resulted in an ever increasing amount of prestige being conferred upon the doctor, and the role of physician began to replace that of clergyman as arbiter of moral life (Foucault, 1973; Turner, 1987).

The role of the physician became both political and moral. Medical practitioners were “relatively autonomous and subject to few non-medical regulations” (Turner, 1987:156). They played a decisive role in defining normative health structures, behaviours, and practices. They were considered as authorities on the subject of health, and were established as experts in helping to determine need for financial assistance. In short, “In addition to his role as a technician of medicine, he would play an economic role in the distribution of help, and a moral, quasi-judicial role in its attribution; he would become ‘the guardian of public morals and public health alike’” (Foucault, 1973:42).

The medicalization of society led to the formation of a field of “experts” who were the makers of judgments, and the deciders of policy. The experts defined, and decided upon the

⁹ Cabanis, *Du degre de certitude de la medicine* (3rd Edn., Paris, 1819: 135 and 154).

norms, and all those who did not fit in were labelled and regulated as deviant.

When one spoke of the life of groups and societies, of the life of the race, or even of the 'psychological life', one did not think first of the internal structure of *the organized being*, but of *the medical bipolarity of the normal and the pathological*...Hence the unique character of the science of man, which cannot be detached from the negative aspects in which it first appeared, but which is also linked with the positive role that it implicitly occupies as a norm (Foucault, 1973:35-36).

The power of the medical profession to dictate and define not only health, but also illness had major consequences for people with disabilities, relegating this group to the margins of society as "incapable," "ineffective," "incapacitated," and "flawed;" depriving them of social rights, and casting their physical, moral and intellectual capabilities in doubt.

The current aim of much of sociology, particularly feminist sociology, is to challenge the universal norms of traditional, positivistic sociology which emerged in the wake of the history that Foucault narrates (see Weston, 1988; Currie, 1988a,b; Storrie, 1988; Smith, 1989; Harding, 1986; and Nicholson, 1992). A major issue in this challenge is to resituate discourse in the "social relations that were their original home" (Smith, 1990:141). For Foucault, this entails analyzing the relations between social institutions (sites of power) and human bodies (sites of submission). Foucault elaborates upon the ways in which human bodies are subjected to disciplinary, objectifying practices, all in the name of creating institutions which function according to scientific ideals. An especially important example of such an institution is the hospital. The development of the hospital, and the refinement of "scientific" medical knowledge, has led to the increasing medicalization of our society, and the power of social control for medical practitioners.

Having discussed the importance of the medical profession in describing and defining human norms, and having examined the historical process by which these norms were

statistically explored and documented, we must now ask: how do these medically and scientifically defined norms influence everyday beliefs and/or reality? Beginning at the everyday level, Smith (1990: 148) discusses the ways in which everyday experiences become translated into scientific, or textual terms (see Figure 1.5). She cites the example of the translation of the everyday phrase “she killed herself” into the sociological and “official” phrase, “she committed suicide.” The second phrase distances us from the reality of the individual, and inserts us into formal discourse, where the subject becomes the object. “We are concerned here [Smith argues,] with a break in the social consciousness between how people experience, tell, and make sense of what is happening from within the particular times and places of their lived actuality and a formalized impersonal mode of knowing articulated to (and indeed an integral part of) an apparatus of ruling” (Smith, 1990:142). The experts tell us what the “truth” is about ourselves and our experiences, all the while obscuring our own personal accounts of these experiences. In other words, “local accounts” are reinterpreted, codified, and categorized according to the definitions of “the ruling apparatus.” These formalized accounts are frequently privileged under the guise of scientific rationality.

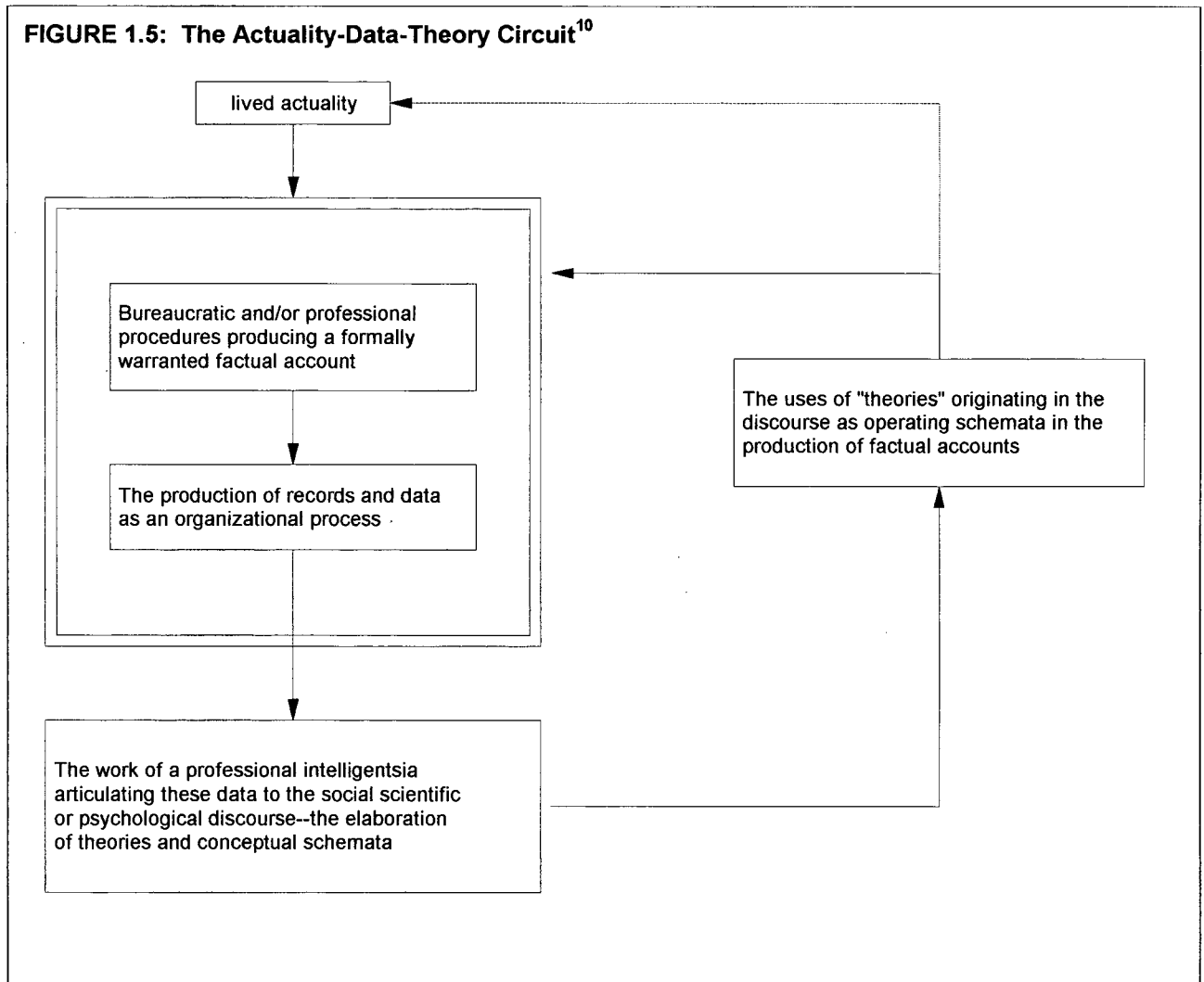
If we examine the top box on the left of Figure 1.5, we see that accounts begin with the “lived actuality,” or real experiences of the individual. In the next box down, these experiences are observed and interpreted by members of a formal institution, for example, by doctors in a hospital. Continuing with our example, the third box in this column represents the process during which observations and interpretations are categorized together into groups based on similarities in the “data,” and formal records of these groupings are made. Once formal interpretations have been made and categorized into groups, members of the “professional intelligentsia” can begin to form theories and schemata which explain the characteristics of membership in each group

(see the bottom box on the left). Although these theories began as observations of the experiences of actual people, these experiences have passed through a process of interpretation, made, in this case, by medical professionals. In the box on the right hand side of Figure 1.5, we can see how these interpretations enter back into the cycle of the production of knowledge about a patient. This diagram differs from that offered by Smith (1990: 148): I argue that once knowledge of the patient has been formalized by the medical professionals, this knowledge not only influences the future interpretation doctors will make of all patients who appear to fall within a given category, but that patients themselves will internalize this formal, medical viewpoint. The dotted line in Figure 1.5 represents knowledge which has been translated and formalized, and which is then reincorporated, and internalized back into the formation of an individuals' account of their own life. In this fashion, science becomes a privileged mode of knowing which "has permeated not only the modes of thinking and acting of our public institutions, but even the way we think about the most intimate details of our private lives" (Harding, 1986:16). Through the process of formalizing everyday language, "Science appears more and more to be a discursive and institutional strategy to impose and maintain a hierarchical order. The claim to epistemic privilege seems to be a tactic to exclude, silence, or otherwise disempower socially threatening or marginal groups" (Seidman, 1992: 54).

Figure 1.5 is a useful pictorial representation of the way in which knowledge about an individual becomes formalized through a social institution, such as the medical profession, and how this formalized knowledge is accepted and internalized by the individual patient. This process completes the cycle of the production of knowledge about the patient, and ensures that the patient will internalize the interpretations and beliefs of the medical professionals. The actuality-data-theory-circuit is particularly relevant in providing an understanding of the

experience of people with disabilities. Historically this group has had little access to the power to describe their own experiences in their own terms, and few means to ensure their own personal rights within society.

FIGURE 1.5: The Actuality-Data-Theory Circuit¹⁰



Do doctors in medical institutions give their patients the impression that they cannot heal? Illich (1976) argues that we have become increasingly dependent upon a medical system which has not grown as fast as the demand it has created. Increased reliance on healthcare professionals has caused us to forget how to look after ourselves, not only physically, but

¹⁰ The dotted line was suggested to me by Thomas Kemple as a way of indicating the incorporation of "theoretically" informed ideological discourse into everyday speech, as in "K is mentally ill" (Smith, 1990), or "She committed suicide" (Smith, 1990).

emotionally as well. In our modern, industrial culture we place so much emphasis on productivity, employability, and a high standard of living (not to mention youth and health), that we have forgotten that for many, or perhaps even most people, life is not all that easy. By removing the means of personal control from the individual, our society has given rise to a group of people who have no knowledge, no skills to prevent themselves from becoming handicapped as a result of their disability. Goffman (1961) calls this the development of an "illness career".

The medical profession plays an important role in determining whether or not an individual's impairment or disability becomes a handicap. Turner, for example, argues that for those who are hospitalized, the process of hospitalization is de-personalizing, and limits the patient's resources and mobility to those services provided by the hospital. This in turn causes a type of patient "recidivism...[I]t has been found that the longer a patient stays in a hospital the more likely he or she is to wish to remain in the hospital, or to be indifferent about returning to their normal round of activities"¹¹ (1987:164). This may be in part because it is not only acceptable, but expected, that a "patient" relinquish all responsibility for her or himself. Help obtained in the hospital may have unintended consequences¹² which lead to ongoing, and increasing dependence on this institution: a type of socially sanctioned surrender. "Learned helplessness" is a term commonly used in educational literature (see Lobban, 1977) to refer to a situation in which an individual decreases her/his efforts because s/he feels failure is inevitable. In the case of people with disabilities, "failure" refers to an inability to return to, or to attain 'normal', or previous levels of health and activity. Decreased efforts toward recovery or independence may be especially likely to occur in cases where the individual feels failure to

¹¹ Turner cites Wing, J.K. and G.W. Brown. 1970. *Institutionalization and Schizophrenia*. Cambridge: Cambridge University Press.

¹² The phrase "unintended consequences" is a reflection of the work of Jim Overboe.

recover is more likely than success. (Failure in this case would be perceived as the lack of ability to heal, rather than a lack of efforts directed toward healing.) If a person feels that s/he can get better by increasing efforts toward rehabilitation, s/he may well increase such rehabilitative efforts. On the other hand, if the individual perceives her or his lack of ability to recover as inevitable, s/he may see little point to increasing these efforts, particularly as the personal and financial costs of rehabilitation can be quite high.

Illness as a career has been created as a result of the social definitions which mediate the institutional management of illness. Locker states that according to this approach, “[d]eviance and mental illness were not attributes of individuals but properties conferred on them by others” (1983:4). In other words, Goffman and Locker argue, chronic illness is, at least in part, a social construction. This construction leads to a problematic situation for the disabled person who must attempt to adapt him or herself for survival in the ‘normal’ world, according to ‘normal’ rules and expectations. People with disabilities do not measure up to what the majority of the population considers to be the requirements for productive, meaningful lives; therefore, they come to be viewed by others, as well as by themselves, as being deviant, as being deficient (Goffman, 1961, 1963). If individuals internalize the definitions and prognoses made for them by the medical experts, this may lead to an illness career which runs contrary to the temporary “sick role” described in the medical sociology of Talcott Parsons (see Proctor, 1982). “Illness” itself becomes defined as “non-productive” or “unemployable” (Illich, 1976), and the ill or disabled person becomes negatively stereotyped. In reality, this person may no longer be able to work, or may have been advised to give up work by their doctor (see Russell, 1989). In addition, there are social barriers, such as the inaccessibility of many jobs, lack of flexibility in employment, and the everyday discrimination against people with disabilities. Solutions, such as making jobs more

accessible to people with disabilities, providing flexible hours, job sharing, improving building accessibility and transportation systems are not readily forthcoming¹³. As a result, people with physical disabilities may come to rely on the social welfare network for support. This becomes increasingly problematic given present day economic conditions. These issues are of particular importance in the development of illness as a career, as the person with a disability may have no other “rational” choice but to become permanently handicapped.

Conclusions

In this chapter I have discussed the development of specific terms used to define disability. The medical profession has emerged as the site of power most influential not only in developing the language used to describe disability, but also in determining whether these terms are positive or negative. People with disabilities have been excluded both from defining the terms used to describe disability, and from determining the social outcomes which may arise as a result of the disabled physical state. The unchallenged power and authority of the medical profession has led to a domain of knowledge and a specialized language which remains unchallenged, and which is internalized by people who have disabilities.

In order to challenge the authority of the medical profession we must deconstruct the language which is used to define disability. We must unravel the disabled identity as it has been constructed by able-bodied people, and build a new identity which is informed directly by the experience of people with disabilities.

“Health,” after all, is simply an everyday word that is used to designate the intensity with which individuals cope with their internal states and their environmental conditions. In *Homo sapiens*, “healthy” is an adjective that qualifies ethical and political actions. In part at least, the health of a population

¹³ For a related discussion concerning gender inequalities and work, see Blau and Ferber (1986).

depends on the way in which political actions condition the milieu and create those circumstances that favor self-reliance, autonomy, and dignity for all, particularly the weaker. In consequence, health levels will be at their optimum when the environment brings out autonomous personal, responsible coping ability. Health levels can only decline when survival comes to depend beyond a certain point on the heteronomous (other-directed) regulation of the organism's homeostasis (Illich, 1976: xv).

In other words, Illich argues, the medicalization of society has removed our sense of power and control, not only over our own bodies but also over our own destiny. We have passed this control to the medical experts, and rely on them to make us well; we are not taught the independent coping skills to manage our lives in a disabled state, and we are not taught to accept disability as a part of a "normal" life. The medical definition of disability, and the negative implications associated with this state create a severe handicap for those who are disabled and who wish to work. In Chapter 2, I explore the ways in which the disabled identity is further constructed through the social institutions of work and education.

Chapter 2

Disability, Work and Education



Today Paul took me to the new "accessible" Koerner Library at UBC. I have been trying to get there for a couple of weeks. The problem: the accessible library has no handicapped parking. In fact, Paul dropped me off as close as he could and I still had to walk about 100 metres. I got out of the car and looked and knew it was further than I could go, let alone come back, and knew I didn't have any choice but to do it anyway. Thank god Paul came with me. Not just to help physically, which he did tremendously, but also as moral support. It's like looking at a wall higher than you can climb and knowing somehow you have to get over it. Not just today, but every time you need to use the library. Knowing that this is the new "main" library. I got very depressed because it feels impossible. All those people just take it for granted that you can get from A to B. The right to use the library. Such a basic right every student takes for granted. Not all materials can be picked up and brought home by someone else. Some of them have to be used there. Nobody with an able body can know what today cost me, not just physically, but also in the sense that I have a place in, that I belong in society. Days like today make me feel that place is gone.

— Personal Journal, January, 1997 —

In this chapter I analyse the relationship between work, education and disability. Is it inevitable that we will associate "able-bodied" people with productivity, and "disabled" people with a lack of productivity? More importantly, will people with disabilities make this association themselves? There are many who believe that personal social value in western society is attainable *directly* through our productivity as workers (Turner, 1987), and *indirectly* through our levels of educational attainment (Vernon, 1996). This relationship is particularly problematic for people with disabilities. I begin by examining the relationship between education and work. Functionalist, human capital, and Marxist theories explaining this relationship will be examined, followed by my own interpretation of this relationship as it applies to people with disabilities. In the second section, I discuss the relationship between disability and work from both a political economy perspective, focusing on the demand and supply sides of labour, and a perspective based on human need, in which I consider the personal needs which must be met for a person with a disability to choose employment over unemployment. Major emphasis is placed on: (a)

the response of the labour market to people with disabilities (discrimination and differential access to education and employment), and (b) why people with disabilities appear to make the “choices” they do regarding education and work.

Theoretical Perspectives Linking Work and Education

While there are a number of theories which explore the relationship between school and work, I focus on functionalist views, human capital theory, and Marxist theories. These three theories provide us with a view of the way the relationship between the institutions of school and work have traditionally been theorized. The primary goal in analysing each of these theories is to understand the phenomena of productivity and wage return within society, and how a stable society is considered to be one in which there is adequate opportunity for each member both to contribute to that society and to enjoy a reasonable standard of living.

Gaskell (1992) argues that most educational policy in Canada, Great Britain and the USA in the 1960s and 1970s was influenced by the functionalist perspective. Talcott Parsons,¹⁴ one of the major proponents behind this theory, held that schools served three major functions. The first was to socialize students. The second was to develop their skills and capacities so that they would be able to be productive participants in the economy, and the third function was to allocate students to occupational roles by evaluating their skills and capacities to do well.

Human capital theory, developed by Gary Becker (1975), is an economic view which relates education directly to productivity. Schools are seen as making people more productive, and the workplace rewards them for this productivity with increased wages. The influence of this

¹⁴ Parsons discusses his theory in “The School Class as a Social System: Some of its Functions in American Society,” in *Harvard Educational Review*, 1959.

theory lies in the belief that if an individual can get ahead by increasing their productivity, then the same should be true for an entire economy (Deem, 1982). In order to boost the economy then, it is necessary to encourage people to attain higher levels of education. Whether or not an individual will invest in training or education which will increase her/his productivity, and therefore her/his wages, is seen as a matter of individual choice. The assumption however, is that opportunities are *equally* open to all, and that all members of society are capable of making “*rational*” choices.

