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**Passing Through Other People's Spaces:  
Disabled Women, Geography and Work**

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Thesis submitted for degree of PhD,  
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University of Glasgow

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## **Declaration**

I declare that the following thesis has been composed by myself and that the work is my own.

## **Acknowledgements**

Thank you to the forty women who graciously allowed me into their lives. Thank you to Statistics Canada, my employers, for Education Leave and tuition. Thank you to the Faculty of Social and Physical Science for field work funding. Thank you to my family and friends for their constant support. Thank you especially to Peter, Hazel, Wendy, Rachel, Gaye and Olive for having confidence in me when I had none in myself.

Finally, thank you to the Department of Geography and Topographic Science and to Professor Chris Philo, my PhD supervisor for making a place for me. Thank you Professor Philo for having the confidence to enable me to find a path and make my way on my own terms. Thank you for always treating me with dignity and respect. Thank you for not being afraid to 'think outside the box.' A good teacher helps a student grow and understand the world. You are indeed a fine teacher and I am richer for it.

## **Dedication**

For Janette, Jackie and Corina, their lives were far too short but their spirit lives on.

## Abstract

The historical social positioning and exclusion experienced by disabled people, particularly disabled women in Western society, is profound. Traditional disability research methods and theoretical approaches are built from a combination of fear and ignorance, reflecting myths and misconceptions about the ‘abnormality’ and ‘dysfunction’ of disability. People with disabilities remain largely invisible and ‘out of place’. Many disability researchers adopt a ‘colonial’ perspective toward disability and arguably fail to engage with disabled people in a substantive manner other than as a particular type of limitation or possible candidate for correction. Quantitative disability data provides a rudimentary reference source from which a medicalised one-dimensional profile of disability has developed, but information gaps and methodological weaknesses with such data can readily be identified. This thesis is hence a qualitative critical disability survey examining the timing and spacing realities of lives for women with physical disabilities. The social context of disability in public/private space is thereby examined from the perspectives of disabled women. The fluidity of embodied geographies, disability, and impairment are explored, moving well beyond individual incapacity in the workplace and looking at wider social perceptions and attitudes. Through a series of in-depth interviews developed in conjunction with and involving twenty women in Scotland and twenty in Canada, the interconnection of education, community and workspaces are explored in relation to disability policies. The ‘voices’ of women with disabilities remain at the forefront, and what emerges are rich contextual profiles of women making spaces on their own terms, allowing new insights into proactive policy interventions.

## Contents

|   |            |
|---|------------|
| <b>Declaration .....</b>  | <b>i</b>   |
| <b>Acknowledgement.....</b>   | <b>ii</b>  |
| <b>Dedication.....</b>  | <b>iii</b> |
| <b>Abstract .....</b>   | <b>iv</b>  |
| <b>Contents.....</b>  | <b>v</b>   |
| <b>Chapter One Introduction .....</b>   | <b>i</b>   |
| <b>Chapter Two Employment, history and social positioning.....</b>  | <b>10</b>  |
| <b>Chapter Three Feminism and disability: from deviant to distinctive, making a place for disabled women.....</b> | <b>29</b>  |
| <b>Chapter Four Building a path in the wilderness: concepts and methodologies.....</b>                            | <b>44</b>  |
| <b>Chapter Five Doing it by numbers!! .....</b>   | <b>82</b>  |
| <b>Chapter Six Segregated spaces of education .....</b>   | <b>102</b> |
| <b>Chapter Seven Community spaces and private places.....</b>   | <b>126</b> |
| <b>Chapter Eight On approval: work, employment.....</b>   | <b>147</b> |
| <b>Chapter Nine Conclusion .....</b>  | <b>172</b> |
| <b>Bibliography.....</b>  | <b>183</b> |

# Chapter One

## Introduction

The face of discrimination is a benign face. It wants to keep us [people with disabilities] in our place. (*Why People Hate Disability*, BBC Radio 4, June 11, 2001)

Most people don't hate me, they just wish I didn't exist.

(Colin Hughes, *Why People Hate Disability*, BBC Radio 4, June 11, 2001)

### A personal journey

'Why are you looking for a job? Aren't you eligible for a pension?' The opening line from my first, and ultimately unsuccessful, job interview after receiving my undergraduate degree has stayed with me for a very long time. It immediately signalled something strange about a person with disabilities wanting to access paid employment. Employment and disability are often viewed as being mutually exclusive. People with disabilities, especially women, appear to be 'out of place' in both work and public spaces. Undertaking this PhD thesis, I am both a product and a part of that which I study, the ultimate reflexivity. As a woman with a disability (I use crutches to aid mobility and I have reduced fine-motor co-ordination), disability and employment hold a deep personal interest. The absence or invisibility of disability in workplace has always struck me as strange. In my working life, being 'the only person with a disability' is not exceptional: that is, with the exception of in the mailroom or on the mail cart, the traditional disability 'career option.' Indeed, sorting the mail was part of my first job at the National Library of Canada.

Subsequently, I started working at Statistics Canada (Canada's statistical agency) on the Health and Activity Limitation Survey (HALS), the principal Canadian disability survey, in 1991. It was the first time I had ever worked with other people with disabilities. One work colleague used an electric scooter for mobility and another had vision impairment. At that point in time, none of us were involved with survey development, only with survey analysis and promotion. On a personal level, whenever my colleague who used the motorised scooter and I left the section, it was like the parting of the Red Sea, in that employees outside the section would literally plaster themselves against hallway walls in an effort to stay out of our way. Sensing a degree of discomfort concerning disability issues in the workplace, my colleague and I went on to develop *How to Mix and Mingle Without Freaking Out*, a workshop designed to address common misconceptions about disability. The experience

gave me first-hand knowledge of the lack of social preparedness for the presence of disability in the workplace.

My work experience with the HALS survey was the catalyst and laid much of the groundwork for this PhD thesis on several different levels. The survey itself was a landmark in that it did, for the first time, provide some *official* visibility of disability in Canada. HALS findings served as a valuable marker underlining the degree of disadvantage experienced by this population group as compared to the non-disabled population. The survey was nonetheless a problem for me as much for what it contained as for what it did not. I felt it was odd that the bulk of the survey was concerned with the type and nature of disability: with individualised, medicalised bodily mechanics rather than with how people manage in day to-day life. The survey still fitted disabled men and women into a neat box, one with little relevance to the complexities and messiness of my 'lived life' or the lives of other people with disabilities. Situational questions of everyday life were not 'disability aware' and reflected a mechanical bodily 'problems' approach. Each of these sections was separate and removed from the other and hence viewed in isolation and compartmentalised. Reading research reports about disability and employment was personally frustrating as they appeared one-dimensional and arguably overly simplified. Moreover, much of the research reflected a simplistic physical-functional-mechanical approach to work. The research examined personal functioning within a traditional office environment, again with a medicalised focus. It seemed remote, distant and superficial, rather like colonial anthropologists studying Aboriginal people. Much of disability research is presented in gender neutral terms. The ubiquitous phrase 'disabled people' peppered even the most progressive disability literature, and gender detail was absent from most of the research material. Yet, I knew from my own education and employment with other disabled women that, in many significant respects, we experience life differently to disabled men. Within an already disadvantaged population, similar to the experience of non-disabled women, disabled women feel greater disadvantage and invisibility than would disabled men.

As a disabled woman, I felt overwhelmed by the frustration, invisibility and absence, and it was as if I did not exist. The absence of disabled women's voices in disability literature was the justification to look exclusively at the experiences of women with disabilities in this thesis. Thus, in a very genuine way this thesis started out looking at what was not there, and why, as much as for what, was there. My previous education (completing an undergraduate



and Masters degree). coupled with my employment experience. gave me a degree of confidence. I was ready to take myself into doctoral research, even if the prompt and the content of the research was to be that which had previously been too close to see (i.e. my own experiences of everyday living and handling disability throughout education into community and on into employment).

Prior to undertaking PhD studies in Human Geography I had not explicitly self-identified as a disabled researcher let alone as a disabled woman anywhere in my research. Yet, I knew that what I really wanted was to examine disability and employment from the perspective of women with disabilities, hopefully to ascertain if the existing programmes and services directed at disabled people (in this case woman) impacted on their career choices and opportunities. In so doing, I wanted to put disabled women 'in the centre of the picture' in real terms, not as an add-on or an afterthought at the periphery of a research project. Ever mindful that I am a Canadian studying in Scotland, I also wanted to develop a research project that might be of use to my compatriots as well as to woman with disabilities in Scotland. So began what I thought would be a straightforward cross-national Scotland/Canada PhD thesis in Disability Studies, but that was not to be. This 'institutional' base was initially a unit within the Faculty of Social Sciences, Department of Social Policy. Strange as it may seem, it became apparent that Disability Studies was not a good 'fit' for me. Rigid perspectives and a lack of flexibility led to a creative vacuum. As has often been the case, I had to find another, a more indirect, route to reach my destination. I understand that the most important lessons are learned from the journey itself. I moved into the Geography Department via a route that need not be elaborated on here, and hardly three months into my PhD studies I found myself in entirely new disciplinary surroundings.

Discovering Human Geography was an amazing experience born out of necessity, much like a photographer moving from black and white to colour film. I was suddenly exposed to an entirely new spectrum, enabling me to add the depth, dimension and context that had been previously unavailable. The shifting, fluid nature of Human Geography instantly presented me with a wealth of possibilities that were simultaneously exciting and daunting. The traditional bio-medical perspective of disability offered to geographers by Golledge (1993) reflects the medical model of disability that is focusing on individual 'defect' in isolation from other factors. Although this reductionist approach mirrors what has gone before in other disciplines, his efforts to put disability on the geography 'map' and thereby to provide it with academic 'space' deserve recognition. The geography of disability is coming of age as the

'everyday' reality of disability geography is being recognised, and is moving in from the 'special' periphery toward the centre of the discipline. In doing so, geographers are escaping the rigid disciplinary isolated 'boxes' of medical geography in favour of a multi-dimensional approach incorporating the more flexible social and cultural aspects of human geography. A more detailed picture of disability in daily life is emerging thanks to the work of Butler and Parr (1999), Parr (2002) and Gesler and Kearns (2002), examining and questioning the seemingly 'fixed' boundaries of medical geography in relation to disability. Similarly, Moss and Dyck's (1996, 1999) explorations of how social control is keeping disability 'in place' parallels those of Longhurst (1994, 1997, 2001) in her studies of pregnancy and social positioning. Gleeson's (1999) work on historical materialism acknowledges that certain forms of physicality acquire social franchise to the detriment of disabled people. McDowell (1983, 1999) and McDowell and Court (1994) provide the groundwork for looking at women's embodied 'place' in paid work. Likewise, Butler and Bowlby (1997) and Chouinard (1997) further refine the complexities of the fluctuating boundaries of disabled women in the social/work/domestic world. Davies's (2001) study of timing and domestic spaces adds yet another component to the mix. To rearticulate Philo (2000), I was able to begin examining the 'messy and disordered nature of geography in the social world' relating to disability. The task of this thesis is hence to 'tease out' the often subtle intersections of outwardly unrelated social, political and economic factors that may impact on disabled women's ability to access the labour force.

The claim is made in this introduction is that there are many points of connection between very different people rooted in their shared experiences of biomedical inscription, pain, social isolation and political and economic marginalisation. Moreover, ... such connections exist with respect to positive experiences in the community, political action and embodied resistance stereotypical labels of illness, impairment and disability.

(Parr and Butler, 1999, 2)

Young (1997), along with Chouinard and Grant (1997), presents a compelling perspective on disabled people's 'place' (or lack thereof) in the 'academy' and the resulting impact on the research process. England (1994) and Mullings (1999) provide the underpinnings for a better understanding of 'reflexivity' and 'positionality' in all social research, while Koboyashi (1994/2001) and Mohammad (2001) bring a critical dimension to the 'insider'/'outsider' debate. Needless to say, I have not looked at the world in the same way since.

In the process of becoming a small 'g' geographer, I had to examine my own 'bodily geography' in an entirely different manner. I have always been proud to be a woman with a disability, but I found that I had myself internalised many of the myths and misconceptions

that are so deeply embedded in Western society concerning disability and ‘non-disabled’ spaces. Those spaces that are designed for able-bodied people with stairs, poor lighting, no seating, communicate information by loudspeaker and no tactile reference points. I started to think about how bodies that do not ‘fit’ the accepted social norm ‘manage’ or interact with and get ‘coded’ by everyday micro-spaces of all types. Acknowledging the fixed reality of time measured against the fluidity of speed, energy and environment was a revelation! Examining how time is linked to accessing, utilising and making oneself ‘competent’ to inhabit and to work in certain spaces was such a provocation. Introducing the concepts of place, time, speed and space into the thesis provided me with the ‘missing pieces’ for the task of further deconstructing, reconfiguring and re-framing perceptions of women, disability and employment, blending well with my prior knowledge from Disability Studies. The reality of disability and impairment in daily life could at last be acknowledged and discussed without becoming fixated on medical descriptors. Furthermore, one did not become caught up in the ‘political’ need to deny the realities of bodily difference, as the constructionist paradigm in Disability Studies tends to urge with justification, but not without a certain loss. Moving too, beyond the arbitrary borders of ‘public’ community or ‘work’ spaces and ‘private’ domestic spaces, I was able to recognise linkages and elements that impact simultaneously in all of these spaces. Hence, community, education, employment and domestic spaces cannot be explored in isolation, if one is to obtain a detailed picture of the factors that influence the employment choices and experiences of disabled women. Thus my basic research ambitions did not alter, but a range of new considerations – ones initially so ‘close in’ that even I did not perceive them – then began to crowd the picture.

### **Absences, theory and method**

Establishing the framework of this PhD thesis, I needed to provide a critical examination of theoretical and substantive issues concerning disability and particularly disability in relation to employment. In my theoretical and methodological reading I was constantly amazed and appalled by the absence of disabled people, especially disabled women, even in the Disability Studies literature. Repeatedly absent, silence and a depiction of stilted, primitive simplicity, arguably grounded in fear, permeated the material in virtually every discipline. Goffman’s writing is an example describing disabled people as ‘the abominations of the body’ (Goffman, 1968, 14). Erevelles states that “the disabled body is often constructed as the “monstrous” body ... (Erevelles, 2001, 97). and this filled me with incredible frustration. Women with disabilities have had virtually no social profile. Consequently, to paraphrase

Chouinard and Grant (1997). I too felt 'nowhere near the project'. I have nonetheless sought to draw inspiration from certain, social political-economic and feminist approaches, but particularly from down-to-earth theories attuned to listening to the voices of others.

Rather than beginning in an abstract conceptual world, it has meant starting in individuals' own accounts and reflections and in their understanding of the world in which they live. As a feminist researcher, it has meant inhabiting the world of women. It has involved taking as my starting point the 'real bodies' of individuals that are enmeshed in timespace.  
(Davies, 2001, 133)

Therefore, my theoretical orientation is closely linked to my methodology. Disabled people, men and women, have been studied, objectified and dehumanised, with bits of our lives fragmented and put on display through traditional forms of research. Erevelles (2001, 103) points out that "the racist construction of the savage is closely related to the concepts of disability" in that people with disabilities have been presented as 'exotic' or 'freakish' in order to make disability more palatable to mainstream society.

For this reason I deliberately chose to avoid a 'voyeurism' of the disabilities or impairments of the women who I interviewed by not profiling them. The whole purpose here not to define or classify women on the basis of their disability or impairment.<sup>1</sup> This is not to say that their individual and distinctive disabilities do not matter, far from it, but I will only touch upon these specificities insofar as the women *themselves* talk about the implications of their disabilities within the grain of their everyday lives. There is admittedly at times a tension between: a) stressing the *differences* between various individuals with disabilities, as both something important to them and a key claim of disability activists; and b) wishing to uncover a certain *sameness* in the broad patterns of experience and oppression within the lives of many people with disabilities. This tension also plays out geographically, and I should stress that I did *not* intend my thesis to be a full-blown comparative study; I simply wanted to undertake a study that would be useful to both Scottish and Canadian population groups. It would be possible to write a *regional* geography of disability, but in this case I

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<sup>1</sup> I am uneasy putting forward a 'definition' of disability or impairment, but here is one that reflects a 'disability positive' perspective. "Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunity to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Barnes, 1991, 2) (drawn from Disabled Persons International – DPI) (see also Chapter Five).

have found the parallels between my two study regions to be significant and more worthy of comment than the differences (given that my prime ambition was to reveal patterns in everyday experience as we ‘pass through’ other peoples’ spaces).

From the outset, I was determined not to adopt the ‘colonial’ research approach of studying research participants in various environments, with an appropriation of their views but with few of their actual voices then added to provide a sense of reality. I wanted to move beyond statistical and medical indicators to a richly qualitative engagement with specific women with faces, voices and, yes, disabilities!

Cultural imperialism consists in a group’s being invisible at the same time that it is marked out and stereotyped. Culturally imperialist groups project their own values, experience, and perspective as normative and universal. Victims of cultural imperialism are thereby rendered invisible as subjects, as persons with their own perspective and group-specific experience and interests. At the same time they are marked out, frozen into being marked as Other, deviant in relation to the dominant norm. The dominant groups need not notice their own group being at all; they occupy an unmarked, neutral, apparently universal position. But victims of cultural imperialism cannot forget their group identity because the behaviour and reactions of others call them back to it.

(Young, 1997, 219)

Clearly, as a disabled woman, for me it was not a case of ‘us’ the researchers and ‘them’ the subjects. The women who I interviewed shared grounded experiences, life stories and insights, and through these materials my thesis and my own interpretations have come to be furnished. The voices of the women who I interviewed had to remain at the forefront. I met with other women with disabilities regularly in order to incorporate and to verify issues that they felt were pertinent to the subject matter of the thesis. Mutual identification and a strong personal ethos led to a series of forty in-depth, candid interviews (twenty in each country) often filled with great poignancy. The women who I interviewed spoke of disability in the real terms of everyday life.<sup>2</sup> Making space often in trying circumstances, they have been dealing with a cycle of limited social expectation that is apparently driven by the spectre of normalisation rooted in a fear of difference. Perhaps one of the most telling elements is the lack of acceptance that women described in a variety of situations, and the amount of time, energy and effort spent on a daily basis actively trying to satisfy non-disabled comfort levels. to make non-disabled people feel comfortable about their embodied disabled presence and

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<sup>2</sup> Many of the Canadian women who I spoke with were interviewed in or near work settings and confined their comments to workplace or domestic issues. Women who were interviewed in shopping centres, coffee shops or their homes spoke about community or social issues.

often compromising their own needs in the process. What emerges is a detailed picture of the inter-linking of 'public' and 'private' space in the lives of women with disabilities.

## **Research questions and chapters**

At a general level, it is possible to spell out the following basic research questions underlying this thesis. In practice, many other interrelated questions and issues have of course arisen.

How does physical disability impact upon pathways through education, negotiation of everyday community life and the various aspects of the employment process?

How does the intermeshing of time and space issues throughout the everyday lives of disabled women impact upon their experiences of accessing, maintaining and changing employment?

How do a range of social policies (employment, disability, education, social security and family policy) shape disabled women's employment opportunity?

How do disabled women make sense of their position in the labour market?

How do disabled women perceive and manage the work environment?

How is the public/private space of disability and gender dealt with in this context?

Chapter Two is a 'map' for the remainder of the thesis, providing the groundwork that underlies the current social positioning of disabled men and women in Western Society.

Chapter Three examines the approach to and treatment of disability within feminist inquiries.

Chapter Four provides an overview of the theory and methodology that usually guides established disability research. The chapter outlines gaps and weaknesses of these practices and informs the research methodology of the thesis.

Chapter Five probes the value and weakness of disability-related statistics, along with the ideology that informs survey development.

Chapter Six looks at the influences and experiences in the education systems, and spotlights the impact here on employment opportunity.

Chapter Seven explores the 'fit' of community and private space and the fluidity of illusory social boundaries, coupled with the need to 'keep up appearances' in order to function in daily life.

Chapter Eight explores the reality of disability in the workplace, the need to perform as virtually able-bodied and to cope with time, space and energy issues largely unknown to the non-disabled.

Chapter Nine is a summing up of the current realities of employment and looks at how social support systems influence employment experience. This chapter also offers broader conclusions, as well as giving the 'last word' to women with disabilities.

## Chapter Two

### Employment, history and social positioning

The pervasive equation of disability with incapacity has meant that the inferior economic and social conditions of disabled people were seen as the natural consequences of their physical and mental 'impairments'.

(Gooding, 1994, xvii)

#### **The disability-employment dichotomy: challenging the 'natural' order**

This chapter basically works as an introduction to more theoretical and substantive issues at the heart of considering the relationships between work (paid employment) and disability (especially of disabled women). Current assumptions about the nature of employment are often in conflict with perceptions of disability. That is, disability and employment are frequently considered mutually exclusive, as disability is equated with incapacity. Consequently, although comprising almost 17 percent of the working-age population, disabled people have made limited inroads into the labour market despite a myriad of programmes and services in Britain and Canada designed to encourage employers to hire disabled workers. Disabled men and women are all but invisible in the workplace because they are not there, and employers are not effectively addressing the needs of disabled employees in the workplace at present (Fawcett, 1996; Barnes *et al*, 1998). Poverty and disability also remain inexorably linked. Many disabled people have education and income levels far below national averages in Britain and Canada (Barnes, 1991; Bickenbach, 1993). Poor education and limited training have a direct impact on employability. This constituency is among the most socially and economically disadvantaged of minority groups. These conditions are exacerbated amongst disabled women as they are further disenfranchised by socially imposed gender-work constraints.

Unemployment is not an innate consequence of disability. Policies and programmes do not manifest themselves in isolation. They are the products of social attitudes and expectations coupled with economic considerations (Rioux, 1985). What has evolved is the notion that dependency is a 'problem' for a certain class or group of people (Roulstone, 1998a). Perhaps this is a reflection of the Western emphasis on individualism, personal responsibility and the perception of personal autonomy. To understand exactly how these various elements have contributed to the employment experience of disabled people, several factors warrant



consideration, including: nature of employment, perception of disability, and the manner in which these elements are enclosed within the larger framework of a capitalist economy.

### **Living in a parallel universe**

People possess physical and mental abilities in a broad spectrum. Society has been constructed so as to meet the needs of only people within a narrow part of that spectrum. A dichotomy is thus set up between 'the able-bodied' who fit in and 'the disabled' who don't.

(Gooding, 1994, xvii)

The cloak of objective neutrality often obscures entrenched cultural values, and the ideal of the able-bodied male is never far from view (Carver and Rodda, 1978). Physicality is a highly valued commodity in Western society. Speech, agility, mobility, sight, hearing and intellect are assumed to be part of the natural order, and those who fail to meet the socially imposed standard are viewed as a class apart (Chouinard, 1997). Power and social control are reflected in environmental design, keeping disruptive elements in their place (Moss and Dyck, 1996). Restrictive environments control access to social spaces, determining in a very real sense who does and who does not 'belong'. Equating disability with illness has had a significant impact on modern thinking. Western society views illness as a private problem to be resolved outside of the public domain (Rioux, 1985). This individualised approach to disability has created little incentive to accommodate the needs of disabled persons in mainstream society (Rioux, 1985). Failure to recognise the potential (economic or otherwise) of disabled persons within the labour market has left this segment of the population with few alternatives for gaining access to essential goods and services. That is, disabled people are perceived as ineffective workers unable to contribute meaningfully to mainstream society. Peripheral access (wheelchair accessible toilets, ramps, tactile reference cues and lowered telephones) is granted according to able-bodied parameters, thereby satisfying the concept of universality without compromising or disrupting the day to day activities of non-disabled citizens (Chouinard, 1997).

As a rule, disabled persons have not been allowed to be actively involved in the process, rather they have been acted upon. With few exceptions the majority of public buildings, housing, educational facilities and transportation systems have been developed without consultation or consideration of the needs of disabled people. At the same time, in many ways, disabled people remain 'type-cast' into playing certain roles. Disabled women face additional isolation and role complexity owing to assumed private domestic and parenting duties, coupled with public gender role expectations (Lonsdale, 1990; Vernon, 1996).

Disabled people must labour under the assumptions imposed upon them by their non-disabled counterparts. even though it may not reflect the way that they see themselves. As a result, this population group inhabits a parallel residual universe of segregated schooling, transport, housing and employment, with standards rarely comparable to those in the mainstream. Recent legislative changes have taken place in Britain and Canada that are geared to improving access to education and employment for disabled people. However, it is too early to determine what the impact of this legislation will be. It is unlikely that these education legislation amendments will effect the women who I interviewed. In any case, socialisation with one's non-disabled peers remains severely restricted and regulated. More importantly perhaps, non-disabled people retain the perception of disability as an anomaly as opposed to a reflection of the diversity of humanity. As a society we have yet to develop a comfort level associated with impairment, pain or fatigue that ventures much beyond avoidance (Wendell, 1996). The disability/abnormality/pathology continuum is firmly entrenched (Young, 1997). Science objectifies and dominates much of the discussion about disability (Young, 1997), and assumptions regarding the static nature of disability and impairment permeates the discourse (McDowell, 1999). Myths, fear and apprehension remain intact due to lack of exposure to or knowledge of disability, and the absence of everyday encounters between the able-bodied mainstream and its disabled 'outsiders' merely perpetuate the ignorance of the former and their fears.

### **Disability and employment: a historical perspective**

[E]arly records suggest that the cultural practice of translating physical abnormality into social inferiority is so deeply rooted as to have had an almost certain impact on both the formulation and implementation of later public policy.

(Liachowitz, 1988, 1)

From earliest times in Western culture, disabled people have been subject to both praise and derision being viewed simultaneously as 'chosen by God' and 'marked by the Devil' (Hahn, 1983, 39). The latter description was more common than the former. References to disabled people as 'cripples', 'the afflicted' and 'invalids' lends credence to this view (Hahn, 1983, 37). It would appear to have laid the foundation for on-going isolation and segregation. Disabled people have been restricted in or absolved from labour force activity (Stone, 1984; Liachowitz, 1988; Oliver, 1990; Barnes, 1991). The following account is a sketch of crucial

developments within European and North American history, albeit most obviously emphasising the British experience.<sup>3</sup>

### *The familial institution and begging*

Dating from the Middle Ages the family has served as the primary institution of care and support for disabled people. The family unit provided for their basic needs while protecting them from public scorn as disability was often attributed to demonic possession (Bowe, 1978). However, despite the apprehension associated with disability, disabled people had an important role to play. The subsistence level feudal economy could ill-afford non-productive family members, and so disabled people played a fundamental role in the economic well-being of the family unit. Most work was done in or near the home, and therefore it was possible to learn a skill of some type from another family member (Ryan and Thomas, 1994). Labour in the form of domestic tasks or handcrafts was crucial to preventing starvation (Bowe, 1978).

The slower pace of daily activity, shorter seasonal working day and lack of regimentation in work was ideally suited for people with impairments (Roulstone, 1998a). Some disabled people were able to secure positions as jesters or fools in noble homes (Thomas, 1982). Lacking skills, many disabled people nonetheless relied on begging as their principal means of support, but beggars as a whole were not generally held in high regard. They “were assumed to be idle, irresponsible, often criminal, and disrespectful of authority” (Stone, 1984, 32). Penalties for engaging in such activity were harsh, ranging from corporal punishment to imprisonment (Stone, 1984). Disabled people were rarely subjected to such treatment since they were considered incapable of gainful employment. Indeed, many were granted special dispensation to practice begging (Marlett and Day, 1984). Though not openly welcomed *per se*, the presence of disabled people in the community was part of daily life. This is reflected in Finkelstein’s writing, discussing early efforts to detect ‘fraudulent’ impairment:

What is of interest here is the way in which able-bodied people could relatively freely ... enter the ranks of the crippled [sic] and that people could make a “profession” of this. The presence of people with impairments freely within the community facilitated this.  
(Finkelstein, 1980, 9)

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<sup>3</sup> Although Britain is the focus here, many of the practices discussed in this section were imported to North America at the time of European colonisation.

## *Church and state*

The pre 16<sup>th</sup> century Christian church often played an integral role in service provision when family support was not forthcoming. Establishing parish almshouses for the elderly, ill and infirm, the Church served as a *quasi-welfare* agency, but, eligibility requirements exacted a heavy toll. Individuals were required to relinquish all personal property and place themselves under guardianship of the Church (Connors, 1985). Disabled people were seen as deserving of charity; their rudimentary needs were met through a system of tithes and donations. Here we see the beginnings of the ‘charity ethic’ that is still prevalent in disability policy today (Oliver, 1990). There was a shift away from the private institution of the family driven by personal duty to the more public institution of the Church driven by moral authority.

With the advent of Mercantilism, initiating cottage industries in the 16th century, relationships with the land changed significantly, as fewer people were engaged in farming activity. Development of a more structured market economy, with small-scale production of items such as clothing and cooking utensils, meant that for the first time cost was reflected in labour, and the bodily abilities of the worker duly took on a new importance (Roulstone, 1998a). The informal support system established by the Church could not adequately cope with the massive influx of unemployed and destitute persons which accompanied the end of Feudalism, spurred by the rise of monetary exchange as an influence on production (Barnes, 1991). Faced with growing social unrest and in an effort to maintain economic stability, the state became actively involved in social policy development (Connors, 1985). The Elizabethan Poor Laws were established and the receipt of charity became highly stigmatised. Public institutions set strict eligibility requirements in order to separate legitimate need from deception in an effort to control access to limited resources (Stone, 1984).

Those who sought to segregate physically impaired people from their class origins ... may well have started to differentiate their attitudes. They may have seen the poverty of cripples [sic] as the result of personal misfortune, whereas the poverty of able-bodied beggars was the result of indolence. (Finkelstein, 1980, 9)

Thus, disability was transformed into a ‘problem’ in need of ‘management’ (Oliver, 1990). Disabled people were officially categorised as ‘unemployable’ and given licenses to beg and to receive charity (Stone, 1984). This served as the catalyst for state-run social policy and the welfare state. More importantly, it marked the beginning of official sanction for exclusion of disabled people from the labour market in favour of the non-disabled.

## *The Industrial Revolution*

The Industrial Revolution in the late 18th and early 19th century was an era of extreme social dislocation for all segments of society. For disabled people in particular, it would seem that this period more than any other can be linked to the social displacement currently experienced by disabled people.