The major emphasis in Marxist theories regarding education is placed on social class. Research in this tradition shows that parent’s social status is an excellent predictor of an individual’s success, both at school and in their first job. Therefore, Marxists replace the assumption that school serves everyone equally, with the notion that it serves some better than others. It is assumed that there is a fundamental conflict between labour and capital, with capital dominating in such a way that the individual is alienated from the control of production. Schools are seen as agents of capital, producing generation after generation of workers who accept their alienation from work (Gaskell, 1992). In this view, schools are permeated by inequality, and are sites where children are not only categorized by class, race or sex, but where they learn to live by the rules pertaining to these categories. Educational institutions then, are seen as being stacked against individuals of the lower or working classes, with this bias being hidden behind a meritocratic ideology (that is, the belief that any one who is “good enough” can “make it” on their own merit). The psychological effect of being a member of a low social class are similar to those experienced by people with disabilities, leading to a negative self-identity, and the expectation that they can neither succeed nor excel. Therefore, Marxists argue, school does not reflect the needs of a *productive economy*, but specifically, the needs of a *ruling class* for

control, cheap labour, and for the selection of their own children for good jobs (Gaskell, 1992).

In both the functional and human capital theories the individual is seen as responsible for her/his own success or failure, so that any problems which may exist regarding an individual and her/his education are seen as lying with the individual and the choices s/he makes, rather than with the structure or organization of the school system. Educational attainment is also seen as the most accurate predictor of occupational attainment, better even, than an individual's social status. This of course, assumes that the school exemplifies a meritocratic and unbiased system in which all people have equal chances to succeed. These theories have been criticized as being based on research of a select group of people: white male subjects (Vernon, 1996; Krahn & Lowe, 1993; Gaskell, 1992; see also Blau & Ferber, 1986). Therefore, issues of disability, race, class and gender are largely ignored. Further, all groups do not have equal access to educational opportunities, nor do they benefit equally from the effects of education (Krahn and Lowe, 1993: 118).

According to human capital theory, the allocation of jobs generally results in a close match between the demands of the work and the skills and abilities of the person in the job...In reviewing some of the major findings of occupational choice, status attainment, and labour market segmentation research, we attempt to demonstrate the degree to which the labour market *does not* operate in this manner. In fact, there is evidence that the open competition assumptions of human capital theory need to be seriously reconsidered, and that *the labour market operates in a manner that often perpetuates social inequalities*. Thus the study of labour markets is not only about who gets better or worse jobs; it also addresses broader questions about social stratification (Krahn & Lowe, 1993: 109, original emphasis changed).

In sum, although a link between work and education is recognized by proponents of functional and human capital theories, the explanatory model really only reflects the experiences of a select group of people, primarily, upper-middle class males.

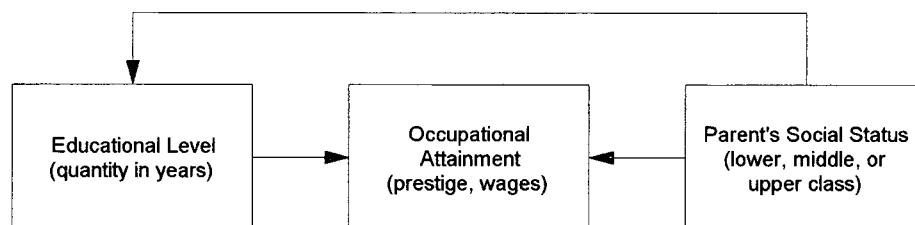
If we examine the dominant strain of Marxist theory which has been applied to

education, we see a tendency to view existing power relations as inevitable. Education is treated as part of the problem rather than part of the solution, and individual agency is underestimated; people's actions tend to be seen as unproblematic responses to social structures. In other words, these theorists present people not as thinking, self-determining actors, but merely as individuals who internalize and act out the dominant ideology (Gaskell, 1992). The result of this is that issues of power are oversimplified. "Even the most oppressed, whether the teacher, the student, or the state bureaucrat, has some leeway for action...The reproduction of social inequality is continually contested" (Gaskell, 1992: 23). Although Marxists feel that the existing school structure is problematic, they have had little impact on educational policy. This is partly because they often threaten or criticize those who are in power, and also because they presuppose a certain inevitability, assuming that little can be changed while we remain in a capitalist system: simply giving individuals more education will not solve the problems of social inequality, or erase the differences of opportunity experienced by those of different class backgrounds. By ignoring differences outside of social class (for example, gender, disability, race) Marxists fail to analyze labour market segmentation as a crucial feature in the division of labour.

I argue that it is not just level of education or parent's social status which need to be considered when we are trying to understand individual differences in occupational attainment (prestige, wages). There are at least three other factors, which I call (a) individual attributes (positive or negative), (b) educational content (subject matter), and (c) educational quality (poor, good, excellent). An individual's attributes refer to whether or not a person is perceived positively or negatively according to mainstream ideologies. If we remember the earlier discussion on the normal curve, we may say that people possess many traits, some which may be perceived as being average or above the average (positive), and some being below average

(negative). For example, I am unusually tall, which is perceived by many to deviate from the norm in a positive way. However, I also possess a disability, a characteristic which is perceived to deviate from the norm of health in a negative way. Deviant subgroups could include people with disabilities, ethnic minorities, people who are poor or are from the lower classes, homosexuals, and women. I include women in this group because most of the theories traditionally used to discuss the relationship between education and work have been based on male subjects; women deviate from male norms. The term educational content refers to choice of subject matter. With regard to people with disabilities, the question is what type of subject matter makes up the student's curriculum; academic subjects, life skills courses, vocational training, rehabilitative programs, etc. The content of a person's education may have serious ramifications in terms of providing her or him with adequate labour market skills. Finally, educational quality refers to whether or not someone has received a "good" education. Good in this sense, refers to such things as the level of skill of the instructor, available and appropriate educational materials and counselling, adequate funding for programs, adequate choice of subject matter, etc.

Figure 2.1: Traditional Theories Linking Education and Occupational Attainment

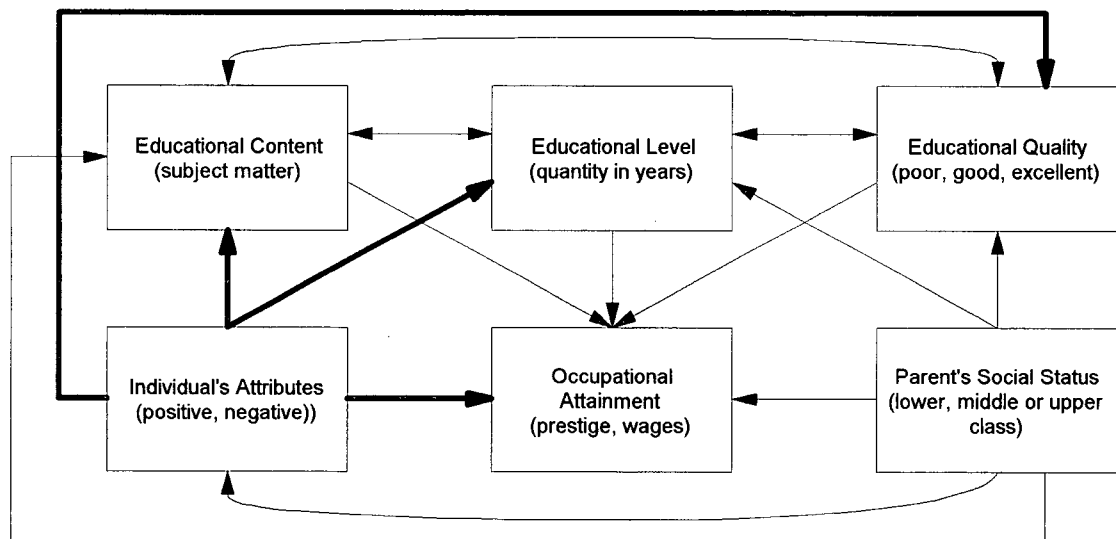


If we were to draw a model of the traditional theories linking education and occupational attainment, it might look like Figure 2.1, in which we can see that educational level (quantity in years), and parent's social status (lower, middle or upper class) are the primary variables used to

explain an individual's occupational attainment (prestige, wages). The model represented in Figure 2.2 is a more complex one, which allows us to combine the additional factors of educational content, quality, and an individual's attributes. By including these three new dimensions, we become better able to analyse the opportunities 'offered' in our society, and the reasons why some individuals may have better access, or access to better opportunities than some other individuals.

Looking more closely at Figure 2.2, we see that each of the five independent variables have a direct influence on occupational attainment. An individual's attributes will also have an influence on educational level, content and quality, and will in turn, be influenced by parent's social status. Educational content, level and quality all have reciprocal relationships with one another, as well as each being influenced by an individual's attributes and her or his parent's social status. As we can see by looking at this model, the relationship is a complicated one. Analysis in the following section focuses on the thick lines connecting an individual's attributes to educational content, quantity and quality, and to occupational attainment.

Figure 2.2: Expanded Model Linking Education and Occupational Attainment



Disability and Work

I turn now to a specific discussion of people with disabilities, their experiences regarding work and the educational (or training) “choices” they make in preparation for work. I argue that there appear to be two major ways of analysing this relationship. The first of these is from a political economy perspective. This viewpoint may further be broken down into two components: that which emphasizes the demand for labour (employers), and that which is concerned with the supply of labour (employees). Discussion of the demand side will focus on “the possible results of...discrimination in the labor market which occurs when [people] with equal qualification find work in different occupations and/or at different wage rates” (Blau & Ferber, 1986: 120). The primary question from this angle is: Do people with disabilities have equal access to the labour market when compared with able-bodied workers? In discussing the supply side I will focus on choices made by the individual regarding whether or not to invest in job-related education and/or training. Which factors facilitate the decision to pursue education beyond the required minimum, and which factors deter an individual from doing so? By taking a political economy approach I evaluate the ways in which society is *not* meritocratic but discriminatory, and how societal discrimination may prevent people from making “rational choices” to further their education and thereby, their opportunities as workers.

I will also, however, examine the relationship between work and disability in another way, one which moves away from a political economy perspective, and toward a perspective of human need (see Turner, 1986; Fraser, 1989; Illich, 1977). This perspective may allow us to take into account real people and their very real needs. Central to this argument are the *social* and *cultural* aspects of the disability-work relationship: What factors influence people with disabilities when they are considering employment? By focusing on these elements I address the

issue of agency which has been left out of the traditional Marxist approach.

There is no shortage of literature documenting the desire of people with disabilities to work, and no shortage of evidence that the relationship between disability and work is an important one. Gould states that the disability-work relationship need not lead to unemployment, but rather, that "disability depends not only on the employee's state of health and the demands of the job but also on the possibilities open for minimising the conflict between work and working capacity" (1981: 56). In other words, people become handicapped when circumstances in their working lives are not adapted to meet their changing physical capacity. In this view, people with disabilities will be able to continue working as long as there is enough flexibility in the workplace to meet their needs. There is widespread evidence however, that not only is there a lack of workplace flexibility and support for people with disabilities (Gould, 1981; Krute & Treitel, 1981; Minister of Human Resources and Development, 1994; Vernon, 1996; Gooding, 1994), but there is also a lack of workplaces (Krahn & Lowe, 1993; Pulkingham & Ternowetsky, 1996). "Thus, the problem is not simply one of poorly trained or uneducated workers. There are deeper problems in the structure of our economy as well, and concerted efforts by government, the private sector, and organized labour are needed to address them" (Krahn & Lowe 1993: 100). Neither the political economy perspective nor that based on human need adequately address the problems inherent in the relationship between people with disabilities and employment. It is necessary, therefore, to combine these two approaches to take into account both the supply and demand of labour, and the personal needs people with disabilities face when considering employment.

Political Economy Approach

Unemployment and poverty have long been problematic in the Canadian economy, and

are serious problems faced by the current Liberal government (re-elected in 1993). Liberal policies favour state intervention, which is supposed

to stimulate employment consumption and economic growth. In this framework the state assumed a pivotal role to ensure job creation and strong levels of economic activity. Although the infrastructure program was initiated, once in office the policies turned to by the Liberals paralleled those used by the Conservatives a decade earlier. Like the Conservatives before them, they asserted the *primacy of the private sector* as the engine of economic growth and job creation. Once profits are secure and predictable, the private sector will invest, jobs will be created, resulting in increased consumer demand that will be translated into further investments and jobs (Pulkingham & Ternowetsky, 1996: 6, my emphasis).

According to this approach, by stimulating the private sector, the government will be able to increase the demand for workers, thereby increasing the number of available jobs. What is not spelled out in this approach, is what the Liberal government considers to be the acceptable rate of unemployment: 8% (Pulkingham & Ternowetsky, 1996: 8). The federal government of Canada deems it acceptable that 8% of the Canadian population is out of work. (Those who are underemployed, and make up the population of the working poor are not included in this figure.) "Gone is even the pretense of interventionist measures that set 'full employment' as a policy priority" (Pulkingham & Ternowetsky, 1996: 8). The crisis of unemployment increases the level of competition for existing jobs, which has a serious impact on people with disabilities.

Taking a political economy perspective, I first examine the demand for labour: do people with disabilities have equal access to the labour market when compared with able-bodied workers? In their analyses of gender inequality in the labour market, Blau and Ferber (1986) provide a number of critical observations which also apply to people with disabilities. These authors argue that the *demand* for labour is determined by the *perceived productivity* of that labour, and the *receptiveness* of the market to the goods or services produced. This "perception of productivity" opens the door for discrimination in the selection of workers made by

employers. Discussing gender inequality, Blau and Ferber argue that

If an employer has tastes for discrimination against women, he or she will act as if there were a nonpecuniary cost of employing women equal in dollar terms to d_r (the discrimination coefficient). To this employer, the costs of employing a man will be his wage, w_m , but the *full* costs of employing a woman will be her wage *plus* the discrimination coefficient ($w_f + d_r$). This means that discriminating employers will hire women only at a lower wage than men ($w_m - d_r = w_f$). Further, if we assume that men are paid in accordance with their productivity, women will be hired only if they may be paid less than their productivity (1986: 202).

In order to apply this equation to people with disabilities who are seeking employment, we must consider if employers will see disabled workers as entailing extra costs, whether in terms of dollars (pecuniary), or other social (nonpecuniary) costs. First I examine pecuniary costs. If the productivity of a worker is measured in terms of any of the following:

- 1) consecutive time at work (i.e., absence of sick days),
- 2) the speed with which goods/services are produced,
- 3) the ability to work under standardized conditions,
- 4) lack of special equipment/renovations required to allow the worker to work in the existing location, and
- 5) the lack of need for any special benefits (e.g., medical plan, disability insurance, etc.),

then the disabled worker will likely *not* be considered to be as productive as an able-bodied worker (see Gooding, 1994; Krute & Treitel, 1981). If people with disabilities are considered to be less productive, and more expensive, then they will be less likely than able-bodied people to be hired by profit maximizing firms, especially in an economy plagued by high rates of unemployment (that is, an economy in which there are many workers to choose from, and relatively fewer jobs), unless they can be paid less than the value of their productivity. People with disabilities would have better chances for employment in a labour market that had a low supply of labour relative to the demand for labour; if there were fewer workers than jobs, all potential employees would be valued. However, much of capitalist industrialism is designed to

prevent an imbalance in this direction: a high demand for labour relative to the supply would increase the power of the worker. The notion that some workers may be perceived to be more productive than others leads inevitably to the conclusion that employers will favour some potential employees over others. In other words, in spite of affirmative action programs, the competition for jobs may not be equally open to all.

Turning now to the nonpecuniary, or social costs, which may be associated with hiring a disabled worker, I examine first the importance of personal connections within the workplace. Discrimination against a worker on this level may be quite personal.

This form of discrimination involves treating people who are disabled adversely without any rational reason or pretext. That is to say it represents a form of 'pure' prejudice, where the employer is not arguing that the disabled people cannot perform the necessary tasks, just that s/he does not want them around (Gooding, 1994: 68).

Discrimination by employers against disabled workers may also be influenced by the medical profession, in that "a process of medical screening" may be required, and, as Begum states, "it is rather worrying that a GP's perception of a disabled woman's 'employability' can be a deciding factor" (1996: 178). Gooding also notes that "People who become disabled are likely to underestimate their own abilities to continue working, particularly as employers, doctors and other 'professionals' are likely to reinforce the attitude that disability inevitably excludes a person from the workforce" (1994: 151). In addition to discrimination based purely on the *presence* of a disability, "inaccurate generalisations" pertaining to people with disabilities may also be a problem. In this type of discrimination employers may make unreasonable assumptions about the abilities (or lack thereof) of people within a certain category of disability, not because these abilities are seen as being part of "the physical or mental requirements of the job" (Gooding, 1994: 70), but as an excuse for hiring an able-bodied worker rather than a disabled

one. This type of discrimination may force the disabled worker to have to prove their capabilities by working harder and longer than able-bodied employees (Campbell & Oliver, 1996; Vernon, 1996). It also may lead to employers making job descriptions with requirements which, while not essential to the job, are in effect exclusionary to certain members of the population (Gooding, 1994; Blau & Ferber, 1986). The purpose of these requirements may be to prevent the majority of workers within a firm or business from having to interact with a person with disabilities, an unusual and disturbing experience for many, which may cause them to feel personal or social discomfort (Vernon, 1996; Gooding, 1994). In analysing the impact of the 1990 Americans with Disabilities Act, Gooding notes that "Congress acknowledged that society's accumulated myths and fears about disability and disease are as handicapping as the physical limitations that flow from actual impairment"¹⁵ (1994: 67).

The lack of informal relationships, or membership in a corporate network may prevent people with disabilities from attaining successful careers (Gooding, 1994). Blau and Ferber (1986) document the importance of such "mentor-protégé" relationships for women in the workplace, arguing that they may not be established because older workers, who are more likely male, may not identify strongly enough with a young female worker to want to take her "under their wing," or, they may be concerned with the social perception of such a relationship. Although efforts to enforce affirmative action legislation will help the situation of many people with disabilities, "it is unlikely to be able to undo the full scale of discrimination for everyone" (Crow, 1996: 219). Gooding (1994:146) supports this notion, stating that anti-discrimination laws should not only address the discriminatory attitudes of employers, but should also require changes to work structures, so that people with disabilities will no longer be restricted to inferior

¹⁵ Gooding cites *School Board of Nassau County, Florida v. Arline* 480 US 273 (1987).

jobs or sheltered workshops. The potential cost of these changes – to be born primarily by government and employers – may make them seem extravagant to the majority of the population. However, the cost of these structural changes may be minimal when compared to the potential cost of maintaining on welfare an ever growing population of people with disabilities. McMurchy and Tubbe state that, based on 1991 figures, “The BC Paraplegic Association once did a comparison of the cost to government of supporting a man unemployed, to the man employed. The unemployed cost was over \$32,000 and the employed man cost government \$63” (1996:28).

Having examined the discrimination which may be found on the demand side of labour, I turn now to an examination of the supply side of labour; here, we begin to see why people with disabilities may make different “choices” than able-bodied people with regard to their preparation for the labour force. The question here is: Why do people with disabilities make the educational/training “choices” they do?

Gould states that “Education is influenced by individual abilities, social status and available facilities” (1981: 58). When we consider the factors which influence the decisions made by people with disabilities, there are a number of additional issues which we must take into consideration. These include *hidden barriers* to education, such as segregation, building inaccessibility, difficulties with transportation, inadequate funding and discrimination (see Gooding, 1994; BC Coalition of People with Disabilities & BC Educational Association of Disabled Students, 1995), which arise as a result of the “negative” attribute of disability. Vernon (1996) also documents a number of the difficulties faced by people with disabilities when pursuing an education. These include: a focus on the physical rehabilitation of the person, rather than on their education (also see Gooding 1994: 140-145); efforts to have the individual perform

tasks in a “normal” way, rather than a way which has been adapted for his or her disability; a poor quality of education, particularly for those in “special” or segregated schools; overprotection; a restriction of choices; and discrimination resulting in a lack of belief in the abilities of the person with disabilities – that is, disabled students are “written off.” In light of the differential evaluation of the abilities between able-bodied and disabled students in Britain,

Gooding notes

special educational needs are relative, and...the distinction between “two types of children, the handicapped and the non-handicapped” is a false one, created by the school system: “Whether a disability or significant difficulty constitutes an educational handicap for an individual child, and if so to what extent, will depend upon a variety of factors. Schools differ, often widely, in outlook, expertise, resources, accommodation, organisation and physical and social surroundings, all of which help determine the degree to which the individual is educationally handicapped...It is thus impossible to establish precise criteria for defining what constitutes handicap¹⁶ (1994: 140-141).

In spite of the recognition that categories of disability are inconsistent and are socially constructed, and that people with disabilities have an equal right to the same level of education (in terms of quality, quantity and content), Gooding states that little has been done in British legislature to improve the situation for people with disabilities.

All of the above factors may contribute to low, or reduced self-esteem (Kennedy, 1996: 127; French, 1996; Campbell & Oliver, 1996). Vernon, who interviewed disabled women who were also members of ethnic minorities, notes that women or minority group members with disabilities often “experience a multiplicity of barriers – a combination of racism, sexism and disablism – in their pursuit for education. This will have major consequences for their labour market experiences where a good education is most critical” (1996: 62). Gooding also believes

¹⁶ Gooding quotes M. Warnock, 1978, *Special Educational Needs: Report of the Committee of Enquiry into the Education of Children and Young People*, London, HMSO, p. 37.

that additional forms of discrimination exist, arguing that "For individuals this is experienced as a strong feeling that discrimination is happening, while being unable to pinpoint precisely where in the system, or how it happens" (1994: 121).

Kennedy (1996) considers a different type of difficulty which people with disabilities receiving their education in a segregated institution may experience: sexual abuse. She argues that the incidence of sexual abuse in an institution is 2-4 times higher than sexual abuse in a community setting. Kennedy notes a number of factors which may contribute to this tendency: "Isolation from the wider society – which may be created by geographical location and/or inadequate links with family and community...[and] Increased numbers of adult care-givers in a residential, as compared to a family, setting will increase the possibility of one being an abuser" (1996: 127).¹⁷

Another factor which may be influential in determining whether or not people with disabilities "choose" to further their education, and thereby enhance their future potential as workers, is their work-life expectancy. In their discussion of the educational "choices" of women and men, Blau and Ferber emphasize that "distinguishing between supply- and demand-side factors is not as easy as it may at first appear. Labor market discrimination may affect women's economic status *indirectly* by lowering their incentives to invest in themselves and to acquire particular job qualifications" (1986: 140-141). These authors argue that because of the traditional expectations for women to have their primary role in the home, they tend to have fewer years of work experience than men. Women are also likely to be viewed by employers as being less committed than men to their jobs or careers. If there is little return from the working

¹⁷ Kennedy cites: N. Rindfleisch and J. Rabb, 1984, "How Much of a Problem is Resident Mistreatment in Child Welfare Institutions?" in *Child Abuse and Neglect*, 8, pp. 30-40; M.F. Shaughnessy, 1984, "Institutional Child Abuse," in *Children and Youth Services Review*, 6, pp. 311-318.

world on a woman's investment in education (Blau and Ferber, 1986; Gaskell, 1992), women may not see the value in investing extra money and extra years in attaining additional education and training. I argue that although the reasons are different, employers have a tendency to view people with disabilities as being unskilled, or unable to maintain a job commitment long term. Both Vernon (1996) and French (1996) state that the women they had interviewed regarding their educational experiences (respectively, disabled women of an ethnic minority, and women from a segregated school for partially sighted girls) had difficulties upon first entering the job market, and that they related these problems to an inadequate, or poor quality education. If a person who is disabled does not have access to an adequate content, quality and/or quantity of education to ensure them an adequate return in terms of occupational attainment, then they may be unlikely to invest time and money in furthering their education beyond the bare minimum, particularly if they expect their participation in the labour force to be minimal or unrewarding.

While future generations may benefit from some of the changes and improvements in the recognition of the rights of people with disabilities to have equal access to an equal quality, quantity and content of education, many people with disabilities from earlier generations will not. This group will continue to face hardships in terms of having educational credentials which will enhance their employability. As Gould states,

Unemployment is often seen as a factor affecting the increase in the number of disability pensions...But even if the pension system is disregarded, there is a direct relationship between unemployment and disability in itself. First of all, it can be assumed that persons with impaired health are in a less favourable position to compete for jobs and thus are more likely than others to be overtaken by unemployment. Secondly, the side effects of unemployment may have a direct influence on the deterioration in health and may thus reinforce the disabling process (Gould, 1981: 70).

Gould also argues that people who have a poor education have fewer choices within the labour market. This in turn restricts a person's occupational choices, allowing them less flexibility in

terms of changing jobs. If a person becomes unable to perform their present job, but is unable to find a job which is less physically demanding, they become handicapped, and potentially unable to work at all.

We must recognize that there is a hidden power structure behind attempts to form legislation addressing educational equality. As Gooding states, a shortage of government resources ensures that legislation reflects "the language, hierarchy and politics of professionalism" (1994: 141). Just as the workplace creates a social distinction between those who are able-bodied and those who have a disability, so too does the school system.

Needs Based Approach

So far I have discussed the disability-work relationship from a political economy perspective, analysing both the demand and supply side of labour. I now address this relationship from a needs based approach. If we combine elements of these two schools of thought we emerge with a clearer understanding of the ways in which a negative image of disability is constructed through the institutions of school and work, and the choices people with disabilities perceive as being open to them. Primary emphasis in what follows is based on the personal and financial needs of people with disabilities in the workplace. Are these needs met in today's market to the extent that the person with a disability will choose to be employed, rather than choosing to exist on welfare?

Krahn and Lowe argue that a person is less likely to be satisfied with her or his job, unless the job contains some components of personal growth and development. "[A] worker whose job is dissatisfying may adopt work values that challenge or contradict the dominant work ideology" (1993: 314). For the person with a disability, contradicting "the dominant work ideology" may mean choosing welfare over employment. The desire for personal rewards from

work are experienced by both able-bodied and disabled workers, with the only difference being that people with disabilities tend to be (a) segregated in low-skilled, low paying jobs, and (b) discriminated against such that they are considered by many employers as capable of holding only low skill, low demand jobs, or in some cases, are considered to be incapable of working at all. In spite of these prejudices however, not only work, but personally and financially *rewarding* work is a necessity for people with disabilities.

Employment is the means to life. It enables our physical survival as well as being a key determinant of our sense of mental well-being. As we enter adulthood, work is a crucial means of gaining emotional and economic independence. This is no different for disabled people; in fact, work may be particularly important as a way of offsetting disabling attitudes and situations which undermine self-esteem and hamper our independence (Vernon, 1996: 53).

In addition to enhancing self-esteem and promoting independence, what we do in our work-life is commonly used as a means "of determining our social status" (Vernon, 1996: 54). If an individual, or a particular group of people tend to be relegated to low-skilled jobs, they may be more likely to be evaluated both by themselves and others as having low social status or low ability. Having their access limited to primarily low-skilled jobs, people with disabilities are also more likely to *be* poor, and therefore, "lower class." The lack of available opportunities, the physical difficulties inherent in working, combined with the potentially unrewarding nature of jobs for which people with disabilities are considered capable may provide serious *disincentives* for people to choose employment over unemployment. In addition, "there are very real systemic reasons why it is more economically feasible to stay on social assistance than to work, if you have to bear the cost of a disability...When a person gets a job, they [sic] face the prospect of paying for attendant care, transportation, housing, and medical equipment and supplies on their own" (McMurchy & Tubbe, 1996: 28; see also The Roeher Institute, 1988, 1994). In order to prevent handicap, the social consequence of disability,

[t]he conditions that limit disability, such as education, humanised work places and meaningful employment must be recognised for their preventive as well as curative value. Greater attention to balance of work demands and working capacity can limit the frustrations that contribute to disability¹⁸, as well as enhance an individual's overall productivity (Gould, 1981: 76).

Providing quality education and meaningful employment however, are not in themselves enough to prevent handicap. The financial needs of people with disabilities must also be taken into consideration, as "Impairment and illness often bring unemployment and reduced earning power" (Keith & Morris, 1996: 99-100). Gadacz argues that

Disabled citizens rightly point out that they find themselves in a position of double jeopardy. On the one hand, because of existing barriers to full participation in economic life, it is virtually impossible for the majority of disabled persons to find fulfilling remunerative employment. On the other hand, low levels of social assistance that are designed to encourage re-entry into the work force actually works to prevent re-entry (1994: 269).

Low rates of social assistance, Gadacz argues, only serve to keep people with disabilities out of the labour force, because benefits are not sufficient to allow participation in the full spectrum of life, including gainful employment. In a Canada Pension Plan Consultation Panel Brief, the BC Coalition of People with Disabilities states (1996b: 3) that under present regulations, people with disabilities are allowed to "keep \$200 plus 25% of their earnings before deductions are made. There are no exemptions for unearned income which is taken dollar for dollar off the recipient's monthly cheque."

In 1994, the Minister of Human Resources Development of the Government of Canada released a supplementary paper titled, *Improving Social Security in Canada*. In this document (p. 10), the primary barriers to training and employment are listed as:

- assessment, counselling and training facilities that are inaccessible or exclude people with disabilities;

¹⁸ The term "disability" is used by Gould in the way that I am using the term "handicap." In this case, it refers to the social consequences of an imbalance between an individual's physical capacity and the societal expectations for that person.

- lack of information, especially in alternate formats, about training and employment programs;
- inadequate support services (particularly personal support services which are ongoing, job coaches, attendant care, interpreters, readers);
- job training and retraining tied to eligibility for unemployment insurance benefits, which effectively excludes people with disabilities without previous insurable earnings;
- absence of remedial programs that provide upgrading to become eligible for training programs;
- screening mechanisms such as criteria that require people to be independently employable after a maximum of three years of training; and
- reduced funding of outreach employment programs that the disability community feels have provided positive results in the past.

Without such supports, people with disabilities may find it impossible to meet the demands of self-sufficiency and productivity that Canadian society places upon its citizens (Bach & Rioux, 1996). If s/he does not have equal access to the labour market, or to an equal quantity, quality or content of education, if s/he cannot find a job which is personally rewarding, and which covers the extra costs associated with a disability, why should a person who has a disability choose to work? The negative way in which this person is perceived in society limits the choices open to her/him to such an extent that the only “rational” choice may be unemployment and reliance on welfare; it may mean s/he must choose illness, or disability as her/his career.

Conclusions

When we combine the political economy and human needs perspectives, we begin to understand the complex relationship between disability, education and work, and how this relationship contributes to the development of an illness career. Returning to Figure 2.2, we see that the individual attribute of disability influences occupational attainment *directly*, as a result

of systemic physical and social barriers in the workplace, and also *indirectly*, by limiting access to an equal content, quantity and quality of education. Further, the personal and financial needs of a person with a disability are frequently left unmet in today's marketplace, leading both to *disincentives* for a person with a disability to work, as well as a *negative* self-identity for being unable to support her or himself. By limiting the options which are available, the institutions of work and school, like that of medicine, go a long way towards constructing an image of disability that is negative.

In order to change the negative image of disability, we must eliminate the discrimination people with disabilities face. By changing the avenues of government spending, by enforcing the mandates of affirmative action and building code legislations, by providing integrated educational settings, by profiling and providing role models of people with disabilities, by providing employment opportunities which are both personally and financially rewarding, we can educate able-bodied and disabled people alike that people with disabilities are very capable citizens, worthy of, and desiring to contribute both personally and economically to society.

Chapter 3

The Surveillance of Disability in the Welfare State



If I don't keep going to school I'm not sure what I'll do. I doubt very much whether I will be physically capable of taking a full-time job, even by next September. I really do not want to be on welfare!...It's hard not to feel hopeless sometimes in this day and age. I very much fear becoming too poor to exist, especially with my severe physical limitations.

— Personal Journal, January 1996 —

In this chapter I outline some of the basic tenets of the welfare state. It is not my intention to provide a catalogue of available welfare programs and benefits, as this is adequately done elsewhere (see for example, Roeher Institute, 1995). I focus instead on the nature of these programs, how they interface with the population of people with disabilities, and whether the needs of this group are actually met. As in Chapters 1 and 2, the issue of power is crucial in understanding the social construction of disability in the welfare state: Will the dissolution of the Canada Assistance Plan (CAP) and the formation of the new Canadian Health and Social Transfer (CHST) block funding program lead to the end of the welfare state, or to its radical reform? Following the discussion of welfare in Canada, I draw a theoretical model based on Foucault's theory of power/knowledge. This model illustrates both the positive and the negative sides of the relationship between welfare and disability in a medicalized society.

Habermas argues that labour power, production, and wages are no longer the defining forces of modern social reality. He states that "[t]he development of the welfare state has reached an impasse. With it, the energies of the utopian idea of a laboring society have exhausted themselves" (1989: 296).

Since World War II, all the governing parties in the Western countries have won their majorities more or less explicitly under the banner of welfare state objectives. Since the middle of the 1970s, however, awareness of the limitations of the welfare state project has been growing without as yet a clear alternative in

view. Thus [he says,] I will formulate my thesis as follows: *the new obscurity is part of a situation in which a welfare-state program that continues to be nourished by a utopia of social labor is losing its power to project future possibilities for a collectively better and less threatened way of life* (Habermas, 1989: 288, my emphasis).

The utopian ideals in the welfare state project are the emancipation of people from alienating labour, and the development of a decent standard of living. The reform of conditions of employment remains crucial not only for humanizing labour, but also for deciding on “compensatory measures designed to assume the burden of the fundamental risks of wage labor (accident, illness, loss of employment, lack of provision for old age)” (ibid.: 289). In order for such a system to work, society must exist in a state of full employment. In other words, it is necessary that all those who are able to work must do so. The welfare state represents state intervention in a bargain which has been struck between capital and labour, designed to serve the needs of both (see Guest, 1985). Thus, we can see how the stage becomes set for the deviant, or non-worker: s/he may not be perceived as having any “right” to welfare benefits, because s/he does not contribute to the economic system, as in the contrast between the “deserving” and “undeserving” poor. As the economic crisis of the present day lengthens and deepens, the distinction between worker and non-worker becomes stronger and clearer.

Fraser states that we must rethink notions of the welfare state, focusing on “*the politics of need interpretation*,” rather than simply addressing “the distribution of satisfactions” (1989: 163). She argues that we must develop a model of social discourse which would provide a “sociocultural means of interpretation and communication,” (MIC) (1989: 164-65). This will provide a perspective in which

needs talk appears as a site of struggle where groups with unequal discursive (and nondiscursive) resources compete to establish as hegemonic their respective interpretations of legitimate social needs. Dominant groups articulate need interpretations intended to exclude, defuse, and/or co-opt counter interpretations. Subordinate or oppositional groups, on the other hand, articulate need

interpretations intended to challenge, displace, and/or modify dominant ones. In neither case are the interpretations simple "representations." In both cases, rather, they are acts and interventions (Fraser, 1989: 166).

Fraser argues that we must arrive at a system of interpersonal communication which includes the voices of both dominant and subordinate group members if we are to be able hear, and understand as legitimate, competing claims of social need. The present system caters only to the needs of the dominant group; and leaves us no way to adequately interpret the needs of subordinate, or oppositional group members. Developing such a system of communication may help to politicize issues and needs which are currently overlooked, or underestimated in the Canadian welfare system, in which "the poor rely on the state, and the remainder on the market" (Esping-Anderson, 1989: 24).

In his historical analysis of the development of social security in Canada, Guest elaborates on the impact of the British North America Act on the development of Canada's social welfare system. He points out that "[w]ithin this framework of order provided by public authority, individuals were expected to work out their own destiny unrestrained and unassisted by governments" (1980: 6-7)¹⁹. Bach and Rioux also discuss the importance of this notion of self-reliance in determining citizenship. "While the notion of citizenship as a broad set of social, economic and political entitlements was being formulated in this period,²⁰ the figure of the 'citizen' that remained entrenched was that of the self-made, rational and independent individual exercising basic democratic and legal rights" (1996: 318). Self-reliance and independence appear to be intrinsic to obtaining personal social value and legal rights. Social welfare policies were developed for those who were unable either to attain or maintain this standard of self-

¹⁹ Guest quotes the Report of the Royal Commission on Dominion-Provincial Relations, Book 1, Canada:1867-1939 (Ottawa, 1940):37.

²⁰ Bach and Rioux quote T.H. Marshall, 1963, "Citizenship and Social Class," *Sociology at the Crossroads and Other Essays*, London: Heinemann.

sufficiency.

In the twentieth century there was a growing recognition in Canada that all Canadians were not able to support themselves all of the time. Periodic social and economic instability could threaten both the continuity and adequacy of income, leading to the need for a social support structure. Prior to World War II, social welfare policies were “residual,” and based on a charity model; help was not perceived as a social right. Help was minimal and temporary, and those applying for assistance had to prove they had already exhausted all other means of support before they would be granted aid by the welfare agency. Receiving assistance under residual policies was demeaning and stigmatizing because failure to support oneself was seen as a sign of incompetence and failure (Guest, 1985), rather than as a result of market fluctuations or times of personal trouble.