The rise of capitalism brought profound changes in the organisation of work, in social relations and attitudes, and these changes had implications for family life. These factors, with the demographic explosion which accompanied them, posed new problems for social order and with the breakdown of traditional social relations, new problems of classification and control.  
(Oliver, 1990, 32)

Industrialisation triggered the demise of cottage industry and many workers were forced to seek employment outside the home in factories. No longer were individuals directly responsible for exchanging or selling the goods that they produced. The shift from subsistence to an exchange-orientated economy further removed the individual worker from the means of production (Roulstone, 1998a), particularly because capitalism placed new and greater emphasis on surplus economic value and profit.

Individual workers were simply commodities whose labour costs were factored into production value, and the time-money equation became closely linked to the able-bodied 'average worker' (Roulstone, 1998a). Mechanised production necessitated order in the workplace. Workers were required to adapt to the stringent regimentation of factory production, long hours in difficult conditions. This change in production caused particular difficulties for disabled persons. Most workplaces were physically inaccessible, and the operation of machinery required speed and physical agility that they did not possess. In an era where time and money became tightly bound together, disabled people were viewed as an impediment to the productivity deemed essential to capitalism (Marlett and Day, 1984). As noted by Finkelstein, 'new productive technology – large scale industry with production lines geared to able-bodied norms' (Finkelstein, 1980, 10).

Increased mechanisation also meant that employers required fewer workers. Consequently, unemployment rose, and disabled workers faced overwhelming competition in an already limited labour market. Previously they had been able to rely on the wages of non-disabled family members to subsidise their meagre income, but, with massive unemployment, this option was no longer viable (Brechin *et al*, 1981). Simultaneously, poor working conditions and inadequate safety measures led to a marked increase in industrial accidents and thereby

even greater numbers of disabled workers (Brechtin *et al*, 1981; Oliver, 1990; Roulstone, 1998a). Referring to the exploitative nature of factory production, Marx writes:

It converts the worker into a crippled monstrosity by furthering his [sic] particular skill as in a forcing house ... they butcher the whole beast for the sake of his hide ...  
(Marx, 1998, 481)

Similarly,

Some crippling of body and mind is inseparable even from the division of labour in society as a whole. However, since manufacture carries this social separation much further, and also, by its peculiar division, attacks the individual at the very roots of his [sic] life, it is the first system to provide the materials and impetus for industrial pathology.  
(Marx, 1998, 484)

Marxism has provided an important foundation from which to highlight power imbalances and distribution weaknesses present in the capitalist economic structure, and this perspective does provide insight into production relations and exchange labour value under capitalism. Marx was right to identify the damaging and disabling effects of capitalist workplaces. This argument could easily be extended beyond factories and mines to all manner of work settings. This assertion is very much part of the historical materialist tradition of critical disability research, echoing the likes of Gleeson (1999) in geography recognising that certain forms of physicality (predominantly, white, able-bodied males) acquired increased franchise. However, similar understanding is not present concerning discussions of disability or impairment. For the most part, both are presented as the opposing elements of capitalism, usually reflective of poor industrial practices.

Marx and Engel's description of capitalism creates both disabled people and the concept of disability as the negative of the normal worker. But this is not an aspect of capitalism Marx seems to present as transcendable.  
(Abberley, 1998, 86)

What is dubious for Abberley and troubling for many disabled people is that:

...an analysis linking impairment to capitalism as a very apparent symptom of its inhumanity and irrationality, is of little use in the struggle against disablement.  
(Abberley, 1998, 84)

Equating disability and impairment with inhumanity does little in itself to strengthen or to alter the social positioning of people with disabilities. Marx ends up positioning *real* disabled people simply as helpless 'casualties' and 'victims' of capitalism, and as, moreover, problematic and unnecessary outcomes of capitalism who, if the world were better organised, *would not exist and would not need to exist*. In addition, notions of productive employment are retained, although Marxists would insist that ideally the nature of work itself should

become more humane. Social worth and identity remains linked to labour force activity. Marx thus ends up regarding disabled people in much the same way as 'mainstream' society: as a problem category with no intrinsic merit of their own, and with no possible meaningful relationship to the realm of production (i.e. employment). It would appear that people with disabilities are presented as:

[I]ndividuals whose useful labor has been devalued by the market economy and has not been regarded as real labour.  
(Erevelles, 2001, 99)

This is problematic for disabled people with impairments that prevent paid employment. However, this does not mean that individuals do not 'participate' in other ways. It would appear that their isolation present under capitalism remains intact even in Marxist revisionist writings:

Disabled people have inhabited a cultural, political and intellectual world from whose making they have been excluded and in which they have been relevant only as problems.  
(Abberley, 1998, 93)

Factory owners had little incentive to train or to accommodate disabled workers given the ample supply of able-bodied unemployed. Poverty was viewed as a sign of personal inadequacy and lack of resourcefulness (Bowe, 1978; Barnes, 1991). Consequently, the state lacked both means and inclination to manage the growing numbers of unemployed, with few social programmes in place. Economic feasibility served as the underlying rationale for policy development, and evolutionary theories of social organisation were used to support this:

'Social Darwinism' dispelled and allayed the qualms of the rich about not helping the disadvantaged by assuring that the latter's sufferings were the inevitable price of progress ...  
(Barnes, 1991, 19)

Oliver maintains that this approach to disability reflects a dual process:

[W]hich takes account of both changes in the mode of production and the mode of thought, and the relationship between them.  
(Oliver, 1990, 32)

Workhouses were established to house unproductive segments of the population - the unemployed, women and children - as social assistance was a commodity to be earned. Although disabled persons comprised a significant portion of the unemployed, they were viewed more favourably than the rest of the unemployed population. They were given fewer duties (Stone, 1984). Yet, it should be noted that disabled people often had great difficulty

adapting to the rigours of the workhouse regime, and as a result many were sent to specialist institutions.

Perceived as having limited ability, and considered incapable of acquiring marketable skills, they were effectively shut out of the workforce. Disabled people were seen as a population in need of 'protection', unable to contend with the rigours of an industrialised society (Brechin *et al.*, 1981). This widely held belief justified the removal of disabled people from mainstream society to asylums and other institutional settings (Finkelstein, 1980; Oliver, 1990; Barnes, 1991). Institutions served as a mechanism of social control and provided a visible reminder of those who did not conform to accepted social norms (Oliver, 1990; Barnes, 1991; Abberley, 1998). Many of these practices were imported to North America at the time of European settlement. This philosophy was instrumental in the development of strict policies prohibiting the immigration of persons with disabilities (Bowe, 1978).

The growth of capitalism generated a significant economic surplus. Therefore, elaborate methods were devised to ensure 'effective' distribution of these excesses in the form of complex bureaucratic and institutional structures underlying the welfare state (Oliver, 1990). Removed from society and cut off from social interaction, opportunities for self-sufficiency were limited. Social isolation and segregation had reduced disabled people to a state of almost total dependency. During both world wars non-disabled women and disabled persons were eagerly recruited to fill positions left vacant by men in the armed services. However, when the non-disabled Veterans returned, the 'new' labourers assumed their residual positions. Women and disabled people were hence the workers of last resort (Hahn, 1986). Large numbers of disabled Veterans did little to influence service provision to disabled persons, other than to underscore the economic loss that disability implied and the need to regain it at some level (Carver and Rodda, 1978).

The 'unfit' were and now are still not held accountable or capable and, as such, disabled people were and are exempted from traditional adult role requirements of self-sufficiency and independence (Gartner and Joe, 1987). Expectations concerning the social and economic potential of disabled people are limited accordingly. Being structurally defined as 'unemployable' in order to access basic goods and services does not then promote availability in the labour market or encourage participation in employment programmes. Thus, in a society where the ability to generate income largely dictates social status, disabled people have come to reside at the lowest end of the social spectrum. A 'personal deficit'



approach to disability has thereby remained thoroughly entrenched, reflected in the application of public policy, a point to which this thesis will return repeatedly.

*From institutionalisation to correction: normalising rehabilitation*

...the human being is perceived as flexible and alterable while the physical and social environments are assumed to be fixed and unalterable. This is clearly unrealistic since historically humans have always moulded the environment to suit their needs rather than the other way round ... People with impairments become objects to be treated, changed, improved and made normal.  
(Barnes, 1991, 24)

... it is assumed that disabled people must adapt to a hostile environment. Those who succeed are sanctified and held up as exemplars of individual will and effort, while the majority who do not are referred to as passive, apathetic or worse.  
(Barnes, 1991, 25)

Rehabilitation is a relatively new phenomenon, a product of the post-World War II era. The primary focus of disability policy continues to be directed toward rehabilitation, that is, restoration of individual function as opposed to social accommodation to the individual (Marlett and Day, 1984). This approach promotes a strict division between the professional and the disabled person. Although the disabled person is the central focus, s/he is expected to assume a passive role. Limits are set and the professional maintains control, and the dependency cycle is maintained (Barnes, 1991). Non-disabled professionals deciding 'what is best' make decisions having a direct impact on the individual. What has developed is, in effect, a 'parallel economy' comprised of complex sectors of expert knowledge and practice grounded in the deficit-medicalised tradition of disability (Oliver, 1990).

Workers already *in situ* in the hospitals were sucked into servicing disabled patients and in time these "para-medical" workers spilled over into the custodial institutions. The growth of professions particularly in the past two decades has been phenomenal. Today there is almost no aspect of life for which there is no profession.  
(Finkelstein, 1980, 11)

Disability is perceived to embody the limitation of medical science, and as a result, there is a tendency to ascribe blame to those identified as disabled (Wendell, 1996). Viability is determined by socially accepted arbitrary standards of speed, time and agility according to what is expected of the 'normal body' (Wendell, 1996). We are indeed restricted by the wider socialisation process and able-bodied values remain just below the surface. Independence is defined in terms of sanctioned physicality and fixed ideals of normalcy rarely attainable in either sphere (Butler, 1990; Wendell, 1997).

Normalisation and correction is the scope of modern medicine, and this philosophy is not well suited to the reality of disability (Wendell, 1996). Parallels have been drawn between

the multimillion pound/dollar commodification of disability through rehabilitation and that of non-disabled women through cosmetic surgery (McDowell, 1999). Its tenets are firmly grounded in the medical model. Hence, the perceived therapeutic value (return to normal function) of programmes outweighs the promotion of challenging career development accepting the realities of a person's disability or impairment (Drake, 1999). The normative aspect of training and education is paramount. The thrust of activity is focused on getting disabled people to 'fit in' to the existing workplace environment rather than exploring how various elements within that workplace could be retooled to better suit the disabled worker. The education process serves as a mechanism to reinforce mainstream social values and expectations (Slee, 1996). According to Carver and Rodda, the essence of rehabilitation is:

remodelling to the functional semblance of the average man [sic]—never a simple repair job on a damaged machine ... [This is] old segregation turned upside down, a tidying up operation to keep disabled people and their needs out of sight of the wider culture.  
(Carver and Rodda, 1978, 10)

Options are presented around a narrow linear framework of merely 'appropriate' career opportunities (Slee, 1996). These settings establish accepted sites for disability accommodation, keeping the 'disabled' in their place (Slee, 1996; Gleeson, 1998). Rehabilitation options differ greatly for disabled men and women. Career expectations for disabled women are much lower than they are for men, as many of the duties traditionally undertaken by women are not highly valued and take place outside of the public domain. As a result, rehabilitation options for disabled women are especially minimal (Lonsdale, 1990; Wendell, 1996).

Education, training and transportation services for disabled people are often far more costly than the generic variety, often of an inferior quality to those in the mainstream, and under constant threat of abolition in times of financial restructuring (Carver and Rodda, 1978). Policies and programmes usually reflect able-bodied norms and values (Oliver, 1990), as indicated, and cost-profit elements often outweigh individual 'rights' to service (Imrie, 1996). The major thrust of programming is geared toward improved manual labour and motor skills as opposed to the development of intellectual ability (Barnes, 1991). This approach therefore condemns disabled people to the most precarious service sectors of the labour market, if, of course, they can ever be sufficiently 'rehabilitated' to meet the demands of these sectors (as usually understood and practised).

This situation also results in the development of a large network of sheltered workshops to protect this 'vulnerable' segment of the population while teaching them supposedly

marketable skills. Again, the focus is on manual labour and piecework rather than meaningful skill development. These workplaces are exempt from minimum wage laws and labour codes since workshops are viewed as 'training' facilities being run by charitable organisations (Barnes, 1991). They provide a ready market of low cost unskilled labour (Barnes, 1991). The primary focus continues to be the supply side of labour, making disabled workers more productive, as opposed to transforming the nature and organisation of work itself, thus leaving the existing economic structure entirely intact (Oliver, 1990).

The nature of the economy has a direct impact on who will be best equipped to find and to sustain employment (Oliver, 1992a). By locating the 'problem' of disability or impairment at the individual level, the onus is left with the disabled person to address it. Society is therefore effectively absolved, to a large degree, from taking substantive measures to address, programme or service 'deficiencies'. Incremental changes can be made without compromising the overall socio-economic framework (Oliver, 1990). This has significant implications concerning the manner in which disability and employment are linked.

As far as disability is concerned, if it is seen as a tragedy, then disabled people will be treated as if they are victims of some tragic happening or circumstance. This treatment will occur not just in everyday interactions but it will also be translated into social policies which will attempt to compensate victims for the tragedies that have befallen them.  
(Oliver, 1990, 2)

The rhetoric of dependency, if viewed critically, can be seen to ignore both the wealth of evidence on disabled peoples' employment barriers, factors clearly outwith the power of individual agency. The rhetoric can also be seen as victim blaming.  
(Roulstone, 1998b, 1)

While the need for such services is recognised, the individualised 'fix-it' approach does not effectively address the broader social realities that interact with disability such as: class, race and gender. This narrow approach over simplifies the complexities of disability and reinforces a 'disadvantaged' marginalised status.

Shifting the locus of disability/impairment intervention away from the disabled person, focusing instead on broader socio-economic barriers, as advocated by social oppression theorists Oliver, Barnes and Abberley, disability-employment issues could perhaps be dealt with at a broader structural level rather than on an individual *ad hoc* basis.

A social theory of disability ... must be located within the experience of disabled people themselves and their attempts, not only to redefine disability but also to ... develop services commensurate with their own self-defined needs.  
(Oliver, 1990, 10)

... increasingly in recent years disabled people have come to recognise that the term 'disability' represents a complex system of social restrictions imposed on people with impairments by a highly discriminatory society.

(Barnes, 1991, 1)

Oliver maintains that both impairment and disability are socially constructed, linked to an elaborate mixture of social and economic factors (Oliver, 1990). An individualised approach has created little incentive for change. It has worked to validate and reinforce differential treatment of this population group by the state:

where attempts are made to influence the work system, they do not have the desired effect because, on the whole, these programmes tend to focus on labour supply. Their aim is to make individual disabled people suitable for work but while they may succeed in individual cases, such programmes may have the opposite effect. By packaging and selling them as a special case, the idea that there is something different about disabled workers is reinforced and may be exclusionary ...

(Oliver, 1990, 86)

This approach reinforces the special but not equal approach to accommodation; entrenching the idea that disability/impairment issues present far too great a difficulty to address in the 'average' workplace. It serves to legitimate the need for the parallel 'sheltered' economy.

Oliver maintains that this approach to disability reflects a dual process:

... which takes account of both changes in the mode of production and the mode of thought, and the relationship between them.

(Oliver, 1990, 32)

### **Education and training: fuelling the political economy of disability**

There is limited acknowledgement of the need for labour market reform, but responses are muted by the need to satisfy the more powerful perceived needs of business and industry (Drake, 1998; Thornton, 1998). There is a serious shortcoming associated with charitable voluntary disability or impairment specific agencies involved with service or programme delivery, particularly job training or employment opportunities. This is not their principal area of expertise. In Britain and Canada these agencies are primarily concerned with community fund raising for a specific client-base. Agencies only deal with individuals who 'fit' their criteria, and many agencies only assist people with specific types of disability.

Focusing on a specific single element may have an undesired side effect:

[A]s a political strategy strategic essentialist political positionings can work in more subtle ways, which support the *status quo*.

(Moss and Dyck, 1999, 160)

This is an incarnation of the 'biomedical' approach' to disability (Moss and Dyck, 1999). It serves to underscore and to reinforce the medicalised, 'differentness' between the non-

disabled and disabled populations. Disabled people find themselves having to meet criteria unrelated to their immediate job training needs. This situation is particularly difficult for individuals with multiple disabilities who cannot easily be 'slotted' into a disability specific grouping, since persons wishing to access a given programme must first fall into the appropriate category (Roehrer, 1990). Unlike non-disabled persons who have a more direct route to job training and related activity, disabled persons face this additional obstacle (Roehrer, 1990). This process is now even more complex given that state-sponsored training programmes are increasingly tied to previous labour force activity (Fawcett, 1996). Again, this presents particular difficulties for disabled women, given that they are much less likely to have had previous labour force exposure given domestic labour and primary childcare responsibilities.

Individual needs may be obscured in the process of meeting programme or funding requirements. Community-based programmes lack consistency and portability (Roehrer, 1990). Throughout the 1980s in Britain and 1990s in Canada the devolution of state-run large-scale institutional settings and the privatisation of training programmes, resulted in the creation of a myriad of largely unregulated private service agencies of varying quality (Barnes *et al*, 1998). Thus has begun a two-fold process, charitable agencies traditionally associated with training programmes for disabled people now being faced with bidding for contracts in association with other private contractors in the field. Furthermore, the need to tie programmes to specific disability groups leads to unnecessary programme duplication and 'territoriality'; that is, various disability groups in competition for limited funds for similar projects.

[T]hey diffuse political strength and groups end up fighting amongst themselves rather than challenging, for example, the domination of insurance companies in designating benefits for particular illnesses ... they do not capture the multiple, shifting and fluctuating character of any one person or any one group, and, as a result ... efforts to challenge the dominance of biomedicine ... are dampened.

(Moss and Dyck, 1999, 160)

This is a questionable method of funding allocation in a field where resources are traditionally scarce. The residual nature of funding for these community-based programmes leads one to ask a difficult but necessary question; are these programmes geared to facilitate meaningful, gainful employment or is it just another manifestation of busy-work, filling in time and keeping people occupied? Is it yet another manifestation of the parallel economy of rehabilitation? Continuous training is not a career choice.

It is noteworthy that, despite the on-going under-representation of disabled women in the labour force, there is very little programme development in Britain or Canada geared to this population group (Barnes *et al.*, 1998). Perhaps this is a further indication of the lack of value placed on women in the workplace. It is almost impossible to expect co-operation in setting common goals and defining objectives when organisations are pitted against each other in competition for limited funding. For example, agencies competing for National Lottery funding must satisfy the programme requirements of undertaking 'innovative work'. Grants are awarded for a three-year period. Thus, when an agency is providing a needed service and again requires funding, if the programme is no longer seen as 'innovative', this funding can be withdrawn regardless of the need for the programme itself. This is not the way to maximise the benefits derived from such resources. This *ad hoc* approach to programme creation does not lead to development of coherent goals and objectives for this population-base as a whole. Agencies find themselves caught up in trying to satisfy the objectives of funding bodies in order to access needed resources. Valuable time and energy is spent completing forms and reports by agencies with few personnel and limited time, whose efforts could be better spent with programme development and delivery.

Although charitable agencies provide a significant amount of employment training to disabled people, a charity's expertise is fund raising, not job training. The needs of the individual may not always correspond with the goals of the agency. Budgetary constraints and the need to access future funding impact directly on the type of programmes offered and the personnel hired. This is of particular significance given the importance of computer technology in the workplace. Computer programmes are changed and up-dated at a dizzying pace, and this does not promote long-term skill viability (Barnes *et al.*, 1998). Chronic under-funding and employment insecurity does not attract highly qualified instructors, often to the detriment of the programme. Furthermore, the emphasis on computer training assumes access to this type of equipment in order to maintain acquired skills. The high cost associated with technology is an insurmountable barrier to disabled individuals, most of whom live in poverty. The expense of computer technology is far too great for many disabled people, and often appropriate support and education services are unavailable (Sheldon, 1998). Reliance on technology, while in some cases facilitating action, may create a reluctance in society to remove other barriers, thereby leading to further social isolation (Sheldon, 1998). There may be additional difficulties for disabled women given that technology has traditionally been treated as a male preserve (Roulstone, 1998a).

From a social perspective, 'integrated' classroom settings with effective support would lessen the perceived 'differentness' between disabled persons and the non-disabled. In addition, the 'comfort level', as in the readiness to be around one another, would be increased for both parties, providing education far beyond the classroom. Failure to initiate integrated training programmes has the effect of maintaining the status quo. Inferior 'special' programmes and services disadvantage disabled people; they remain prisoners of a segregated society. Often, disabled people do not receive relevant career information, and the traditional service worker manual labour market niche held by disabled workers has been seriously eroded due to down-sizing and technological advancements (Berthoud *et al*, 1993).

Access to both quality adapted and 'generic' mainstream programmes with adapted services and support is the only means by which this deficiency can be effectively addressed. While it is recognised that some people with severe multiple disabilities would require more creative adaptation and support, this is not an impossible task. The advantages of such an approach are numerous. Disabled persons would have access to the same calibre of training programmes and services as their non-disabled counterparts, thereby increasing the likelihood of post-training employment. Quality skills and education greatly increase the prospects of employment, particularly for disabled women (Fawcett, 1996).

### **Reshaping the normal workplace (or not): technological fixes and more modest solutions**

Rehabilitation and training programmes still do not examine the deeper nature and philosophy of employment, nor address the realities of the everyday workplace environment (Drake, 1998). An important caveat is that job training does not mandate paid employment. Workplace culture itself remains grounded in the deficit perspective of disability. That is, the focus of disabled person's employment initiatives continues to be getting the individual disabled person to 'fit' into existing work settings or environments. There is little thought here about reshaping the workplaces into which such people may possibly (if they are lucky) be admitted: the work environment itself is often perceived as being sacrosanct. Where thought is given to reshaping, all too quickly technology is held out as the ultimate solution, often to the detriment of considering more modest solutions addressing questions of time, space and social attitudes. So long as this perspective and its underlying structures are unaltered, substantive improvement in the employment status of disabled people will continue to be incremental.

## *The technological fix*

New technology is changing the nature of the workplace and work itself (Roulstone, 1998a). Software innovations ensure physicality and dexterity are no longer paramount. Finkelstein is positive in his assessment of the technical age, believing that it will provide the mechanism to challenge the 'professional' control experienced by many disabled people:

The most important stimulation for this development ... has been the new electronic technology for automating the production-line. This technology enables the most severely physically impaired people to operate environmental controls which enable them to live relatively independently in the community.  
(Finkelstein, 1980, 11)

In many ways the determinist view of technology and disability reflects elements of the medical model, as it holds out a technological 'fix' as the latest panacea to integrate disabled people into mainstream society (Sheldon, 1998). Oliver is therefore more guarded in his assessment of the benefits of technology as a means to positive change for disabled people, criticising such views:

They are over simplistic in that they assume a simple relationship between the mode of production and perceptions and experiences of disability, without considering a range of other influential factors.  
(Oliver, 1990, 29)

If then, the disability movement is central to ensuring that technology is used to liberate rather than further oppress disabled people, then a clear understanding of this double-edged nature needs to be developed within the movement.  
(Oliver, 1990, 126-27)

Employers may hold the misinformed view that expensive technology effectively eliminates impairment, whereas simple adaptation or assistance may be far more useful (French, 1994). Furthermore, the technology may actually place greater pressures on the disabled individual to produce more work at greater speed (Roulstone, 1998c). Although technology can hold great potential for disabled people, technology is not social destiny; it works in conjunction with a multiplicity of other factors (Sheldon, 1998). Many people with disabilities live in extreme poverty, lacking the financial means to access technology (Erevelles, 2001) The technology itself may act as a barrier to integration, in effect 'de-humanising' people with disabilities in the workplace. However, this element is not presented here as an argument against its introduction, only that technology be introduced in a thoughtful manner.<sup>4</sup> Often

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<sup>4</sup> The introduction of technology is a complex issue and is not simply 'good' or 'bad' as it is part of the larger social-cultural context in which it is placed. While technology has enabled many disabled people to participate more fully in daily life, at the same time, some aspects of technology may create barriers to access. It may mean



simple but hard truths can be obscured by the trendiness of technology. As Michalko and Titchkosky rightly point out, technology cannot be introduced in order to *avoid* addressing many other basic workplace culture and attitude issues:

[W]hile adaptive technologies and techniques may make it possible for disabled people to “function” in some segments of society, they do not guarantee that disability will be conceived as belonging in and to society.

(Michalko and Titchkosky, 2001, 212)

Serious gaps still exist concerning disabled employment policy and its relationship to daily activity in the workplace (Lunt and Thornton, 1994). Implementation of employment equity and anti-discrimination legislation for disabled people has had little impact thus far. Employers are reluctant to alter traditional hiring and recruitment testing methods or job descriptions for fear of being perceived as giving undue advantage to disabled people. Change to established practice is often uncomfortable, especially when the need or reason for it may not be accepted or understood. Employers’ wage allocation subsidies and awards underscore the dominant notion that disabled people are inferior workers (Lunt and Thornton, 1994). Consequently, disabled employees may feel pressured to work at an exceptional level order to gain approval and to counter misconceptions. Accommodation may be viewed as disruptive to the work environment rather than as a required component enabling the employee to work effectively (French, 1994; Pinder, 1996). There is limited understanding of the disabled person’s organisation of time and speed factors associated with disability or impairment so as to function effectively in daily life. There is hence a pressing need to acknowledge the embodied time and space needs of disabled employees in the quest for ‘equality’, and this will be addressed again in the qualitative part of the thesis. Little, if any, thought has been given to possible defects inherent in the regular work environment that may require correction (Imrie, 1996). Attention to the location of toilets, the presence of stairs and adapting shelving height are mundane but necessary elements. The popularity of ‘managing diversity’ courses does not necessarily lead to a knowledgeable employer-base, as many are unaware of employer assistance programmes addressing disability issues in the workplace (Barnes *et al*, 1998); and so the possibilities for engineering more modest – but probably much more useful solutions remain largely unknown.

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different things to different people over time and space. The coexistence of these factors may be a source of tension requiring a delicate balance be maintained.

## Conclusion

Social and cultural attitudes towards disabled people as workers or as potential employees remain unaltered. Often it is the disabled employee who is expected to be the complete disability information source on the job (French, 1994), and this situation can create additional pressures in the workplace. Many people with disabilities are coping with embedded social practices, cultural attitudes and prejudices of non-disabled co-workers and employers. Again this will be dealt with further in the qualitative portion of the thesis. There are few, if any, support systems for disabled people in the workplace, and often employees are alone and isolated (French, 1994). Moreover there is very limited consideration of disabled women's work experience beyond quantitative differences with male counterparts or non-disabled women, perhaps because women, disabled or not, are still considered atypical in the work environment (Morris, 1994; Barnes *et al*, 1998). Exploring the education, community and work realities of women with disabilities in Britain and Canada today is an effort to shed light on this 'obscure' minority group. Putting disabled women's voices at the forefront presents a rare perspective, providing a forum for the views of those individuals about such realities and impediments.

## **Chapter Three**

### **Feminism and disability:**

#### **from deviant to distinctive, making a place for disabled women**

Traditionally, there has been a tendency to view disabled people as one homogeneous group with no gender distinctions. The reality of being a disabled woman and having a physical disability has, to a large extent, been overlooked by both the disability and feminist movements.

(Begum, 1992, 61)

### **Introduction**

The foundation of mainstream feminist theory and practice questions the apparent neutrality and normality of the dominant patriarchal social/political hegemony found in Western society. Feminism has played a pivotal role in underscoring and reducing the power differential experienced between men and women stemming from the historical position of privilege yielded to white, non-disabled males. Feminist theorists have begun creating place and space for women, valorising their traditional private wife/mother roles in the social mainstream (Brown and Smith, 1993; Thompson, 1997). In addition, feminism disputes the value of paid-work as the sole means of acquiring a valued social position (Brown and Smith, 1993).

There are many parallels to be drawn between the tenets of feminism and the disability rights movement characterised most strikingly by historic power imbalances attributed to the presumed physical and mental dominance of non-disabled white males (Thomson, 1997). At its heart, the disability rights movement challenges social assumptions concerning human physicality, ability and intellect (Thomson, 1997).

Both the female body and the disabled body are cast as deviant and inferior, both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority.

(Thomson, 1997, 19)

Despite these common points of reference, disabled women have had few opportunities for inclusion in the wider culture. They have remained all but invisible on the fringes of the feminist and disability rights movement (Morris, 1991a; Begum, 1992). Chouinard (1999) refers to disabled women as, the “relatively ‘invisible’ sisters in the supposedly common struggle for women’s rights”(Chouinard, 1999,146). This lack of presence may be attributed to two principal factors; the inability of mainstream feminist theorists to recognise the

concerns of disabled women as 'women's' issues, coupled with the inability of the disability rights movement to acknowledge gender issues (Dreidger, 1989). The dearth of recognition within the disability rights movement may be ascribed, at least in part, to the lack of female representation within the leadership and a corresponding lack of emphasis placed on 'women's' issues (Dreidger, 1989). There is an assumption that other aspects of identity (gender or sexuality) will be addressed by other groups within the community, but this has not happened (Vernon, 1998). Few allegiances found with disabled women are found amongst non-disabled feminists (Begum, 1992 meanwhile), and mainstream feminism has been slow to recognise that the category 'women' encompasses disabled women (Brown and Smith, 1993). It is as if gender and disability are perceived by mainstream society as being mutually exclusive (Morris, 1993). The phrases 'the disabled' and 'disabled people' found in some feminist literature underscore the non-gendered approach to disability issues (Morris, 1991a/1992a; Shakespeare, 1996), and there have been few attempts to integrate these elements within feminist discourse (Morris, 1994).

Mainstream feminism is a curious mix of politics, individual identities and practical processes that do not always meld well together (Thomson, 1997). There is significant discontinuity between the comfort level afforded by theoretical abstractions and the uneasiness which renders itself in reality amidst centuries of dubious social conditioning. Feminism is not immune from the enculturation of negative attitudes associated with disablement: "[c]ulture mediates all individual experience, imposing systems of perception that are not easily revised" (Thomson, 1997, 34). This may also reflect the private/public dichotomy of disability in that certain aspects of disability reality may be accommodated, such as the provision of public accessible toilet facilities, while there remains a reluctance to accept supposedly private matters of gender or sexuality as part of the disability reality (Shakespeare, 1996). Comparisons may be drawn with mainstream feminism's advocacy of 'the woman's right to choose' whether or not to terminate a pregnancy, as contrasted with some lack of acceptance of 'the right to choose' a same sex relationship (Butler, 1990).