“Institutional” welfare policies emerged with the Second World War, along with some tolerance for those in receipt of social support. World War II created a unique situation in the Canadian economy; provincial coffers which had been emptied by the recession and the need for public relief became full as the war led to increased financial security and economic productivity (Guest, 1985). The federal government also gained in power during World War II, and, copying the British model, adopted the notion “that social services were not a luxury to be dispensed with in a time of more pressing need but were a vital element in the smooth functioning of the wartime economy” (Guest, 1985: 105). Although the major developments at this time included unemployment insurance and family allowances (Guest, 1985), other benefits were not far behind. Following the close of the war, the Canadian welfare state began to develop along institutional lines. Under the institutional concept, welfare policies were considered to be a social right: it was recognized that adversity could affect any member of society. The notion

“that hard work, thrift, and foresight are virtues likely to be found wanting in the poor and dependent” (Guest, 1980:205) was challenged. In spite of a shift to greater tolerance however, insecurity within the Canadian economy has caused many of the negative residual implications not only to remain associated with the receipt of welfare benefits (Guest, 1985; Pulkingham & Ternowetsky, 1996), but also to increase since the announcement of the 1995 Canadian federal budget. This budget marked the reduction of federal funds available for welfare programs (Bach & Rioux, 1996; National Council of Welfare, 1995).

The Canada Assistance Plan (CAP) was enacted in 1966, and marked an era in which the federal government was committed to sharing with the provinces and territories “50 percent of eligible costs incurred by the provinces and municipalities in providing financial assistance to persons in need; and 50 percent of eligible provincial and municipal costs of providing welfare services to persons who are in need or are likely to become in need if such services are not provided” (CAP, 1991-92: 7). The federal contributions under CAP continued according to the original 50-50 sharing terms “until 1990, when the federal budget speech announced a “cap on CAP” in the three wealthiest provinces: Ontario, Alberta and British Columbia” (National Council of Welfare, 1995: 6). This cap on expenditures arose as a result of the *Government Expenditures Restraint Act*, under which the maximum rate federal transfer payments could increase was 5 percent per year. Originally this cap was to last for two years only, but under *An Act to amend the Canada Assistance Plan* it was extended until 1995 (CAP, 1991-92: 7).

The announcement of the 1995 federal budget marked a new era in federal contributions to welfare expenditure. It was announced that the Canada Assistance Plan would be repealed as of April 1, 1996, and in its place would be the Canada Health and Social Transfer block funding program (National Council of Welfare, 1995; Bach & Rioux, 1996; Pulkingam & Ternowetsky,

1996; Battle & Torjman, 1996; Silver, 1996). In addition to replacing the CAP, the CHST was also to replace the Established Program Funding, under which provinces and territories had previously received transfer payments for health and post-secondary education (Battle & Torjman, 1996). Silver notes that "Given that a nation's budget is the economic expression of collective values and shared commitments, this budget represents the symbolic and substantive retreat of the federal government's commitment to social programs" (1996: 67). The introduction of the CHST in 1996-97 has several important consequences. The first is that funding levels, measured as a ratio of Gross Domestic Product, are reduced to the levels used in 1950-51 (Silver, 1996;). The second major change is a restructuring of policy through which the federal government has ensured national standards (Silver, 1996;). Not only have funds been reduced under the new CHST, but because this is a *block* funding program, the federal government is no longer involved in deciding the allocation of funds (Silver, 1996; Battle & Torjman, 1996;); with block funding the discretionary power of allocation is left to the provinces and territories. A further consequence pointed out by Battle and Torjman is that

The loss of CAP also means the loss of built-in countercyclical protection, which has been an important economic policy objective of the federal government. When provincial costs rise in the face of higher welfare caseloads that result from recession, [under CAP] federal costs increase as well...In the next recession, provinces will have to cope with the pressures of rising caseloads entirely on their own; there will be no federal offset to compensate higher costs (1996: 58).

It is precisely because welfare expenditures are so unstable compared to those of health and education that two separate funding systems were originally established (Battle & Torjman, 1996; National Council of Welfare, 1995). The National Council of Welfare (1995: 15) illustrates the difference in federal transfer payments which would have existed had the CAP always been funded under a *fixed* transfer payment, similar to that received by the Established Program Funding (EPF) rather than a cost *sharing* program. Table 3.1 illustrates these

differences.

Table 3.1: Cost Sharing vs. Block Funding for Welfare and Social Services (in Billions of Dollars) *

Fiscal Year	Actual Increase in EPF (%)	Actual Federal Spending on CAP (\$)	Federal Spending Using EPF Formula (\$)	Loss to CAP Using EPF Formula (\$)
1977-78	---	1.562	1.562	0
1978-79	14.5	1.684	1.788	0.014
1979-80	14.1	1.895	1.788	-0.145
1980-81	12.6	2.220	2.040	-0.078
1981-82	12.6	2.585	2.587	-0.002
1982-83	12.3	3.234	2.906	0.328
1983-84	9.4	3.682	3.181	0.501
1984-85	7.4	3.973	3.415	0.558
1985-86	7.6	4.291	3.675	0.615
1986-87	6.6	4.519	3.917	0.603
1987-88	5.8	4.862	4.142	0.720
1988-89	5.8	5.300	4.380	0.920
1989-90	6.5	5.765	4.665	1.100
1990-91	1.6	6.221	4.741	1.480
1991-92	2.0	6.780	4.837	1.943
1992-93	1.5	7.339	4.909	2.431
1993-94	1.4	7.719	4.978	2.742
1994-95	1.1	7.952	5.034	2.918
1995-96	1.2	7.952	5.094	2.858
Totals	226.1 %	\$ 89.535	\$ 70.145	\$ 19.389

* Reproduced from the National Council of Welfare, 1995: 15.

The first Column of Table...[3.1] shows the actual escalation of federal support for Medicare and post-secondary education in percentage terms from the 1978-79 fiscal year through 1995-96. The second column is actual federal spending on CAP under cost-sharing. The third column estimates what the federal share of CAP would have been if Ottawa had adopted block funding using the same formula as EPF. The last column shows the loss of federal funds for CAP that would have occurred if the EPF formula had been used instead of cost-sharing (National Council of Welfare, 1995: 14).

Although initial losses to the provinces and territories would have been small if the CAP had always been funded according to the EPF formula, these losses would have begun to increase dramatically through the 1980s and 1990s. In 1995-96, this loss would have been close to three

billion dollars, and would have totalled over nineteen billion dollars between 1977-1996. Table 3.1 also allows us to examine (a) the decrease in the percentage rate at which EPF funding was provided by the federal government, and (b) the actual dollar figures which were the federal contribution to the CAP. If we divide Table 3.1 into five year periods, we see that between 1980-81 and 1984-85, EPF funding increased by 54%. Between 1985-86 and 1989-90, funding increased by 32%, and between 1990-91 and 1994-95 EPF funding rose by less than 8%. These numbers mark an astonishing decrease in the federal contribution to transfer payments received by the provinces for health and post-secondary education. If we turn to column 2, and examine the actual federal spending on the CAP over the same 5 year periods, we see that between 1980-81 and 1984-85 the federal contribution rose 1.753 billion dollars. Between 1985-86 and 1989-90 funding increased by 1.474 billion dollars, and increased another 1.731 billion dollars between 1990-91 and 1994-95. Although these figures show as increases in terms of current dollar values, if we take into consideration the consumer price index over this same period, we see that in constant dollars federal contributions have actually decreased (see Battle & Torjman, 1996). Battle and Torjman predict that federal transfer payments may actually cease altogether as early as 2005-06. This will leave provinces and territories with sole responsibility for funding health, welfare and post-secondary education, a situation which will likely increase the huge regional disparities which already exist in Canada.

In spite of present day attempts on the part of people with disabilities to ascertain their *right* to support, the Canadian welfare state was premised on English Poor Laws, and therefore, like the British system, remains based on the notion of charity rather than rights (Guest, 1985; Bach & Rioux, 1996). According to the charity model, two categories of dependence may be established: the "worthy" and the "unworthy" poor, or, as such welfare recipients are also called,

the “deserving” and the “undeserving”. “The deserving were those who through no fault of their own, either by birth, or accident, or disaster, were not able to care for themselves either temporarily or permanently.” The undeserving, on the other hand, “were considered to be lazy, irresponsible, improvident, and indeed evil members of society and were thus not deserving of help. To help such persons was viewed as unfair and unjust and contributing to further indolence” (Turner, 1986:3). Despite the fact that they are “deserving,” people with disabilities frequently experience anxiety and guilt over their reliance not only on family members, but also on the social support system (Locker, 1983:176).

Some disability activists advocate that there should be a separate welfare system for people who have disabilities. The cross-disability committee Ad Hoc ‘95²¹ argues that “the general welfare system is not designed for people with disabilities. Its purpose is to provide assistance for individuals or families who are *temporarily* in need” (Ad Hoc ‘95, 1995: 5, my emphasis). They contrast this to the need experienced by people with disabilities which is *ongoing*, and which also entails the need for “assistance to cover the additional costs of disability such as personal and technical supports, transportation and housing expenses, medication, therapy, and developmental needs” (ibid.). A separate system, following this argument, should not differentiate between those who are “more worthy” and those who are “less worthy,” but will provide support which better meets the needs of people with disabilities, support which will also receive greater protection in this era of federal cuts to social expenditures (BC Coalition of People with Disabilities, 1996c: 5-7). The opposing view is that a separate welfare system cannot help but create a division between those who are “worthy” and those who are not, a division which can have negative implications for both. Bach and Rioux

²¹ This group consists of representatives of the BC Association for Community Living, the BC Coalition of People With Disabilities and the Canadian Mental Health Association, BC Division.

argue that "The category of 'worthy poor'...has become a double-and triple-edged sword for people with disabilities...Considered incompetent to function in society, this being the ticket to becoming 'worthy,' the welfare state established systems of segregation for people with disabilities. These systems segregated them from their families, educational institutions, labour markets, political participation, from the exercise of rights of self-determination and from their communities" (1996: 318).

My own beliefs lie in the second camp: I do not see how the formation of a separate welfare system can possibly avoid the distinction between those who are more or less "worthy." This distinction is very important, because it returns us to the notion of residual welfare policies, under which receipt of welfare is seen not as a right, but as a mark of personal and social failure. Further, by distinguishing between those who are "worthy" or "unworthy," "abled" or "disabled," we must make clear the differences *between* the groups. Therefore, in order to guarantee their right to support, particularly in an era of such radical cutbacks in social welfare expenditure, people with disabilities *must be different*. They must look, act and behave differently. In order to fit into preconceived categories of need and disability, people with disabilities may have to sabotage their own appearance, their own capabilities. Whether this is done in fear of the loss of benefits, or is the result of actual limitations, the end result is the same: the picture of people with disabilities is of a special group, limited in productivity and independence. By forming a separate welfare system for people who have disabilities I argue that we formalize the negative image of disability received by society, and internalized by the person with the disability. We also develop a two tiered system, one arm of which serves the "worthy" person with a disability; the other arm dedicated to the "unworthy" poor.

In spite of their categorization as "deserving," or "worthy," people with disabilities still

live according to the dominant social values: they must be responsible for themselves. Any failure to do so results in personal feelings of guilt and stigmatization. As one woman who attended a school for the partially sighted stated, "as long as you can earn your living, have a nice home, and be independent then your life is not a failure" (French, 1996: 46). On the other hand, people with disabilities are frequently encouraged, both directly and indirectly, to be dependent: doctors frequently advise prolonged, and sometimes permanent rest; social welfare policies are grossly inadequate in terms of providing for rehabilitation, or the erection of facilities (both in the figurative and the physical sense) that would allow the individual to gain some degree of financial, social, and personal independence. A strong emphasis on independence, and on individual responsibility in Western society is the source of much of the guilt that people with disabilities face. They too, are subject to many of the same pressures that those who are poor face: Why aren't you working? Why can't you support yourself? However, the needs of disabled workers are frequently overlooked. Although social class, age, and disability will sometimes overlap, the case of the person with a disability is arguably different: many people who have a disability have never been able to work, and others are forced into long periods of absence from the labour force, or early retirement; many are excluded from employment because they have a disability. This separation from the workforce, whether temporary or permanent, is usually involuntary, and changes the relationship that people with disabilities have with the market system.

The relationship between the Canadian social welfare system and people with disabilities is a problematic one. In a study on Canadian Workers' Compensation from 1914-1984, Doran notes that Workers' Compensation developed a system of codification such that "[w]orkers must describe their injuries for the board, but in terms which have already been preformed by the

board such that description itself constitutes a disciplinary technique" (1994:453). Drawing on the work of Foucault, Doran argues that Worker's Compensation is subjected to disciplinary procedures which limit an individual's ability to describe her/his own illness/injury in her/his own terms, providing instead, a general scheme of codification. This type of codification minimizes the ability of the individual to explain the "disruptive experience" (see Bury, 1982) of illness or injury in terms which have relevance to their own lives. The ordinary, everyday language which is used by those who are ill or disabled is transformed by state agencies into a formal language (see Figure 3.1). Anyone whose descriptions do not conform to these formal definitions, may be in danger of being denied aid. This is particularly problematic when social policies are not updated to meet the changing needs of people with disabilities, or the changing nature of disability.

Most welfare policies applying to people with disabilities have not changed significantly enough to match the changing nature of disability in the population. "Thus policies are still developed in relation to the idea that the disabled are mainly young people in wheelchairs. The ages of impaired persons...show how inappropriate this idea is when we look at the community as a whole." (Bury, 1979:39). There is a problematic relationship set up whereby the very institutions that are supposed to help people with disabilities, actually hinder them: the categories defined by medical and welfare agencies are not reflective of real people. Ursel (1992:346-347, 351, 360-361) provides numerous examples of Canadian welfare policies as they pertain to people with disabilities. It is interesting to note that many of these policies were originally created for "deserving" war veterans (and their families), who had become disabled in the service of their country. It was much later that these policies began to include individuals whose disabilities arose from other sources. In his review entitled *Personal Social Services for*

the Handicapped, Hepworth (1977:9) discusses the limited nature of a number of these policies.

The federal legislation for health care, for pensions, and for housing has provided some of the underpinnings for a basic system of support for the handicapped. The legislation has not, however, been very specifically oriented to the needs of the handicapped, and some of its basic deficiencies are further highlighted when the needs of the handicapped for personal social services are considered.

Despite the fact that they are considered "deserving," people with disabilities frequently experience anxiety and guilt over their reliance not only on family members, but also on the social support system. In his study of individuals with rheumatoid arthritis, Locker quotes one of his respondents as saying the following about her dependence on welfare:

Everything you get you feel like a beggar, it's terrible. This woman came to see me to do something about clothing and I said 'I'd like some shoes'...and she said "If you're housebound you don't need any shoes." I said 'Come on, I don't know what other people do but I don't slop around in slippers,' there again, it's like a rebuff you see, then you don't feel like going again which maybe is the idea, I don't know. You already feel awkward to ask for anything and then when you do they damned make a remark like that. You don't feel like going again (1983:176).

The actual validity of the disability in the eyes of social service workers often seems to be in doubt, especially in situations where the symptoms are felt primarily as pain, a phenomenon invisible to the observer (Locker, 1983). Locker illustrates at some length the difficulties people with rheumatoid arthritis face when dealing with the social welfare system. He concludes that

It is clear that existing provision falls far short of its goal of meeting the needs of those it aims to help; the categories with which the system operates do not match the needs of those to whom they are applied, provision is fundamentally unjust creating artificial divisions between people with the same needs and, in some respects, it perpetuates the disadvantage of those who have little choice but to rely on it for help (1983:167).

As an example, he notes the case of one respondent in his study who was offered, by the British department of social welfare, a fifth floor apartment in which she had to descend seven steps in order to reach the living space. "When Mrs. W pointed out that she was confined to a wheelchair, the reply was, 'Can't you get out of it while somebody carries it down for

you?””(1983:174). Not only does this example illustrate a lack of understanding of the situation/limitations of the person in question, but it also shows the assumption made by the welfare agency that “Mrs. W” would have someone at home to help her. Due to severe limitations in funding, many welfare policies presume the availability of help from family or friends, thereby increasing the dependency of the person with a disability, who may not have the financial resources for independence.

I argue that as with worker’s compensation, the definitions and categories set up within social welfare policies go a long way towards mediating the behaviour, choices, and adjustment strategies of people disabled by chronic illness, accident or disease. In her study of people with multiple sclerosis, Susan Russell notes that

[p]revious sociological and social-psychological research on the chronic illness multiple sclerosis (MS) and post-diagnosis adjustment to the illness has posited a dichotomous patient response: ‘normalization’ or ‘withdrawal’...[T]he posited choice of strategies *ignores the social factors* that influence how individuals diagnosed with a chronic illness such as MS respond. In fact, the research findings indicate that people with MS choose adjustment strategies, but they do so *in a social and cultural context that powerfully constrains both the range of choices available to them and the probability of making one choice rather than another* (1989:276, my emphasis).

The present day welfare system is premised on the problematic notion that illness is a temporary phenomenon in our society – one that can be erased with adequate medical and social intervention (Guest, 1985; Turner, 1987; Illich, 1976). In reality however, some portion of the population will always be *relatively* less-abled, differently abled, disabled. We must overcome the belief that we can eliminate this group with temporary aid or policy plans, such as those developed for war veterans after World War II. “Disability” is here to stay, and the most positive way to address this phenomenon is to come up with long term, permanent solutions. We must change the way illness and disability are perceived in society. It is only in this way that we can

end the marginalization of the person with a disability, and allow her/him options beyond that of an illness career. In the next section I use Foucault's theory of power/knowledge to further explore the surveillance of people with disabilities in the welfare state.

Power/Knowledge: The Role of Welfare in Perpetuating Disability as Dependence

In this section I use Foucault's theory of power/knowledge as research a tool in order to formulate a theoretical perspective regarding the relationship between a medicalized welfare state, and disability. A theoretical model is developed which illustrates the positive and negative aspects experienced by the person with disabilities as s/he interacts with the social welfare system. Many ill or disabled Canadians rely on the welfare state for survival. However, this powerful institution, in conjunction with the medical profession, also helps to construct the identity of people with disabilities as "others" who occupy a marginal position on the edge of society, leaving them little alternative but to develop illness as their career. I argue that both medical and welfare institutions contribute to the creation of a negative and dependent self-identity for the person with a disability. Cutbacks in health care coverage and welfare benefits have had, and will increasingly have a severe impact on this group, perhaps increasing their dependence on the state as the level of aid they receive becomes less and less adequate, and meets fewer and fewer of their needs (Gadacz, 1994).

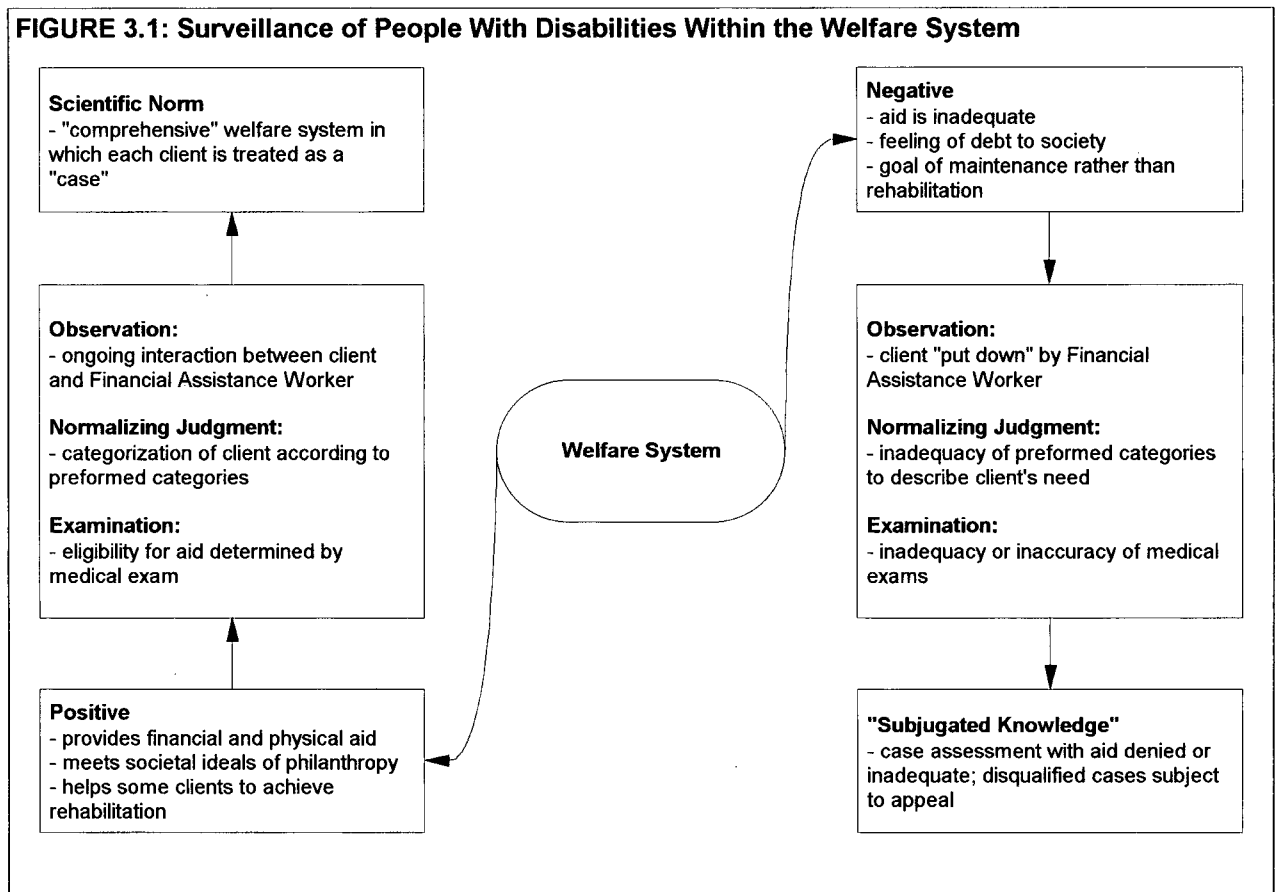
Following Foucault, I argue that the power of a scientific medical discipline (the medicalized society) is enforced by and in turn influences the welfare system through hierarchical observation, normalizing judgment, and the examination (see Figure 3.1). Power is exercised and justified first of all by hierarchical observation. The major principle of

hierarchical observation is that those being observed must be made visible, whereas those observing remain relatively obscured or hidden. Bentham's Panopticon, discussed in *Discipline and Punish*, provides for Foucault the perfect example of the disciplinary gaze: it "makes it possible for a single gaze to see everything constantly" (1965: 173), while those being watched are never quite sure whether they are under observation or not. This gaze is hierarchical, in that the watchers are themselves being watched by their own superiors. At each level, individuals are subject to a supervisory, regulating gaze. Because any deviance is greeted by punishment or stigmatization, those observed *internalize* the behaviours required by those in charge, and they begin to police themselves, behaving as they are expected to. For the person with a disability, this means that s/he is likely to internalize the rules and definitions set out by medical experts and welfare policy makers, rules into which s/he has had little or no input. Therefore, if s/he is treated in a negative way, s/he is likely to internalize this identity, or if told s/he does not qualify for welfare, s/he may be unlikely to object. This could have two possible consequences: (a) it could lead to increased dependency on the welfare state, as it provides disincentives for people with disabilities to work (The Roeher Institute, 1988, 1994; National Council of Welfare, 1995; McMurchy & Tubbe, 1996); and (b) it could also lead to stigmatization for the person with a disability, as her/his status as disabled may be questioned or denied, impacting upon her/his receipt of benefits, and causing her/him to doubt her/his own right to help (Locker, 1983). In other words through hierarchical observation, the person with a disability is identified as seriously departing from the "norm," as this norm has been constructed within the medical and welfare institutions.

Departing from expected norms may have serious consequences. Through the normalizing judgments of professional authorities, individuals are compared to one another, and

expectations are established which must be met. Normalization "individualizes by making it possible to measure gaps, to determine levels, to fix specialties and to render the differences useful by fitting them one to another. It is easy to understand how the power of the norm functions within a system of formal equality, since within a homogeneity that is the rule, the norm introduces, as a useful imperative and as a result of measurement, all the shading of individual differences" (Foucault, 1977:184). Through normalizing judgments categories of comparison are constructed by which the person with a disability is measured. As discussed in Chapter 1, this process of categorization, or codification, begins with the experiences of the individual which are worked up to form general categories. The ultimate goal of codification is a general model which will explain the experiences of *all* individuals. What results in the end however, is not a complete knowledge based on the experiences of real people; it is a knowledge based on *other people's interpretations* of these experiences, and their categorization into manageable forms (see Figure 3.1). On the positive side, people who meet the requirements as laid out in these normalizing judgments, or general categories do receive aid. The negative consequence of this codification for the person with a disability, is that these "general" categories may not fit her/his circumstances. If this is the case, s/he may be denied welfare, or given insufficient help to meet her/his real needs. A further danger may arise when categories are changed, based not on the experiences of people themselves, but because of the desire of government agencies to cut social expenditures. Thus, a person who is one day categorized as disabled and entitled to certain forms of help, may the next day no longer be "disabled," and no longer be able to get that help.

FIGURE 3.1: Surveillance of People With Disabilities Within the Welfare System



In order to qualify for help, the disabled person must undergo a medical examination, the third form of surveillance in the power/knowledge model. The examination is the culmination of “the techniques of an observing hierarchy and those of a normalizing judgment. It is a normalizing gaze, a surveillance that makes it possible to qualify, to classify and to punish [or reward]” (Foucault, 1977: 184). There are three major techniques by which the examination facilitates the judgment and comparison of individuals. The first is the process by which the exam makes the individual visible: one is measured and compared according to standardized criteria. Secondly, “The examination also introduces individuality into the field of documentation” (ibid.: 187, original text in italics). This leads to the development of “a system of intense registration and of documentary accumulation” (ibid.: 189). Embedded in the rules of the welfare system are “qualifications” each applicant must meet in order to be assessed as

disabled and eligible for aid (see Chapter 1). Each applicant undergoes examination by a physician; the results are compiled and compared with the required list. Only those people whose medical condition meets the categories which have been pre-established by the welfare institutions will receive aid. Finally, the knowledge which is gained about each individual is used to construct a "*case*: a case which at one and the same time constitutes an object for a branch of knowledge and a hold for a branch of power" (ibid.: 191). When applying for welfare, one must surrender the most intimate details of one's life to the welfare agency. The process by which policies are set, and aid is granted or denied is kept secret from the applicant (see Bach & Rioux, 1996). On the positive side, the doctor, after examining her/his patient, may decide that this person meets the criteria to receive welfare. On the negative side, aid may be denied. Whether aid is denied because the medical tests or the categories of disability are inadequate is irrelevant at the most practical level, the level of human need.

Hierarchical observation, normalizing judgment, and the examination are techniques designed to ensure that individuals internalize the dominant norms, or challenge them only in fear of punishment or stigmatization. If we examine the ultimate ends of the positive and negative sides of Figure 3.1, we see that both sides rely on an institution of surveillance, and neither end is really all that good for those seeking benefits. Positively, people fit in with the categories of the social and scientific norms; they receive benefits which leave them far below the poverty line (The Roeher Institute, 1988). On the negative side, a person with a disability who does not conform to these norms is denied aid, and must appeal. However, with the dissolution of the Canada Assistance Plan in 1996, and the removal of the national standards guaranteed under its policies, the federal government can no longer force each province to retain the right of appeal for welfare recipients (National Council of Welfare, 1995). If a person with a

disability is denied aid by the welfare institution, and has no right to appeal, then s/he will be truly stigmatized and "punished."

Fraser states that "the welfare system works by linking together a series of juridical, administrative, and therapeutic procedures" (1989:154). The individual is assessed and categorized according to medical terms. S/he then has her/his needs defined by the state. These needs become formalized in terms of legal definitions. What results from this is a system in which political (welfare) policy is executed "in a way that appears nonpolitical and tends to be depoliticizing" (ibid.). It is difficult for people with disabilities to organize and combat such a system, as many have deeply internalized an "inferior" status. In order to challenge the Canadian social welfare system, people with disabilities *must* organize, speak for themselves, and redefine their lives and needs according to their own experiences. The norms as they are defined by medical and welfare institutions must be criticized and challenged. It is only by doing this that many can hope to avoid the lifelong dependency of an illness career. As academics, we must re-theorize disability from the perspective of people with disabilities themselves, politicizing their everyday experiences in order to recognize the legitimacy of their social needs.

To attain the re-theorization not only of disability, but of all categories of deviant or "subjugated knowledges," we must deconstruct currently existing social definitions and theories; we must reexamine the concept of the scientific norm in all of its totalizing ideologies; we must cast out the notion of stigma, and embrace that of difference. In order to do this we must give people with disabilities the opportunity to speak for themselves, giving political attention to personal experience. Official categories must be broken down and reexamined in order to determine their applicability to people with disabilities today. Most importantly, people with disabilities must come together in order to challenge the alienating medical and welfare

institutions, in order to regain power over their own lives and bodies. The organization of a community, or communities of people with disabilities is crucial to this process (see Gadacz, 1994; Davis, 1995). For too long people with disabilities have remained isolated and powerless, unaware perhaps, that many others share their fate. By grouping together and throwing off the stigmatizing consequences of societal norms, people with disabilities will exercise their collective power and gain a more positive self-identity, redefining what is "normal" may lead to a rethinking of what it means to be a full citizen in our society.

Conclusions

Canadian welfare policy denies and disqualifies the lived reality experienced by people with disabilities, both with respect to the nature of their disabilities, and their personal needs. Policies which may at one time have been adequate, now misrepresent, restrict, and stigmatize people who rely on them as a means of subsistence. People with disabilities historically have had little input into the definitions and categorization of disability, and the policy initiatives affecting them. As a result, people with disabilities are likely to internalize a self-identity which is demeaning and demoralizing. It is only within the past twenty years or so that disability rights activists have begun to organize to protect the rights of people with disabilities, and to defend their need for help and understanding as full citizens.

The Canadian welfare system is based on an ideology of maintaining people with disabilities in their present state, rather than creating initiatives to break down the social barriers which frequently prevent people with disabilities from being able to work.²² This system is self-

²² In the introduction to this thesis I specified the way in which the welfare institution was more than happy to pay me a sustenance benefit for the rest of my life; they were not willing to put up more money, over a shorter term, to allow me to complete a rehabilitative program which my doctors believed would return me to the "employable" status.

perpetuating because it does not make efforts to create a society in which people with disabilities have equal opportunities. Disability is not seen as a permanent problem requiring long term solutions: funds are dedicated to *supporting* people with disabilities on welfare who are unable to work (or unable to find work), rather than to creating permanent structural changes, which would allow this group to become *self-supporting*. This is particularly unfortunate given today's economic climate, in which benefits, even those for the "deserving," are being eroded through stealth (Bach & Rioux, 1996). Wendell notes that "It is in the interest of many providers to define disability narrowly, so that fewer people are seen to be entitled to the benefits they are supposed to provide than if disability were defined more broadly" (1996: 24). By narrowing the categories and definitions of disability, access to help is limited to only a very few. Government and welfare agencies, as well as members of Canadian society, do not have to feel bad, because we are still willing to help (to some degree) all those who are "disabled." What most of us are unaware of, however, is that the operative categories continue to become more and more restrictive, and the actual benefits granted fewer and fewer, thereby reducing the number of people who are able to qualify as disabled and diminishing what help they are entitled to receive.

Chapter 4

The "Official" Picture of Disability in Canada: HALS, 1991



I am still not used to having so much of my life exist only in my head, in the form of thoughts and ideas. It is not that I didn't have ideas before, it's just that the biggest component to me was always my physical self...There is no physicality in my life now. The exercises I do are so minimal, my strength so small. I do not understand who I have become. I cannot form a picture of me in my head.

— Personal Journal, January, 1996 —

In this chapter I evaluate the efforts which have been made on a large scale to present us with an "official" picture of disability in Canada. To date, this research initiative has been quantitative in nature, addressing not individual voices, but population averages; fixed definitions have been used in order to organize people with disabilities into pre-established categories. I discuss the statistics derived from the post-censal survey conducted in 1991 by Statistics Canada, *The Health and Activity Limitations Survey* (HALS). I present a selection of tables from HALS 1991, related to the identification of the Canadian population of people with disabilities, and the relationship of this population to the institutions of education, work and welfare.

The data presented in this chapter do appear to provide support for the theories I have articulated in Chapters 1-3, although some gaps do remain. With reference to Chapter 1, I examine the way disability has been defined in HALS 1991, the reliance of this definition on a medical model, and the limitations of this definition for describing disability as it actually exists in the Canadian population. Regarding the relationship between disability and the institutions of school and work (Chapter 2), HALS 1991 appears to have been based on the traditional theories linking school and work. I examine the figures presented in two ways: barriers to education and

work arise as a *result* of having disabilities, and, school and work are themselves *disabling and restrictive* institutions that lead people with disabilities to begin an illness career. Finally, I turn to an exploration of welfare as the end-point of an illness career. Featured in this section are analyses pertaining to labour force participation and personal income levels. I argue that the presentation of data by Statistics Canada, particularly in the area of personal income, is misleading, making it difficult to interpret the real needs of people who have disabilities. I contrast the personal income data presented by Statistics Canada with a different presentation of the same data by another government body, the Ministry of Human Resources Development.

Throughout this chapter I have striven to interpret the data derived from HALS 1991, and presented by Statistics Canada. It is important to emphasize that I have selected only a portion of the results provided by Statistics Canada, that selection guided by my theoretical arguments in the earlier chapters of this thesis.²³ Statistics Canada too, has made choices about the survey results selected for presentation to the public. Although it is possible to attain the microdata files, the cost of doing so is \$3,000 for the information on adults residing in households, \$1,500 for adults living in health-related institutions, and \$1,000 for children residing in households (Statistics Canada, 1991: 17). Statistics Canada will also prepare tables to requested specifications, but this service also costs money. This essentially limits access to this information to those who can afford it; part of the problem faced by many people with disabilities is a lack of money. Although these limitations are not intended to exclude people from gaining access to the national database on disability, this may be the end result. My intention here is not to underestimate the importance of HALS 1991, or the efforts of Statistics

²³ The survey instrument constructed by Statistics Canada to gather information from adults with disabilities living in households was 53 pages long, and included hundreds of variables. To analyse the entire survey would be a massive undertaking, outside the scope of this thesis.

Canada. On the contrary, my aim is to understand not only the goals which motivated HALS, but also the official means of interpreting disability in Canada. To this end I have endeavoured to describe both positive and negative aspects of HALS 1991 – in some cases this includes a discussion of what has been left out, as well as what has been included.

Health and Activity Limitations Survey (HALS), 1991

Defining Disability

Beginning in 1980 the federal government of Canada began to take a formal interest in issues surrounding disability. The *Special Parliamentary Committee on the Disabled and the Handicapped* “was formed to investigate the needs and concerns of persons with disabilities in Canada” (Statistics Canada, 1991: 2). A report of their findings was submitted to the House of Commons, and a recommendation was made that a national database should be developed through Statistics Canada. In 1986 Statistics Canada launched the first HALS survey, designed to collect data on: “the nature and severity of disabilities; the barriers that persons with disabilities face in household tasks, employment, education, accommodation, transportation, finances, and recreation and lifestyles; the use of and need for assistive devices; and the out-of-pocket expenses related to disability” (Statistics Canada, 1991: 2). The population to be studied was identified through screening questions on the Census of Population, the advantage to this being that census data could also be linked to any information gathered through HALS.

Three separate surveys were used in HALS 1991, one for children under 15 years of age and living in households (outside the scope of this thesis), one for adults aged 15-64 living in households (response rate of 87%), and a final survey for adults living in health related institutions (response rate of 96%). Responses from the probability sample were assigned

weights to reflect the corresponding distribution of people in the Canadian population, and these weights were modified to offset non-response, and discrepancies between the observed population and the target population (Statistics Canada, 1991: 13).

Two questions were used on the 1990 census long form (distributed to every fifth household) to identify the population of people with disabilities:

1. Is this person limited in the kind or amount of activity that he/she can do because of a long-term physical condition, mental condition or health problem:

At home?

- ☐ No, not limited
- ☐ Yes, limited

In other activities, e.g., transportation to or from work, leisure time activities?

- ☐ No, not limited
- ☐ Yes, limited

At school or work?

- ☐ No, not limited
- ☐ Yes, limited
- ☐ Not applicable

2. Does this person have any long-term disabilities or handicaps?

- ☐ No
- ☐ Yes

Results of these questions were used to develop a sample for HALS 1991, which included 35,575 people who answered "yes" to these questions, and 113,275 people who answered "no." The "no" group was selected in order to sample the population who did have a disability, but who answered no to the questions on the census (about 5% of this group did have a disability according to HALS criteria). Of the group who originally identified themselves as having a disability, approximately 20% (7,000) were found *not* to have a disability according to HALS criteria. Does the HALS definition of disability capture the "true" nature of disability in Canada?