There are certain aspects of women's oppression, which highlight the parallels and differences between disabled women and non-disabled women. The basic issues may be the same for both groups but the impact of disability means that the implications or effects may differ.  
(Begum, 1992, 64)

For the most part, mainstream feminist scholarship has been lacking any meaningful analysis of disability issues. There appears to be a reluctance to theorise disability and gender as though it were a lesser element of feminist studies (Erevelles, 2001). The current limited

analysis provides an important opportunity to adapt existing theoretical and political foundations to reflect better the reality of *all* women. Disabled feminist scholars have assumed a leadership role in this process. The task has not been an easy one as Chouinard (1999) explains:

Struggles to empower the disabled are waged largely by people who have committed themselves to the struggle for disability rights; and because of this their personal passages are out of step with those in power. Perhaps this is what struggles to make space for disabled women and men in academia and beyond are all about: *disrupting* spaces of power and privilege to the point where those who dominate such spaces are forced to recognise the difference that disabling differences make, and are confronted with the roles they play in sustaining such cultural oppression.

(Chouinard, 1999, 146)

There is a need to de-code, deconstruct and reconfigure core elements comprising mainstream feminist discourse in order to move beyond the current marginal understanding of disabled women and hence to:

Go beyond the narrow focus of the gender socio-political critique of systemic, inequitable power relations based on social categories grounded in the body.

(Thomson, 1997, 21)

## **Knowledge and research**

The subject of Feminism is produced and restrained by the very structures through which emancipation is sought.

(Butler, 1990, 2)

People who want to address dirty (Other) topics, people who themselves may be defined as Others (such as the physically weak, frail, diseased, homosexual, elderly, black, poor, working class, and so on), are forced to struggle for legitimation of their interests in the discipline.

(Longhurst, 1997, 494)

Traditional feminist research reflects the privileged Western perspective of a comparatively small group of women (hooks, 1982; Butler, 1990; Chouinard and Grant, 1997). Therefore, the multiplicity of identities comprising women has proved secondary to the over-all social and political dynamics of the 'women's movement'. Inclusion of oppressed populations has not always been an integral part of the feminist theoretical process (Morris, 1991a). The unity and universality present in the concept of 'common oppression' has worked to exclude, or at the very least, to obscure difference, with questionable results (hooks, 1982; Butler, 1990; Young, 1997). There has been a tendency to:

[m]inimize differences to achieve equality and those who would elaborate differences to valorize the feminine has been complicated by an interrogation of gender construction itself and a recognition of multiple axes of identity, both of which profoundly challenge the very notion of “women” as any kind of unified identity category.

(Thomson, 1997, 21)

Therefore, examining disability has largely taken place in the absence of disabled women without taking into account their experience or knowledge base (Morris, 1992a). Wendell (1996) maintains that being labelled ‘special’ has worked to exclude the experience of disabled women in the development of feminist theory. Mainstream theorists have for the most part failed to attribute the strength in diversity argument to disability in the same manner that it has slowly been accorded to other marginalised groups (women of colour and lesbians) on the periphery of the ‘sisterhood.’

Feminist researchers are not immune from the cultural influences that shape attitudes and values. Cultural norms of physicality are present in benign circumstances and have a direct impact on perceptions. (Wendell, 1996; Bordo, 1997; Young, 1997). According to Chouinard and Grant (1997), ableist presumptions (negative attributions about disability) are present in every element of social interaction. Much of mainstream research draws on deeply embedded ableist stereotypes reflecting cultural norms which are restrictive and deficient (Hawkesworth, 1989; Lisi, 1993).

A superficial understanding has resulted in a reductionist and dismissive approach to disability (Morris, 1991; Chouinard and Grant, 1997). The basis for current theoretical weaknesses is thereby rooted in a deep-seated fear of difference that is rarely recognised and almost never acknowledged. The deviance present in the disabled body may be perceived as a threat to the much coveted social order (Hahn, 1989; Corbett; 1997; Morris, 1997; Thomson, 1997).

Just as white skin is presented as the norm - in the sense of being average and the goal to be strived for -- so lack of physical and learning impairment is also the norm.

(Morris, 1997, 21)

Feminists ought to be able to critique their own internalisation of such norms, therefore, and in so doing embrace disability as part of the feminist project.

Disabled female bodies are judged to be redundant and subordinate (Asch and Fine 1997; Thomson, 1997). The ‘tragic but brave’ disabled woman is perceived as a liability to the normative strong, independent, ideal of womanhood (Peters, 1996). Disability is expected to

be individual, isolated and, above all, private (Morris, 1991). Corbett, a disabled woman, thus writes as follows:

Assimilation is not the answer it denies our differences, our needs and our perspectives. It makes our identities invisible. Yet, such is the power of the status quo that we are usually socially conditioned to hide our differences.

(Corbett, 1997, 167)

The invalidation experienced by disabled women is not unique; other disenfranchised groups have encountered similar social alienation. bell hooks, an African American feminist, has expressed similar concerns, although her use of the term 'blindly' gives pause for thought in the following argument since the use of the term is offensive to many people with vision impairments:

American women, irrespective of their education, economic status, or racial identification, have undergone years of sexism, racist socialisation that has taught us to blindly [sic] trust our knowledge of history and its effect on present reality, even though that knowledge has been shaped by a repressive system ...

(hooks, 1982, 121)

Thomson, a disabled African American feminist, echoes hooks' sentiments:

Disability is the attribution of corporeal deviance - not so much as a property of bodies but as a product of cultural rules about what bodies should be or do.

(Thomson, 1997, 6-7)

This process of social stigmatisation is rarely questioned, except to study the coping mechanisms developed by those individuals who are most directly impacted by it (Peters, 1996). The end result is often replication of the oppressive social roles found in the wider society (Peters, 1996). An important further step must hence be the recognition that these influences have also had a significant impact on much of the critical analysis completed to this point. Serious information and interpretative gaps can be found in much of the conventional feminist research concerning disability. Disabled women find themselves in the midst of a curious balancing act straddling simultaneously both inside and outside the category of 'women' (Thomson, 1997). "Disabled women live within two sets of devaluing expectations" (Brown and Smith, 1993, 162). Disabled women are not viewed as distinctive, but, rather, as deviations from the norm (Lisi, 1993). There is a distinct 'us'/'them' division found in much of the literature (Morris, 1991a; Wendell, 1997).

At a fundamental level, the traditional role of women has been deemed inappropriate for disabled women (Young, 1997). Disabled women are rarely seen as ideal role models for motherhood or reproduction and at times their very existence is called into question, as is

shown by the often unquestioned arguments concerning the elimination of so-called 'defective' births (Corbett, 1997; Morris, 1997; Thomson, 1997). Yet feminist theorists have focused their discussion of disability, insofar as it has occurred at all, merely to the impact on non-disabled women as caregivers. Community care is discussed in terms of exploitation and a lack of institutional availability compromising the lives of caregivers, as opposed to considering what might facilitate independence, personal autonomy, choice and agency for those cared for (Wendell, 1996, 1997; Meekosha, 1998). In addition, mainstream writers fail to acknowledge that disabled women themselves may be carers (Morris, 1991, Wendell, 1996). One writer surmises:

Separating out of disabled and older women from the category 'women' comes about because of a failure of the feminist researchers concerned to identify with the subjective experience of 'such people'. The principle of the personal is political is applied to the carers but not 'the cared for'. (Morris, .1991a, 29)

Hillyer (1993) examines the concept of reciprocity in terms of care provision, yet, the voice of the woman receiving care remains silent. Therefore, a crucial balancing element is absent and the power differential remains unchanged (Wendell, 1996; Meekosha, 1998), with disabled women left as mute objects of care:

The ethics of 'care' as approached by mainstream feminist scholars undermines semicircular reciprocal relations amongst disabled and non-disabled women ... Making disabled women objects of care risks casting them as helpless in order to celebrate the nurturing as virtuous feminist agencies. (Thomson 1997, 26)

Thomson (1997) asserts that the caring elements presented and critiqued by mainstream feminism supersede equality issues and maintain an overreaching oppressive structure detrimental to disabled women:

To be granted fully human status by normates (able-bodied people) disabled people must learn to manage relationships from the beginning. In other words, disabled people must use charm, intimidation, ardor, deference, humor or entertainment to relieve non-disabled people of their discomfort. (Thomson, 1997, 13)

Mainstream feminist writers readily identify the subject-object dichotomy that non-disabled women experience in the world at large, and mainstream feminism would therefore appear to provide the ideal theoretical platform to address the current power imbalances experienced by disabled women (Thomson, 1997). But there is an apparent inability to apply this insight to disabled women, perhaps because this group represents the ultimate loss of control and independence as defined by the wider culture (Wendell, 1996; Young, 1997). Disabled women remain disembodied, largely absent from the analytical process (Young, 1997).



Questions of context and interpretation raised by disabled women are often misinterpreted as frustration arising from disablement as opposed to a lack of social justice (Morris, 1997). There is a tendency to over-simplify and to infantilise disability issues particularly relating to issues of personal care and sexuality (Corbett; 1997, Morris; 1997, Thomson; 1997). Perhaps this can be traced to an inclination to confuse the need for personal assistance with childlike dependency and similarly to treat children as non-sexual beings (Corbett, 1997, Thomson, 1997). This level of discourse creates little if any place or space for the adaptations theoretical and otherwise to participate on a substantive level in the processes of research, politics and effecting social change (Morris, 1997).

Disabled women are restricted by the wider socialisation process, and able-bodied values remain just below the surface. Independence is defined in terms of linear physicality and fixed ideals of normalcy rarely attainable in either public or private sphere (Butler, 1990; Wendell, 1997).

However, while some disabled women may have found 'voice', much of the disability experience remains shrouded within the community of disabled women and caught up in the public/private dichotomy of tentative social acceptance (Wendell, 1997). Certain aspects of disability reality are thought to be too disturbing for mainstream sensibilities. Distorted preconceptions frequently permeate discussions concerning autonomy, independence, choice and pain, often reflecting more the fears of the non-disabled than the reality experienced by disabled women (Wendell, 1997, Thomson, 1997).

Breaking the silence on gender and disability issues has been left to disabled women themselves, writing and speaking of their own experiences. These efforts have been instrumental in moving away from the objectification that permeates most disability discourse (Meekosha, 1998). Disabled women are demonstrating their social agency as social actors. However, individual experience has often been devalued in academia as being atheoretical and dismissed as anecdotal (Morris, 1992a). Theoretical in-depth analysis and synthesis remain absent (Meekosha, 1998). In order fully to develop feminist perspectives on disability requires that disablement and impairment be carefully integrated within the race, class and gender continuum. A broader spectrum of analysis is necessary in order to achieve a complete analytical framework incorporating the numerous factors that impact on gender and disability issues. Validation of the lived experience of disabled women is central to this process; coupled with the recognition that disability and impairment are important elements in women's reality.

Mainstream feminism has been slow to incorporate the scholarship of disabled women (Lisi, 1993). Disabled women have slowly begun to make inroads within the broader feminist movement. However, the knowledge base of this constituency remains profoundly displaced and invalidated. *Who's* knowledge is considered 'valid' and *what* is 'recognised' as knowledge remains a point of contention (Longhurst, 1997). Linear notions of disability and burden remain intact (Meekosha, 1998). The power differential is omnipresent, and 'place' in 'the project' is granted on an 'on approval' basis (McDowell, 1999; Peters, 1996). The non-disabled majority determines terms and conditions of membership, often for reasons that benefit that same group and usually as 'add-ons' or after-thoughts (hooks, 1982; Morris, 1992a). Altered phrases and politically correct language are insufficient if the underlying value structure remains intact (Connors, 1985). A fundamental shift is required if disability is to become an integral part of feminist discourse accepted truths must be challenged with the same critical vigour that has been applied to other women's issues. A central element is to:

"[r]ecast disability from the medical context of bodily particularities into the context of social power relations"  
(Thomson, 1997, 6).

Innovative funding and knowledge gathering processes require development by and with disabled women in substantive roles at every stage (Haraway, 1997). Key to this process is the recognition and acceptance that disability is no longer a matter for 'us' or 'them', but centrally located as part of 'we' (Wendell, 1997).

## **The body**

Averted and silenced, the disabled body presents a threat to the very idea of the body, the body in its pure, empty form. It is this idea that informs the prevailing normativities of the body. And it informs current theoretical views of the body as well.  
(Porter, xiii, 1997)

Society subjectively defines certain characteristics as valuable, while others are to be avoided or eliminated (Young, 1997). Gesler and Kearns (2002) explain how this subjective process is used to validate differential treatment:

The strategy is often used in constructing cultural difference is to *naturalize* it or make it appear as though it is only natural, the way of the world, an understood truth, not subject to question. Naturalization serves also to *legitimise* a system of difference.  
(Gesler and Kearns, 2002, 99)

Western society arbitrarily imposes fixed bodily expectations on its membership (Morris, 1991). Acceptable shape, size, colour, height, sexuality and physicality are all culturally mediated (Butler, 1990; Young, 1997):

Concepts of race, gender and class shape the lives of those who are not black, poor or female, so disability regulates the bodies of those who are 'normal'. The concept of normalcy by which most people (by definition) shape their existence is in fact tied inexorably to the concept of disability. Normalcy and disability are part of the same system.  
(Davies, 1995, 2)

Much of what society accepts and understands of disability is driven by history, economics and productivity which is based on dogma rather than wisdom or facts (Davies, 1995): (see Chapter Two) Indeed, the tenets of the Industrial Revolution and associated labour market practices lie at the heart of assumptions concerning bodily worth and inferiority (Hahn, 1989; Brown and Smith, 1993; Davies, 1995). These elements also play an integral role in determining and regulating normative practices related to the body, segregating those individuals who do not meet the desired value standard (Hahn, 1989, Davies, 1995, Thomson, 1997). The ideology of eugenics haunts the discourse of average capacity of the body as machine in an industrial society (Hahn, 1989). Perfection is equated with uniformity and the norm (Davies, 1995, Morris, 1997), and disability is equated with the non-standard deviant population (Hahn, 1989, Davies, 1995). Thus, disabled women represent extreme bodily eccentricity, non-male imperfection:

Nowhere is the disabled figure more troubling to American ideology and history than in the concept of work; the system of production and distribution of economic resources in which abstract principles of self government and self-determination, autonomy and progress are manifest most completely.  
(Thomson, 1997, 46)

Mainstream feminists have been instrumental in underlining the degree of bodily objectification experienced by able-bodied women in Western society in all aspects of daily life, from media representation to the cosmetics industry (McDowell, 1999). These efforts have established important parameters of socially acceptable portrayals and behaviours toward women (Young, 1997). Disabled women are not at odds with these gains; the approach is from a slightly different angle. Culturally accepted symbols such as cosmetics are often used to affirm humanity, gender and sexuality as there are so few positive cultural markers relating to women and disability (Begum, 1992). Using traditional markers is a means of 'passing' and addressing negative imaging in the wider society (Asch and Fine, 1997: See also Chapter Seven).

The feminist movement has its critics in this respect. McDowell (1999) maintains that the body image presented by the mainstream assumes a level of fitness and aesthetic perfection to which few disabled or even non-disabled women can aspire. Disabled women are not usually readily identified as sex objects (Lisi, 1993). Similarly, Wendell (1996) and Young

(1997) assert that feminism has yet to address the so-called negative, ugly or disabled body image:

There is a need to pressure feminism to acknowledge physical adversity, [and] more thoroughly acknowledge the immediacy and complexity of physical existence.  
(Thomson, 1997. 24)

The disability rights movement has also ignored the concept of impairment and body image, perhaps because of assumed links to the medical model (Morris, 1991; Wendell, 1996: See also Chapter Five). Avoiding the intimate aspects of disability impairment and the body has meant that much of the disability/abnormality dichotomy remains intact and unchallenged. A growing number of disability theorists are advocating that the concept of impairment be reconfigured, however, so as to better reflect the diversity of disabled women without detracting from the pivotal rights elements of the social model (Crow, 1996; Pinder, 1996).

Whether or not group membership is valued can have profound social and personal consequences. Throughout history various racial, social and religious groups have been singled out as unacceptable (Young, 1997). The disabled body, and within that context the disabled female body are not seen as a 'natural' part of the community (Asch and Fine, 1997). Open 'public' spaces with little or no seating, many stairs and poor signage mark subjective expectations of physicality (Chouinard and Grant, 1997). Systems of segregated housing, education, transportation and employment keep those who do not fit the mould in their place (Baird, 1992). According to Thomson (1997), public and private environments are designed for the non-disabled privileged body. Fear of difference is arguably the underlying rationale, although it is rarely articulated as such (Baird, 1992; Young, 1997).

Able-bodied people can often make the leap into the skins of people physically unlike themselves; women can identify with the male protagonist in a story, for example, and adults can identify with children or with people much older than themselves. Something more powerful than being in a different body is at work. Suffering caused by the body, and the inability to control the body, are despised, pitied and above all, feared. This fear, experienced individually, is also deeply embedded in our culture  
(Wendell, 1997, 267).

In many ways disability has been a pivotal factor in defining cultural norms of the body, but this matter has not been taken up by the mainstream feminist movement (Dorn, 1998). There is also a tendency to view ability as good and disability as evil (Butler, 1990). As a society we have yet to develop a comfort level associated with impairment, pain, or fatigue that ventures much beyond avoidance (Wendell, 1996). Disabled women are viewed as somewhat removed from the 'normal' (Thomson, 1997a), and here the

disability/abnormality/pathology continuum is firmly entrenched (Young, 1997). Science objectifies and dominates much of the discussion about disability (Young, 1997), while assumptions about the static nature of disability and impairment permeates the discourse (McDowell, 1999).

Society has medicalised disability in much the same way that it has childbirth (Wendell, 1997). Baird (1992) maintains that on a per capita basis world-wide most disability is caused by malnutrition, yet the bulk of funding is directed toward genetic screening. Discourse around abortion and disability is directed toward elimination as opposed to accommodation (Finger, 1992). Many disabled feminists support reproductive choice for all women, but a problematic element here is the absence of the knowledge and experience of disabled women (Morris, 1992; Finger, 1992). In many countries disabled women are routinely subjected to sterilisation (Finger, 1992). Sexuality and reproduction are deemed inappropriate for disabled women (Thomson, 1997). The elements of contested control, choice and integrity over, for and of the body present in much of mainstream feminist writing are found here, the difference is only a matter of degree.

Technology presents opportunities for disabled and non-disabled women, and this possibility has been touched on in Haraway's (1991) writings about feminism and cyborg technology. However, disabled writers approach such theorising with reservation, maintaining that it presents an oversimplification of technology and the body, ignoring the real-life complexities that impairment presents (Dorn, 1998; Meekosha, 1998). As Erevelles (2001) states:

Those disabled people who face economic deprivation on a daily basis seldom have access to the technology that can offer their "unliveable" bodies the cyborgian possibilities, that poststructuralists extol ... By locating their emancipatory practices within the space of the social imaginary, as opposed to the actual materiality of economic conditions, poststructuralists continue to uphold a utopic vision of emancipation that can never be achieved because it exists within the realm of fantasy. (Erevelles, 2001, 98-99)

Furthermore, writers are concerned by the aberrant representations which may foster ableist comparisons of impairment and disability with mutant life-forms, a reflection of the medical model (Dorn, 1998). A more appropriate and challenging vision, though, would be to insist that:

Imperfection is the essence of being organic and alive. Cardboard ideals of perfection are flat and pale by comparison. (Tollifson, 1998, 106-112)

Medical authority remains paramount in shaping and controlling all aspects of disabled women's lives (Baird, 1992; Dyck, 1995; Wendell, 1996, Parr, 2002). Feminism and the disability rights movement can together play an important role in moving away from perfect body syndrome. Deeply held truths about what comprises the 'woman's body' require critical and creative analysis outside of the narrow objectifying boundaries of science. In many ways, it represents the natural evolution of how the movement has created a new set of perspectives beyond the overreaching normative which has gone before, and here the authority of medical science cries out for critical mediation. Above all, the disability/pathology dualism must be abandoned in favour of a model that values and respects bodily difference (Thomson, 1997); physicality should not be the sole determinate of bodily worth (Lisi, 1993).

## **Social role**

Throughout history, those who live with disabilities have been defined by the gaze and needs of the non-disabled.  
(Fries, 1997, 1)

As a society, we do not incorporate difference easily (Lisi, 1993). Disabled women have been deeply devalued in both in their traditional individual role as women and on a broader social level as participants (Connors, 1985). The gender aspect of disability remains largely invisible in all respects (Shakespeare, 1996). Many disabled women have difficulty reconciling the role of woman with the role of disabled person, as they are often placed in an untenable either / or situation of having to choose between the two (Peters, 1996). There has yet to be an effective social synthesis of identities, perhaps because neither role is particularly valued (Asch and Fine, 1997). The common perception of disability in public domain is a disabled male in a wheelchair (Shakespeare, 1996). This is a very narrow continuum and does not reflect the diverse reality of disability. There is a widely held belief that the 'global nature' of disability effectively prevents disabled women from assuming either an individual or social role (Begum, 1992).

The onset of disability is believed to be far more devastating for men owing to their traditional public role ('hunting') association with greater physicality (Morris, 1994). Women are expected to deal with disability more effectively because perceived fragility is more 'naturally' part of the woman's traditional role (Asch and Fine, 1997). The concept of 'independent living' and physicality as it is understood in the wider culture is thus 'at odds' with the more radical personal autonomy perspective advocated by the disability rights

movement (Pinder, 1996). Parallels can be made with mainstream feminist writings and the need for greater equality in social participation and the wider social understanding that women can now 'do it all'.

Disabled women face additional isolation and role complexity owing to assumed private domestic and parenting duties coupled with public gender expectations (Lonsdale, 1990; Vernon, 1996). Career expectations for disabled women are much lower than they are for men because women are perceived as secondary income earners (Lunt and Thorton, 1994). As many of the duties traditionally undertaken by women are not highly valued, and take place outside of the public domain, rehabilitation is minimal (Lonsdale, 1990; Wendell, 1996). Whereas, disabled men receive assistance with domestic labour as a matter of course, disabled women are expected to manage with household duties as part of their everyday activity (Marks, 1996), but, lack of assistance with housework often prevents disabled women from accessing the paid labour market (Fawcett, 1996). Another aspect of the public/private life split that causes particular difficulty is personal attendants or carers. State funded carers or attendants are only to be used in the 'home' environment yet, many disabled women would be able to function in the workplace with the provision of similar kinds of personal assistance in the workplace as well (Fawcett, 1996). Lack of flexibility in the public/private sphere effectively keeps disabled women in their place, on the periphery of mainstream society:

The career focus adopted by both the feminist and disability rights movements as a mechanism for emancipation and integration is nonetheless problematic for many disabled women:

Puritanism equates productive work with moral worth, idleness with depravity. Industrialization rapidly converted work into unrecognizable forms.  
(Thomson, 1997, 47)

The nature of disability or impairment may prevent women from paid work participation and therefore require personal validation outside of the workplace environment (Dyck, 1995). In addition, many disabled women are on means tested benefits and the 'all or nothing' philosophy common to these programmes fails to recognise the diversity and complexity of disability (Morris, 1994: See also Chapter Nine). This poses particular difficulties for individuals with variable chronic impairments such as MS or arthritis. These individuals may not need income support on an ongoing basis, but the nature of the benefit system is such that they may be forced to leave positions in order to qualify for benefits needed during a

'flare-up' period (Pinder, 1996). The bulk of training and skills development remain directed toward development of manual motor skills, and this type of skills development often leads to exploitation as opposed to liberation. Similar concerns have been expressed by African American feminists (hooks, 1982).

There is very limited consideration of disabled women's work experience beyond quantitative differences with male counterparts or non-disabled women, perhaps because women, disabled or not, are considered atypical in the work environment (Morris, 1994; Barnes *et al*, 1998). The workplace environment is often inflexible, maintaining non-disabled space, time, production and evaluation constraints (Chouinard and Grant, 1997). There is limited understanding of the time elements and personal organisation factors associated with disability or impairment, and as a result any accommodations may be viewed as disruptive to the work environment rather than as a required element (French, 1994; Pinder, 1996). There are few, if any, support systems for disabled people in the workplace, and often employees are alone and isolated (French, 1994). The daily experience of disabled people in the work environment, particularly concerning disabled women, is largely unknown given their limited profile (Drake, 1999: See Chapter Eight).

## **Conclusion**

Long held social beliefs remain largely unquestioned and the underlying network remains intact (Lisi, 1993). It is not enough to make incremental changes within an oppressive system.

Disabled women cannot be treated as a single unitary group; factors such as types of disability, race, sexuality, class and so on, will influence our individual experiences and these may differ from the experiences of other disabled women. However, it is essential that we use our common experiences to develop a political analysis which creates bonds and forges positive strengths ... the concerns of disabled women strike at the core of both the disability rights and feminist movement.  
(Begum, 1992, 61)

Mainstream feminism and the disability rights movement has made modest efforts to incorporate disability and gender into their respective discourses. Adaptations have been gradual, and for the most part poorly conceived (Lisi, 1993). The challenge ahead is to examine oppression experienced by disabled women without recreating it in yet another form (Thomson, 1997a). Traditional forms of academic and medical research have objectified disabled women (Vernon, 1996; Chouinard and Grant, 1999). The task ahead is to find alternative egalitarian methods of undertaking disability research beyond the block identity



‘add disability and stir approach’ (Morris, 1992a). Knowledge must be recognised, respected and gathered from all sectors.

Disabled women’s experience and history is largely absent, lost, owing to perceived invalidity or lack of worth (Barton, 1996). However, it is not enough simply to rework the material concerns of feminist theorists with experiences of disability; there is a further need to engage in critical analysis seriously challenging existing constructs in feminist and mainstream ‘knowledge’. There is a need to move away from traditional value-laden fixed physical constructs of the body and the ideology of independence (Wendell, 1996; Meekosha, 1998), and as a culture we have to examine and challenge all current value systems. True inclusion requires that dominant groups move beyond just making incremental changes to existing terms of reference (hooks, 1982). In this way disabled women can move from the periphery to the centre of feminist discourse. It is time to listen, really to hear disabled women at the centre of the discussion. My own research, however flawed, attempts to do exactly this; but, before reporting on my own research, it is necessary to offer a critical reading of the wider conceptual lenses prevalent within existing disability studies.

## Chapter Four

### Building a path in the wilderness: concepts and methodologies

#### Introduction

I write this as a disability activist; as an academic trained in a traditional establishment context; as a researcher who believes that parallels with other movements can give clues as to the development of Disability Studies.

(Shakespeare, 1996, 115)

As a disabled, feminist researcher, I do not approach the field of disability studies with 'academic detachment'. I truly care about disability issues because they impact on me directly. There is a 'partiality in my perspective' (England, 1994).

A researcher's knowledge is therefore always partial, because his/her positionality (perspective shaped by his/her unique mix of race, class, gender, nationality, sexuality and other identifiers), as well as location in time and space will influence how the world is viewed and interpreted.

(Mullings, 1999, 337)

Developing the methodology component of this research study has proven far more complex and frustrating than I had originally envisioned. In the process of writing this chapter, I have turned myself 'inside out' on intellectual and emotional levels trying to 'fit' into the 'approved' methodological convention. I often find myself at odds with traditional methodology practices, no matter how 'progressive' or 'inclusive' they purport to be. I am not 'conventional', indeed, a distaste for 'convention' is the principal reason that I began to study disability in the first place. Now that the 'black box' of research has been opened, I find the box itself still remains confining. Perhaps this is because the ableist assumptions of society, the belief that there are uniform standards of mental and physical ability, have kept disabled people 'boxed in' for generations. Like oft replicated photocopies, vestiges of the original, although less distinct, remain intact. Hence, despite claims to the contrary, elements of positivist thought permeate even the most progressive research process. Ableism and positivism are not far removed from one another. The task at hand, then, is to highlight these weaknesses within the research process and eliminate or compensate for them as far as possible. As I have done so many times in other circumstances in my life, I have to make my way around 'the box', or indeed outside of the box, and to shape a 'space' that suits.

After studying established geographical and sociological methodology, the basic question remains; where are disabled people, particularly disabled women, in the context of the research methodology? The sense of invisibility is overwhelming. This absence, although extremely perplexing, is by no means unique. Chouinard and Grant (1997) describe as a

'virtual wasteland' the references to disability in the field of human geography research, although this situation has begun to change in this discipline at least with the appearance of various texts whose contents have been a positive influence on my recent thinking (eg. Butler and Parr, 1999; Gleeson, 1998; Imrie, 1996). A more troubling element is the arrogance often brought about by the unquestioned power and privilege within the academic institution itself, which effectively silences those individuals located on the margins (Pratt and Hanson; 1994; Chouinard and Grant; 1997; Corker, 1999). Scholars maintain that the invisibility experienced by disabled women and lesbians reflect a lack of 'space' within the academy. They themselves are not 'permitted' to become academics.

As a disabled researcher I am placed in an interesting situation, devalued within the academy and having a fragmented visibility in a social context (Chouinard and Grant, 1997; Thomas, 1999; Corker, 1999). At times, I find it difficult to determine where I 'fit' both within society as a whole and within the disability community itself. Inclusion and exclusion is not a simple duality: they can coexist (Kepins, 2000). The academic research establishment tends to view research concerning marginalised population groups, particularly disabled people, as somewhat of a novelty on the periphery of legitimate research (Kobayashi, 1994; Chouinard and Grant, 1997; Sibley, 1995). Established research and/or academy practices often fail to account for the possibility that members of that elite group may *themselves* have disabilities. Phrases such as 'professionals *and* disabled people' or 'researchers *and* disabled people' found even in the most progressive disability literature cause intense personal consternation. There is a staggering sense of irony contained in these statements, and it seems that ableist concepts and barriers become so deeply entrenched that they are invisible. Is it not possible for disabled people to be both professional and researchers too?