HALS 1991 uses the definition of disability derived from the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH). Statistics Canada argues that the model put forward by the ICIDH differs from a purely medical model, in that it "provides a new

framework, which explains and measures the *consequences* of chronic and progressive, or irreversible disorders/diseases. The capability to classify these consequences is most significant, since peoples' ability to perform functions and maintain the social roles expected of them depends to a great extent on the impact of disease or disorder on their lives" (Statistics Canada, 1991: 4). This model is similar to that used by the World Health Organization (see Figure 1.2): disease leads to impairment, which leads to disability, which leads to handicap. Or, impairment may lead directly to handicap; handicap is the social consequence of impairment or disability. HALS focuses specifically on the component of disability and the functional limitations to everyday living that may result from disability. One of the goals of HALS is to determine if an individual is limited in her or his

day to day activities (Activities of Daily Living) because of a condition or health problem which has lasted or is expected to last six months or longer. The respondents are asked to indicate whether they have problems performing certain activities even when using assistive devices such as glasses, hearing aids, braces etc. Other questions are asked about limitations due to learning disabilities and long-term emotional, psychological, nervous, and mental health conditions or problems (Statistics Canada, 1991: 21).

HALS 1991 measures disability in terms of level of severity. This differs from HALS 1986, in which disability was measured as the presence of multiple disabilities. Six major areas have been identified as being a source of limitation to a person's daily activities.

Mobility	limited in ability to walk, move from room to room, carry an object for 10 metres or stand for long periods.
Agility	limited in ability to bend, dress or undress oneself, get in or out of bed, cut toenails, use fingers to grasp or handle objects, reach or cut one's own food.
Seeing	limited in ability to see newsprint or to see someone from four metres even when wearing corrective glasses.
Hearing	limited in ability to hear what is being said in a conversation with one or more people, even when wearing a hearing aid.
Speaking	limited in ability to speak and be understood.

Other limited because of a learning disability, a mental health condition, an intellectual ability, or because of labelling by others.

A seventh category, "nature not specified," was developed to include people who responded that they did experience limitations, but who did not reply positively to any of the other screening questions used in HALS. A person is not considered to have a disability if any of the above mentioned difficulties s/he experiences are eliminated by the use of an aid or assistive device.

Table 4.1: Total Population, by Disability Status, Sex and Age Group, for Canada, 1991

Age and Sex	% of Total Population	% of Total Population Who Have a Disability	% of People with Disabilities Living in a Health-Related Institution
Both Sexes (number)	26,916,720	4,184,685	262,240
0 - 14	20.7	1.4	*
15 - 34	31.8	2.5	0.3
35 - 54	27.0	3.8	0.6
55 - 64	8.8	2.4	0.4
65 +	11.6	5.4	5.6
Total	100.0	15.5	6.9
Males (number)	13,247,725	1,967,040	89,100
0 - 14	10.6	.9	*
15 - 34	15.9	1.2	0.2
35 - 54	13.5	1.9	0.3
55 - 64	4.3	1.2	0.2
65 +	4.9	2.1	1.6
Total	49.2	7.3	2.3
Females (number)	13,668,995	2,217,640	173,145
0 - 14	10.1	.6	*
15 - 34	15.9	1.3	0.1
35 - 54	13.7	1.9	0.3
55 - 64	4.5	1.2	0.2
65 +	6.7	3.3	4.0
Total	50.8	8.2	4.6

Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Tables 1.1, 1.2 and 1.5. Data for each category was given only in numbers. I have calculated percentages by dividing the number in each category by the total number in the population, and multiplying by 100. This was done to improve comparability. Percentages for column 4 were obtained by subtracting the number of people aged 0-14 from the total number of people, then dividing the number in each category by the new total, and multiplying by 100. This was done because the survey of people with disabilities living in institutions did not include people aged 0-14. Due to rounding, percentage totals may not be exact.

* Not included in this survey.

In Table 4.1, I examine the population of people with disabilities in Canada as it has been presented by HALS 1991. From this table, we can see that there are more women (51%) in the total population than men (49%). The total portion of the Canadian population with disabilities

is reported at just over 15%, consisting of 8% of women and 7% of men. This 15% does not include the people who identified themselves as having a disability but who did not meet HALS criteria. It does not include people living in Indian reserves, penal institutions, correctional facilities, military camps, campgrounds and parks, soup kitchens, merchant and coastguard ships and children's group homes (Statistics Canada, 1991). Not mentioned, but also left out are people who are homeless. There is no estimation included in the data presented by Statistics Canada of what impact the inclusion of these groups would have on the figure of 15.5%. While I think we can consider this figure to be a reasonable estimate of the percentage of the population who have disabilities, I do not feel we should read it as accurate to its decimal place. We must not forget about those who have been left out, particularly as the people who have been left out are likely to be the most marginalized groups. Although HALS appears to have done a good job in describing the disabilities of the majority of the population, it appears that some refinements in the definition of disability still need to be made in order to account for the 20% of the sample population who felt themselves to have a disability, but who did not meet the HALS criteria of disability.

Also presented in Table 4.1 is an estimation of the proportion of Canadians with disabilities who live in health-related institutions. These "institutions" include nursing homes, residences for senior citizens, hospitals (general, maternity, etc.), psychiatric institutions and treatment centres and institutions for the physically handicapped. Approximately 7% of Canadians over the age of 15 who have disabilities live in a health-related institution. The majority of this group consists of women (5%), particularly women aged 65 and over (4%). I draw attention to this group for a particular reason: although they are presented initially, as an overall portion of the Canadian population of people with disabilities, people who live in health-

related institutions are not reported in most of the subsequent tables of HALS 1991 data. Specific information about people who live in health-related institutions *is* available in separate publications, but it is not presented here, that is, with the mainstay of statistics about people with disabilities. Statistics Canada makes no secret about the fact that this group is excluded, and this exclusion may have made sense in terms of performing statistical analyses: it is impossible to analyse very small groups using statistics. These data then, may be skewed in a way which minimizes, or underestimates the experiences of some of the most severely disabled people in Canada. This is not good, because it is precisely this group which may face not only the greatest limitations in their day-to-day lives, but also the greatest degree of discrimination by society. It is also problematic because this group consists mainly of elderly women, one of the poorest socioeconomic groups in the country (see Guppy, Curtis & Grabb, 1993). Any policy initiatives based on the results of this survey should have the interests of the most severely disadvantaged Canadians at heart, not just the interests of those who reside in the largest disability categories. At the very least I think the presentation of HALS results could be improved by presenting statistics side by side for both of these groups. Although a much smaller questionnaire was used to survey those living in health-related institutions, I think it is imperative that at least the major areas questioned should be comparable.

In Table 4.2, I present the HALS data outlining the nature of disabilities experienced by Canadians. The figures do not total to 100 because people may report having more than one kind of disability. For people under the age of 65, the major types of disability are those related to mobility (53%) and agility (50%). The third most common is "other," the category related to learning disabilities, a mental health condition, an intellectual ability, or labelling by others (32%). For people over the age of 65, mobility and agility become increasingly prevalent as

limitations (72% and 61%, respectively), and the third highest limitation is listed as hearing (41%). The level of severity of disability experienced by Canadians is addressed in the bottom section of Table 4.2. For those under the age of 65, disabilities are more likely to be mild (54%) or moderate (32%) than severe (14%). For those aged 65 and over, the level of disability becomes increasingly severe (25%) – perhaps reflecting a tendency for people to experience greater numbers of disabilities, or to be more likely to succumb to the limitations imposed by societal barriers as they age – although the majority of people still tend to be found in the categories of mild (39%) or moderate (35%) disabilities. The data presented by Statistics Canada do not include people with disabilities who live in health-related institutions, and so the category of those who are most severely disabled is likely underestimated.

Table 4.2: Nature and Severity of Disability for Adults Residing in Households, Canada, 1991

Nature of Disability	15-64 years of age	% of total	65 + years of age	% of total
Mobility	1,205,025	52.5	886,605	71.7
Agility	1,153,710	50.2	750,615	60.7
Seeing	229,505	10.0	318,480	25.7
Hearing	568,515	24.7	508,035	41.1
Speaking	179,175	7.8	63,220	5.1
Other	744,530	32.4	317,390	25.7
Nature not Specified	193,175	8.4	39,160	3.2
Total	2,297,130	*	1,235,955	*
Severity of Disability				
Mild	1,248,500	54.4	487,425	39.4
Moderate	725,430	31.6	435,155	35.2
Severe	323,200	14.1	313,380	25.4
Total	2,297,130	100.0 **	1,235,955	100.0 **

Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Tables 1.4, 2.5, 2.6, 4.5 and 4.6. Percentages were calculated by dividing the number in each category by the total number in the population, and multiplying by 100.

* Totals do not equal 100 because people may report more than one type of disability.

** Total may add to 100 due to rounding.

Earlier I discussed the model used by Statistics Canada in order to construct HALS 1991. I stated that the idea behind HALS is to understand the impact that disability can have on an individual's everyday life. I argue that we must also take into account the social factors that actually go into *constructing* disability. That is, disability does not necessarily lead directly to

handicap; the social response to disability often intervenes, and may be what causes disability to *become* handicap. Statistics Canada states that "The *consequences of disability* are the barriers persons have to face in their day-to-day lives" (Statistics Canada, 1991: 6, my emphasis). I argue that this must also be seen the other way around: *disability and handicap are the consequences* of the barriers persons have to face in their day-to-day lives. Disability is socially constructed because the social response to people who have disabilities limits the options and opportunities open to these people. If we were to remove these social barriers, people with disabilities would still experience difficulties, but they would no longer be handicapped; they would not be *socially* restricted to a role which puts them at a disadvantage. We must change not only existing social structures, but also the way we respond socially to disability in order to prevent handicap from becoming the inevitable consequence of disability.

Although extensive efforts have been made in HALS 1991 to define disability as it is experienced by Canadians, it seems that the pre-formed categories are not entirely adequate. I do not, however, think we can say that the HALS data actually hinder our understanding of disability; these data have provided valuable information. It is necessary that we continue to expand our understanding of disability, and to this end we need to add a qualitative component to these analyses. In particular, interviews with the portion of the sample which self-identified as disabled, but who did not meet HALS criteria could be extremely useful in expanding our understanding of disability. It would also be worthwhile to enclose open ended questions on the questionnaire, which would allow people with disabilities the opportunity to explain their own experiences in their own words. The fact that this method has not been incorporated is indicative of the continued prominence of statistical analyses. The use of "hard" numbers and the assertion that they represent "facts" holds with the prestige still attached to positivistic sociology and its

endeavours to emulate the natural sciences. We must understand however, that statistical analyses of the type presented here are static; they paint a picture of a particular group at a particular time, according to pre-formed categories and definitions. Any person who does not fit into this schema is simply left out of the picture. In order for HALS to encompass these notions, it is important that the survey move away from using only closed questions and fixed categories.

Disability, Education and Work

In this section I explore the relationship between disability, education and work. This relationship was discussed in Chapter 2, in which I stated that a person's attributes (in this case disability) affect occupational attainment directly, but also indirectly by impacting on educational quality, quantity and content. Addressing this theoretical model in light of the HALS data allows us to evaluate the relationship as proposed in Chapter 2, and also to consider the role the institutions of education and work play in creating handicap and perpetuating disability.

In Table 4.3, I examine the highest levels of education achieved by the population of people with disabilities and the population without disabilities, aged 15-64. HALS 1991 provides an excellent breakdown of this material, including analyses by age and gender. Looking at Table 4.3, we see that for all age groups and both genders, people with disabilities are more likely to have lower levels, and less likely to have higher levels of education than people without disabilities. They are also slightly more likely to have completed secondary school, but less likely than people without disabilities to have completed a certificate/diploma program or a university degree. Once again, however, the population of people with disabilities living in health-related institutions was excluded. This is unfortunate because this group may be the most likely to have experienced differences in the ability to pursue as much education as they would

have liked or needed. It is also an indication that these data are slightly skewed to represent the less restricted group. Possible barriers to education caused by disability are examined in Table 4.4, as well as some ways in which the educational institution may contribute to the process by which disability becomes handicap.

Table 4.3: People with Disabilities Residing in Households and People Without Disabilities, Aged 15 - 64, by Sex, Age Group, and Highest Level of Schooling, Canada, 1991

Age & Level of Schooling	Population with Disabilities (all severity levels)			Population without Disabilities		
	Men	Women	Total	Men	Women	Total
15 - 64 Years (number)	1,136,325	1,160,810	2,297,135	7,909,400	7,949,635	15,859,035
No formal schooling	1.7	1.7	1.7	0.5	0.4	0.4
1 - 8 years	19.8	16.4	18.1	7.6	7.8	7.7
Secondary	43.3	46.5	44.9	42.7	43.5	43.1
Some post-secondary	10.6	11.0	10.8	12.7	13.0	12.9
Certificate/diploma	18.5	18.9	18.7	21.5	23.2	22.3
University degree	6.2	5.6	5.9	15.0	12.2	13.6
Total	100.0	100.0	100.0	100.0	100.0	100.0
15 - 34 Years (number)	328,435	346,615	675,050	3,950,550	3,919,140	7,869,150
No formal schooling	2.2	1.9	2.0	0.3	0.4	0.3
1 - 8 years	6.1	5.2	5.6	2.9	2.5	2.7
Secondary	55.3	51.2	53.2	48.4	45.7	47.0
Some post-secondary	14.9	15.4	15.1	16.1	16.5	16.3
Certificate/diploma	17.7	20.9	19.3	20.3	22.8	21.5
University degree	3.8	5.5	4.7	12.0	12.1	12.0
Total	100.0	100.0	100.0	100.0	100.0	100.0
35 - 54 Years (number)	491,740	501,095	992,835	3,116,495	3,137,625	6,254,120
No formal schooling	1.8	1.6	1.7	0.6 ^a	0.3 ^a	0.5
1 - 8 years	17.4	14.4	15.9	8.9	9.4	9.2
Secondary	39.4	46.7	43.0	36.4	40.3	38.3
Some post-secondary	10.4	9.7	10.1	10.1	10.1	10.1
Certificate/diploma	22.5	20.5	21.5	24.7	25.7	25.2
University degree	8.5	7.1	7.8	19.3	14.2	16.7
Total	100.0	100.0	100.0	100.0	100.0	100.0
55 - 64 Years (number)	316,150	313,100	629,245	842,890	892,875	1,735,765
No formal schooling	1.1	1.7	1.4	0.8 ^a	0.8 ^a	0.8 ^a
1 - 8 years	73.7	31.9	34.8	24.6	25.1	24.8
Secondary	36.9	41.2	39.1	39.0	45.0	42.1
Some post-secondary	6.3	8.0	7.2	6.1	7.8	7.0
Certificate/diploma	12.9	14.1	13.5	15.7	15.5	15.6
University degree	5.0	3.2	4.1	13.8	5.8	9.7
Total	100.0	100.0	100.0	100.0	100.0	100.0

* Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-554, Tables 4.1, 4.2, 4.3 and 4.4.

^a Sampling error is between 16.6% and 33.3%. This figure should be used with caution.

-- Sampling error is greater than 33.3%. Figure is not reliable, and has not been presented.

The first section of Table 4.4 provides us with an estimate of the proportion of people who had disabilities *before* they completed their formal education or training (25%) compared with the proportion who became disabled *afterward* (72%). The answers may be misleading because not everyone surveyed answered this question, and further, Statistics Canada did not supply us with the total number of people who *did* answer. According to my calculations,²⁴ approximately 81% (1,852,540) of the people between the ages of 15 and 64, who did not live in health related institutions answered this question. Taking omissions into consideration, it still seems likely that the majority of people with disabilities in Canada became disabled *after* completing their formal education or training. This means we must evaluate the disability-education relationship in two ways: (a) What role does disability play in limiting access to education? (b) What role does the institution of education play in creating disability and handicap? The first question may be considered by examining the bottom sections of Table 4.4, whereas the second question will require a more in depth investigation of Table 4.5 and Figure 4.1.

It appears that about 25% of people (457,035) between the ages of 15-64, who reside in households and who have a disability replied that their "condition" affected their education. This number is consistent with the percentage of people who reported that they had disabilities prior to completing their education or training. It is important to realize that the people who answered this question are most likely the same people who were disabled prior to completing education or training. If this is the case, it would seem that disability affected the education of most of this group, although it may have affected different people in different ways. If we examine the results in the middle section of Table 4.4, we can see that a person's disability affected their educational

²⁴ I added the number of people who were included in each of the three categories, divided by the total number of people with disabilities in this age and residential grouping, and multiplied by 100.

content, quality and quantity. Educational content was affected in the following ways: 61% reported that their choice of courses or careers was influenced, 28% reported they had to change their course of studies, 31% enrolled in fewer courses or subjects than they would have otherwise, 18% took courses by correspondence or home study, and 28% attended a special education school, or took special education classes in a regular school. Educational content overlaps somewhat with educational quality, which may have been affected by: having to take courses by correspondence or home study (18%), having to attend a special school or special education classes (28%), changing schools (32%), or having their education interrupted for long periods of time (38%). Finally, the quantity of education a person with a disability might achieve may have been affected by: having their education interrupted for long periods of time (38%), beginning school later than most other people of the same age (16%), returning to school for retraining (33%), or leaving their community to attend school (17%).

In Table 4.3, we saw that approximately 2% (38,065) of people with disabilities had no formal education. When we consider the final section of Table 4.4, regarding whether or not people considered their disabilities to be the major reason for having no formal education, there is some confusion. If we add together the total number of people listed under each of the options in the last question in Table 4.4 (condition is main reason for having no formal education, condition is not main reason, and those who did not specify), we get a total of 84,675, or close to 4% of the population of people with disabilities aged 15-64 who live in households. This is double the proportion of people who replied that they had no formal education. Some people must have replied to this question who did have some formal education; who they are however, is not clear. Regardless of this discrepancy, of the people who did answer this question, a large majority (65%) stated that their "condition" was the main reason for having no formal education.

Table 4.4: People with Disabilities (Residing in Households), Aged 15 - 64, by Effects of Disability on Education, Canada, 1991

Effects of Disability on Education	% of Population, Aged 15 - 64
Presence of Condition Prior to Completion of Formal Education or Training	1,852,540 **
Condition was present	24.9
Condition was not present	72.4
Not specified	2.7
Total %	100.0
Number of Persons Reporting Their Condition Affected Their Education	457,035
Number not specified	120,720
Choice of courses or careers was influenced	60.7
Changed course of studies	27.7
Enrolled in fewer courses or subjects than would otherwise	31.0
Took courses by correspondence or home study	18.0
Attended a special education school or special education classes in a regular school	28.2
Changed schools	32.2
Education was interrupted for long periods of time	38.2
Began school later than most other people of same age	16.0
Returned to school for retraining	32.9
Left their community to attend school	16.9
Total %	+
Persons With No Formal Education	84,675 **
Condition is main reason for having no formal education	65.0
Condition is not main reason for having no formal education	33.3
Not specified	1.7 ^a
Total %	100.0
Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Table 2.8.	
^a Sampling error is between 16.6% and 33.3%. This figure should be used with caution.	
+ Percentages cannot be totalled because categories are not mutually exclusive.	
** I have calculated this total. Total was not given by Statistics Canada.	