Often one's professionalism is called into question because the subject matter is indeed personal and political, and at times cuts very close to the bone (Kobayashi, 1994; Chouinard and Grant, 1997; Thomas, 1999). As a critical researcher I share the convictions of Kobayashi (2001):

*A critical perspective transcends methodology to view qualitative methods as a basis for challenging dominant ways of understanding, and for exploring the contradictions that give rise to social inequities and patterns of marginalization.*  
(Kobayashi, 2001, 56)

Planning, organising and spacing of my daily activity are of paramount importance if I am to achieve the appearance of moving through a largely inflexible environment with apparent ease (Chouinard and Grant 1997; Moss, 1999). Frequently, it is so much a part of the process

of life - my life for instance - that it commonly takes place at an unconscious level. One is nonetheless expected to adjust and to produce to a non-disabled time line (not taking into account the extra time required to shoulder daily activities) or risk being labelled as somehow lacking in professional competence (Chouinard and Grant 1997; Moss, 1999). Despite my best efforts, I am sometimes perceived as being 'severely disabled', although I do not see myself in that way. Only when one is in a supportive environment where professionalism is not equated with production, speed and timing are these elements ever discussed. Even in this situation, it is difficult to outline personal components of one's daily life, toileting and stair climbing ability, for instance, as a 'public property' issue. The public/private boundary is nonetheless blurred on a daily basis for people with disabilities as discussed further in Chapter Seven.

As Moss (1995, 448) aptly points out, there is "social order embedded in our ways of knowing". There is a false sense of security in accepted knowledge which in itself imposes a form of social distancing (Corker, 2000). The unrecognised and/or unquestioned concepts accepted as intrinsic are the ones that provide the greatest difficulty for disabled people, being presented as the 'natural' order of things (Kobayashi, 1994). Similarly, Corker (2000) underscores the 'taken-for-granted' elements such as spoken language impacting on her work as a deaf academic.

Parallels can be drawn between the weaknesses often present in cross-cultural research and those of traditional disability research, in that much of what is accepted as 'knowledge' is culturally coded from a non-disabled reference point reflecting a limited 'cultural' sensitivity (Ryen, 2000). Therefore, an examination of the underlying principles of both the research 'paradigm' and the research process itself is necessary to determine how best to explore those aspects that remain overlooked or invisible, and how this absence may be rectified and new ways of knowing valorised (Reinharz, 1992; Wight-Felske, 1994). Thus, there is a concern that ableist assumptions are embedded in the conventional academic structures and processes of research methodology and methods, those which produce knowledge and ways of knowing. Both elements require critical examination. Chouinard and Grant (1997) believe that in the process there is a need to look at research 'by' and 'with' as opposed to 'on' people with disabilities. The way forward will require far more than basic accommodation (Kobayashi, 1994). As Kobayashi (1994) observes:

Racism and sexism have gained academic legitimacy through practices of essentialism. Inscribing essential and immutable qualities to a category of persons on the grounds of race or sex and

naturalism maintaining that such qualities are “naturally” produced as opposed to socially produced. (Kobayashi, 1994, 76-77).

Kobayashi (1994, 77) goes on to state that the “build-up of naturalistic assumptions of racism and sexism cannot be overcome without fundamental changes”.<sup>5</sup> Young (1997) reiterates this sentiment, calling for a:

revolution in subjectivity. Rather than seeking a wholeness of the self, we who are the subjects of this plural and complex society should affirm the otherness within ourselves, acknowledging that as subjects we are heterogeneous and multiple in our affiliations ... (Young, 1997, 220- 221)

There is a need to respect, understand and acknowledge at a substantive level the intrinsic value of diversity and the knowledge base within it (Chouinard and Grant, 1997). Established or accepted theories, models, methods and practices appear to be inherently ableist and sexist in their fundamental assumptions (Pratt and Hanson; 1994; Chouinard and Grant; 1997; Corker, 1999). Finding a ‘voice’ to challenge these fundamentals is hence crucial to a critical analysis of the existing body of knowledge concerning disabled women (Reinharz, 1992). Yet:

The segregation that dominates disabled people's experience of education, and the discrimination that determines our unequal access to the labour market, means that few disabled women are currently in a position to attract funding to carry out research on the issues that really concern us. (Morris, 1996, 9)

Endeavouring to incorporate disability issues within traditional methodological frameworks has proven unsuccessful. The search for ‘absent voices’ is not satisfied by means of add-ons or afterthoughts to the existing process (Morris, 1992). Developing a genuinely inclusive methodology requires a new beginning. To this end, Chouinard and Grant (1997) introduce an important caveat in the development of inclusive research designs, suggesting that the issue is:

not simply giving voice and validity to subjugated knowledges (although this is important) but also developing research designs in which participants have a say in the conduct, interpretation and use of research, and where both researcher and participants “live” the research process. (Chouinard and Grant, 1997, 157)

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<sup>5</sup> .Parallels can be drawn with ableism .and disability because the same essentialist beliefs are often applied to physical and mental ability.

With this in mind, disabled people are beginning to question established tenets concerning disability, as their realities are largely underrepresented (Corker, 1999): that is, the 'front-line' experience of daily life and the manner in which access at an ideological and structural level is negotiated. Predominant social doctrines determine what is or is not worthy of academic study, and the manner in which it is to be investigated (Reinharz, 1992; Wight-Felske, 1994). For this reason, research is not value-neutral (Oliver, 1992; Rioux 1994). Therefore, it is important to ask whose standards are accepted and for what reason (Corker, 1999). Why are some forms of knowledge readily accepted whereas others are summarily dismissed (Pratt and Hanson, 1994). Which differences have value (Corker, 2000)?

In order to better understand the predominant patterns and absences of disability research, it is necessary to examine the various approaches that have been suggested. Beginning with what is the hegemonic 'research paradigm' and, subsequent to that, several alternative 'research paradigms' in their various forms that challenge the authority of the 'dominant view' in several respects and in so doing now become influential within social science disability research. I will be critiquing these paradigms but in doing so seeking also to provide more constructive ideas to frame my own research efforts.

### **The research paradigm and its limitations**

The paradigm is a notion developed by Kuhn to refer to periods of so-called 'normal' science when a discipline (e.g. physics) is basically underpinned by a widely agreed-upon set of beliefs, understandings, principles or methods. There are periods punctuated by 'enlightenment' when the 'normal' or 'accepted' ways of working are challenged or cast aside in favour of new ways of working, which in due course, become the next 'paradigm.' For many there is of course a sense of sureness and certainty in using a clearly established theory and methodology. However, some caution is warranted because loyalty to convention may conceal bias and inhibit research creativity (Patton, 1990), whereas care should always be taken to view theory and method as work in progress rather than a finished product (Glaser and Strauss 1970). Applying Denzin's perspective, Silverman aptly points out that

...methods cannot be neutral instruments because they define how the topic will be symbolically constituted and how the researcher will adopt a particular definition of self vis-à-vis the data.  
(Silverman, 1994, 47)

Kuhn understood paradigms and paradigm shifts to occur according to a process or logic internal to a given academic discipline (Kuhn, 1970), so that habit, disciplinary convention and traditional perspectives often combine to influence theoretical and methodological

choice, rather than appropriateness to a given situation (Patton, 1990). As one writer elaborates:

A paradigm is a worldview, a general perspective, a way of breaking down the complexity of the real world. As such, paradigms are deeply embedded in the socialisation of adherents and practitioners: Paradigms tell them what is important, legitimate, and reasonable. Paradigms are also normative, telling the practitioner what to do without the necessity of long existential or epistemological consideration. But it is this aspect of paradigms that constitutes both their strength and their weakness-their strength that it makes action possible, and their weakness in that the very reason for action is hidden in the unquestioned assumptions of the paradigm.  
(Patton, 1990, 37)

This observation begins to signal how Kuhn's views are criticised by those who believe that paradigms and paradigm shifts - insofar as such elements can be substantially identified at all - are as commonly shaped by far wider external political, economic and social processes and prejudices. Widely held theories of reality do not necessarily reflect objective truth, therefore but they may well be influenced by the manner in which reality is popularly discussed and conceptually constructed (Fielding and Fielding, 1986). Often, then, formalised ways of thinking have more to do with accepted social conventions than with established scientific rigor (Smith, 1988). As such, arguably research serves as a mechanism to reinforce established patterns of social order (Sibley, 1998).

Young (1997) refers to this mechanism as 'cultural imperialism', a process by which the practices and attitudes of the dominant group are presented as the universal norm (Young, 1997). Certain elements are identified as atypical or deviant when they do not 'fit' the norm in terms of physical or mental ability, gender, sexuality, and race or class (Chouinard and Grant, 1997; Young 1997; Sibley, 1998; Thomas, 1999a). Hence, pairing normal and abnormal, ability and disability, sexuality and gender creates a subjective duality of 'good' or 'bad' depending on the social value attached to various elements (Chouinard and Grant, 1997; Corker and French, 1999). This also reflects a feminist critique underscoring that the masculine pole of any binary is usually more highly valued, e.g. '*rational*'/'*irrational*,' '*hard*'/'*soft*' (Haraway, 1997). Knowledge is a product of social construction, drawn from a particular historical and geographical context, and it is only as reliable as the methodology used to acquire it (Cicourel, 1964, Oliver, 1992). Barnes (1998, 205) states: "Knowledge is soaked with social and cultural assumptions deemed to be correct because they are accepted". In short, factors such as ableism and sexism are present in the wider society and therefore influence the academy.

According to Haraway (1997), Corker (1999) and Thomas (1999), conventionally valued forms of knowledge stem from situated positions of privilege and power. Much of what is being studied is rooted in economic structures of capitalism, production and individual commodification, (see also Chapter Two) being preoccupied by how one fits into the production process rather than into or as a legitimate object of social research (Corker, 1999). Formal logic or social 'truths' merely represent a subjective consensus (Kirk and Miller, 1986). When group affiliation is limited to a small number of individuals, the perspective obtained may be somewhat restricted. Similarly, when academic researchers are drawn from the same 'select' group, thus excluding various alternative modes of thinking, perceiving and ways of being, it follows that the research generated in such a homogeneous environment is likely to be limited. Exclusions have been justified as a means of ensuring the dominance of the established research protocol and, most notably, that scientific objectivity is seemingly demanded by many different paradigms (Oliver, 1992; Rioux, 1994; Silverman, 1994; Wight-Felske, 1994). Haraway (1997) cautions that objectivity is an illusory term drawn from the familiarity of deeply embedded practice. Similarly, Young (1997) reinforces this perspective, believing that scientific objectivity merely serves to reduce naturally occurring social diversity:

One has to be "seen" in order to be part of a worldview. If one is not seen there is a sense of unimportance associated with knowledge gained from personal experience. People are defined as powerful in society, not only in societal resources but as producers or participants in the creation of knowledge, in "ways of knowing" themselves and the social structure in which they live. (Wight-Felske, 1994, 187)

The dominant worldview, 'our' accepted social conventions, has hence had a profound impact on the nature and quality of academic research. Although some progress has been made, the perspectives of under-represented individuals or groups such as women, racial and cultural minorities, gays, lesbians, disabled and Aboriginal peoples remain largely obscured or invisible on the social and academic spectrum. The collective knowledge base gained from personal experience is also, at the same time, devalued owing to the pre-eminence given to objectivity. Because subjectivity is doubted, the subjective experience of *all* researchers is obscured, and the end result is that the *unexamined* 'perspective' of hegemonic peoples (who form the majority of researchers) remains exactly that: a subjective realm that is unexplained. The perspectives of the majority of researchers are naturalised in a sense, positioned as the 'normal' markers of objectivity. Haraway (1997) refers to this as 'situated knowledge' mistakenly transformed into a universal standard. As a result, the different



experiences and perspectives of 'other' peoples are duly marginalised, cast as un-objective or too subjective.

These groups are thereby overlooked or treated as anecdotal to the research norm, and the knowledge-based experience of these groups is not usually valorised or recognised (Reinharz, 1992; Rioux, 1994; Wight-Felske, 1994). However, lack of valorisation within the research academy by no means negates the importance of studying so-called marginalised population groups (Katz, 1994, Kobayashi, 1994). Often, owing to a profound level of academic invisibility, one must rely on personal narratives from within the community being studied in order to provide a credible foundation on which to build sound research (Kobayashi, 1994, Thomas, 1999). Yet, conventional research methodology devalues personal perspectives in the belief that crossing the sacred public/private divide somehow compromises objective and hence professional rigour (Kobayashi, 1994; Thomas, 1999). Personal private or intimate aspects of daily life outside of the public (predominately masculine) domain have long been considered outwith the realm of traditional research (Mattingly and Falconer-Al-Hindi, 1995; Thomas, 1999). Feminist research methodology has aided significantly in the critique of this state of affairs, as explained in Chapter Three recognising the narrative element of the research process and validating the individual alongside the collective 'voice' (Reinharz, 1992; Corker 1999; Thomas, 1999).

As a disabled researcher, I have an opportunity to put my training and knowledge to use for the disabled community. My 'community membership' enables me to shed light on certain issues of concern to disabled people that may otherwise be obscured:

We need to locate ourselves in our work and to reflect on how our location influences the questions we ask, how we conduct our research, and how we write our research.  
(England, 1994, 87)

Similar sentiments have been expressed by researchers in the Asian community (Kobayashi, 1994). However, community membership brings with it a profound sense of responsibility, often accompanied by intense soul-searching and at times painful confrontation (Kobayashi, 1994). From personal experience, I am well aware of the dangers and pitfalls of exploitation (Chouinard and Grant, 1997). I have no wish to inflict any elements of the process on the women who are going to talk with me. I am reluctant to use the phrase 'study participants' as it evokes images of researchers in white coats and white rats running through mazes. For far too long disabled people have been objectified by traditional research methods, being viewed simply as fodder for study material (Ryen, 2000). Consequently, I move at a careful,

measured pace checking factors so as to make every effort to eliminate anything that may be remotely construed as voyeurism or unwanted interference (Chouinard and Grant, 1997). The realisation that my community membership brings privileged access is always with me and I have no wish to abuse it.

Scholarly pioneers of the disability rights movement have nonetheless maintained strict dominion over the manner in which disability is delineated and discussed (Corker, 2000). Disabled academics (myself included) are from time to time at odds with the disability rights movement, being perceived as having 'sold out' by working within the 'able-bodied establishment' and thereby demonstrating a limited commitment to disability activism (Shakespeare, 1996). Happily, this has not been my experience with this current research project.

### *Positivism*

Positivism is a philosophical approach making epistemological assertions, the tenets of which are similar to the assumptions of universality of 'laws' discovered and formulated by 'natural' science. This intellectual position, despite its shortcomings, has provided the foundation for what has been viewed as the authoritative research paradigm within both the social scientific academy. Utilising the fixed conventions of the natural sciences, this approach and methodology draws parallels between the natural and social world (Oliver, 1992; Rioux, 1994). Positivism solicits universal principles through supposedly objective analysis of quantifiable factors found in daily life (Silverman, 1994). However, the relevance of this naturalistic mechanism to 'social' science remains the focus of intense debate. Silverman (1994) argues that it is impossible for a researcher to assume a 'value-free' perspective, no matter how many safeguards are put into place because we are all products of a socialisation process. However, the strength of scientific doctrine remains largely unquestioned (Rioux, 1994). At present, the bulk of conventional disability research is highly medicalised, since disability or impairment is viewed as deviant. The resulting research focus has been correction or elimination (Young, 1997). We are left with what Thomas (1999a) refers to as the 'healthy male paradigm.' The paradigm is a mechanism usefully taken to refer to legitimate knowledge and is a source of power (Wight-Felske, 1994). Furthermore, this paradigm is usually portrayed as fundamentally positivist in orientation.

Disabled men and women have not arguably been well served by researchers using this positivist paradigm (Oliver 1992; Morris, 1992a; Barnes, 1996). Several key factors are

worth noting concerning the nature of disability itself as understood through a positivist lens. Body function is taken to be a 'known quantity' as defined by the majority (Higgins, 1992). The absence of disability is viewed as the norm (Morris, 1992a). Parallels to these ableist assumptions can evidently be drawn from the experience of racial, ethnic, disabled and lesbian and Aboriginal and poor women in early feminist research (Reinharz, 1992). Historically, research concerning marginalised population groups has been viewed simply as supplying adjuncts to the universal 'male paradigm' (Thomas, 1999a). Disability is framed in a primarily, individualised, deterministic manner, which assumes that the experience of white, non-disabled males is representative of the norm (Higgins, 1992). The resulting 'problematic' or pathologised view of disability reflects the governing premise of the research paradigm and of subsequent disability methodology (Morris, 1992a; Oliver, 1992; Rioux, 1994). This positivistic stance mirrors and arguably shapes the approach taken with medical research and disability.

Critics point out that the dysfunctional focus of this disability research reflects the medicalised-rehabilitation origins of this model (Barnes, 1992, 1996; Oliver, 1992; Rioux, 1994; Wight Felske, 1994). They argue that positivism is a one-dimensional methodology examining a small range of quantifiable bodily factors in a limited way with little context or application to the everyday lives of disabled people (Oliver, 1992; Rioux, 1994). A multiplicity of factors can influence any given situation. As a result, social perceptions of disability and disabled people may have been seriously misconstrued because the relevant factors have been ignored or through a lack of compatible quantifiable elements (Oliver, 1992; Rioux 1994; Wight-Felske, 1994).

[T]he traditional questionnaire-based survey...while sometimes able to reveal regularities in actions, have not been able to uncover the complexity of motivations behind those actions.  
(Mullings, 1999, 338)

It is arguably incumbent upon the researcher only to utilise quantitative research as a starting point from which further complexities can be explored utilising qualitative methods that allow for greater flexibility in exploring population group depth and texture (Smith, 1988).

Positivist research has had a significant political impact. Government agencies in Britain and Canada rely heavily on this type of analysis to develop and to implement disability policy (Oliver, 1992; Rioux, 1994). Often social/ political constraints and ideology drive framework development rather than the experience and knowledge of disabled people (Davis, 1995, Abberley, 1996a). Disability programmes and services focus on quantifiable difference

ensuring that recipients meet strict eligibility criteria (Chouinard and Grant, 1997). Information obtained from this type of study may bear little relation to the actual requirements of disabled people in daily life and can prove detrimental over time (Oliver, 1992; Wight-Felske 1994). The primary focus of disability survey analysis tends to be cataloguing productive ability or inability in conjunction with individual mechanics, which does little to improve the individual circumstances of disabled people.

Oliver (1992) examines the concept of research as alienation. He maintains that, historically, disabled people have been considered remote from the research process itself. Critical disability theorists assert that the key element in understanding the inappropriate nature of positivist disability research is the power differential experienced between the (disabled) participant-subject and the (seemingly non-disabled) expert researcher (Oliver, 1992; Rioux, 1994; Wight-Felske, 1994). The quest for knowledge and social control are here often confused with one another. Regimented systems of scientific protocol maintain the appearance of objectivity while arguably serving as an individual or even group control mechanism (Rioux, 1994). Rigid perimeters are established which are remote from the real concerns of research subjects. This is done in the belief that pure truth will emerge as a result of rigid scientific process, whereas in actuality the status often quo remains intact (Reinharz, 1992). Some types of research may bring change to the lives of disabled people, but a fine line develops between developing medical technologies that assist disabled people in day to day activities, such as motorised scooters or adapted computer technology, and the development of cochlear implants to produce types of sound for deaf people, and the likes of the Human Genome Project geared to eliminating certain types of disability.

Although this method of research is grounded in traditions of objective neutrality, it provides a type of space and visibility from which greater detail may be obtained in conjunction with other qualitative research methods (Mattingly and Falconer-Al-Hindi, 1995). A form of recognition is achieved for disability on a peripheral level; it is linked to identification of individual anomalies rather than in-depth analysis (Oliver, 1992; Wight-Felske, 1994). Traditional disability research endeavours to examine these differences in relation to various types of 'valued' individual, with productive functions in daily life activities at home, at work or leisure activity being measured against fixed subjective able-bodied norms (Wendell, 1996). But these norms are taken as 'objective' norms of what 'we' should all be and do. According to French and Corker (1999), there is an understanding of the 'disabled body' only in terms of its tangible value and the possibility for a 'normalising' conversion

into a 'productive' body. Certain forms of physicality (predominantly, white, non-disabled males) have acquired an increased value (Gleeson, 1999).

However, there is little recognition of the transitory, situational nature of disability (Chouinard and Grant, 1997; Corker and French, 1999; Thomas, 1999). Consequently, a degree of invisibility remains which may, in effect, disembody the individual (Higgins, 1992). What emerges are thus disjointed elements lacking context, underscoring the belief that these individuals are somehow set apart from the status quo (Oliver, 1992). We are left with the notion of a singular unified mass, which obscures the rich diversity of the group in question (Young, 1997; Corker, 1999). The result, although unintended, may be interpreted as diminished importance or worth of these individuals as individuals within the social scientific process often very different from one another (Higgins, 1992).

Understanding that theoretical perspectives evolve in relation to the quality of information provided that how well we, as researchers, really 'know' the world around us is based on the context in which that knowledge has been framed (Higgins, 1992). How representative is the research 'norm', with numerous perspectives ignored or excluded from the process? Care should be taken to view theory as a work in progress rather than a finished product (Glaser and Strauss, 1970).

There is an inherent scepticism and lack of trust to be found in positivism. This methodology implies distance, strangeness and neutrality. There is limited personal ownership or concern about the process beyond maintaining the validity of the study itself and proving one's hypothesis. This is indeed research 'on' certain people as opposed to 'with' or 'by' certain people (Chouinard and Grant, 1997). A type of social distancing occurs, with the separation between the 'expert' researcher and research subject (Wight-Felske, 1994). Again, this type of disability research also tends to position the 'expert' as non-disabled and the research subject as having a disability. There is an implied superiority of the supposedly objective researcher. The research subject is seen only as a commodity for study, not a valued participant in the operation. No attempt is made to involve the research participant in the workings of the process beyond the task at hand. Nor is there an effort made to share the findings with participants once the research is completed (Oliver, 1992). As a result, it is unclear the extent to which participants benefit on any level.

Positivism is an important, although primitive, attempt to bring a sense of order to the world, but substantive knowledge of our disordered and fluid social world moves beyond the ability

to categorise and to quantify. Sibley (1998) repeatedly warns about research which seeks to put 'knowledge' into neatly ordered boxes. The simplicity of the research protocol and uni-dimensional analysis that it arguably affords can provide little true insight concerning the varied and variable lives of disabled people. The demand for either/or logics 'fails' in the face of a multi-faceted, multi-dimensional human world. Over-generalisations that result from this type of methodology may work to exclude the complexities of many population groups from the social mainstream (Oliver, 1992; Rioux, 1994):

Most positivist theories of knowledge, which tend to focus on rationality, separate the nature and knowledge of an individual from his/her life experiences, actions and social context. From this kind of theorizing [sic] comes the belief that there are standards and norms of knowledge based on scientific, 'rational' norms rather than acquired through living life and gaining experiences. (Cohen-Mitchell, 2000, 149)

Further and different efforts are clearly needed to illuminate the 'real' situation, bridging the gap between subject and researcher while furnishing context or depth to disability issues.

### *Interpretivism*

Contrary to positivism, interpretivism focuses on qualitative elements, believing that the natural world is distinct from the social world and that new approaches are needed to reflect this difference (Silverman, 1994). Qualitative research recognises that life is made up of a network of complex inter-dependencies which cannot be diminished to uni-dimensional cause-and-effect relationships (Patton, 1990). The world is also recognised as being inherently and unavoidably meaningful for its human participants. The realm of human meaning needs to be explored if a more and I would insist, a worthwhile and accurate detailed picture of social life is to emerge. The central component of interpretivism is that the researcher becomes, in effect, the research instrument (Patton, 1990). The interpretative skills of the researcher are enlisted and s/he is no longer viewed as an empty shell or neutral vessel.

The 'hands-on' approach of the field researcher counters the remote and inflexible aspects of positivism. Freed from the constraints of the artificial setting with its fixed categories, the researcher is able to learn at first hand about the social world (Burgess, 1993). However, with liberation comes greater responsibility, with success linked even more directly to individual skills and ability (Patton, 1990). For this reason, qualitative research has often been mis-labelled 'soft' and 'speculative' as compared to the 'hard', 'rigorous' and 'objective' features attributed to more established quantitative methods (Burgess, 1993). Patton (1990) also argues that qualitative methodology of this type provides a far greater

opportunity for openness and detail, but limits generalisation, and hence there remains the difficulty in getting policy makers to take it seriously. This is something that I realise all too clearly from my experience with Canadian social survey work.

Patton (1990, 41), contends that the advantages of qualitative research far outweigh the perceived disadvantages of this methodology, allowing for: “[d]esign flexibility open to adapting inquiry as understanding deepens and/or situations change; avoids getting locked into rigid designs that eliminate responsiveness ...”. The primary objective is to provide detailed observation and description of a given phenomenon, generating data from which theories may be developed (Silverman, 1994). Burgess (1993) identifies three basic research strategies: participant observation and in-depth, un (or semi-) structured interviews, and ethnographic studies. Many researchers would maintain that participant observation and ethnographic studies are one and the same. Patton (1990, 40) maintains that interviews are an excellent source of raw data providing: “[d]etailed, thick description; inquiry in depth; direct quotations capturing people's perspectives and experiences.” An excellent example of this development of the interview process is found in Cottle's (1982) life history studies. Here, no excuse is made about the researcher needing to distance him/herself from his/her study participants:

I make no pretence at objective assessments of these people's lives, the inquiry being subjective and dependent on my relationship with these families, and on paying attention to what is transpiring. One encounters people, listens to them speak about what matters to them, hears attitudes and opinions they only naturally cultivate and records what they say.  
(Cottle, 1982, 123)

While this approach is more respectful of participants, there is often still little or no analysis or sharing of information with the individuals involved in the study, but there is no reason why these elements could not be part of the process. This is therefore a potentially significant step forward over positivist approaches provided that care is taken to avoid voyeurism and exploitation. The interview is a simple extension of everyday activities whereby the researcher endeavours to find out what is going on in the world by talking to people. Respect and trust should be at the core of such a process, moving well beyond the artificial proprieties advocated by conventional interview protocol (Oakely, 1993). The argument is that full insight for the researcher comes from the ‘naturalness’ of the conversational dynamics, albeit recorded, transcribed and carefully assessed. As a researcher, one is placed in a unique and privileged position, being party to the intimate aspects of individual lives. With such access comes a great deal of responsibility. It is incumbent upon the researcher to be respectful and responsive to study participants, ensuring that their voices are heard

throughout the process, and that they have access to information that may be generated as a result of the study (Shakespeare, 1996). Often, with critical disability research, more 'conventional' academic sources are non-existent or inappropriate. Field interviews provide information essential to building or refocusing a given knowledge base. Since entering the Department of Geography I have been encouraged to think beyond just conducting interviews themselves, and urged to examine the 'field' by going 'out and exploring the very nature of the field itself: going out to the places where disabled women live and work to interview them there, if possible and if they are amenable, in their 'own settings'. This is in part an ethical point (where interviewees are most 'comfortable'), but it is also an academic research point. I am likely to learn *more* from disabled women (myself included) by seeing or sensing something from them in their regular world contexts.

As a disabled researcher, the prospect of 'entering the field' nonetheless presents its own particular difficulties, as I will elaborate shortly.

What is of particular importance in this project are the encounters faced by disabled women in the context of employment-related issues. Their incidence gives a commonality that goes towards describing a view of reality that is not otherwise seen, known or accounted for. The purpose here is not to explain, examine or judge disabled women's reactions to their experience, but, rather, to obtain 'the view from here' and this is both a personal 'here' (the women interviewed) and a spatial 'here' (the homes, community spaces and workplaces involved). This being said, I, the researcher, will to some extent explain and seek to judge the social logistics and structural connections revealed in these experiences. It is still important to look beyond the 'raw experience' to how it is 'framed,' but in part the women themselves explain what happens to them and so give me 'hints' about the bigger picture of their worlds. Interpretivism has been dismissed in some quarters as mere 'story telling' (Wright-Felske, 1994), but, this simplistic critique wrongly negates the importance of personal narrative in building 'new knowledge.' As Thomas (1999, 78) states:

Experiential narratives offer a route in to understanding the social structural. This is particularly important for marginal population groups such as disabled people who may have very few avenues of expression available within so called authoritative institutional structures.

Thomas (1999, 78)

Issues of physicality acquire a much greater relevance in ways not commonly studied. Timing, organisation and spatial awareness gain an enhanced significance when one's movements are measured and one's energy levels are distinct. Kerbs, steps, doors, signs and toilets assume crucial importance. These seemingly mundane factors have a profound impact on



the daily lives of disabled women. Taken-for-granted elements in the non-disabled life experience are often unexpected premiums for disabled people. As a disabled woman and researcher, I draw upon my interviewees to make visible what is commonly not visible because disabled women are 'not visible', and this process of 'making visible' demands the intensive and reflexive use of qualitative methods. Although disabled women may adopt various survival mechanisms to function in mainstream society, for the most part they do not construct the broader economic, political, social and cultural contours of their world. Disabled women find themselves in a world not of their making nor construction and not of their permission. Yet, in a more perceptual mode, they do 'construct' imaginatively and discursively a sense of their own world. It is this 'inner' construction, that warrants access and understanding, but in order for me as the researcher to tease further out this 'inner construction' I must interact fully with study participants. Simple observation and deduction from observation is not sufficient.