I turn now to the second question: what role does education play in *creating* disability and handicap? This relationship is more difficult to ascertain. Gould (1981) states that people with disabilities tend to have lower levels of education than people who are not disabled, and if we return to Table 4.3, we see this tends to be the case for people with disabilities in Canada in 1991. However, if we take into consideration that more than 70% of people claim to have become disabled *after* completing their formal education or training, we must find another way to understand the relationship between disability and education. Statistics Canada has carefully and thoroughly analysed the information pertaining to educational level and labour force participation collected through HALS 1991. Detailed tables are presented which allow us to

compare this relationship taking into account gender, the presence of a disability, and labour force participation.

Table 4.5: People with Disabilities (Residing in Households) and People Without Disabilities, Aged 15 - 64, by Labour Force Activity and Highest Level of Schooling, Canada, 1991

Age & Level of Schooling	Population with Disabilities (all severity levels)			Population without Disabilities		
	Men	Women	Total	Men	Women	Total
Employed (number)	633,565	472,635	1,106,205	6,305,335	5,253,610	11,558,945
No formal schooling	1.3	1.2	1.2	0.3	0.2 ^a	0.3
1 - 8 years	14.1	7.3	11.2	6.3	4.6	5.5
Secondary	42.2	44.0	43.0	39.9	38.8	39.4
Some post-secondary	12.6	13.1	12.8	12.8	13.6	13.2
Certificate/diploma	21.8	26.0	23.6	23.5	27.5	25.3
University degree	8.1	8.4	8.2	17.1	15.2	16.3
Total %	100.0	100.0	100.0	100.0	100.0	100.0
Unemployed (number)	95,990	90,310	186,300	680,600	574,770	1,255,365
No formal schooling	--	--	0.7 ^a	--	--	--
1 - 8 years	20.5	14.2	17.3	13.0	8.1	10.8
Secondary	48.3	50.1	47.1	44.9	43.6	44.3
Some post-secondary	10.0	11.8	11.3	15.4	18.6	16.9
Certificate/diploma	18.2	18.6	19.3	19.1	21.1	20.0
University degree	2.3 ^a	5.0	4.2	7.5	8.3	7.8
Total %	100.0	100.0	100.0	100.0	100.0	100.0
Not in Labour Force (number)	406,765	597,860	1,004,625	910,595	2,112,175	3,022,770
No formal schooling	2.7	2.2	2.4	--	0.5 ^a	0.5 ^a
1 - 8 years	28.5	23.9	25.7	12.7	15.5	14.6
Secondary	43.9	48.6	46.7	60.8	55.2	56.9
Some post-secondary	7.5	9.0	8.4	9.8	10.1	10.0
Certificate/diploma	13.3	13.0	13.1	9.8	12.9	12.0
University degree	4.1	3.3	3.6	6.5	5.9	6.0
Total %	100.0	100.0	100.0	100.0	100.0	100.0

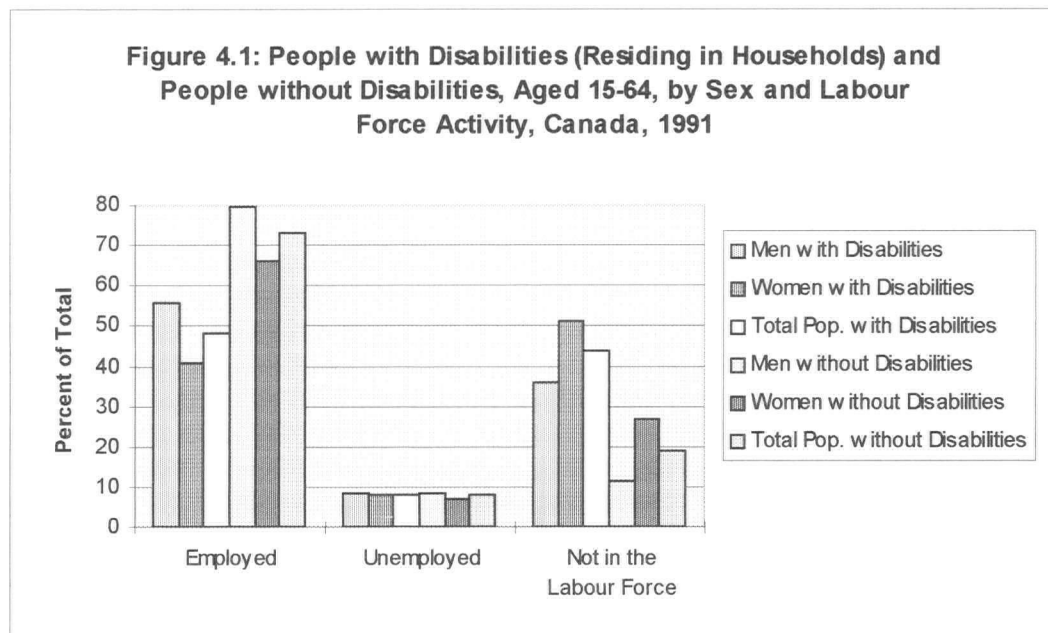
Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-554, Tables 5.1, 5.2, 5.3 and 5.4.

^a Sampling error is between 16.6% and 33.3%. This figure should be used with caution.

-- Sampling error is greater than 33.3%. Figure is not reliable, and has not been presented.

In Table 4.5 I have summarized the results presented in HALS 1991 comparing educational level, gender, and labour force participation. A number of things become apparent when we look at this table. First of all, people who are employed tend to have, on average, higher levels of education than people who are unemployed. The unemployed group in turn, have higher levels of education than people who are not in the labour force. This relationship appears to hold regardless of whether people are male or female, have disabilities or not. The

second comparison is that people with disabilities tend to have lower levels of education when compared with people who do not have disabilities. This appears to be the case regardless of a person's gender or labour force status. The third comparison is that overall, women tend to have higher educational levels than men who are in the same health and labour force status categories. This is particularly likely for women who have disabilities, and only slightly less likely for women who do not. Before I can explain how education may help to create disability however, I must present the figures comparing the occupational status of men and women, both with and without disabilities. This is done in Figure 4.1.



Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue #82-554, Tables 2.1, 2.2, 2.3 and 2.4.

Figure 4.1 allows us to compare the percentages of men and women who are employed, unemployed or not in the labour force, both for people with and without disabilities. Although both groups are approximately equally likely to be unemployed, people with disabilities are much less likely to be employed, and much more likely to be outside of the labour force than people without disabilities. Women are also less likely than men to be employed, and more likely to be unemployed, regardless of whether they have disabilities or not. For men who have

disabilities, 56% are employed, 8% are unemployed, and 36% are not in the labour force. Women with disabilities have lower participation rates in the labour force: 41% are employed, 8% are unemployed, and 51% are not in the labour force. Overall, 48% of people with disabilities are employed, 8% are unemployed, and 44% are not in the labour force. These rates differ from those of people who do not have disabilities, of whom 80% of men have jobs, 9% are unemployed, and slightly more than 11% are not in the labour force; compared with 66%, 7% and 27% of women, respectively.

Some people have lower levels of education than others, and this may reduce the number of choices they have in the labour market. Gould (1981) argues this reduction in choices may actually contribute to the creation of disability or handicap. People who do not have the educational credentials they need in order to be able to move freely from a job which is physically demanding to a job which is less so, may be more likely to *become* injured or disabled; they work until they are able to work no longer. In addition to this, people who have lower levels of education may be more likely to work in jobs which are physically demanding or hazardous, thereby increasing the risk of becoming ill or disabled as a result of injuries, accidents or stress in the workplace. In sum, having low levels of education may reduce a person's options in the labour market. A reduced choice of jobs leads to a reduced ability to change jobs in order to protect one's health. If a person cannot protect her or his health in this way, s/he runs increased risk of becoming disabled. Once disabled, a person's labour force options become reduced even further, insofar as the labour market is largely not set up to accommodate people with disabilities. If a person cannot function in a world which is set up for "normal" people, s/he becomes handicapped.

The effects of educational content, and quality on the occupational attainment of people

with disabilities cannot be assessed, because results were not presented by Statistics Canada which would allow for these analyses. Educational level alone is not sufficient to explain differences in occupational attainment, as may be seen in Table 4.5 when we compare the educational levels and occupational status of women and men. It has long been argued that although educational level is a good predictor of men's occupational attainment, it cannot predict that of women. Even when women and men have equal levels of education, women tend to have lower rates of participation in the labour force, and receive lower wages than men (Gaskell, 1992; Blau & Ferber, 1986). HALS appears to have been fashioned on the logic of human capital theory, despite convincing arguments that this is a theory based on male norms which cannot account for the occupational experiences of "deviant" groups such as women, ethnic minorities, or people with disabilities. Without the use of a theory which has explanatory power, how can we hope to understand the experiences of people with disabilities? All we can attain in this case is an analysis that tells us this group deviates from the "norm" in terms of educational level and occupational attainment.

Work or Welfare?

In the final section of this chapter I explore the relationship between disability and welfare. The institution of work is important in framing this relationship, as it helps to determine both a person's capacity to meet workplace requirements, and is also the deciding factor in whether or not work is sufficiently remunerative to encourage labour force participation. The HALS data provides us with information on some of the labour force characteristics of people with disabilities, barriers to working, employment and total income levels, and other sources of income for those who do not work for pay. Once again, I am concerned with the way these issues are presented through the "official" statistics of disability in Canada, and the implications these

results have for people with disabilities in this country.

In the previous section I discussed labour force participation, and compared the rates that Statistics Canada presented for people with and without disabilities: whether or not they are limited in the kind or amount of work they can do, or if they are completely prevented from working. In Table 4.6, I present the breakdown given by Statistics Canada on the labour force characteristics of people who have disabilities. People with disabilities who are unemployed (55%) are more likely than those who are employed (34%) or outside the labour force (20%) to be limited in the kind or amount of work they can do. Those who are not in the labour force are most likely to be completely prevented from working (59%). Of the 48% of people with disabilities who are employed, 60% experience no limitations, compared with 39% of those who are unemployed, and 14% of those who are not in the labour force. One problematic feature of this data is that no comparable information is provided for the population of people without disabilities. Without being able to compare the limitations of these two groups, it is difficult to ascertain if disability is the primary cause (however likely this may seem), or if people who do not have disabilities also have limitations (for example, commitments to children or other family responsibilities). A further problem is that results are not presented separately for men and women. This seems a particularly cogent comparison to make given the differential rates of participation of men and women in the labour force, and the differences in the rates of disability for women and men. The third factor which is overlooked is age. Although the population covered in this table is between the ages of 15-64, we do not know which of these people are more likely to participate in the labour force, and which are more likely to suffer limitations preventing participation. Finally, based on this information, we cannot differentiate which limitations occur as a result of a personal state, such as disability, and which occur because of

imposed societal or structural limitations.

Table 4.6: Labour Force Characteristics of Persons With Disabilities (Residing in Households), Aged 15 - 64, Canada, 1991

Characteristics Related to Employment	Employed	Unemployed	Not in Labour Force
Number of Persons Reporting That Because of Their Condition They are...	1,106,205	186,300	1,004,630
	(48.2%)	(8.1%)	(43.7%)
Limited in the kind or amount of work they can do	34.0	55.4	20.0 ^a
Not Limited	60.3	38.6	14.0 ^a
Completely prevented from working	N/A	N/A	59.4 ^a
Not specified	5.7	6.0	--
Total	100.0	100.0	100.0

Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Table 2.7. Percentages were calculated by dividing the number in each category by the total number in the population, and multiplying by 100. Totals may not equal 100 due to rounding.

^a These percentages should be used with caution, as 6.6% of cases are not accounted for in the total.

-- Sampling error is greater than 33.3%. Figure is not reliable, and has not been presented.

The focus of HALS is on disability; barriers are perceived as being the result of personal limitations. To the contrary, I argue that disability and handicap frequently arise as the *result* of social and structural barriers. Looking at Table 4.7, we see a list of some of the accommodations people with disabilities may require in order to be able to work. By far the most common of these are job redesign (48%) and modified or reduced hours (43%). These seem far easier (and cheaper) to supply than some of the other accommodations required – such as: handrails or ramps (11%); parking (12%); accessible workstations (11%), elevators (11%), washrooms (10%) or transportation (15%); communication services (6%), technical aids (9%); or human support (10%) – and yet they may be the biggest barriers to working. In addition to asking what accommodations people with disabilities need to be able to work, HALS also asks respondents whether or not these needs have been met. These results have not been reported by Statistics Canada. It is understandable that results cannot be presented for all data obtained in the survey; the end product would be overwhelming both in size and cost. However, by choosing to omit the data which would tell us whether the above needs were met or not, Statistics Canada has made it impossible for us to judge the effect that these workplace requirements actually have on people

with disabilities. The results appear to have at heart the needs of people with disabilities. In reality, they make it impossible for us to interpret what these needs really are.

It is important to recognize that only a minority of people with disabilities (19% of the employed, 37% of the unemployed, and 45% who are not in the labour force) responded to the question about required accommodations, and that therefore, these responses may not be representative of the entire population. It is probably reasonable to assume that these responses are representative of people with disabilities who *do* experience limitations, but without knowing how many people do not, we cannot generalize to the *entire* population of people with disabilities in Canada. For those who did respond however, it is legitimate to consider these responses as fairly accurate.

Table 4.7: Selected Characteristics Related to Employment of Persons With Disabilities (Residing in Households), Aged 15 - 64, by All Levels of Severity of Disability, Canada, 1991

Characteristics Related to Employment	Employed	Unemployed	Not in Labour Force
Number of Persons With Disabilities who are...	1,106,205	186,300	1,004,630
Number of Persons Reporting Accommodation Required for	207,860	69,510	450,620
Number not specified	18,030 **	11,145 **	78,165 **
Human support	10.1 %	7.3 %	11.5 %
Technical aids	8.5 %	5.0 %	4.5 %
Communication services	6.0 %	5.4 %	4.2 %
Job redesign	47.9 %	58.1 %	55.0 %
Modified or reduced hours	43.2 %	48.7 %	68.4 %
Handrails and/or ramps	10.7 %	17.8 %	28.2 %
Appropriate parking	11.6 %	9.7 %	18.0 %
Accessible elevator	11.4 %	1.3 %	18.5 %
Accessible workstation	10.7 %	15.4 %	23.1 %
Accessible washrooms	9.7 %	15.7 %	20.3 %
Accessible transportation	14.6 %	12.1 %	16.6 %
Other	21.2 %	12.3 %	11.7 %
Total	+	+	+
Number of Persons Dismissed or Refused Employment, Promotion or Training in the Past Five Years Because of Their Condition	118,610	47,060	120,520
Number not specified	64,740 **	12,170 **	74,850 **
Refused employment	60.0 %	66.6 %	62.0 %
Refused promotion	41.5 %	20.3 %	21.1 %
Refused access to training courses	15.2 %	16.2 %	21.1 %
Dismissed	37.6 %	65.2 %	54.5 %
Total	+	+	+

Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Table 2.7. Percentages cannot be calculated because categories are not mutually exclusive.

** This figure does not appear to be included in the total number who answered this question, therefore, the percentage cannot be calculated.

+ Percentages cannot be totalled because categories are not mutually exclusive.

In Tables 4.8 and 4.9, I address the issue of income: do people with disabilities receive an income which is adequate to cover the costs of living, as well as the extra costs of disability? In Table 4.8, I discuss income derived from employment, whereas in Table 4.9, I address income received from all sources. People who had disabilities were much less likely than people without to have received income from employment in 1990 (61% compared with 82%). The average employment income for people with disabilities is calculated by Statistics Canada to be \$22,055, less than the average employment income reported for people without disabilities, \$25,400. In the middle column of Table 4.8 we see the distribution presented by Statistics Canada. Only the people who received an employment income had this income calculated to attain the average; people who received no income were not included in determining this average. Although the same formula was doubtless used to calculate the average income for people without disabilities, there is a rather extreme difference between the 39% of people with disabilities, and the 18% of people without disabilities who were left out of the calculations. Although I cannot calculate what the average income would be if *all* people with disabilities had been included as part of the population, I can evaluate the change in the distribution of people at each income level. These figures are presented in the third column of Table 4.8.

If we use the average employment income provided by Statistics Canada, it falls in the range between \$20,000-\$24,999. Comparing the percentages of people in the second and third columns, we gain an idea of the impact of omitting such a large percentage of the population from this calculation; a much greater proportion of people have below average employment incomes. In column 2, 10% of people fall into the average range, compared with only 6% in column 3. In column 2, 53% of people with disabilities received lower than the average employment income, whereas the figure was 71% in column 3. Finally, 37% of people received

higher than the average income according to column 2, whereas the figure was only 23% in column 3. By excluding the people who had no employment income from the calculation of the average employment income for people with disabilities, this figure has been skewed to a considerable extent, resulting in a much higher estimate than is actually the case. As mentioned above, although the same formula would have been used to calculate the average employment income of people who do not have disabilities, far fewer people without disabilities had no employment income, therefore the overall average, while positively skewed, is so to a lesser extent.

The total 1990 income (income from all sources) for people with disabilities is presented in Table 4.9, for those aged 15-64 and those aged 65 and over. Two columns have been presented for each age group, with the left column including only those who received an income (as per Statistics Canada), and the right column including all people with disabilities. Results for both age groups change when we consider all members of the population, although this change is much less than that we saw with employment income. Following Statistics Canada, the majority of people aged 15-64 were still below the average income level: 9% received an income within the average range of \$20,000-\$24,999, 58% fell below this average line, and 33% were above. Including the entire population of people with disabilities aged 15-64, 8% received an income in the average range, 63% were below, and 29% were above. The difference between these two calculations is minimal for those over the age of 65: according to both calculations, 13% received an income in the average range of \$15,000-\$19,999, and 23% received above average incomes. According to Statistics Canada, 64% were below average, compared with 65% when we include the entire population.

Table 4.8: Average of Total 1990 Employment Income of Persons With Disabilities (Residing in Households), Aged 15 - 64, and 65 +, Canada

Number of Persons	People With Employment Income	People With and Without Employment Income
Without income in 1990	N/A	39.1
under \$2,000	9.8	6.0
\$2,000 - \$4,999	9.1	5.5
\$5,000 - \$9,999	12.3	7.5
\$10,000 - \$14,999	11.4	6.9
\$15,000 - \$19,999	10.1	6.1
\$20,000 - \$24,999	10.1	6.1
\$25,000 - \$29,999	8.4	5.1
\$30,000 - \$34,999	8.3	5.1
\$35,000 - \$39,999	5.0	3.0
\$40,000 - \$44,999	5.2	3.2
\$45,000 and over	10.6	6.4
Total Percent	100.0	100.0
Total Number	1,399,790	2,297,135

1990 Average Employment Income for those aged 15 - 64 is \$22,055

Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Tables 2.9 and 4.7. Total income includes income from all sources. Data for each category was given only in numbers. I have calculated percentages by dividing the number in each category by the total number in the population, and multiplying by 100. This was done to improve comparability. Due to rounding, totals may not be exact.