The distance here between quantitative processes and interviews is not always so marked, however, and there are vestiges of the differential power dynamic between the 'expert' researcher and study participant displayed in positivism. Indeed, Glaser and Strauss (1970) maintain that, while lay people can undertake this type of activity, the procedure itself should only be developed by trained sociologists. There is a danger here of professional elitism. In response, Reinharz (1992) and Oakley (1993) assert that the interview should be a reciprocal information exchange. While interactionist researchers may have left the confines of the artificial research setting, though, it could still be claimed that many of its long-established parameters remain intact. The researcher may be simply observing the 'live action' of the research subject in a much larger, less restrictive venue, although researchers working in this tradition do also conduct interviews and focus groups. There is a danger of not making much attempt to gain input or perspective from research participants, leaving the researcher as the sole conduit of data (Oliver, 1992), and one has to move with extreme caution in order to avoid making voyeuristic observations. Oakley (1993) raises a related criticism when writing about the questionable virtues of the traditional field interview, indicating how traditional social science concerns about being too subjective and unstructured can lead to research protocols that do indeed recall positivism and the 'experimental' setting:

textbooks advise interviewers to adopt an attitude towards interviewees which allocates the latter a narrow and objectified function as data interviews are seen as having no personal meaning in terms of social interaction, so that their meaning tends to be confined to their statistical comparability with other interviews and the data obtained from them.  
(Oakley 1993, 30)

Oakley thus maintains that conventions established in the quest to gain scientific 'legitimacy' have been particularly damaging to women, and the lack of valorisation of disabled women's experience has proved equally detrimental:

social science researchers' awareness of those aspects of interviewing which are "legitimate" and "illegitimate" from the viewpoint of inclusion in research reports reflects their embeddedness in a particular research protocol. This protocol assumes a predominantly masculine model of sociology and society. The relative undervaluation of women's models has led to an unreal theoretical characterisation of the interview as a means of gathering data which does not work in practice. (Oakley 1993, 31)

Quoting Burgess (1980), Silverman writes:

It would appear that field research involves observing and analysing real-life situations, of studying actions and activities as they occur. The field researcher, therefore, relies upon learning firsthand about a people and a culture. (Silverman, 1994, 23-24)

Again, though, there is an implied distance, strangeness and neutrality from study participants. Although this type of research provides the opportunity for revealing greater depth and context, the researcher is, in effect, removed from those who are the focus of the study. Burgess, citing Stephenson and Greer (1981), discusses the merits of adopting an 'artificial naivete' or 'stranger value' when exploring familiar subject areas (Burgess, 1993). Recounting Delamont (1981) and a research study of adult education for disabled adults, focusing on 'bizarre' and 'different' classrooms is advocated as a means of maintaining 'stranger value and avoiding familiarity' (Burgess, 1993). There is an innate sense of moral superiority expressed here through evocative terminology that is disconcerting. The danger of elitism is apparent; deciding who can and who cannot do research properly. The language used is not value-neutral and it betrays a serious lack of researcher knowledge concerning the project participants. The researcher is expected to remain remote and to be aloof from the process, aided by professional training. Knowledge of participants is not recognised or valorised after all. Concern is grounded only within the parameters of the benefit to the project itself. This is particularly evident in certain aggressively social science disciplines, (such as disability studies) that rely on doctrine, and, despite claims to the contrary, interpretivism does thereby retain many of the rigid characteristics of positivist methodology (Barnes, 1992; Oliver, 1992; Wight-Felske, 1994). Study participants in this lexicon cannot be researchers themselves, yet ideally research should be 'by' and 'with' participants not just 'on' them (Chouinard and Grant, 1997).

Similarly, researchers are admonished to avoid 'going native', in the belief that close association between the researcher and study participants will compromise the objective validity of one's research (Cicourel, 1964; Burgess, 1993). There is an arrogant sense of innate superiority, with the assumption that the researcher is and should always be a stranger to both people and culture. So, what of those researchers who may be 'native' and proud to be so? Subject matter familiarity and accountability to study participants should not be confused with a lack of professionalism or analytical ability (Shakespeare, 1996). As a disabled woman and activist, I cannot be dispassionate about disability rights issue. However, the desire to advocate social justice should never cloud one's ability to undertake research in a professional manner. As a researcher I may be able to help shift the power differential by simply providing further depth and/or detail in a largely unexplored subject area, and need not always be taking a 'political' perspective on materials (Kobayashi, 1994). I can defer but not deny my own politicised judgements when dealing with certain research materials. I can do my utmost to ensure that I hear what my interviewees are saying in their words and terms, and to be 'honest' in not then twisting their words and terms into the more 'politicised' disability rights vocabulary that I might at times prefer.

According to Silverman (1994, 27), a field research study is "a systematic attempt at description and explanation, whether quantitative or qualitative" of everyday information. Cicourel (1964, 14) argues that of primary importance in social science is the rigorous examination of the "study of the problem of meaning in everyday life." In both instances there is an assumption of what is 'everyday life' and that assumption is 'normalcy' in whatever context presented. The very core of the issue is that normative assumptions of all types are far too narrowly drawn. There is thus a two-fold process in my study: to discover just what 'everyday life' is like for disabled women related to employment issues; and, from the information obtained from disabled women, to critique the 'normalcy' assumptions which so unmistakably compromise their everyday encounters with the physical and social 'environments' of work.

While interpretivism may go some distance in providing greater flexibility and depth, some critical disability theorists grounded in Marxism remain highly sceptical of interpretivism and its methodological processes. Oliver (1992) asserts that, although sociologists may be 'out in the field', the underlying suppositions of positivism remain intact (or already noted). Changing the location of the research may have a limited bearing on the relationship between study participants and the researcher. Barnes (1992) maintains that the mere presence of the

researcher in this setting distorts the 'reality' of a given situation, so that the resulting interpretation may be incorrect. Furthermore, he asserts that in many cases such studies may be morally wrong because researchers have been less than forthright with subject participants. However, wholesale comparisons of interpretivism and positivism are misleading and dismissive, ignoring the subtleties of much good interpretive research. Perhaps his Marxist political philosophy and a dislike for agency-orientated research mediate Oliver's scepticism. Parallels may be drawn with research involving disabled people and research involving other socially under-represented groups such as non-disabled women, ethnic and visible minority women and lesbians (Oliver, 1992; Reinhartz, 1992; Oakes, 1993). There *is* undoubtedly the possibility that the power dynamic can remain unchanged and that participants can remain outside of the research process, but this need not be the case (Barnes, 1992; Oliver, 1992; Rioux, 1994; Wight-Felske, 1994).

### *Emancipatory methodology*

Traditionally, marginalised groups such as disabled people have had little control over the means of research production, the bulk of which has been controlled by policy-makers or large institutions (Zarb, 1992; Gleeson, 1998). Challenging this monopoly, emancipatory methodology makes an ideological shift away from the medically individualised focus of earlier research mechanisms, adopting instead a broader, rights-based socially oriented perspective (Oliver, 1992). This approach reflects a strong Marxist inclination rejecting the traditional biological concentration of disability research examining the role of disabled people in the material conditions of production and consumption (Gleeson, 1999). The advocates believe that, by being directly accountable to study participants, shifting the balance of power, disabled people will be in a better position to influence public policy and to gain personal empowerment (Barnes, 1992; Oliver, 1992; Rioux, 1994). Barnes (1992) makes the important distinction that having a disability does not immediately qualify one to undertake this type of disability research. He notes that other factors such as class and education warrant due consideration. Finally, Barnes (1992) points out that this type of research may be more costly and time consuming than conventional research, but this objection is discounted by greater depth and validity.

Emancipatory methodology is not without its detractors, inside and outside of the disability constituency. Recently, serious concerns have been raised by critical disability theorists outside of the Marxist stream as to the danger of emancipatory research having too much of an agenda, particularly when researchers encounter disabled people who do not think in

terms of a 'rights' or materialist based perspective. Bury (1996a) argues that the oppression rationale put forward by this approach is far too narrow to address effectively the complexity of the issues involved in this subject area. Similar concerns are shared by Shakespeare (1996), referring to the analysis as 'simplistic and reductionist' and also still having distinct parallels with positivism. Vernon (1997), whilst supportive of the emancipatory aspects of critical disability research, acknowledges the researcher's continuing control of the study process. It is important that participants are respected at all times and that knowledge and experience is valued, but there is a danger of this not happening if the participants hold views which do not mesh with a 'politicised' disability rights model. The complexity and diversity within the disability community warrants multiple interpretations, or there is the risk of yet another form of silencing:

knowledge is not something that we have, but something that we do. The first stage of this process cannot happen for many disabled people if personal narratives are confined to or hidden within certain means of expression or certain media---indeed this simply colludes with the culture of 'silence' which is part of disability oppression. And it is also impossible if personal narratives are censored in the interests of homogeneity and reductionism, because it must ultimately only lead to partial political unity.

(Corker and French, 1999, 10)

Emancipatory research was first embraced by minority and feminist researchers, linking research to socio-economic issues (Oliver 1992; Reinharz, 1992; Oakley, 1993). The central elements of this methodology are trust, respect, reciprocity and involvement of study participants (Oliver 1992; Reinharz, 1992; Oakley, 1993), but there is this danger that those members of the minority in question who do not share the emancipatory researcher's political philosophy may not be accorded 'respect'. Further credence is given to this argument by exploring critical theorist Barnes's (1998) pejorative references to those disabled people who choose to make reference to the reality of impairment in their lives as 'the true confessions brigade'. He is hostile to assumed vestiges remaining here, in these people's 'confessions', from the medical model. As a result, social oppression theorists have been subject to criticism from researchers within the disability community. The relational, changeable, fluid aspects of disability and impairment in daily life, particularly in the work environment, for individuals with variable chronic conditions such as arthritis, diabetes or multiple sclerosis highlights changeable bodily realities which clearly obscure the body/society dividing line (Pinder, 1996). Failure to address physical impairment hence effectively denies the complexity of disability in daily life situations (Bury, 1996). A growing number of disability theorists are advocating that the concept of impairment be reconfigured so as to better reflect the diversity of disabled people without detracting from

the pivotal rights elements of the social model (Crow, 1996, Pinder, 1996). The current debate amongst social theorists reflects added depth in a comparatively new social movement.

It would appear that in an effort to distance himself from the most damaging elements of 'conventional' disability research (normalising, medicalism and functional limitation), Barnes has moved to the extreme opposite of the scale, a complete denial of the reality of the body and impairment. This is poor scholarship and damaging to many people who Barnes is claiming the 'right' to represent. If one is caught up in dogmatic arguments about language and correct ways of thinking and expression, disabled people yet again become disenfranchised, in this instance by pioneer elites within the disability community (Corker, 2000). Dialogue stifled in the name of disciplinary political 'purity' creates selective access policy as damaging as the scientific strictures proceeding it (Corker, 2000). Truman (2000, 26) makes the important point that, "[g]iving voice to oppressed people does not ensure social change". Similarly, French and Corker, (1999) caution that if multiple factors are ignored in the interest of theory building, one risks recreating in yet another form the singular identity elements that have proved oppressive to disabled people in the past. As an academic and a disability activist, I therefore feel an affinity for the sentiments expressed by Shakespeare:

I have major reservations with the concept of emancipatory research, even while admiring the motivation and commitment of those engaged in it. I am cynical about the possibility of research achieving major change, whether it is radical and emancipatory, or traditional social policy research. Ideas clearly have a role, but actions decide the day, and while it is possible to make the research process more balanced, grandiose claims for its revolutionary potential seem to me to be over-optimistic. Furthermore, while few would now argue in terms of objectivity, a notional independence and balance is still seen as critical to the academic endeavour.  
(Shakespeare, 1996, 118)

Unless this delicate balance is maintained, there is the danger that new biases, prejudices and exclusions may enter the research process. Truman (2000) echoes similar concerns:

A focus on epistemology and the internal creation of knowledge may provide the basis for exploring the 'black box' of research production, but it does not necessarily provide the basis for social change.  
(Truman, 2000, 27)

The validity of arguments is often lost when individuals espouse doctrinaire ideology of any kind (Shakespeare, 1996). The rich depth and texture of views and practices within the disability community has largely been overlooked in the name of formal theory building (Corker and French, 1999). The complexity of disability issues, coupled with the diversity within the movement itself, warrants a multiplicity of views and perspectives. The

cornerstones of the disability rights movement are strength in diversity and inclusion. Consequently, the multiplicity of ideas, expression and knowledges within the varied landscape of the disability community does not have one voice (Corker, 2000).

The continued growth and maturity of emancipatory methodology mandates a shift away from politicised dogma without compromising political commitment. According to Corker (1999), the need is to cultivate the motivation for developing the discursive strand of disability theory that works, individually and collectively, alongside the materialist simplicity of the social model and its challenge to the structural world:

In other words, those of us who have an interest in discourse are not waging war on the social model. We are encouraging its reflexive use. But more importantly, we are engaged in a different kind of production - the liberation and acceptance of silent 'voices', new knowledges, and therefore a greater range from which disabled people can subvert hegemony and act in the social and political arenas. (Corker, 1999, 209)

I firmly believe that no individual or group has ever been 'saved' by the research process although it can have some beneficial social, policy and personal implications. I have endeavoured in my own research to pursue a more 'democratic' interpretative approach, bringing in a diversity of interpretations in a non-hierarchical manner: that is, not prioritising one line *a priori* over another. Yet I wish to retain a clear awareness of the wider structural/ social prejudicial constraints on the worlds of the women who I have interviewed. By being respectful and receptive to study participants and their concerns, a more complete picture of the depth, dimension and complexity of disability emerges, I would argue, which may facilitate increased visibility for disabled people and enable more voices to be heard. In this way, a radical politicised edge *is* there which does speak of empowerment and possibilities for effecting change or improvements.

### *Studying one's cultural self*

The researcher cannot conveniently tuck away the personal behind the professional because field-work *is* personal. (England, 1994, 85)

Studying one's cultural self (I am disabled woman exploring the employment experience of other disabled women) puts one in some very interesting situations. In a very real sense, I am in effect 'living' my thesis. I am an 'outsider' and an 'insider' at the same time. For me, reflexivity is not an abstract theoretical concept. I realise that my education and employment experience brings with it 'privilege', which is distant from the experience of many disabled women. At the same time, however, I share with them many of the day-to-day realities of

having a disability in Western society. My background has given me more opportunities and options, but only insofar as I am 'allowed' such options within perimeters established by the non-disabled majority. To quote Snow, a Canadian disability rights activist, "I have been stepping on my own toes" (Snow, 2000). I have been acting in the way disabled people are 'supposed' to act, asking for what is attainable rather than what is needed, as we are not expected to do 'powerful' things or aspire to be 'powerful' people. Much of what I have read outlining the mechanics of field research has caused me a great deal of personal consternation which has proven difficult to resolve. The literature tends to be obsessed with practicalities, not with the bigger picture of possibilities. To this end I find myself musing lately. There are no limits when you dream, making it far easier to get out of or around 'the box'. As Snow (2000) succinctly states, "[i]nspiration to do things differently comes from various places at the same time". Indeed, the field research element of this project has taken me and the women with whom I have spoken in directions that I could not have imagined or planned for at the outset of this research study. Seemingly mundane or simple aspects have provided a voyage of self-discovery for both me and many of the women who I have had the opportunity to interview, revelations stemming from these interviews providing either insight or anxiety. The acquisition or development of knowledge is rarely a straightforward linear process. Rather, it is like building a three-dimensional puzzle working on several levels at the same time, even though one might not be aware of this at the outset (Corker, 2000).

As Thomas (1999b) observes:

There is not a straightforward relationship between experience, 'truth' and knowledge, and accessing experience as researchers does not mean that we access and reproduce something unmediated. (Thomas, 1999b, 80)

I am hence always aware of my own 'positionality', and take great pains to keep it in check so as not to impose on or to influence unduly the women who I am interviewing. I am aware that as a result of the interview, some women did embark on a voyage of 'self-discovery.' However, perhaps this was a result of the process of the interview itself, providing a 'sympathetic space' of mental and emotional 'safety' in which to 'voice' themselves and just as importantly to be 'heard'. In addition, I am aware that as I come from a foreign country (Canada), I may have cultural or language differences which require clarification, at least in relation to my Scottish research.

Although writing one's self into one's work is a long-established tradition amongst feminist writers, I approach this element with some degree of trepidation (Moss, 1999; Thomas,



1999). I have no desire to cross the line between including relevant biographical elements and descending into the depths of the personal confessional (Moss, 1999). Yet I am one of the participants. I embody part of what I research both as researcher and researched. However, I do not want my *own* experience to overshadow the experiences of the women who I have interviewed. For this reason at some points in the thesis the autobiography of the researcher is made clear when I say “I”, but elsewhere in the thesis the biography of me as participant appears in another set of quotes from a participant. These two elements are to be held apart.

I did not wish to engage in the voyeuristic practices of many researchers in disability, focusing on type of impairment the what is ‘wrong’ with individual participants as a curiosity or titillation. People with disabilities are always being asked what is ‘wrong’ with them I did not wish to reduce people to a manifestation of their impairment and for this reason I resist a profiling of disability. I do respect that there are different embodiments of disability and impairment but only in so far as the women *themselves* wish to discuss them. I do not want to focus on typologies of impairment. I am happy to unsettle the reader by not knowing that the disability is. For this reason, individual disability or impairment is not dealt with in detail. This research project is the first time that I have ever introduced personal elements of my own life into academic research, despite my life-long experience with mobility disability. Yet, I do believe that my experience as a disabled woman enables me to establish a level of credibility and trustworthiness with the women who I interview (Moss, 1999). It does, even so, raise interesting questions concerning the position of the researcher in the research process (Moss, 1999; Thomas, 1999). As Thomas (1999a, 48) aptly states, I need to “construct an account which interprets other women’s experiences according to the contours of my own intellectual and experiential biography”. After all, if I was going to interview women about their experience of disability and impairment, it is only fair that I was forthright about my own.

To that end, I began a process that I had never undergone before, exploring my own human geography as a disabled researcher undertaking field research. Although I had done ten field interviews as part of my Master’s thesis, I had never allowed the realities of my own disability to enter into the research process itself. I did not associate disability with ‘fault’ and, yet, I did view it as solely my responsibility to ‘manage’. An inability to do so might somehow be perceived as a lack of ‘professionalism’ on my part. Consequently, I had internalised the mantra that, as a disabled researcher studying disability, I dare not get too

close to the subject matter so as not to lose my objectivity. Indeed, I never mentioned before that I had a disability in my writing. The explicit, written acknowledgement of my disability was therefore a watershed for me. I did not wish to dismiss the very real physical mobility, access and restricted motor (writing/typing) speed realities that manifest themselves with my disability. I was somewhat overwhelmed by the fact that the population base I had planned to study was doubled from the original twenty women (ten in Scotland and ten in Canada) to twenty in each study site, largely at the suggestion of my thesis supervisor. This change would result in my incurring significantly greater personal physical demands and financial costs owing to a doubling of the sample grouping. I was nonetheless in full agreement with the reasoning behind such a decision, but, I did not want to be 'held hostage' by the physical processing elements of the field research that I could not manage without assistance. An increase of such magnitude in the fieldwork portion of the study would have a definitive impact on my own ability to function in the field. Time is a genuine concern for me as the nature of my disability is such that any physical activity takes significantly more time and effort than it would for a non-disabled researcher. As a result, any increase in the research sample would impact exponentially on all other time factors associated with my project and my personal life. My situation is not unique, Sally French, a university lecturer with a vision impairment, has expressed similar concerns:

Another vital issue for me is time. Equal opportunities policies never tackle this issue, even though it is so crucial to visually impaired and other disabled people. ... My job involves a lot of reading and my reading speed is slow. I have never calculated the exact hours I work. Perhaps if I did I would have to acknowledge how little time there is left for me beyond my employment.

(French, 1994, 157-158)

As a result, well before I began to look for women to interview, it was important for me literally to work out the mechanics of the various field elements of the information gathering process. Some disabled academics have referred to the course of acquiring job accommodation as "a long and often lonely struggle"(Chouinard, 1999, 144) but thankfully this has not been my experience. Discussing my own positionality with my thesis supervisor in such a full and frank manner was a positive negotiation process, made possible only because of a high level of trust, excellent rapport and genuine interest established by my supervisor in the early stages of my PhD. studies. Without this substantive support, my own silence on the micro-details of timing and spacing would have been maintained, which is ironic given the subject matter of this study. These crucial factors engendered the confidence for me to discuss this at the outset of the study, in Chapter One, contributing directly to my own emancipation.

### *The field research process: beginnings*

As a disabled woman studying disabled women's employment experience (or lack thereof) I became acutely aware that most research on the subject of employment and disability is de-gendered, referring almost solely to disabled people with few if any references to distinctions between disabled men or women. More disturbing, however, is a fixation on the personal mechanics of disability in the workplace; that is, focusing on individualised mental or physical difference which is almost dehumanising. The hegemonic 'knowledge' of functional capacity and representations of disability are often framed in the 'discomfort zone' of the non-disabled.

The disability community is haunted by a legacy of 'bad practice', a fixation with normalising and objectification, and I had no wish to join the ranks of what had gone before, although many of the women who I interviewed did in effect address such issues themselves. One is often faced with having to rebuild research frameworks from their basics, owing to faulty precepts found in work lacking a critical perspective (Barnes 1992; Oliver, 1992; Zarb, 1992). Studies of smaller groupings within the population, including sub-groups within the overall disability community, are likely to provide a critical perspective beyond the generalised 'boxes' because it enables 'other' (non-mainstream) voices to be heard. Qualitative research studies are better suited for studying smaller groups (Barnes 1992; Denscombe, 1998). This approach allows greater access to and understanding of the social reality as experienced by study participants (Morris, 1992a; Barnes 1992; Zarb; 1992; Odette 1993). There is also a greater opportunity to explore the interrelationship of numerous factors, moving beyond a superficial understanding of the issues.

I wanted to know if my own education and work experiences were unique or if other women had similar occurrences. I knew that the knowledge base of disabled women was a largely untapped resource, judging from the profound lack of disabled women's experiences and perspectives in the employment literature. From the outset I wanted to make the research process as inclusive as possible, and to gain a better understanding of disabled women's employment or unemployment experiences at the 'grassroots level'. Well before the field research stage in the first year of my PhD studies, and over several months, I contacted members of front-line disability-led groups (groups run by and for disabled people) in Scotland and Canada to determine what were the key issues related to employment and disabled women. I wanted to ensure that the research which I was interested in undertaking would be relevant and useful to the to the disability constituency, and would address on-

going information gaps concerning disabled women's employment which had been identified by the groups themselves. The standard but inflexible disability questionnaire surveys utilised by OPCS in Britain and HALS in Canada (see Chapter Five) reflect an individualised deficit perspective provide at best, a basic understanding of the social impact of disability and impairment. I viewed building the research project as peers working together.

Meetings I had with disability led groups in Scotland and Canada provided first-hand insight from service users themselves into current social security policy legislation and implementation gaps in both Scotland and Canada. Interest in such a research project was indeed strong, owing to the apparent lack of data in the field areas. This was repeatedly identified as a problem. There was a genuine willingness on the part of all parties to share resources and information, owing to both the limited available material and the belief that any information provided will be of benefit to all concerned. Information provided and issues identified by these individuals and groups at such an early stage was instrumental in building an effective multi-layered interview guide later in the research process. In addition, these groups provided a contact point from which to meet possible women to interview, although it should be noted that affiliation with a particular disability group or agency was not a prerequisite to an interview. In addition, I did not want to restrict my interviews to disabled women who were already 'politicised' about the issues involved.

Building the interview guide proved a more involved task than I had originally envisioned. I wanted to avoid questions that would in any way be perceived as voyeuristic or objectifying. I began working on an interview guide in December 1999. I found it difficult to focus my questions into specific groupings of themes. Initially, my approach was rather disjointed and I wanted to ask everything all at once, rather than developing a gradual, considered framework on which to build and through which to explore the issues in as systematic a manner as possible (but without becoming rigid or inflexible). After several preliminary drafts, I decided to 'field test' the interview guide on myself as I had no wish to inflict a rough prototype on an unsuspecting stranger. Testing in January 2000 yielded mixed results, as the questions were often rambling, unclear and lacking in much needed context. I added basic 'daily life' questions. If the 'designer' of the instrument experienced such difficulty using it, clearly further distillation was necessary. As an 'insider' I had similar experiences to Mohammad (2001):

I found that I also took some knowledge for granted so was not aware of highlighting certain issues that cropped up in the research until others in the academy pointed out specific instances when this happened.

(Mohammad, 2001, 108)

Eventually, I decided on four main groupings of themes. which reflected the original research questions contained in my research proposal: Identity; Everyday life related to work; Social relations and power relations at work; Experiences outwith the paid labour force. The interview guide was in its final form by mid-March 2000. I used the questions as cues and triggers for myself rather than referring to each question directly, so as to keep the interview 'flow' going naturally and to avoid the 'stilted' nature of a formulaic interview 'process'. Therefore, subject areas were grouped together and covered rather than being referred to with the specific questions contained in the interview guide. In many ways the guide was indeed just that a 'guide'.

#### *Original Research Questions (see Chapter One)*

How does physical disability impact upon pathways through education, negotiation of everyday community life and the various aspects of the employment process?

How does the intermeshing of time and space issues throughout the everyday lives of disabled women impact upon their experiences of accessing, maintaining and changing employment?

What is the position of disabled women in the labour market?

How do a range of social of social policies (employment, disability, education, social security and family policy) shape disabled women's employment opportunity?

How do disabled women make sense of their position in the labour market?

How do disabled women perceive and manage the work environment?

How is the public/private space of disability and gender dealt with in this context?

## The Interview Guide

|                             |  |
|-----------------------------|--|
| <p><b>Section One</b></p>   | <p><b>Profile/Identity</b></p> <p>Age</p> <p>Type of disability and age of onset (being careful to avoid “disease of the month” elements common to the medical or limitation model).</p> <p>Ethnicity</p> <p>Gender and/ Sexuality (only if interview participant volunteers this information as I have no wish to pry)</p> <p>Where do you live? Implications for access or service delivery</p> <p>Family circumstances</p>  |
| <p><b>Section Two</b></p>   | <p><b>Everyday Life Related to Work</b></p> <p>Education</p> <p>Tell me a bit about your work history?</p> <p>Take me through a typical day from the time you get up on the morning</p> <p>Time, organisation, planning and spatial preparation elements of which most people are/not even aware of: ‘the art of being “professional”</p> <p>Details of everyday life related to work either directly or indirectly</p>  |
| <p><b>Section Three</b></p> | <p><b>Social Relations and Power Relations at Work</b></p> <p>Where do you work?</p> <p>How long have you worked there?</p> <p>Contract or permanent?</p> <p>How did you get the position and how long did it take you to find it?</p> <p>Did anyone help you look for a paying job? If so who and how did they help?</p> <p>Tell me about your job interview experience</p> <p>Does the disability benefit system impact on you in relation to work?</p> <p>Tell me about what you do in a typical work day</p> <p>Details, job specifications and requirements</p> <p>What does your job consist of?</p> <p>How does your education and/or training suit this job?</p> <p>Do you have opportunities for training?</p> <p>How is the atmosphere at work? Is it a pleasant place to work</p> <p>What makes it good or bad place to work?</p> <p>What are the satisfying parts of your job?</p> <p>Are there things that you do/do not like?</p> <p>Is there anything about your job that you would like to change? Part-time</p> <p>Are there things you would like to add or change at work or at home to</p> |

|                     |   |
|---------------------|---|
|                     | <p>make it easier for you to do your job? i.e. Home help? Assistive devices? Work from home?</p> <p>Have you ever discussed this with anyone?</p> <p>How does everyone get on? Colleagues, peers, superiors</p> <p>Can you be yourself? Do feel like you 'fit' in? Disabled/non-disabled power relationships, interconnections, socialising</p> <p>Do you have the opportunity to talk or meet with your workmates? Are they friendly and supportive?</p> <p>Do you get an opportunity to see your supervisor? Is s/he supportive of you?</p> <p>Is the Disability Discrimination Act (DDA) Canadian Charter of Rights and Freedoms a help to you?</p>  |
| <b>Section Four</b> | <p><b>Experiences Outwith the Paid Labour Force</b></p> <p>Unemployment/Out of the Labour Force</p> <p>Does the disability benefits system impact on you in relation to work?</p> <p>Have you thought about education and training courses?</p> <p>What type of education and/or training have you had?</p> <p>Do you do volunteer work?</p> <p>Did anyone help you look for this job If so who and how did they help?</p> <p>Tell me about your job interview experiences</p> <p>Tell me about your day</p> <p>Detail all activities of the day from the time you get out of bed onward at home in community</p> <p>Are there any changes that would enable you to take on a job for a salary?</p> <p>How long did you look for a paying job?</p> <p>What type of job did /do you want?</p> <p>Did/does anyone help you look for a paying job? If so who and how did/do they help?</p> |
| <b>Conclusion</b>   | <p>Is there anything you would like to add or change or dispute or clarify?</p>   |

*Field interviews: setting parameters*

I was so afraid of somehow falling into the traditional interview persona of being a white-coated clipboard-clutching researcher that I entered this phase in an extremely cautious manner. It is a matter of finding and maintaining a suitable balance. The needs of the women whom I interviewed were paramount. I did not want to treat people as mere 'vessels of

information' (Kobayashi, 2001). I wanted the 'comfort level' of the women with whom I spoke to be as high as possible. I did not want to treat social oppression as a fundamental concept of disability, and for this reason I took the decision from the outset not to critique the women I interviewed. I wanted to treat disabled women with respect and to take *their* interpretation of their lived experiences at face value.

Not all of the women I interviewed did tell the same 'story'. Some women did *not* ally themselves with the wider disability experience and politics. As (Kobayashi, 2001) states:

We spoke for the community but not with a single voice. We had therefore, simultaneously to represent the diversity of the community and to present its common concerns ...

(Kobayashi, 2001, 62)

And as Mohammad (2001,113) adds: "... knowledges produced are always versions." However, my approach here is *not* to question women's motives nor to deconstruct their interpretations. If this is to adopt a somewhat *acritical* approach, then so be it. The thrust of the project is to criticise the wider structures of thought and action into which these women are inevitably inserted, ones over which they and other people with disabilities have so little power and influence (historically and today). These experiences may well be shaped by the women's impairments, but like Kobayashi (2001) I too believe strongly in:

Anti-essentialism, or the belief that human characteristics are not determined by so-called biological conditions...

(Kobayashi, 2001, 62)

Scottish and Canadian women had similar experiences in virtually every respect, and social oppression does not respect national boundaries. Regardless of their precise impairment, women will experience the manifestation of disability/discrimination in broadly similar ways.

I viewed the entire process as very much a power sharing process. I reinforced the idea, which I truly believe, that the women's input was important and that they had information to offer that would benefit other people. Foremost in my mind was the participants' access requirements. For instance, when I interviewed women who had hearing impairments I asked if they would like to have sign language interpretation (in each case it was declined). I adapted to their schedules and went to environments where they felt comfortable. I wanted to make sure that my participants' options were open. This was a new experience for some women as I was often asked what suited my schedule, to which I replied that I wanted to 'fit in' according to what best suited their daily activities. I adapted elements of the question



guide to suit best the particular individual's life experience. In addition, if the person being interviewed focused on employment issues, then a considerable length of time was spent with that. If education was viewed as pivotal with someone else, then that is where energy was focused. I tried to make the interview as unstructured as possible so that people would not get caught up the mechanics of the interview, and so to facilitate participation and disclosure. I did not make assumptions about what was said, nor was it questioned except for clarification. I was also careful to tread lightly, when questions, though seemingly value-neutral, evidently cut close to the bone or triggered an emotional response. I had no wish to cause emotional distress or to 'push' the women. In my view, no one is well served by such tactics.

### *The Scottish element*

I began field interviews in mid-April 2000. Since moving to Stirling I had made many friends, several of whom were disabled women. My friends were my first contact and they agreed to participate without hesitation. I must admit to a certain degree of discomfort on my part in approaching these women as I did not want my friends to feel like 'subject matter,' but much to my relief I soon discovered this was not an issue. My friends passed my name and details onto other disabled women who they knew who were also eager to take part. Three women were contacted via friends in Stirling. Outwith my group of friends, at no time did I make the initial contact with these women. I did not want anyone to feel pressured into giving an interview. I wanted to build in equity at every level of the study, and I did not want to be intrusive in anyway. However, I did make contact with the women either via telephone or in person depending on their preference once I received a positive response. I had also made several friends within the University of Glasgow who I also approached regarding the possibility of an interview, again with positive results. One friend was kind enough to give me an interview. I had begun giving a lecture component at the School of Medicine. One of the instructors had taken interest in my academic career and wanted to know at what point I was with my studies, and I mentioned that I was looking for women to interview for my thesis, at which point she mentioned that she knew of some women who might like to be interviewed. I made contact with two women through her. In addition, I contacted the disability groups that I had met with earlier with a brief sketch of myself and the work I was about to undertake. I made contact with eight women through this method, although it should be noted that not all of these women were members of the groups contacted. Again, word-of-mouth played an important role. I approached the women who worked in these organisations

who by this time had become friends to ask if they would consent to an interview. Two women agreed to an interview. I also interviewed one woman that I met at a disability issues conference.

Through this rather unconventional networking process, I had the opportunity to meet and to talk with a very interesting cross-section of disabled women in Scotland. Without conscious field sample engineering, the women I interviewed comprised a wide variety of education and employment experience, ages, type and onset age of disability and impairment, social class and sexual orientation. I spoke with twenty women in Scotland, ranging in age from their early-20s to mid-60s. Initially, I had planned to restrict the study to a comparatively narrow age range, reflecting the standard age of waged working life: that is, 19 to 55 years of age. I decided to abandon that in favour of the wisdom, knowledge and perspective that manifests itself with greater age, and so some of the women whom I interviewed were older than 55. At present, there is a very limited social history of disability, and extending the age range is therefore an attempt to address this information gap, gaining insight through a form of oral history with some older women. This was coupled with the knowledge that disabled women often enter the labour market at a later age. My field study area in Scotland was at first confined to the Central Belt. However, the quest for interesting life stories soon led me to understand that one should not be limited by 'post-code eligibility'. Consequently, the field study area soon stretched from Bridge of Allan to Troon and many points in between.

Consequently, I spent many days travelling by train or taxi to meet the women who I was interviewing. I found fieldwork very demanding. Travelling to 'the field' was not always easy for me, clambering on and off trains and in and out of taxis took its toll in muscle pulls and bruised shins. Added to that was my ever-present concern of being 'on time' for the women who I interviewed, which highlighted my own issues to do with pace of movement and getting around areas with which I was largely unfamiliar. Some days I would be able to complete three interviews, while at other times I would be doing one to three interviews per week. I found the pace quite hectic and at the end of the day, despite having enjoyed the actual interviews immensely, I was often physically and mentally exhausted just organising myself. Fieldwork is an exciting prospect, however, but the ableist tenets of the process itself assume the indulgence of ease of access that is often remote to many geographers with physical disabilities.

Places for interviews were varied from my home, the interviewee's home, workplaces, pubs and coffee bars. I viewed it as a matter of building trust, respect and equity, and I also

thought that it might facilitate good communication. In addition, if women were interviewed at my home I prepared a meal or some type of repast. Similarly, If I were invited to their home for a meal I would bring something to contribute to it. If I was meeting women in pubs or coffee bars, I would buy them a beverage. I wanted these women to know that I valued their time and input and that I genuinely wanted to hear what they had to say.

Interviews lasted between forty minutes and two hours, and confidentiality was paramount. Participants were asked whether or not they would like a pseudonym for interview purposes, but most women opted not to. However, I have still decided to provide pseudonyms for all interview passages in the paper. All the women were very gracious and genuine. I was struck by the number of times I heard the phrase 'It's the first time I've ever been asked' or 'I hope I'm not wasting your time'. Many times I felt like a catalyst, facilitator or conduit. It should be noted that the above-mentioned occurrences happened only three times in the forty interviews in Scotland and Canada. In one instance in Scotland a woman's experience with the education system was painful and she began to cry. All the women who were interviewed were positive about the experience. I felt privileged to share their time. For me, the fieldwork was enjoyable, if at times physically and emotionally taxing, forcing me to develop further and to refine my own organisational skills, again underscoring at a micro level the organisation - meticulous attention to timing and spacing - that is the substantive focus of my research. I completed the final Scottish interview on June 22, 2000, the day before I returned to Canada that summer. There have been several unexpected bonuses for me. As a result I can now count among my friends many of the women who I interviewed, people who had previously been strangers. In addition, two of the women I interviewed are now pursuing or about to pursue their own PhD studies. The interviews seemed to prompt these individuals in particular to reflect on often taken-for-granted issues, hence causing them to begin thinking about such issues, realising that study was possible and perhaps wishing to explore such issues further for themselves. Conceivably, here has been a specific instance of 'emancipation'.

### *Field interviews: the Canadian element*

I approached the Canadian component of my field research with less apprehension, and, in contrast to the Scottish research experience, I found the Canadian portion of the research much easier. This could be attributed to several factors. I had completed twenty interviews in Scotland and I now had my own 'comfort level' with the interview process. In addition, because I was on 'home turf', cultural differences were less of a factor. As a Canadian

interviewing other Canadians, I was familiar with cultural cues. I was also familiar with the geography and transport systems of the region. Travelling distance was shorter within the Canadian study region and as a result I spent far less time getting to the field. Prior to leaving for Canada, I contacted Canadian disability organisations via post and telephone with my details and research project information, with a view to contacting women to interview. I also contacted various friends of mine to arrange interviews. As was the case with the Scottish interviews, the word-of-mouth proved very successful. My details were passed along to other women through friends who knew about the research I was doing, and the network grew. I also met women who used the same specialised (disability exclusive) transit system that I did. My previous post with Statistics Canada dealing with disability issues enabled me to have a network of contacts within the disability community both within and outwith the labour market. When some women heard that I was doing research, they even contacted me in order to participate. I kept the contact process as 'open' as possible. That is, with the women I did not know, initial contact was made through mutual friends, and the woman would then contact me or I would contact them according to their preference. On one occasion, a woman had agreed to an interview and then decided not to participate.

In addition to undertaking the Canadian portion of my fieldwork, I was working in a full-time post with Statistics Canada, and as a result my opportunities for scheduling interviews were somewhat constrained. I was able to interview women over my lunch hour (my employers were supportive of this), in the evening or at the weekend. In an effort to free-up more interview time, I took holiday time and moved to a four-day week. This proved to be very successful. The Canadian participant group was very similar in virtually every aspect to that of the Scottish participant group, with the one exception being an interview with a woman of colour. Overall, the Canadian interviews were somewhat shorter because I was often interviewing women on their lunch hour or mine.<sup>6</sup> Interviews ranged from thirty minutes to two hours in length. Increased interview speed might also be attributed to my own familiarity with the interview process and cultural cues. I found the Canadian research element far less emotionally and physically taxing for the reasons alluded to earlier. I must

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<sup>6</sup> As noted previously, numerous Canadian interviews took place in or near the workplace setting, and for this reason many of the women who I spoke with confined their comments to work or domestic issues. Women who were interviewed away from the workplace (i.e. restaurants, shopping malls, at home or in coffee shops) were more inclined to discuss broader 'social' issues.

admit to some degree of 'interview fatigue' after participating in forty interviews in five months although the Canadian interviews themselves were as exciting for me as the ones that had gone before.

As had been the case with the Scottish fieldwork, I worked to fit into the women's schedules as far as possible. I met participants in venues that they chose, where they would feel as comfortable as possible, including cafeterias, shopping centres, offices, homes and restaurants. Again, I made efforts to underscore the value and importance of the information that participants had to offer. For many participants, it was the first time they had discussed any of these 'close in' experiences. There were two instances in Canada where the interview triggered an emotional response. In one case, a woman discussing her disability drew herself up into a ball and her 'body language' conveyed that she was distinctly uncomfortable, so we moved on to another portion of the interview. Another woman when asked if she thought that her disability was a factor in her hiring process, she stopped and repeated several times 'I don't know, I honestly don't know.' The question seemed to cause genuine anxiety, and so, as was done with the other interview, we moved on to another section of the interview. Participants were forthcoming, gracious and genuine, and they apparently found the interview itself to be positive. The first Canadian interview was completed on June 28 and the last one was completed on August 16, 2000.

### *Research process: on-goings*

#### *Transcription*

The transcription process was an integral part of my research project, not only because it provided much needed material for analysis but also because it became one of the few elements of my research that is completely outwith my control. The nature of my disability impacts directly on my manual-motor speed which is exceedingly slow as compared to a non-disabled person. My typing speed is approximately ten words per minute, and consequently undertaking extensive transcription of interview tapes without assistance was impossible. As a result transcription arrangements were made through my supervisor contacting personnel within the Geography Department. In addition, he had made arrangements for funding through a University disability access programme for assistance with transcription fees. Having my supervisor make these arrangements (funding and transcription) significantly lessened my stress levels concerning this aspect of my research,

for which I will be *forever* grateful. As a result, I was able to conserve my energies and use them to greater effectiveness for other parts of my research. Various individuals agreed to transcribe tapes for a competitive rate. I gave the Scottish interview tapes to my supervisor on June 15, 2000 and the Canadian interview tapes were shipped to Scotland on August 18, 2000. I had made arrangements to have the Canadian tapes transcribed in Canada, but circumstances evolved such that transcription had to be done exclusively in Scotland, which was in the end, for the project's betterment. Transcription was completed in January 2001, with all transcripts being received in early February 2001. I transcribed three of the interview tapes myself because the professional transcribers were unable to understand the unique accent which stemmed either from their nationality or certain types of disability.

### *Coding*

I had no wish to objectify the interview participants in any way and therefore I wanted to avoid a mechanised software approach to the coding process. I wanted to maintain the 'hands-on' approach that I had begun with the interview process. This need was magnified because I had not transcribed the bulk of the interview tapes. I wanted to be able to get back 'in touch' with the transcripts once again, and to catch the various nuances and subtleties of language and expression which I thought may have been over-looked had mechanical coding been used. The written transcripts were studied and reviewed in detail and, at first, each transcript was read as if it were a short story. Transcripts were then re-read looking for broad themes through passages of dialogue such as 'public' or community space and 'private' or personal space. These themes were marked out with different colour codes. Transcripts were read for a third time to refine further themes into specified areas such as education, employment, home and community, and each 'area' was again defined by a specific colour. Transcripts were reviewed subsequently on an on-going basis in order to refine then still further and to define micro themes and elements, again marked out with a colour code.

### **Conclusion**

A critical review of existing disability research has lead me to shift to an 'interpretivist' approach. Traditional approaches to disability research design have arguably not included people with disabilities in any meaningful way other than as subjects to be 'studied'. For this reason I chose to undertake an in-depth qualitative methodology. Therefore, from the outset, I tried to develop a truly inclusive research design ensuring that the 'voices' of disabled women remained at the forefront at every stage not only during the interviews. Creating a

space of dignity and respect, and building in flexibility according to the needs and wishes of each woman who I interviewed, enabled everyone to participate on their own terms. The end result is a series of interviews of rare depth, richness and candour. However, I have not completely jettisoned quantitative procedures and I actually return to these measures with a critical eye, in Chapter Five. My own approach to research *does* echo some themes from ‘emancipatory’ research, but tries to be more circumspect about imposing a certain form of radical disability politics on the women who I interviewed, *and* crucially, wishes to retain more of an awareness to the embodied (and variable/changeable) dimensions of ‘impairment’ (rather than seeing these as a residual concern of the positivist, medical model). My own ‘positionality’ in the midst of this research, studying my own ‘cultural self’ does become a crucial ingredient in thinking conceptually about the issues involved *and* in the kinds of approaches to the methodology laid out in the final sections of this chapter.

## Chapter Five

### Doing it by numbers!!

#### Introduction

Initially, when I began to gather the background research for this thesis my intention was to use statistical data on disability from Britain and Canada. Through working for Statistics Canada on disability issues measured in both the Health and Activity Limitation Survey (HALS) and the Survey of Labour and Income Dynamics (SLID), this seemed like a good idea. However, upon closer examination I found the established framework of disability statistics to be of limited utility, relying on the traditional assumptions of fixed medicalised or defective bodily mechanics that permeates most mainstream disability research. Men and women with disabilities have had little substantive input into the background development of the disability statistics collection mechanism. Consequently, many of the residual able-bodied beliefs around disability have been 'imported' into the collection instrument. 'Official' statistics do provide a form of 'visibility', in that this recognition does provide a reference or starting-point which is an improvement over invisibility or a lack of official status. These individualised limitations-based approaches to disability nonetheless provide a limited profile, but little in the form of context or dimension that is the reality of life with a disability. This chapter is hence a sustained deconstruction and critique of disability statistics, but in the process I am trying to raise positive possibilities that would improve such statistics. More specifically, my claim is that such evidence can be made more relevant through learning from qualitative research. By exposing deficiencies in the statistics, certain issues are raised, particularly the activity, variability and interconnected nature of the lives led by women with disabilities to be explored in much greater detail in the qualitative research to follow. To some extent, though, it has also been this qualitative research that now informs my critical stance on what disability statistics can and cannot achieve.

#### Statistical analysis of disability in an historical context

Statistics are not benign; they reflect the history, ideology and expectations of the larger social order (Carver and Rodda, 1978; Abberley, 1992; Davies, 1995). Indeed, statistics often have a definite social and cultural context (Barnes, 1998). The production component of capitalism is the focus of statistical development (Barnes, 1998), and economics often serve as the underlying rationale, providing the concrete mathematical reference points used to justify current practice (Smith, 1988). The formalised language provides an air of



exactness or correctness that mitigates the arbitrary nature of the process (Barnes, 1998; Sibley, 1998). As statistics have gradually become institutionalised by the state, they promote an element of social control, providing the framework upon which social policies are developed and maintained (Barnes, 1998; Sibley, 1998).

Statistical analysis in its modern form dates back to 18th century Germany and was originally developed as a descriptive form of measurement (Barnes, 1998). However, one hundred years later, in the midst of the European Industrial Revolution, statistical analysis was appropriated by embryonic social theorists as a means of reflecting the economic and social considerations of the day (Davis; 1995, Barnes, 1998). Thus began the fixing of 'norms' related to disability. The standardisation and quantification elements of statistics attracted the interest of scholars who were anxious to import the perceived rationality afforded by mathematics into the study of activities of daily living (Barnes, 1998). This new found logic provided the scientific rigour and justification for a new perception of the embodied individual in society (Smith, 1988; Barnes, 1998). Embodied materialism became the order of the day, that is, the value of the body in relation to the space and place it occupies and can utilise:

Biological beings and physiography are held to be transformed through practices and social spaces. The practice of transformation can delimit the form of social being which physiography may take. (Gleeson, 1999, 51-52)

Value is always mediated by changing social, cultural, economic and political factors, and the Industrial Revolution had a profound impact on the organisation of education, employment and transportation in society, and commodification of the human body was an integral part of the new industrial order. Statistics provided a powerful tool, particularly for eugenicists who were eager to prove that certain groups of people were more suited to the demands of an industrialised society than others, and statistics hence legitimated this 'new' social order (Barnes, 1998). Statistical analysis represented an attempt to quantify and to standardise the 'average man' and thereby the 'average worker' for industrial labour (Davis, 1995; Abberley, 1996). 'Average' acquired a value-added worthiness status representing all that was good (Barnes, 1998; Gleeson, 1999), and certain forms of physicality (predominantly, white, non-disabled males) acquired the greatest prominence (Gleeson, 1999).

Thus, what once represented as the 'ideal' soon became 'average' which was then transformed to the 'norm' (Barnes, 1998). Individuals measured themselves according to a

central normative standard. Conformity was the key, and those individuals who did not represent the normative standard acquired a social pathology reflected in the 'error curve' (Davis, 1995; Barnes, 1998). Statistical methodology effectively divided society into standard and non-standard groups with devastating results for disabled people. Those individuals who did not 'fit' this new social order (i.e. women and disabled people) were viewed as a threat to the physical uniformity considered necessary for efficient production (Sibley, 1998). Gleeson (1999, 52) states that: "[c]reation of social spaces can constrain or devalue the identities of collectives defined by specific forms of embodiment". The body as standardised machine forged ever stronger links between physicality and humanity, and statistics and eugenics bonded together in the concept of the 'norm' (Davis, 1995).

Social perceptions of certain groups may blend with the statistical process (Lawson, 1994). The deviant, non-normative elements highlighted by statistical analysis of those individuals on the margins, such as people with disabilities, frequently dominate policy developments. Thus, statistics are used to maintain and to ratify central tenets of the dominant social order: notably, the ability to engage in socially acceptable, productive activity. In return social/political constraints and ideology commonly drive the development of statistical frameworks rather than the experience and knowledge of disabled people (Davis, 1995; Abberley, 1996). This being said, federal government departments (Human Resources Development Canada) and Provincial governments (Ontario) may fund elements of post-censal surveys in order to obtain more detailed information in certain geographic or subject areas to suit political objectives (HALS, 1994). This information currently provides the framework for all types of policy development related to disability.

Most disability statistics and resulting policy reflects the individual functional limitations/deficit perspective common to the World Health Organisation (WHO). Within the International Classification of Impairments, Disabilities and Handicaps (ICIDH):

**Disorder or Disease** is the intrinsic situation, the cause of abnormality, which may be present at birth or acquired later.

**Impairment** is an abnormality of body structure and/or appearance caused by the disorder. It is a disturbance at the organ level, measured in terms of its presence or absence.

**Disability** is the consequence of impairment in terms of functional performance and activity by the individual. This constitutes a disturbance at the personal level, measured in terms of degrees.

**Handicap** (called barrier in the Canadian model) is a disadvantage that limits or prevents the fulfilment of a role that is normal [sic]. It is the result of impairment and disability, but is conditional on circumstances in which individuals may find themselves.

(HALS, 1991, 4-5)

Contrast the ICIDH definitions with those developed by Disabled Persons International (DPI):

**Impairment** is the functional limitation within the individual caused by physical, mental or sensory impairment.

**Disability** is the loss or limitation of opportunity to take part in the normal life of the community on an equal level with others due to physical and social barriers.

(Barnes, 1991, 2) (drawn from Disabled Persons International – DPI)

These latter definitions, developed by the disability community, relocate disability and impairment by moving away from the individual and into the social sphere. This shift begins to recognise the power imbalance experienced by disabled people.

The association of disability with an absence of health or the presence of illness nevertheless remains largely intact. The ‘mechanical’ focus of the WHO model appears to have a dehumanising impact on disabled people, and the link with disability or impairment as defect rather than difference is reinforced (Gleeson, 1999). This being said, although the deficit perspective present in the functional limitations approach does reflect the medical model, at a rudimentary level the social impact of disability is acknowledged. More importantly, statistical visibility provides ‘official’ recognition and thereby gives space and place on the public agenda from which to initiate substantive social change. Statistics do then provide some context for the narrative process (Moss, 1997), and, according to Lawson (1995), they can indicate placement or position. McLafferty (1995, 438) maintains that “[q]uantitative elements do provide substantive information [and] provide broad contours of difference when linked to a strong theoretical base to provide context”. For this reason it is important for disability rights activists to try to work with disability statistics, not always against them. Statistics provide the impetus to examine critically the traditional inflexibility of disability-related programmes and services in relation to the real work environment, moving beyond fixed theoretical structural concepts and mere quantification.

### **Canadian and British disability statistics**

Quantification of disability statistics in Canada is a comparatively recent phenomenon, commencing in the 1980s, following the recommendations of the Special Parliamentary Committee on the Disabled and the Handicapped Obstacles Report (1981) in which Statistics Canada, the Federal statistical agency, received direction:

To give high priority to the development and implementation of long-term strategy which will generate comprehensive data on disabled persons in Canada ...  
(HALS 1991.2)

Although 1981 being designated United Nations International Year of Disabled Persons was no doubt the catalyst, official statistical recognition was a pivotal development. Official visibility is a first step to obtaining official recognition in the public domain. Positive elements must therefore be highlighted along with gaps, weaknesses and shortcomings. Prior to this, little was known by the state about the lives of disabled people, but, recognition has an associated cost. Terms of reference are defined by policymakers and rarely by the population in question, although they may well be part of a consultation process. The resulting survey framework does tend to reflect official perceptions and concerns rather than the reality of the population base. The first national survey to address disability was the 1983 Canadian Health and Disability Survey (HALS, 1991) (now the Participation and Activity Limitation Survey PALS). The juxtaposition between health and disability here remained intact, and the medicalised status of disability remained unquestioned (as is still basically the case today). Thus, the focus remained individual dysfunction and defective bodily mechanics in the home, in the workplace or in the community. The interconnectedness of these settings was not recognised, and neither was the everyday social reality of coping with such settings. Everything is studied in isolation, related solely to the individual's 'defect'.

The first national census in Canada to include a disability question was conducted in 1986 and it has been incorporated in each subsequent census. Unlike Britain and the United States, Canada does not have a disability component in the Labour Force Survey (LFS), although questions from the LFS have been incorporated into Canadian disability surveys. Current statistical information is critical to the development of policies, programmes and services which begin to address the requirements of disabled people as perceived by non-disabled bureaucrats (CHRC, 1999). Yet, although the census is conducted every five years, an in-depth analysis of disability data has not occurred since 1991 owing to lack of funding for a post-censal survey. The census disability question identifies the disabled population, but it does not provide the level of detail necessary for in-depth analysis of disability data. The post-censal survey is the vehicle through which greater detail is obtained for a specific population group. Unlike the census, post-censal surveys are not funded via parliamentary mandate, and funds, if available, are secured through other government agencies. Lack of funding often reflects a lack of political willingness within both the public and private

sectors fully to understand the barriers encountered by this under-valued sector of Canadian society (CHRC, 1999).

Despite shortcomings to be discussed shortly in the existing disability statistics, concerning the basic framework and subsequent analytical gaps, important information about disability can still be gleaned from an incomplete statistical model. The caveat is that one recognises the limitations on what can be inferred in such a context. A few relevant findings are nonetheless as follows, bringing in British data for comparative purposes:

### **Highlights From The 1991 HALS Survey**

(Taken from HALS,1994; Fawcett, 1996; CHRC,1999)

One in six Canadians has some form of disability or 15.5% of the population (4.2 million people)

Mobility agility (walking, movement) disabilities are most common, 50% and 52% of the disabled population respectively

Among disabled people of working age, 54% have mild disabilities, 32% have moderate disability, 14% have severe disabilities

More women than men have a disability, 16% as compared to 15% of the Canadian population as a whole

48% of disabled Canadians in work have either full or part-time employment, as compared to 78% of non-disabled Canadians

Disabled women experience higher levels of unemployment than disabled men 16% as compared to 13.2% for disabled men among disabled people looking for work

48.5% of working age disabled women and 64.2% of working age disabled men report labour force participation – labour force participation means being available for work, either employed or unemployed

Federally regulated workplaces account for employing 50% of disabled people available for employment

44% of disabled people are not in the labour force as compared to 22% of non-disabled Canadians

Disabled women were more likely to be outside the paid labour force than disabled men, 33% as compared to 23%

21.9% of disabled people live in poverty (below Statistics Canada's low income cut-offs) as compared to 12.6% of non-disabled people (used as a measure of poverty, although Statistics Canada does not have a definition for poverty as such)

25% of disabled women live in poverty (below Statistics Canada's low income cut-offs) as compared to 18% of disabled men

14.3% of disabled women who are in employment earned over \$35,000 per annum as compared to 37.9% of disabled men

65.6% of disabled women earned under \$25,000 as compared to 38.4% of disabled men

two out of three of disabled men has assistance with household duties as compared to one out of five of disabled women

82% lone disabled parents are women

Among those disabled individuals not in the labour force, 21.4% cited possible loss of needed income and service supports - 13.4% cited possible loss of medication coverage and transport

Among this group 20% did volunteer work

56% of those disabled people not in the labour force showed labour force potential and willingness to work with a change in circumstances

### **Highlights from British Disability and Employment Surveys**

(From Labour Market Trends September 1999 and Employment of Disabled People Assessing the Extent of Participation DfEE Research Report RR69)

18% of the working age population living in private households in Britain have a long-term disability or health problem (6.4 million people 3.4 million men and 3.1 million women)

47% of disabled people identified a mobility disability as their principal disability, 37% of those with disabilities reported musculo-skeletal problems, 37% for men and 38% for women

The economic activity rate is approximately 51% for disabled people as compared to 85% for non-disabled people

Over 75% of economically active disabled people have a partner who is in work

89% of disabled people receive some form of state benefit

The unemployment rate for disabled people of working age is almost twice that for non-disabled people, 11% as compared to 6%

41% of unemployed disabled people have been out of work for less than six months, 27% have been unemployed for two years or more

Almost 50% of economically inactive disabled people would like to have paid employment

Disabled women are far more likely than disabled men not to have looked for work owing to domestic responsibilities

Among disabled people who are working, 99% are in 'open' as opposed to supported employment

Approximately half (41%) of those individuals identified as economically inactive were disabled (53% for men and 33% for women)

Disabled people who are economically active are more likely to be young, white males

Economic inactivity increases with severity of disability

Disabled women have less than 70% of disabled male 'odds' of being economically active

Presence of dependent children has a significant impact on the economic activity of disabled women: every child under 5 reduces the odds of economic activity by 30%

Nearly 75% of disabled people who are working do so on a full-time basis, very similar to non-disabled people

Increased educational qualifications greatly increase the odds of economic activity of disabled people

47% of disabled women who are working do so on a part-time basis as compared to 9% of disabled men

Disabled people are more likely to work in manual low-skill occupations than non-disabled people; very few disabled people occupy management positions; disabled men are more strongly represented in management – there are high concentrations of disabled women in the service sector: (clerical, operational, craft and secretarial)

Employed disabled men earn an average £238 per week as compared to £152 for disabled women

Disabled women home workers are far more likely to be 'outworkers' of family workers, whereas disabled men are far more likely to be self-employed

Disabled people have lower than average qualifications than their non-disabled colleagues

Below the degree level, disabled women are markedly less qualified than their male counterparts

Disabled men are more likely to be users of technology than disabled women

More disabled people are in temporary work than non-disabled people

16% of disabled people have reported employment-related discrimination

The above Canadian and British statistics <sup>7</sup>demonstrate the significant degree of economic and social disadvantage experienced by disabled people in Canada and Great Britain. The poverty rate among disabled people is far greater than for the general population. The difference in employment rates between disabled and non-disabled people illustrates the barriers encountered by disabled people. The differences may be attributed to various factors interacting in combination with one another, some of which may be explored with reference to socio-economic, gender and education variables.

### **Critical perspectives on statistical analysis**

Despite being able to draw out findings such as those above, statistical analysis of disability remains arguably over-simplified, and fixated on individual bodily mechanics. Agility, dexterity and speed are, as a rule, considered in terms of the individual and his or her disability type. Singular 'block factor' analysis of disability by type remains intact. In some ways 'block factor' analysis implies a degree of cultural arrogance and remoteness from the disability constituency, and there is accordingly a failure to recognise many other key differences within this population group. Moreover, elements of physicality are usually examined in isolation, left in a vacuum remote and isolated and unconnected from the other factors of daily life.

The individual deficit approach adopted by Statistics Canada and the Office of Population, Censuses and Surveys (OPCS) surveys concerning disability does not promote or facilitate widespread ease of access to goods and services for disabled persons. Indeed, Abberley

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<sup>7</sup> Working for Statistics Canada (the Canadian Statistical Agency) provided me with access to and knowledge of the survey development and analysis process. This level of access was not readily available to me with regard to the British Office of Population, Censuses and Surveys (OPCS) Surveys. However, the British and Canadian surveys use the same world ICIDH model and the statistical results obtained are similar.



maintains that this type of survey process is yet another mechanism for governments to distinguish between the 'deserving' and 'non-deserving' poor, here masked by clinical definitions (Abberley, 1992, 1996a). Furthermore, he postulates that this type of research is used to validate state programmes and issues (Abberley, 1996a). The above definitions assume that disability and impairment are static, unchanging and unaffected by situation or context (Abberley, 1998; Oliver, 1990; Roulstone, 1998b). Other disability researchers echo Abberley's concerns. Barnes *et al.* (1998) also caution that policy-driven research examines the efficiency and effectiveness of broad policy mandates in isolation from other important factors. For example, focusing solely on the ability to engage in paid employment underscores the degree to which unpaid or volunteer work is devalued. Pension schemes often preclude engaging in any form of paid labour (Fawcett, 1996). This effectively excludes a significant number of disabled people from being counted in the first place. It should also be noted, importantly, that the quantification process does not address actual workplace experience or satisfaction (Barnes *et al.*, 1998). However, while some disabled people may have found 'voice', much of the disability experience remains shrouded within the community of disabled people caught up in the public/private dichotomy of tentative social acceptance (Wendell, 1997).

As a result, information taken from the data may not provide a clear or inclusive picture of the population and its real but varying concerns. Policy structures derived from the information-base mirror the survey framework. In many ways they thereby work to maintain the status quo. A dysfunctional (medicalised) perspective on disability ensures that the majority of funding from government sources directed toward disability programmes and services will continue to be concentrated in the health care and corrective rehabilitation field.

Disabled women are disproportionately affected as they are often primary caregivers, domestic labourers and are perceived as secondary labour market participants (Fawcett, 1996). Non-disabled women have voiced similar concerns around employment, childcare and housework (West, 1996). Indeed, parallel claims have been made by non-disabled women about the failure of statistics to recognise traditional women's unpaid domestic labour inside the home. Women are left largely invisible in much of the labour market analysis and policy recommendations. The majority of social and economic analysis is based solely on the value of paid employment, paid work is the singular evidence of 'productive' or socially valued labour (Rose, 1989). As a result, the key contributions of 'housewives' [sic] to socio-economic life are obscured. In 1991, Carol Lees, a Canadian 'housewife,'

refused to complete her census form on the grounds that her housework was not recognised as 'work,' and she sent a bill to the Prime Minister of Canada in excess of \$ 90,000 representing her equivalent yearly wage (Herstory, 1999). Since 1996, Statistics Canada has included housework on the census form (Herstory, 1999). Culturally embedded conventions about disability coupled with gender expectations then intertwine in a complex manner. The majority of disabled lone parents are women (HALS, 1994), but disabled women are far less likely than disabled men to receive domestic assistance (Fawcett, 1996). Cultural beliefs concerning the secondary nature of women's employment, as compared to that of men, is consequently reflected by the heavy concentration of disabled women at the lower end of the income scale as compared to disabled men.