The only major criticism I have remaining of the data presented in Tables 4.8 and 4.9, is that average incomes were not calculated separately for men and women. By ignoring these differences we disregard the huge discrepancies between the wages of women and men. The end result is that it becomes extremely difficult to evaluate personal needs. In 1994, the Minister of Human Resources Development published a document titled *Improving Social Security in Canada. Persons With Disabilities: A Supplementary Paper*. This document also drew on data from HALS 1991, and included a table of individual income for adults with disabilities aged 15-64. Percentages for average incomes in this table are consistent with those in Table 4.9, when we include the entire population in the calculation as I have done, rather than just those with an income. Figures for Canada presented by the Minister of Human Resources Development are reproduced below in Table 4.10.

Table 4.9: Average of Total 1990 Income of Persons With Disabilities (Residing in Households), Aged 15 - 64 and 65 +, Canada

Number of Persons	Aged 15-64		Aged 65 +	
	% of Total with 1990 Income	% of Total Including Those with no Income	% of Total with 1990 Income	% of Total Including Those with no Income
Without income in 1990	N/A	11.4	N/A	0.6 ^a
under \$2,000	8.0	7.1	2.1	2.1
\$2,000 - \$4,999	8.2	7.3	3.8	3.8
\$5,000 - \$9,999	19.1	16.9	26.0	25.8
\$10,000 - \$14,999	12.6	11.2	32.3	32.2
\$15,000 - \$19,999	10.4	9.3	12.8	12.7
\$20,000 - \$24,999	8.9	7.9	7.5	7.4
\$25,000 - \$29,999	7.6	6.7	4.2	4.2
\$30,000 - \$34,999	7.0	6.2	2.7	2.7
\$35,000 - \$39,999	4.7	4.1	1.8	1.8
\$40,000 - \$44,999	4.0	3.5	0.9 ^a	0.9 ^a
\$45,000 and over	9.3	8.3	5.9	5.8
Total Percent	100.0	100.0	100.0	100.0
Total Number	2,035,955	2,297,135	1,228,665	1,235,955

1990 Average Income for those aged 15 - 64 is \$20,710

1990 Average Income for those aged 65 + is \$16,940

Source: Health and Activity Limitations Survey, 1991. Statistics Canada Catalogue # 82-555, Tables 2.9 and 4.7. Total income includes income from all sources. Data for each category were given only in numbers. I have calculated percentages by dividing the number in each category by the total number in the population, and multiplying by 100. This was done to improve comparability. Due to rounding, totals may not be exact.

^a Sampling error is between 16.6% and 33.3%. This figure should be used with caution.

The difference between women and men regarding the distribution of wages is extreme. The overall average income presented by Statistics Canada was in the \$20,000-\$24,999 range. If we compare the figures provided in Table 4.10 for men and women, we see that 8% of both men and women had average incomes in this range. However, only 50% of men, compared with 76% of women were below this average, and 43% of men compared with 16% of women were above. If we consider personal need to be based at least partially on adequate income levels, Table 4.10 shows us that women and men have vastly different resources and needs. By presenting income data together for both genders, Statistics Canada has obscured the potentially different needs of women and men which are revealed in the figures presented by the Minister of Human Resources and Development.

Table 4.10: Adults with Disabilities, Aged 15 - 64, by Level of 1990 Individual Income, Canada

Income Level in \$	Men	Women	Total
less than %5,000	16%	35%	26%
5,000 - 9,999	15%	18%	17%
10,000 - 14,999	10%	13%	11%
15,000 - 19,999	9%	10%	9%
20,000 - 24,999	8%	8%	8%
25,000 - 29,999	8%	6%	7%
30,000 and over	35%	10%	22%
Total	100%	100%	100%
Number	1,136,320	1,160,810	2,297,140

Reproduced from: Minister of Human Resources Development, *Improving Social Security in Canada. Persons With Disabilities: A Supplementary Paper*, 1994. Data originally from the Health and Activity Limitations Survey, 1991.

What is evident in the data from both sources, however, is that the majority of people who have disabilities have below average income levels. People with disabilities who receive an income from employment may not receive enough income to offset the costs of disability, thereby not making it worth their while to work, particularly if we take into consideration the other barriers discussed in this thesis. Unless we can offset the discrimination and disadvantages people with disabilities experience in the labour market, the only "rational" choice for many may be an illness career with reliance on social welfare.

Conclusions

The "official" picture of disability in Canada revolves around the collection of statistics; we are still averaging, normalizing, and forcing people into predefined categories without truly accounting for their own interpretations of their everyday experiences. In spite of this, the 1991 Health and Activity Limitations Survey is a good survey which provides sensitive measures for hundreds of variables related to disability and the problems experienced by people with disabilities.²⁵ My problem lies not with the survey itself, but with the presentation of results made by Statistics Canada.

²⁵ A copy of this survey may be obtained from the 1991 Health and Activity Limitation Survey User's Guide.

Why have I chosen to analyse Statistics Canada's presentation of the data on disability rather than analysing these data firsthand? First of all I am interested in the "official" portrayal of disability in Canada; the ambiguity of many of the results presented by Statistics Canada – such as: inadequate definitions and categories of disability; the omission of people living in health-related institutions; a lack of sensitivity regarding gender differences; the exclusion of those with no income in the determination of average income levels; the presentation of the majority of the data in incomparable forms (most of the data were presented only as raw numbers, not as a combination of numbers and percentages); and unclear or missing explanations of data analysis – may lead to grave misconceptions in the interpretation of these data, and perhaps even misrepresentations of the population in question. Secondly, I am an unemployed woman who has a disability; I cannot afford Statistics Canada's prices to purchase either additional information or the microdata file.

While I recognize the very real limitations to presenting all of the HALS data, the selection of results which have been presented by Statistics Canada do not necessarily reflect the needs or interests of people with disabilities. Many people who are confronted with the "official" picture of disability as reported by Statistics Canada will not have any background training in reading or interpreting statistical analyses. Accepting summary figures, particularly when they are presented in a format that is difficult to understand, without careful examination can have very serious consequences, both for those who have the power to form policy, as well as those who are influenced by it.

Conclusions



I am listening to the Ani Di Franco tape Nicole gave me...The songs are sad but strong – they make me feel the same way. It helps me believe I will never ever give up, no matter how many times I have to start over. There will always be a way. It's just up to me to find it.

– Personal Journal, February, 1996 –

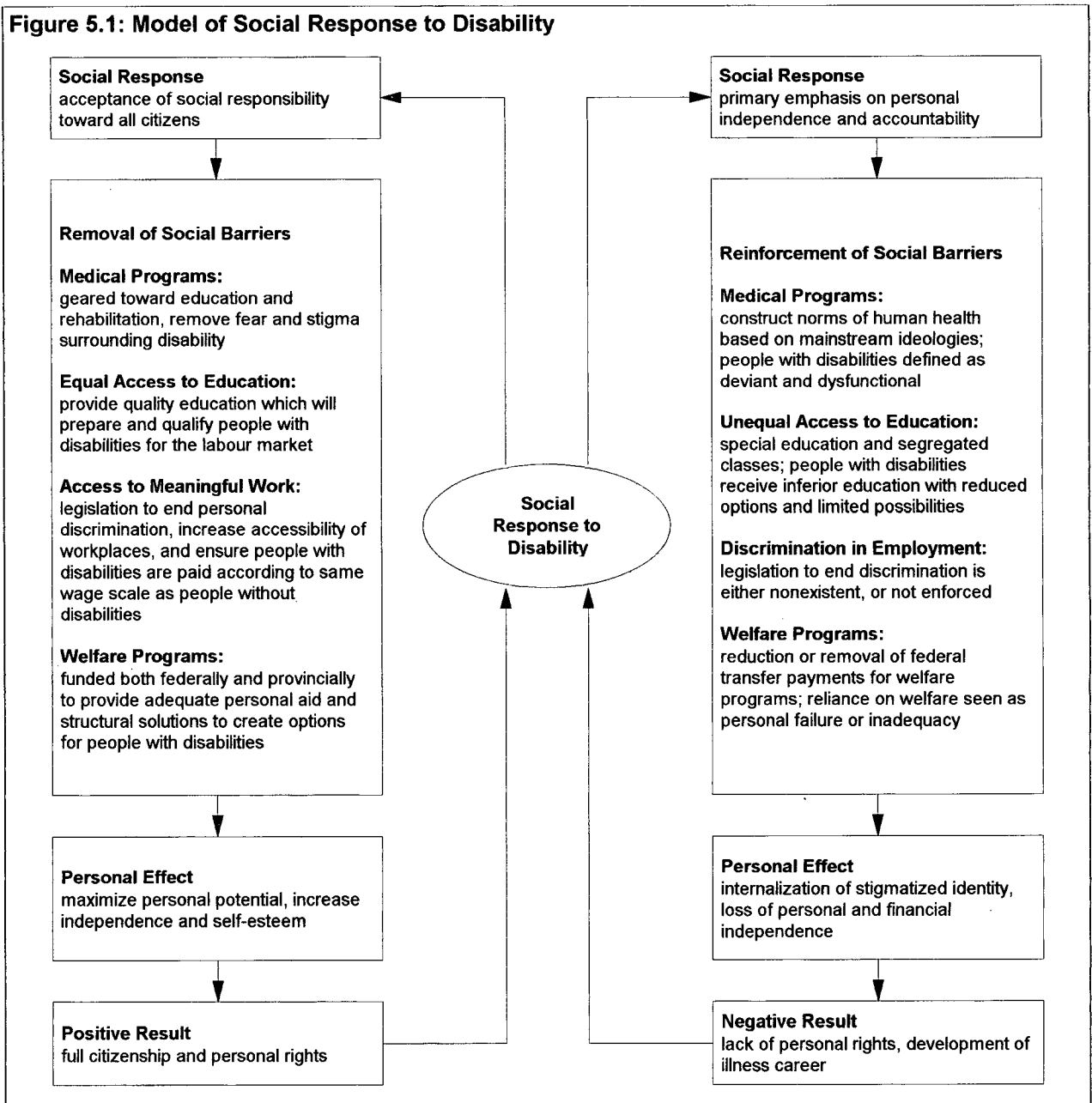
Throughout my thesis I have discussed the ways in which disability is defined, defiled, and even created by the institutions of medicine, education, work and welfare. Disability has been linked almost exclusively with the medical model which defines medical control and intervention as the only avenue to hope. This model, however, emphasizes the negative aspects of disability, presenting the process by which disability becomes handicap as inevitable, with social barriers being the unavoidable reality people with disabilities must accept. This model reflects a normalizing mainstream ideology which overlooks the possibility that people with disabilities can live complete and happy lives, provided we break down the social barriers which prevent them from doing so. Treating people who have disabilities as “flawed,” “incapable,” powerless victims limits the available options, leaving illness as the only career many people can afford to have.

Social institutions in Canadian society function on the premise of individual responsibility, and yet, through the medical model, we deny people with disabilities the power to take control over their own bodies and lives. We deny the fact that disability is part of the normal life process, defining it instead as dysfunction. Treating disability as dysfunction, and people who have disabilities as deviant, prevents us from adopting positive attitudes which could prevent disability from becoming handicap. Social institutions have so far, functioned to atomize people with disabilities, making them feel solely responsible for any difficulties they may

experience in trying to function in mainstream society. By adopting a social model (as illustrated in Figure 5.1), by becoming aware how our social institutions contribute to the creation of disability and handicap, we may begin as a society to take responsibility for our actions. We empower people who have disabilities, and give their personal claims political status. Attaining political status for personal needs is not easy; it is a bitter struggle in which people who are relatively powerless must challenge federal and corporate bureaucracies. It entails overcoming personal differences which can hamper this political cause.

The social model, originally developed in the 1970s by the Union of the Physically Impaired Against Segregation, has been crucial in drawing attention to the social barriers which may lead impairment or disability to become handicap (see Campbell & Oliver, 1996). However, ongoing struggles in the arena of disability rights have caused many people with disabilities to challenge the continuing adequacy of this model. The reaction appears to frame two major debates. First, although it still provides hope and liberation for many people with disabilities, it is argued that the social model may not provide adequate scope (or protection) for people to express their own experiences of their bodies and lives in their own words. Many people with disabilities still do not feel it is "safe" to express their personal experiences of impairment or disability in a public or political arena. To do so, it is argued, will only confirm mainstream impressions that life with a disability is tragic, and possibly not worth living (Morris, 1996). On the other hand, some people feel it is imperative to state plainly and clearly the role impairment or disability play in the life of a person with disabilities. "[T]he suppression of concerns related to impairment does not mean they cease to exist or suddenly become more bearable. Instead this silencing undermines individuals' ability to 'cope', and, ultimately, the whole disabled people's movement" (Crow, 1996: 210). The second debate addresses the role medical intervention

should play in the social model. On the negative side, medical intervention may be perceived as impinging on the rights and opportunities of people with disabilities (Begum, 1996), or even as giving rise to dangerous eugenics policies (Bailey, 1996). On the positive side, however, “for many disabled people, high-quality medical services are just as important as the removal of social barriers” (Campbell & Oliver, 1996: 145) with regard to allowing maximum functioning of the body, mind, and person as a whole.



I argue that we must recognize the process by which impairment or disability may become handicap to be dynamic and ongoing, involving a complex series of actions and reactions at both the personal and social levels. I feel we must acknowledge the role that disability and impairment play in the life of the person with a disability. To understate personal difficulties which may arise as a result of these factors is to obscure the experience of people who have disabilities, making it impossible to interpret what the needs and goals of this group really are. With respect to medical intervention, we must recognize that there are two kinds: that which is based on fear and misunderstanding, and that which contributes to an improved level of physical and/or mental functioning for the person with a disability. The former contributes to negative stereotypes and stigmatization; the latter provides help, understanding, and increased liberation from personal constraints. The model presented in Figure 5.1 attempts to capture the positive and negative ways in which a disabled identity may be formed when we take into account the social response to disability in light of the institutions of medicine, education, work and welfare.

The left half of Figure 5.1 represents the ways in which a positive social response to disability may lead to an acceptance of social responsibility and the removal of social barriers in the areas of medicine, education, work and welfare. This will allow the person with a disability to maximize their personal potential, increase their independence and self-esteem, resulting in the possession of full citizenship and personal social rights. On the other hand, the right half of Figure 5.1 represents the state of Canadian society today. With primary emphasis placed on personal independence and accountability, the social response to disability is negative. Barriers created in medicine, education, work and welfare are reinforced, leading people with disabilities to internalize a negative and stigmatized identity, lacking in personal and financial

independence. The resulting lack of legislated and substantive personal rights leaves many no option but to choose an illness career.

Part of the process of attaining political power lies in gaining the power to define disability. There are conflicting interests represented when we examine narrow versus wide definitions of disability. Institutions of power, such as medicine, education, work and welfare, all benefit from a narrow definition of disability; the fewer people who are defined as disabled, the fewer people for whom the state must assume responsibility. In a sense, society at large also benefits from a narrow definition of disability, particularly when there are a limited number of dollars to allocate for social spending. If someone is not defined as disabled, we, as a society, do not have to feel guilty about denying them support.

In some ways it is also in the best interests of people with disabilities to endorse a narrow definition of disability (although the aims of some activist organizations is to broaden the definition). The question of who or what should be defined as disabled, or a disability, is a highly contentious issue amongst the "disabled community" precisely because there is as yet, no unified community of people with disabilities, although efforts are being made in this direction. For example, many people who are deaf do not want to be considered part of a greater disability community; they have their own community of the Deaf. This community is well established, with its own language and rules. Inside the community, many people who are deaf do not feel disabled in any way, and they do not want to be associated with other disadvantages which may be perceived to be part of a more general disability community (Davis, 1995; Wendell, 1996). If we consider the more general "disability community," again we note that there are those who may desire that access to this community is restricted. Why? In an effort to avoid unnecessary stigma which a person does not feel is inherent in her or his own disability. For example, a

person paralyzed in an automobile accident may not want the added stigma of mental illness heaped on that already associated with paralysis. Someone who is mentally ill, or learning disabled may not want to be put in the same category as a person who is HIV positive. The end result is that "the disability community" is, and may always remain divided to a certain extent. A second reason people with disabilities may want to restrict the definition of disability is to protect access to ever-decreasing social resources (pensions, welfare benefits, etc.).

The new definition of "handicapped," implemented in BC in legislation relating to GAIN for the handicapped, was brought about largely due to the efforts of the BC Coalition of People with Disabilities. This definition is seen as positive by the "disability community" because it asserts that one need not be permanently unemployable in order to be considered eligible for disability status or benefits. The recognition that some disabilities are cyclical is landmark: it provides protection for many people who are either unable (that is, lacking medical certification), or unwilling to accept the status of "permanent unemployability." It should also help to alleviate some of the disincentives to work, simply because work will not be an all or nothing affair.

Can we construct a new identity of disability which is positive? Yes, to a certain extent I think we can. To do so we must debunk the myth that disability, any disability, necessarily leads to tragedy, inability, or even incompetence. To some extent we must "normalize" the notion of disability, removing the fear, ignorance, and stigma with which disability has always been greeted. It is in this direction that I feel advocacy around disability must take us if we are ever to remove the disadvantages and discrimination which are automatically coupled with disability in today's world.

Constructing a new, more positive identity, however, has its advantages and

disadvantages. If we are concerned primarily with maintaining access to an ever shrinking social safety net, then perhaps we should be cautious in trying to portray disability in a positive way. It may only be possible to maintain access to this help by asserting the *differences* which exist between people who have disabilities and people who do not. Unquestionably there will always be some portion of the population who are unable to sustain a working life, even if all other social and cultural barriers to participation are removed. These people should be protected by, and provided for through the social safety net. On the other hand, if our primary concern is to make social and financial independence a reality for many people who have disabilities, then we *must* actively try to create as positive an identity as possible. We must break down the physical, social and psychological barriers which isolate and create disadvantages for people with disabilities, preventing them from enjoying the full rights of citizenship. Only by doing so can we allow people in this group to possess their full share of social rights and personal potential; to live in a world in which physical limitations do not rule out life chances.

Even after living with disability for five years, and researching and writing about it for the past two, I have not been able to entirely prevent myself from internalizing a negative self-identity. Nor can I shed a feeling of individual responsibility and culpability related to the difficulties I have in earning a living. This may be apparent in the comments which head each chapter, in which my “unofficial” feelings sometimes conflict with my “intellectual” views. Joining what may be two different sides of myself is a complicated process, one which may take a lifetime of seeking to rectify the way society is with the way I feel it ought to be.

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