Particularly for persons with disabilities, the domestic and workplace spheres share connections which can barely be discerned in statistical surveys. Depending on the nature and severity of the disability or condition, it may take longer for a person with a physical disability to complete personal care or domestic tasks. Elements of personal care such as bathing, washing, dressing, eating and housework activities, for example meal preparation, have been studied in terms of the individual isolated mechanics of physicality and agility. Quantitative statistics do not address qualitative life experiences, as they cannot be easily quantified, but this is not to say it cannot be done. Even though the numbers cannot adequately represent qualitative findings or issues, perhaps quantitative information *can* be made to reveal aspects of life for people with disabilities that have previously been neglected. One task ahead, then, is to explore mechanisms through which they may be examined simultaneously.

*A clearer picture: the reality of time, a table is worth 1000 words*

Knowing whether a person with a disability requires assistance with a task or is able to complete it unaided provides an incomplete picture. At present, there is a basic statistical outline coming available, but the detail remains to be filled in. A clearer picture of the impact of disability or impairment in daily life can be shown through the measurement of time an issue that has become increasingly obvious to me as a highly significant one from my interviews with disabled women. However, as yet, time usage in association with domestic and personal care activities for people with disabilities remains largely unmeasured. There are no time use questions included in any survey including disability. Failure to consider the finite reality of time in a disabled person's daily life again reflects an innate arrogance

concerning the nature of personal bodily mechanics and the supposed 'fixed' nature of the environment and the manner in which the individual moves within it.

Individuals with sensory impairments such as deafness or vision impairment also experience time deficits. People who are deaf spend far greater amounts of time and energy processing information in a hearing environment. Similarly, individuals with a vision impairment use more time to process visual cues or printed materials in a sighted environment.<sup>8</sup>

Time use is a pivotal factor for individuals with restricted levels of mobility, agility, dexterity and energy. The table of basic household and personal tasks below drawn up by myself initially as a thought experiment provides a simple but graphic illustration of the time use differential between a person with a disability and a non-disabled or able-bodied person. Both individuals are the same age, sex and of similar physical stature, with the exception of the disability.

| Task                             | Person With Disability<br>(Mobility Disability) | Able-bodied or Non-Disabled Person     |
|----------------------------------|---|--|
|                                  | Time to Complete Task<br>(Approximate)          | Time to Complete Task<br>(Approximate) |
| Washing/Drying Hair              | 45 minutes                                      | 15 minutes                             |
| Bathing                          | 40 minutes                                      | 5 minutes                              |
| Dressing                         | 30 minutes                                      | 5 minutes                              |
| Preparing Breakfast              | 30 minutes                                      | 10 minutes                             |
| Changing the Bed                 | 1 hour  | 10 minutes                             |
| Taking Out Rubbish               | 15 minutes                                      | 5 minutes                              |
| Doing a Load of Laundry          | 1 hour  | 10 minutes                             |
| Loading/Unloading<br>Dishwasher  | 40 minutes                                      | 10 minutes                             |
| Using Stairs 1 Flight<br>(Short) | 4 minutes                                       | 10 seconds                             |

With each succeeding survey and a growing number of social surveys which include a disability/limitation module, the data on people with disabilities continues to increase. The inclusion of a time use question related to personal care and domestic activities is hence a

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<sup>8</sup> Deaf women and women with vision impairments who I interviewed told of the vast amounts of time and energy expended managing in hearing and sighted places and spaces.

natural progression toward a more comprehensive view of life with a disability. It provides a quantitative measure of the effects of disability in the nitty-gritty of a person's life. With a clearer picture of the use of time and its effect on the lives of people with disabilities, linking questions could be developed between time use in the personal/domestic sphere and available time use in the workplace. The additional data provided by these questions would provide clearer detail and contextual sensitivity concerning people with disabilities: it would provide the basis for a critical disability statistics, and might just trigger changes in disability policy directed not just at the homeplace but also at the workplace.

*a still closer look; critiquing and reworking SLID*

Begun in 1993, the Survey of Labour and Income Dynamics (SLID) survey is a unique measurement tool enabling researchers to conduct a focused long-term study of social, labour and economic elements comprising family life in Canada. The SLID Survey is a longitudinal and cross-sectional survey that follows panels of selected families (several thousand in number) over a six-year period. Respondents are interviewed on a twice yearly basis in January and May. Incorporating ethno-cultural domestic life elements and 'activity limitation' (disability) variables within the survey illustrates a commitment on the part of survey designers to attempt to reflect the diversity of Canadian society.

The SLID survey has included a disability section or module since its inception although the approach taken again reflects the traditional ICIDH and WHO medicalised approach to disability and impairment. As originally envisioned, one of my tasks in this thesis was to examine quantitative data generated from the disability module of SLID, the hope being to arrive at a more detailed statistical profile of life and work experience of disabled people in Canada, particularly in the Ottawa-Carleton region. Yet, it soon became apparent that the level of detail yielded from the disability module was far too general to be of use to a researcher such as me. The focus of my research thus shifted to looking at the nature of the SLID survey disability questions themselves in order to determine the utility of questions in relation to the nature of information gathered, and to sensitise myself further to the sorts of issues that I would need to pursue in much more detail through my qualitative research.

Prior to my research in the summer of 1999, the disability elements of SLID had not been analysed. My experience with and personal knowledge of disability was instrumental in developing my approach to SLID research. During my final week at Statistics Canada, I submitted a detailed report of my findings to the Programme Chief responsible for the SLID.

It has since served as the catalyst for on-going discussions concerning both the refinement of the SLID survey disability module and the harmonisation of all disability survey information at Statistics Canada. For my own thesis purposes, the exercise has become more one of revealing the limitations of what can be extracted from such statistics, underlining the extent to which the main issues of concern for this project - the grounded experiences and, particularly, work experiences on the part of disabled people, as cross-cut by issues of gender - cannot really be illuminated by a quantitative approach except in the most abstracted and aggregated form. However, my experience with the SLID survey did provide the impetus for my later research, and has prompted my ideas for incorporating time elements into existing quantitative disability surveys.

The disability module has largely been developed by incorporating disability questions from other Statistics Canada social surveys, with little thought given to 'flow' or 'fit' with the rest of the SLID survey (Lathe, 1999). Disability elements have arguably not been added with the same degree of attention accorded to other modules of the SLID survey. The survey designers wished to cover the issue of disability, but apparently lacked knowledge about the varied nature of the population group. Often, within disability research, there is a tendency to globalise, that is, to reduce disability to a single, static all-encompassing component. The multiplicity of factors comprising activities of daily living and disability are thereby obscured in favour of perceived simplicity at the expense of necessary context.

### **SLID 1998 Disability Filter Questions**

Is [respondent] limited in the amount or kind of activity he/she can do at home or in other activities because of a long-term physical or mental condition or health problem (by long term we mean more than 6 months)?

Response choices: Yes/No

Does he/she have any long-term disabilities or handicaps?

Response choices: Yes/No (SLID, 1999)

The module does provide a very basic disability-related information, but currently, the level of detail is not available to the degree present in the ethno-cultural module, for example. The ethno-cultural module contains highly detailed ethnic and cultural descriptors concerning race and ethnic origin, and, as a result, it is possible to generate data with much greater population detail. As awareness of diversity issues becomes increasingly sophisticated, so

too should the mechanisms of data capture in reflecting these aspects of social and economic life. In their 1998 research study concerning wage opportunities for visible minorities, Hum and Simpson underscore the need to refine the analysis, addressing this subject area rather than treating those individuals identified as visible minorities in one homogenous mass. They caution against over-simplified generalisations related to skin colour and low wages, maintaining that a much clearer picture emerges if factors such as language ability, education, gender and immigration status are considered, since each of these factors are a significant influence on the employment status of someone from an ethnic minority (Hum and Simpson, 1998). Therefore, filtering elements within a survey or analysis should move beyond 'block identity' concepts to reflect the complexity and diversity within the population base itself. Various factors impact in conjunction with race or ethnicity and, as a result, should be routed differently through the survey not *en mass*.

The principal focus of the disability module of the SLID survey is assumed to be the impact of disability on work activity, rather than the nature of the disability itself. The disability module hence focuses on the act of looking for work and on factors limiting or preventing one from working rather than considering the work activity itself. If the intent of the module is to examine disability and its impact on work-related activity, then serious consideration should be given to question flow, routing disability questions more clearly toward the labour-related elements of the survey, since disability response options *are* also located in the labour section of the survey. The way in which questions are adapted for the disability module of SLID means that the work questions are first asked in relation to disability, and a positive or 'yes' response means that the respondent does not receive the remaining screening or filter questions. A positive response means that the individual is 'filtered out' out of the bulk of the survey, routed away from further questions related to work or home. This seems to imply that a disability which causes difficulties at work would likewise cause difficulties in the home. Depending on the nature of impairment or disability, and also on the support systems and services available and the obstacles present in one or both situations, difficulties in one circumstance should not automatically be assumed to carry over to the other.

It may also be that the work experiences of disabled people end up being 'factored out,' because a positive or 'yes' response leads them to be routed past other work-related questions. It would appear that the sole purpose of the disability module is to determine whether an individual has a disability or not and there is little, if any analysis beyond that. This means that the employment experiences of disabled people are not assessed by the

survey design, possibly reflecting ableist notions that disabled people do not work or cannot work as a rule. Employment and disability are not mutually exclusive, although disability/impairment may impact or be a factor in the work environment. It may be that such an individual is unable to engage in paid employment but, one should not assume that in every case disability precludes employment; and, of course, part-time work or voluntary work may also be an option.

At present, the SLID disability module provides a basic information framework concerning disability in relation to social and working life. The possibilities do exist within the current survey to move beyond the austerity of single 'block factor' analysis concerning disability, thus echoing the call from Hum and Simpson (1998) on race and ethnicity issues. With limited modifications to the SLID survey, a similar approach to that adopted with visible minorities could therefore be adopted with the disability elements of the survey. Exploring in greater depth the inter-linking of disability with daily life factors and work activities, moving beyond a single dimension approach to disability, would enable greater exploration in an experiential context rather than via a singular-defining element. Disability may be an aspect of a person's life, not its entire focus. Although disability can at times be an overreaching factor, in certain situations it is not and certainly should not unthinkingly be assumed as such. These are key points for my thesis research to flesh out in many ways using a more in-depth qualitative investigation.

Although most modules of the SLID survey are being regularly adapted and refined to improve data collection to reflect the changing elements of Canada's economic, working and family life, the disability module has remained largely untouched. However, this is about to change. After extensive consultation, the SLID survey will adopt the Census 2001 filter questions in January 2000 for disability, in order to better address population-base concerns and maintain survey comparability.

### **Draft Questions 2001 Census Filter Questions – Disability**

Does this person have any difficulty hearing, seeing, communicating, walking climbing stairs, bending, learning or doing any other similar activities?

Response choices: Yes, sometimes/, Yes, often/, No

Does a physical or mental condition or health problem reduce the amount or kind of activity this person can do:

a) at home

b) at school or at work

c) in other activities, for example transportation or leisure?

The response choices are the same as those outlined above.

There are hence several important refinements to the disability filter questions for the 2001 Census. The key element derived from the consultation process was the need to add a 'graduated' yes response, that is, 'yes, sometimes' and 'yes, often'. This approach recognises the situational context of disability. Disability is rarely static and the degree to which it impacts on a person's life at any given time is mitigated by a host of circumstances, such as family composition, class, income or access to required services and facilities. This phrasing recognises that the degree of difficulty is rarely static and often in a state of flux, whereas previously, ability to work questions had a simple yes/no response. It was recommended that a 'graduated' yes response be adopted to cover variable circumstances. Rarely is disability an either or situation, as there are many shades of grey. Often, therefore, whether or not a person is able to work is contingent on a myriad of factors such as transport, access, home or work support or social policy and time constraints, which are not always static. Again, introduction of 'time use' questions such as the ones that I proposed above would further refine and develop the disability module without compromising the established framework.

A further proposal is that the wording should be modified to reflect better respondent sensitivities, so that the word 'limited' will be replaced in favour of 'reduce'. The wording change shifts the focus away from the individual and onto the disability itself. People may experience difficulty with certain tasks or situations, and they do not consider themselves to be limited individuals. It does not change the information obtained from the question, and there may be a greater response rate given the attention to respondent sensitivity. Another factor under consideration is the impact of proxy reporting. There may be instances where observers may attribute components or project their own insecurities that do not reflect the individual's perception of their reality. At present there are also composite disability/health related questions on the survey, and it has been recommended in the evaluation of the module that these questions be dropped because many disabled people consider health and disability to be separate issues. Although at times there can be illness associated with disability, an arthritic flare-up, for example, or an episode of depression, this is not always the case. A person with cerebral palsy may use crutches to aid mobility and have dexterity and balance deficits, but the person's state of health *per se* may well be excellent.



Another recommendation has been made for the addition of a perception of employability question. Often the individual's belief in their own employability is not shared by prospective employers. According to the Canadian Human Rights Commission, the vast majority of employment related discrimination complaints are filed by disabled people. Similarly, employer perspectives have not yet been examined and it would be interesting to insert questions that might expose deeply rooted cultural perceptions linking disability and incapacity. An important caveat is that job training does not mandate paid employment. Workplace culture remains grounded in the deficit perspective of disability. Employers may be reluctant to hire disabled people owing to perceived risk or inability, but these attitudes have not been acknowledged or questioned.

Recommendations have additionally been made for adding a question on volunteer work. Disabled people who are not working or unable to engage in paid work because of the nature and severity of the disability or social circumstances often engage in some form of volunteer activity. Volunteer work often has greater flexibility, and the limited work hours better accommodate the fatigue that may accompany some types of disability. Moreover, segments of this population base may experience gaps in education and training. The increasing 'professionalisation' of the labour market works as a barrier to accessing paid employment for this group of disabled people. Volunteer work provides alternative opportunities for social contact, skill acquisition, increased self-worth and well being. Had this type of data been available to me personally, it would have been possible to do rather more 'statistically' in a meaningful fashion in my thesis. As such, this experience has necessitated serious considerations about my own qualitative research design and question format. As a result my thesis information *had* to be much more qualitative, and could not proceed at all quantitatively.

While questions recognise that that disability may impact on one's work schedule, consideration should be given to examining elements in combination with one another rather than a single factor. Many disabled people, particularly women, are also lone parents and care providers. Another factor to consider is that many disability support programmes have strict income ceilings. Without these service-related support mechanisms, many disabled people would not be able to live independently within the community. Disabled people may choose to work a reduced number of hours per week in order to deal with other aspects of disability reality: fatigue factors, personal care requirements, transportation or childcare issues. Questions related to paid work at home hold particular significance for disabled

people, given that access requirements and workplace accommodation for this population group remain somewhat tenuous. For disabled people, often the 'home environment' remains most accessible. Many support services are linked exclusively to the home along with required assistive devices. Computer technology has the potential to enable some disabled people to access the workforce without leaving home.

Questions related to absence from the workplace demanding simple 'yes' or 'no' answers fail to get at different aspects to how such absence may have an impact on disabled people, specifically for those individuals who may experience periodic changes. People with depression, M.E. or arthritis may from time to time experience more pronounced symptoms requiring periods of absence from the workplace. Individuals in working environments that provide for absence periods are able to maintain their employed status with greater success. Questions concerning the ability to look and not to look for work are also still restricted to a single choice response. Disabled people find job searching difficult, irrespective of education levels. Service sector industry employment is often not suitable given the demands of physicality, professional appearance, speed and dexterity. Similarly, disabled people often do not have access to the more informal 'word of mouth' employment networks. Increasingly, job training is geared to previous employment experience or employment insurance eligibility. Training offered by private contractors can be of variable quality and is rarely adapted for those individuals requiring 'accommodation' of some type in the work environment. Education, training and rehabilitation programmes are aimed at getting disabled people 'job ready' for workplace participation. There is a perception that the workplace environment is inflexible and the focus has been on getting disabled people to 'fit in'. There has been little attention paid to the workplace culture itself and adaptation possibilities. This approach reinforces the 'special' approach to accommodation entrenching the idea that disability/impairment issues present far too great a difficulty to address in the 'average' workplace. No questions really tackle such matters, and they have not yet been identified as an issue.

Unemployment levels amongst this group are significantly higher than the non-disabled population. Wages from part-time, entry level or service sector jobs are often not enough to cover added costs associated with disability (Drake, 1999). This poses particular difficulties for people with variable chronic impairments such as MS or arthritis. These individuals may not need support on a continuing basis, but the nature of benefits system is such that they must resign their positions when benefits are needed (Pinder, 1996). Moreover, race,

ethnicity and gender elements have yet to be analysed in conjunction with disability (Abberley, 1992). Statisticians are reluctant to introduce such multiple factors, and prefer instead to standardised analytical techniques that rely on simplification and summary (West, 1996). Yet, moving beyond 'disabled people' and incorporating the complications of gender is a significant move, one which increases the likelihood of someone being identified as unemployed and/or in poverty.

## **Conclusion**

The exploration of the SLID survey underscores both the deep entrenchment of the medical model within official quantification mechanisms and the lack of analysis that accompanies the process. Bureaucratic process moves by degrees so as not to disturb too greatly that which has gone before. There is difficulty incorporating social elements within a limitations-based framework. This is complicated by lack of knowledge about disability issues on the part of statisticians. The lack of detail found in existing disability surveys has fuelled the need to rely extensively on qualitative information for the development of this thesis. My own experience with the 'flow' and 'fit' of disability in the spaces of daily life, in addition to the field interviews with forty women, have underscored the need to incorporate 'time use' questions into the disability modules of surveys. This would provide a finer level of detail for analysis, and would work well with the established framework, going some way to address current statistical gaps and weaknesses by providing detail or context. I hope that this can be a substantive policy recommendation growing out of my critique of disability statistics, informed too by my findings from the detailed qualitative research reported in the next three chapters.

## Chapter Six

### Segregated spaces of education

#### Primitive beginnings, primary elements

What are regarded as acceptable qualities of the body today have their origins in primitive historical concepts of physicality and what is taken to be the 'natural' state and order of the body (Wrigley, 1997). Less familiar forms of the body often assume a pathological nature, being viewed with suspicion and fear because of a lack of exposure and awareness. In European societies there is also a tendency to connect physical disability with intellectual disability, a reflection of these ancient beliefs. Victorian and subsequent eugenicists imported this fundamental notion of associating bodily 'perfection' with intellectual capacity, supporting their claims by the safety and security provided by 'natural' science, supposedly unfettered by cultural tenets (Gleeson, 1999). This discriminatory framework has been in place for over 150 years, well beyond living memory, and as such its arbitrary nature has acquired the comfort of convention and rationality. For this reason, the elements of the frame have rarely been questioned or examined, merely seen as 'the way things are' (Wrigley, 1997). In much the same manner as statistics gradually transformed the ideal to the 'norm' around which all else is 'deviance', dominant elements of physicality have assumed an essential unitary nature (Barnes, 1998). Those individuals lacking socially essential elements of physicality are thereby viewed as lacking in humanity, in effect as sub-human, although this outcome is rarely discussed or acknowledged.

Education authorities have assumed a primary gate-keeping facility, incorporating the mechanistic philosophies of the larger social order by protecting the status of common physicality. Thus, entry of the individual into the education process is perhaps the earliest exposure to the effects of this embodied materialism; that is, recognising the dominant form of physicality as social capital (Gleeson, 1999). In the process, one is not only reduced to one's physicality, but also defined by it. Non-disabled people, women and members of racial minorities have all experienced this displacement at various points in history, and here the physicality link with intellect remains firmly and deeply entrenched. Non-disabled people perceive access to education as a natural rite of passage into the adult world. However,

education for disabled people is not viewed as a usual element, but rather as a privilege granted to these individuals on a highly contingent basis. Indeed, the very presence of disabled people in educational space is often perceived as unnatural and disruptive. Access points to education are therefore limited, strictly regulated, tentative, peripheral, often medicalised, always on approval and subject to withdrawal. Whereas early education for non-disabled children nurtures creativity, where expectation develops potential, the situation for disabled children commonly entails a narrow focus on physical deficit correction. The space itself is frequently removed from or on the fringes of public mainstream spaces. As a result, it has been customary practice to educate disabled people, even more notably disabled women, separately from their non-disabled counterparts. Often the space itself is residual, and devoid of intellectual stimulation, reflecting a lack of expectation.

Audrey provides a telling account of what was common practice half a century ago:

*That's obviously a long time ago but when it came time for me to go to [mainstream] school, I was just about to go to school, and the education authorities at home said 'don't let her go' I wasn't educable ... Hadn't done any tests or anything, they just looked at my medical condition and said 'people like that are not educable.'*

*(Audrey, 55, Scotland)*

Babette's experience further underscores the impact of the medicalised approach to school admission:

*I was misdiagnosed as 'mentally retarded' because of the condition, it was quite a severe condition, it was diagnosed at the age of 9 months and my vision problems, although they are congenital as well, they weren't diagnosed until I was 5 and went to school, where a very attentive teacher said 'this child isn't mentally retarded she's blind'!*

*(Babette, 47, Canada)*

What has been the purpose of this segregated or 'special' education to which many disabled people have been consigned? In much the same manner as colonial administrators 'managed' the cultural indoctrination of indigenous peoples, similarly trained educationalists have supervised and controlled the disabled education process, channelling disabled children into appropriate disabled spaces. It appears as though the focus of 'special' education is geared to obtaining an arbitrary physical standard commonly known as 'normalcy', which is largely unattainable for this population group, thus firmly attaching to these individuals the label of different. This is perhaps directed at addressing the projected discomfort of the social majority in schools and beyond around physical difference, rather than improving the quality of life for disabled individuals. The aim is to develop a socially acceptable appearance rather than to improve and to develop intellect. Consequently, the education that is provided

appears to be adapted to occupy time in a limited space, rather than to foster intellectual stimulation. As Stacey reveals, and note that her education was rather more recent than Audrey's:

*I used to go to boarding school special school in Edinburgh ... physical activity was the focus and you had to walk better, talk better and sit right. I remember once I missed my English class because they made me walk to class unaided [Stacey uses a metal walking frame], so by the time I got there it was finished! ... I just thought the English was more important. Who cares if you can walk unaided but I needed to write.  
(Stacey, 29, Scotland)*

Or as both Heather and Elise elaborate:

*Until the age of ten I went to segregated school and I still refer to the day I left segregated education as emancipation day! I don't even count my years in the Ottawa Crippled Children's Treatment Centre as education. It was a real mishmash. Perfect body syndrome physiotherapy took precedence over academics. I remember that in the weeks before I went to regular school they pulled me out of class twice a day for physio!  
(Heather, 43, Canada)*

*I got it at the Kelburne, which is a school for people with cerebral palsy but at the time there wasn't many people as young, that young, with a spinal cord injury, it's more of a thing, that happens when you're out skiing, doing things, you know, really at that time there wasn't a lot of special schools, special schools were really just for, if you had a disability you got shoved into a special school ... Very poor when I was young [laughter], it was very much emphasis on physiotherapy, speech therapy or occupational therapy, which is good, but there was practically no emphasis on education. I found that ... they gave me a book to read, and that's what I did for the whole day, more or less, you know, I was given a kind of workbook, an English workbook, and if I had any problems I would ask the teacher, but basically that's mostly what I did, you know I was more self-taught than anything ... [M]y parents did try and fight for me to go to the normal local school but they wouldn't have it at that time, we moved house and outwith the district so I had to go to another school which was even worse, it was everybody mixed in, it was such a big school to start with and then there was actually only four people in wheelchairs, but it was such a big school and there was so many different types of disability there ... It was very poor, it was sitting doing jigsaws, sitting with Lego, you know if you could read a book that was a bonus, so quite often if I didn't read a book I was sitting playing with some kind of toy, by this time I was about 8, and it was really abysmal, it was like in the dark ages the school ... I did eventually get out of that school and I went to another school, I went back to the school I was at, because it was the best, although it wasn't really ... but by this time I was about 11, and the teachers were saying, one of the teachers especially who was really good, had said that I should be going to a more mainstream school, but at that time they had built a school which did mainstream education for people with disabilities but you had to have a certain IQ to get in to this school and you had to be more or less able to cope, so they sent me to a psychologist to see if I had the IQ and I was turned down! I don't know why! ... I wasn't very good, I suppose they were going on my education and my education wasn't up to standard, so obviously I was going to fail the test as I hadn't been taught anything, my arithmetic was totally rubbish.  
(Elise, 35, Scotland)*

Segregated education did have a positive impact on the lives of some disabled women, particularly in circumstances where medical treatment was required in conjunction with educational requirements, and some women felt that the special school environment may have provided the support, formal and also more informal (through friendship networks), that

was non-existent in mainstream spaces. This underscores the lack of accommodation provided to disabled people in public mainstream spaces. Often, one is faced with choosing between two extremes, neither one of which is really acceptable; segregated environment, which has some support but little stimulation, or an integrated mainstream environment with no support. The following quotes capture something of this ambivalent attitude toward special schools, indicating a few positive assessments, but even here the key message seems to be that the women found the schools ultimately limiting in academic terms:

*I went to a special school until I was 11, and it was a wonderful experience in terms of the range of subjects, it was like primary school, we got a different teacher for every subject at primary level and we had languages and all sorts, I was totally challenged by the curriculum, but then I don't know what happened, by the age of 11 I was in hospital on and off for a year and so, the school sent me in stuff, and shortly after that I became very unsettled I think it was because my sisters had gone to the local grammar, and so their mates were around in the community and I wanted to be part of that as well and also I felt that academically I had been challenged and stretched to the age of 11/12 and then the pace was slowing and I was very unhappy.*

*(Kim, 49, Scotland)*

*I came over from China, immigrated to Canada when I was 9 years old, so for the first year and a half I didn't go to school because my parents didn't know what facilities were out there for children with disabilities and I hooked up to the Crippled Children's Treatment Centre. This was done by my physicians and my paediatrician who was also a physician at the Children's Hospital of Eastern Ontario so that's how I came to be hooked up with that particular facility, there I received not only educational services and rehab services ... at the age of 10 I started grade 1 learning the basics...but at the end of three years at the Treatment Centre I was thoroughly proficient in the English language ... I was moved to another facility for children with physical disability, there I did grades 4,5 and 6 in one year ... [T]he good thing about being in a specialised education programme was that I think I was able to work at my own pace according to my ability and I was really motivated to learn the new language, and I was motivated to learn period, so I excelled and made the grade quickly because of my age I was 13 by then so I was mature not only chronologically but also emotionally.*

*(Lilly, 34, Canada)*

*I went to a special school, didn't feel particularly special! I hated it, just found it like lack of stimulation, over protective, just like really out of it in terms of holidays and stuff, I didn't have friends that stayed local, like local area, all my friends were from all over Scotland basically, yes I've got good friends from it, I'm still friends with a lot of people I went to school with but I just found it limiting academically, and no lack of like, there was just no drive in it at all. I went to Stevenson College from school when I was 17, and did Highers. I'd done some Highers at school but I'd done really badly just because I was sick of being there, I was there from the age of 5.*

*(Vicki, 29, Scotland)*

Interestingly, a few women did wonder if experiences might actually may have been better for them had they attended special school:

*Interviewer: Did you ever go to special school?*

*No never. When I went to primary school I was fine, 5 –11 that was fine I got on great but when I went to high school, because I have got like my processing of stuff is not as good because there has been some light brain damage, I am a bit slower. I am better now, but I just felt that in high school I could have been doing with extra help, I think that some of these special schools, there is one in*

*Glasgow, which is great. I think I would have benefited from that.  
(Brenda, 28, Scotland)*

*It was very difficult, I couldn't take notes, I wasn't sure what the teacher was saying so I was studying by myself, I was coming home and was studying, I was only 10 years old but I was up until midnight studying ... I think if I had gone to deaf school I wouldn't have left my country. I would have felt uncomfortable with hearing people, I wouldn't have learned how to communicate. I'm glad I went to a regular school, what I miss a lot is if I had gone to a deaf school I would have learned sign language, but I don't know.  
(Sahara, 40, Canada)*

The overwhelming impression is nonetheless that segregated education served as a holding area for entry into the disability management industry, for subsequent entry into suitable disabled spaces. Although the Disability Discrimination Act (DDA) will no doubt have an impact on access to education in the future, for many of the women who I interviewed amendments to education legislation have come too late. The Canadian Charter of Rights and Freedoms has been in place for almost twenty years and the impact on access to education has been marginal. The measure of success is dependent upon how the legislation is interpreted and applied. Segregated education has in effect been arguably acting as a diversion programme, keeping disabled individuals out of the mainstream economy or at the very most directing them into appropriate vocational spaces:

*When I left special school they didn't really stretch your mind as to what you would like to do, it was all about what you could do. It was mainly guiding you into office work and office technology. At that time I just thought I'll do this because that's what I can do but I find it so boring!  
(Stacey, 29, Scotland)*

## **Making primary spaces in public places**

The arrival of disabled children in 'public' education space is seen as an anomaly. Making space for them in the mainstream places of learning is not expected or welcomed, and is perceived as disruptive to the 'natural' social order. Those individuals entering into this environment are usually championed by a non-disabled advocate, often a parent demonstrating exceptional personal fortitude to fight against the barriers of fear, ignorance and simple lack of imagination that have preceded this outcry. Ariel's story in this respect is telling:

*My mother had to fight like hell to get me in, though, into regular school. When I started grade school the nuns that were looking after the school that I went to told my mum that they really weren't able to accept somebody with a disability because it required too much attention and that they thought that I should be placed in a special school. So the very next day my mother pulled my sister out of school and when the Principal called to find out why my sister hadn't attended school that day ... my mother said 'well if you're not equipped to take care of one of my daughters', then you're not*



*equipped to take care of either of my daughters, so they called back and said that 'ok we'll pay for an attendant, we've got an attendant to come in and she can start school', but they wouldn't have done that if my mother hadn't pushed the envelope.*  
(Ariel, 27, Canada)

Patsy's parents, meanwhile, insisted that she remain in mainstream schooling, saying that 'there's nothing wrong with her brain' (Patsy, 25, Canada). The physical difficulties of accessing and moving around in the mainstream school environment were often stressed, and the teachers clearly worried about the different ways in which disabled children had to move, but the following two quotes demonstrate how, with a little open-mindedness and readiness to accept 'unusual' practices, successful integration can be achieved:

*Didn't help the fact that I didn't have a wheelchair until I was 7! ... They didn't give out wheelchairs to children in those days, and that was another fight! ... I know they didn't give them out because I used to be pushed in a pram or I would crawl around everywhere. I only lived around the corner, and they eventually got agreement that I could go for a trial period, by this time I was 8 and they put me in with the 7 year olds, and that lasted a day, and the teacher of the 7 year olds said 'ah ah, she's far too fast for this' ... So I went in with the 8 year olds, and one of the pleasures I had in my life in that year was, I'm bragging about this, there were 36 pupils in the class and ... there was another girl I was friendly with, the Director of Education's daughter and I knew her too in class (laughs), touché ... but then I stayed on at that primary school until I was 11 or 12. If it hadn't been for my mother fighting the cause I would probably have never got into a convent school.*  
(Audrey, 55, Scotland)

*[L]ike our house, there's never been a modification in it, three storey terraced, so you stretch yourself, you just do it your own way, that's always been the gist of it, so they had to, I think they had to fight quite a bit to get me in the local school, ... but really I was going to be happier in the local school, I was lucky it was a small community, it was a small convent, I had two sisters at the school and there was loads of stairs to classrooms, there wasn't going to be a problem with lifting me up the steps or anything, because at that stage I used callipers and crutches but I was always quite light, so my classmates just lifted me, carried me up, so I had the normal schooling of any teenager, and so I did all the exams at the appropriate time and went off to university at the appropriate time which I think for me was very important because you know people that I had once been a school at who did it later, I think was a lot harder for them, and also leaving home at 18 was the right thing.*  
(Kim, 49, Scotland)

However, once in mainstream education things are certainly not always straightforward for disabled children. Candi's and Joyce's experience reveals much about the everyday problems of bullying, trying to fit in, teachers' suspicions and the like:

*I was in a regular school all of my academic life ... When I went to school, I was very clumsy and so I got teased a lot because I didn't know that things were that close and I would trip over them or I would run into somebody and I'd get smacked, or, you know, somebody would hit me or whatever because they just thought I was doing it on purpose. I always sat at the back of the class, I didn't sit at the front of the class and they would force me by the end of the year to go back to the front of the class which would single me out all of the time, because I wasn't seeing so therefore I wasn't learning, but I didn't want to be singled out but I also wanted to be part of the group, so I tried to sit at the back like everybody else. So it wasn't until, I guess I was 9, when my mother and father decided that there was something really wrong with me and they wanted to do something about it, so they took me to an eye specialist and they got me glasses and the glasses were broke within three days because I didn't want to wear glasses and, because of the weak points and the strong, my eyes*

would get strained and so I would get motion sickness and so it was better for me not to wear glasses than it was to wear them. My teachers would always say 'she could do better, she could always do better', but I was doing the best that I could in the times that they were giving me to do it. I quit school when I was 16.

(Candi, 45, Canada)

I always remember the teacher saying 'look at your sister she can't see and she's streets ahead of you, how come you can't do this?' and sort of making out to Sara that she was really bad and here I was, I couldn't see, and I was doing better than her, you know it was just like a slap in the face.

(Joyce, 34, Scotland)

The difficulties in mainstream education of adapting to the needs of disabled children is evident in many ways, often in the creation of well-meaning regimes which nonetheless still set the disabled child apart or seek to be overly helpful to the point of 'cocooning':

They were very understanding, I think perhaps too much, I think what would happen a lot of the time was if I was having difficulty in a particular area they would just take my hand and walk me along and give me a passing grade, you know sometimes I did really well like English grammar and social studies, but it was the Maths, Geography, those areas, so I never learned how to think for myself like other people do, I had help all the time, I learned helplessness.

(Dolly, 34, Canada)

It as if the mere presence of disabled people is somehow threatening to or compromising of the academic standard of non-disabled students. Again, this lack of willingness to accommodate disabled children within mainstream education is due in part to a lack of exposure to disabled people or disability issues. As a result, disabled children can feel isolated and alone in mainstream education:

In Ottawa I think I was one of the first integrated students. My first year at school kindergarten was not a happy time for me. My teacher didn't know how to treat me she didn't know how to treat any of the students! She pretty much made a big thing that I was not co-ordinated and she tried everything in the book to get me out of school ... Finally, in grade 1 ... they basically put me in the library on my own with a [non-professional helper] ... I was not integrated with the rest of the students and the Teacher's Aid taught me! ... When a 6-year-old comes home and tells her parents that I'm alone in the library ... my parents didn't believe me ... so then one day my Mother's friend came to pick her son up and saw me in the library and then she went and told my Mother ... My Mom went to see the Principal [Head Teacher]. The Principal didn't even know this was happening ... I was out of that school faster than you can say your name! So then I went to Brook Lane Public [primary]. I had a pretty good experience there ... All through elementary school I was the only disabled student ... I had one to one Teachers' Aid, which I found very, very tough. The Teachers' Aid made me feel like they owned me. In grade school I was judged by my braces [callipers] and crutches. They didn't judge my potential, which I now feel I was robbed of.

(Patsy, 25, Canada)

The mainstream primary education experience of these women can best be described as an interesting dichotomy. Although they felt fortunate to have avoided or limited their exposure to segregated school, at the same time they were often painfully aware that their presence in the regular school environment was perceived as a source of tension and conflict. Indeed, the necessity to provide adaptation is frequently perceived as disruptive, and seemingly

compromises the education standards of non-disabled students. Difference is often emphasised by education authorities in a negative fashion, a sign of intellectual limitation rather than a failure on their part to provide effective accommodation. Consequently, most of the women rarely felt welcome in these spaces, although they believed that they had the right to be there. The women also identified the need to struggle against 'common knowledge' or negative social perceptions of difference in disability. In their efforts to gain approval, many of the women identified an internalised feeling of personal inadequacy taking root during this period in school at the primary level. In order to 'fit in', much physical and academic effort was spent trying to pass as non-disabled, or to blend in with their non-disabled counterparts, often at great personal cost and minimising their own needs. There was a necessity to prove their right to be in the 'regular' space, particularly since in childhood there is limited awareness of a larger social or environmental inflexibility, yet at no time did the women ever express the wish to be non-disabled as a means of dealing with their physical reality. What can also be added is that from a very early age essential lessons were here being learned about navigating in an essentially hostile environment, concerning the realities of making space and using time in 'public' places, minimising difference in order to gain approval or acceptance.

## **Secondary spaces**

In the higher school grades, the pressing realities of time and space and difference are more acute on a number of different levels. The nature of study changes in secondary school, both in the increased volume of work to be done and the demands on the amount of time required for completing it. Movement of disabled students between classes is also a change, placing far greater demands on physical effort and navigation skills. The speed/time management skills developed in order to pass and to function to this point no longer work to the same extent as before. Academic streaming is also a part of high school, and in several instances slower physical processing of material was often interpreted as a lack of intellectual ability. Women who could not keep pace were placed in less challenging academic or vocational classes. As was the case in primary school, few if any changes were made to the existing academic environment, and adaptation was left to the women themselves. As a result, many of the women again felt alone or isolated. Feelings of isolation were accentuated because notions of the body difference and physicality become more fixed and acute in teenage years, as does the need to gain social acceptance. Joyce and Brenda's experiences provide a fitting illustration of the need to 'fit in' in the midst of demeaning attitudes and bullying at

secondary level. The women internalised a sense of what is 'normal' and of one's distance from that:

*We went to secondary school, the blackboard was used a lot for everything and I fell way behind, [Joyce has a vision impairment], and then when people are saying to you you're just thick, well you're told that so often, that if you're told it often enough you just begin to believe it, well I'm thick, but I used to feel so frustrated because I could understand what was going on but I just couldn't ... do the tests and I used to think this made sense at the time, why can't I follow it, and you know I was just written off as being thick. It's funny because I was in the lowest class for Maths because I was very bored and frustrated but I was in the highest class for English because I wasn't, and I got an A band one for O level English, and actually ... in the end I finished school with 8 O levels and 3 Highers, which is kind of I suppose kind of average.*  
(Joyce, 34, Scotland)

*I was a bit slower but I'm not now. I had to find my own way of processing things ... I think that when you are a teenager you are so mixed up in it ... They tended to send you to remedial classes which made you feel thick or stupid and I knew I wasn't ... There was a lot of bullying and name-calling. I had my own friends, when you are that age, it is sort of like if you don't fit in you're not worth knowing. There was a lot of bullying and I think that's what made it worse because I was bullied at school. I think it made me more timid, more self-conscious and more unaccepting of who I was because I wanted to fit in with everybody else.*  
(Brenda, 28, Scotland)

Similarly, Marilyn's quote illustrates how when people's disabilities are labelled at a somewhat later stage of youth, there appears to be less negative association with 'difference'. However, the quote does still illustrate that difficulties remain in the managing of the 'regular' school environment:

*I was diagnosed when I was 15 and I had treatment and stuff. I was always kind of like the dunce in P.E. ... I was kind of in betweeny bit when I was younger because I didn't really know what the problem was, it wasn't until a bit older when I was diagnosed.*  
(Marilyn, 39, Scotland)

Several women gave accounts of missing school or being taken out of school in order to undergo surgical procedures. None of the women questioned the need for the surgery, although, upon reflection, many women expressed regret concerning the impact of hospitalisation on attaining long-term educational qualifications. The medical model appears to remain paramount, and the quest for 'normalisation' took precedence over qualifications. The purpose here is not to berate or to downgrade the importance of medical intervention, but it is to wonder if more care should be taken to co-ordinate better these medical elements to lessen the negative educational impact on the young individual. There was little thought given to assisting the women in a manner that best suited them, and it was left to the individual women to deal with the situation with limited information or resources. Placing medical matters before educational ones has clearly had enormous and often-negative implications for several of the women who I interviewed, as these quotes reveal:

*I left school at 15 to get an operation, it was my bladder problems, I was incontinent at school [spina bifida]. I left in March, ... missed my O grades ... because I was going to get an operation.  
(Brenda, 28, Scotland)*

*I went to Stirling High School ... A hip operation put me back a year, the school was wanting me to not go back a year, I went no, so it was me that had a choice of whether I could go back a year or not to do the year's studying, but I didn't want to, so I should have but I didn't, if you know what I mean life may have been different now if I did but I never, so I only really did three years instead of four at High School, even though I did sort of do four, ... but I wasn't there for a full year.  
(Rhonda, 31, Scotland)*

*Secondary school wasn't an option, and the Secondary school in Bothwell was simply not accessible, so I went to special school, just outside Edinburgh, a boarding school for the severely disabled children, and I was there until I was 16, ... but I spent two and half years of that in hospital ... So I came out of school with pretty well not a lot of qualifications.  
(Audrey, 55, Scotland)*

Various women had a positive experience in high school because of a positive self-image and an effective support system enabling them to study effectively and to more fully integrate into the social academic environment:

*In high school I was lucky in that I was at Canterbury. They had an orthopaedic unit in the school itself, which integrated disabled students in the regular curriculum. I was lucky people didn't judge me. The teachers didn't judge me because of the chair [Patsy uses a wheelchair]. They judged me for my potential and what I did.  
(Patsy, 25, Canada)*

*I went through high school, regular high school in the neighbourhood. My classmates and teachers were really supportive.  
(Heather, 43, Canada)*

Unfortunately, several women did not have a positive experience. Secondary education proved to be a turning point for many women, providing a crucial marker for adulthood:

*When I was in grade 12, senior matric, I actually filled in an application to go to McDonald Teachers College, and it had to go through the Principal's office for them to sign and the Guidance Counsellor. Well the Principal, the Vice Principal and the Guidance Counsellor called me in for an interview in their office, and well didn't they say they were very sorry that they couldn't sign the application ... Well, they all thought it would be wonderful if the world were such that I would ever find a job, [but] I may as well not waste my time because they certainly wouldn't have hired me to be a teacher in their school system, and that they felt that no other school system in Ontario or Quebec would hire me because of my being so crippled.  
(Alice, 51, Canada)*

*I desperately wanted to be like whoever ... I was just so glad to get out ... I didn't realise it would affect the rest of my life. I was going for jobs and I had no formal qualifications. I had no confidence and I no self-esteem. It took me until I was in my 20's to accept who I was.  
(Brenda, 28, Scotland)*

It is important to recognise that even a poor initial school experience can eventually build a bridge to fulfilled later education:

*I went back to Forfar when I was 16 and they let me go to this other, a different secondary school, I went there for a year to sort of catch up on some things and then I left still without qualifications apart from shorthand and typing and things like that, then I went to college to further that in book keeping and then in the 80s, late 70s, I ended up at University, applied to do that, and then after eight years I got an honours degree.  
(Audrey, 55, Scotland)*

This quote from Audrey hence leads us to a consideration of disabled women in higher education.

### **Post-Secondary spaces: college and university places**

*Yes, and I've actually been told to my face that I shouldn't be complaining so much because a couple of years back I wouldn't have even been allowed into the university! So yes, I've actually been told to my face you know that I should think myself quite lucky because a couple of years back I wouldn't even be allowed in, so it's like 'I am not worthy'.  
(Trudy, 33, Scotland)*

Remnant elements of the medical model still remain as part of the procedure at this level of the educational system. Indeed, frequently, the medical profession provides the gate-keeping access mechanism to the process of entering further or higher education. Academic qualifications are often secondary to the need for an arbitrary level of physicality, which is another manifestation of an exceptional status provision. The individual is faced with having to prove an everyday coping ability to undertake the course before it has even begun. Whereas non-disabled people are provided access without this added hurdle, it is as if disabled students must provide this insurance as added proof of the right to be in the space concerned. Access to academic space is hence conditional and regarded as a kind of privilege, which is yet another manifestation of an 'on approval' mechanism which is all too often subject to withdrawal:

*I filled out my application for college when I was in hospital and I remember having this enormous debate, I mean I must have been a social model follower [of disability] before the social model existed ... I was having this enormous debate with a friend of mine who had come to give me a hand ... because I had just had surgery on my spine and I was completely flat out ... I had done my Highers then gone straight to hospital for surgery and I was in plaster from my neck down to my knees, completely flat out in bed, but I felt fine ... was just literally recovering, waiting on the bones to knit together. And I was filling out this form and it said 'are you in good health?' and I ticked 'yes', and [my friend] was like how can you write 'yes', you are lying in a hospital bed, and I was like fine there was nothing wrong with me ... I am here for a particular reason, but as far as my health is concerned I am perfectly fine. But, however, you still had to write down on the form the type of impairments you had and stuff. I had done really well at school, I had good results in my exams ... There was absolutely never any question about me not being academically capable of doing the course, but what got me into college was a letter from my consultant to say I was fit to do it.*

*Interviewer: They wouldn't have let you in otherwise?*

*No, I actually wanted to be to be an occupational therapist for a profession and I wanted to do physiotherapy, but I couldn't have got into physiotherapy, I wasn't deemed fit enough at that time. I*

*think maybe things are different now, but at that time I wouldn't have got in ...*  
(Marilyn, 39, Scotland)

Marilyn's story reveals many points, such as the gulf between her understanding of herself, her body and her intellectual potential and what others, the gatekeepers of post-secondary spaces, may perceive in terms of her as a viable applicant for a place at college: the simple question being, could the latter ever see past Marilyn's body 'difference' to the capabilities of her wholly unimpaired mind? Lynda's experiences illuminate the same issue, including the need for 'independent' medical statements about the individual's competence to do a course:

*I had an informal interview with the assistant admissions officer at Liverpool University ... and she advised writing round all the medical schools in Britain before I submitted an application to UCAS to find out if they would accept an application from me with my physical problem [a neuro-muscular disability], so I did that ... It was mostly the London medical schools that said there was absolutely no way you should be thinking about doing medicine, and I think they thought I should be committed to a desk job, something completely sedentary ... But there were a handful of universities, there were different levels of responses, there were those that were completely negative, there were those that were half and half, then there were those that were positive and said they would accept an application and really it wouldn't matter at all as long as my academic qualifications met their criteria, and there were those like Glasgow and Liverpool that were particularly positive ... They had taken the time to contact my neurologist in Liverpool but also contacted their own neurologist, to get an independent opinion because obviously my neurologist would be a little bit biased.*  
(Lynda, 23, Scotland)

Other issues of course arise to do with institutional concerns about an individual's 'fitness' (physical not mental), and the clichéd problem of wheelchair accessibility as a reason for blocking someone's application cannot be avoided:

*They said that my academic qualifications were fine but they just couldn't have somebody in a wheelchair on their premises because it wasn't accessible at all, so obviously I didn't accept that at all, so they had to move lectures from one building to another, it was ok, I mean it wasn't fantastic for getting about but I got by.*  
(Vicki, 29, Scotland)

*I'm doing an undergraduate course in community education and that's been a real struggle, they did say, they knew I was coming four months before I came, they told me it would be an accessible course, but it turned out it wasn't an accessible course! Well I got there and some of the lectures we had were like three flights up with no lift, so I couldn't attend them, so then they suggested we had a video link and I said I didn't want to be in the library on the video link, what if I wanted to ask questions, you know there would be me viewed to 300 other students and there was no way I was going to do that and it would cost more, so I just said why don't you just move it to a lecture theatre that's accessible, so they did move one of them, there's one of them I can't attend because I just can't get up three flights.*  
(Trudy, 33, Scotland)

Preconceptions of physical incapacity and access may be used as convenient means to mask the deeper underlying social insecurities or objections about sharing non-disabled spaces with disabled people. Echoing earlier comments, it is almost as if the presence of disabled

people compromises or contaminates these higher education elite 'public' able-bodied spaces:

*I had to do an undergraduate degree in Psychology and I did it at York University, and hated it and then I had applied to and was accepted into a Masters programme at University of Toronto in Speech Pathology, and the day after I was accepted is the day I had my haemorrhage and I had already had a stroke when I was 18 and I had a little bit of neurological residual damage, and they said that they shouldn't but they would be willing to overlook it because my application was strong in other areas, so they overlooked that and they accepted me into the programme, but then when I called them and told them I'd had a haemorrhage they said you can't come in and not calibrate your own equipment so they rescinded their acceptance. I didn't know what I was going to do then. ... [B]ecause when I had my stroke I vowed I would become a speech pathologist because there was no one to help me when I lost my speech, so I vowed I would do it, so twelve years later I went to university and get accepted into the programme only to have it rescinded.*

*(Babette, 47, Canada)*

*Well at first they turned me down, they said they couldn't provide facilities for somebody in a wheelchair. In fact they tried to put me off coming as well, even after I'd been accepted ... Well the Head of Department came to my house and he said you know 'do you actually know what Psychology is?' And I was, you know I did say to him, I was quite cheeky back, 'do you think I would have fought this hard and not found out that's what I wanted to do? Of course I found out what it was about', and he said 'oh you have to be really good at maths and biology,' and I said 'yes well that's my best subjects, so what other trick do you want to try?' Certainly they wouldn't have asked other students that.*

*(Vicki, 29, Scotland)*

Another impediment to post-secondary access is the lack of available funding. It can be difficult to juggle limited physical resources in order to compensate for limited financial resources. The situation is not helped by inflexible institutions and staff who are unresponsive to individual needs:

*I was doing an external PhD programme overseas in Britain at Stirling University on a part-time basis because disability studies weren't developed in Canada and I thought if I wanted to develop my teaching prospects further I had to go overseas and Stirling had a part-time external PhD programme, but I found that that was problematic because I was working four jobs in order to pay for this and I was tired all the time because I was working four jobs and trying to do PhD work and my PhD advisers weren't really aware of the amount of energy involved in the whole thing and it was difficult ... I would let my PhD adviser know six months in advance when I would be coming and I would come in every six months for three weeks and they still wouldn't have a place for me to study or a computer for me to use, so finally ... I withdrew from the PhD programme because of the lack of support that I had and I was really ... it sort of made me think about my ability academically ... it sort of ... like I never really factored my disability into all this stuff, four jobs, plus a disability, plus PhD work was just too much.*

*(Heather, 43, Canada)*

Even in supposedly mainstream post-secondary education, 'special needs' segregation still occurs. There appears to be a will to 'teach' life-skills to people with disabilities, and perhaps this is a continuing reflection of the desire to 'normalise' this population group in an appropriate vocational manner:



*I was at College three days a week in administration. The whole course was inaccessible to me. It was a very frustrating experience in college. I was in a 'special needs' class, it was awful. I needed a key guard for my computer [a metal frame placed over the keyboard, which facilitates typing for individuals with restricted hand movement]. I was waiting six months for this bloody guard, a metal plate with holes in it! ... So most of the time I was sitting waiting for this guard. It wasn't a positive experience so I left and came back to Edinburgh ... I went to Stevenson College [FE College] for a year and they were more supportive. They had the Access Centre and I could use their services. I was in a mainstream class, it was more accessible. Then I went to Napier University to do an HND in accountancy.*

*(Stacey, 29, Scotland)*

*I went to Stevenson College then, they were just, the school were just absolutely adamant that I couldn't be part of the normal [curriculum] ... I said 'well I'm doing Highers so that's just the end of it I'm going to be part of it', so the compromise was you have to one day a week, when everybody else was off, we had to go to some special group on a Wednesday when all the other students from mainstream would have a day off to study, [and] we would have to participate in some special class. Cookery and woodwork and just, I can't even remember, it was so hideous I used to not go and lost the time, then they would complain because that was part of the condition you were at college. That disabled students would have great difficulty fitting in because they had been at special education for so long, which I think on the one hand its true, it was a bit of a shock to the system, but I think I would have preferred one-to-one support rather than actual classes which I couldn't do anyway, which were all physical classes which were of no interest to me or like .... The second year, because I went two years, the second year of course I didn't go to that, because I was like 'don't be ridiculous I'm not doing it', so the second year it was better, I just did my Highers like other people.*

*(Vicki, 29, Scotland)*

*I didn't tell them I was disabled, I didn't mention my disability, until I went for my interview, I phoned on the morning I was going to ask if they were accessible and she said why, and I said because I used a wheelchair, and they and ... and they were all like horrified and could hear them on the phone, like oh, and they did like eighteen phone calls and they came back and said yes the building you're going to is accessible because I thought I'm going to university and I knew beforehand that they had an access policy, so I thought ... you don't need to know I'm disabled [b]ecause ... you have an access policy, which is probably quite mean of me.*

*(Trudy, 33, Scotland)*

Disabled students are sometimes called upon to enlighten other students about the realities of life with a disability, another manifestation of the novelty and the 'public property' of disability in the academic sphere (a theme to be revisited in a slightly different context in the next chapter). Disabled students remain very much 'on display' much of the time. Trudy's experience illustrates the central role that Academics play in a student's experience:

*Interviewer: What about your Profs, are they good?*

*Most of them are, there's been a couple who I won't mention but there's been a couple who referred to me ... And she once used me as an example in class, which really irritated me. She was completely contradictory as well, that was the worst bit, she was going on about the fact we shouldn't assume that because people are black they don't have the same experience as every other black person in the world, and she said so you shouldn't assume that one black person has had a bad experience in a white culture because people often look at a black person and think they've had a terrible life, because some black people have had a great life and positive times. And maybe we can count one (laugh). So then she said 'I want to ask Trudy a question', so everyone in the class turned to look at me, I'm the only disabled person in the class ... She said to me, 'I want to ask you what has your life been as a disabled person, have you had hard times?' And I said 'well I'm not going to answer*

*that', and she said 'why not?' and I said 'because you just said to the class that you shouldn't assume that everybody's experiences are the same, so no matter what I tell you about what my experience is, every other [disabled] person's experiences will be completely different', and she was really embarrassed, and I also said 'I also don't appreciate the fact that you've drawn me as the centre of attention'.*

*(Trudy, 33, Scotland)*

Trudy also gives a graphic illustration of just how visible and 'public' disablement is in society, even in the most private aspects of daily life:

*Oh asking for the key! I know in the university I have such a problem because there's only me and another student who uses wheelchairs and they've got all these access accessible toilets separate from the women and men's toilets and every time I go in them I think if the toilet roll is all gone they'll know it's just me or John because we're the only two students in the whole of the university, and I've got a real hang up about it! I just think oh God!*

*(Trudy, 33, Scotland)*

Patronising comments from non-disabled people appear to be an everyday occurrence in academic life. Often disabled students must justify accommodation requirements while proving individual academic competence in the face of social stereotypes:

*She [disabled student services advisor] got me a reader that day and she got me somebody to do my exams with me, we were in the middle of exams, [and] the person who did my exams answered the questions for me in a way that he thought was appropriate, not the way I answered them ... And when I got my mark back I was stunned because I did really well in university and I got a D in the exam, and the Professor's read of it was that my vision must really be interfering and I said 'no that's not true', so I said 'I need to go over the answers with you', and he started to give me the answers and I said 'I didn't say that, I didn't say that', and I started justifying why I wouldn't have said it and he knew my work luckily, and he said 'you know I think I know what went on here' and he went and got the person's exam that had been filled in and sure enough the answers matched mine, so I got to redo the exam but I mean that was just a horrific experience ... It was horrible ...*

*(Babette, 47, Canada)*

*The thing that they keep firing back at us is 'well you know it's only a couple of years since we've had disabled students', and you know I'm one of the first couple of wheelchair using students and it's all very new to them and they'll learn by their mistakes, but the thing is it's a lame excuse.*

*(Trudy, 33, Scotland)*

Some of the interviewees were far more willing to bring these and other shortcomings to the attention of education authorities and to make their own suitable arrangements. Progressing through the academic environment, such individuals have refined and developed more skills necessary to manage in a largely inflexible academic environment:

*My first degree was a Bachelor of Fine Arts, I graduated in 1992. Well, at first I didn't get into the Fine Arts because there were concerns that I was not able to handle the physical aspects or demands of the programme, so firstly what I ended up doing was majoring in Art History and I took two studio courses ... I demonstrated that I could not only meet the minimum requirement but I exceeded the requirements, so I had to demonstrate you know, not only that I have the talent, but I was able to meet programme requirements. I got accepted into second-year status and I was fine after that, so there was very little modification that was needed for me to do the programme. The only problem was when I had to do at the high school [placement for teaching degree]. It was the Principal [at the high*

*school with a unit built for physical disability] who didn't want me to do my practical there because he didn't think again that I could handle the physical demands of my practical assignment.  
(Lilly, 34, Canada)*

Although many of the women did not relish the idea of drawing attention to themselves, they were aware of the type of accommodation and support that they needed to study effectively. Although the larger environmental framework remained quite rigid, within individual educational spaces, the nature of study could be somewhat flexible. Again, it was left to the individual to negotiate with instructors or to form alliances with fellow students in order to build supports into the environment, thereby increasing the likelihood of success. Candi's and Stephanie's accounts in this respect demonstrate this aspect, but, as ever, things were never ideal or plain sailing:

*I went back to school when I was 18, and went through adult education at Algonquin college, which was a learn at your own pace so it was a lot better for me because I could sit and read the stuff, I didn't have to follow along and I didn't have to read off the board and I didn't have to worry about being asked to read something in class and things like that, because I wasn't able to read at the same pace as everybody else was. I went back to University and I got my degree in Sociology and Women's Studies in 1995.  
(Candi, 45, Canada)*

*When I was in school [college] I had a lot of doctor's appointments. I told the Prof. that I would have a lot of doctor's appointments. He said 'that's fine', but every time I came back from an appointment he made me feel guilty about that ... I'd say I told you that I had a doctor's appointment. He was very unforgiving. But most of the time they were okay ... If I couldn't hear I'd move up [Stephanie has a hearing impairment]. If I couldn't understand the teacher I would ask about it.  
(Stephanie, 29, Canada)*

The fact that obstacles are always waiting to 'trip you up' is strikingly revealed by Babette, who also shows the profound frustration associated with trying to secure assistance, even from professionals who are supposed to be specialising in assisting students with disabilities:

*My undergraduate years were wonderful up until I had a haemorrhage in my eye, and I was at university, I was in my third year at university at that time and I had a massive haemorrhage that was responsible for knocking the vision out of my [my right eye] ... [The] left was already gone. I was totally blind, my world was black, and I took the subway down to the university and prayed that I didn't step into the subway because I couldn't see a thing, and of course I didn't have a cane or any training at that time, and I got to the university and I asked somebody to take me to the disabled students office and I got there, to be told that they wouldn't do anything for me until my disability had been in place for three weeks. And I said why, and they said 'well because you need time to adjust', and I said 'I'm adjusted, help me', you know, it's been there all day, help me, and they insisted that I go away and take some time to deal with this and come back in three weeks. I was in the middle of doing my thesis ... So I went out and I sat in the waiting room and the woman came out about an hour later and she said 'what are you doing here?,' and I said 'I'm waiting, I'm not leaving here until I get help', and she said 'we're not going to help you' and she walked back into her office. She came out after her next appointment and she said 'we're not going to help you', and I said then you'll have to call security to get me out of here because I'm not leaving on my own.  
(Babette, 47, Canada)*

*I got really annoyed at Christmas because there's all the stress about exams and I couldn't get to the study room because the lift was broke, and they didn't have another area that I could go to and I said 'well can't I just use one of the empty rooms?' And they said 'oh well em', but I said like I need a computer in it and as soon as I said 'computer in it', they said 'oh no we can't do that'. So I couldn't go and study quietly and I really needed to do it and I said 'how long will the lift be out of order?' And they said three weeks ... so in between trying to fight with them, and they kept saying to me that every complaint I had I had to put it in writing and send it to my head of studies and the director of the university, so I'm trying to study, do my exams, study for my exams and in between write bloody complaint letters and it's just, I can't do this!*

*(Trudy, 33, Scotland)*

Returning to the theme of disabled women in post-secondary education sometimes becoming more assertive in trying to sort out arrangements that are more conducive to their own needs, Heather tells us about her revelations over the problems resulting from dealing with the timing and spacing of activities. These revelations led her to be more proactive in aiming to organise 'time and space' in a manner that put less pressure on her, while recognising that her use of precious resources was very different from that of many other students:

*I didn't figure out that I had a disability until I was 33, like Da! I was doing my graduate programme and I said to my friend 'Olive look, I don't know what it is, I'm running around doing this that and the other thing and I can never seem to keep up like between my classes, between doing the disability disabled students stuff and all that, I can't seem to keep up, I don't know what it is', and she said 'Well Heather you have a disability and that's a factor'. And I swear it's the first time I figured that out ... Don't get me wrong I have always used crutches, but there are time-space relations to this whole thing but I'd not figured out before then, which is kind of weird, you don't realise your own situation. And as soon as I gave myself permission to take longer it made things better, like I would ask for a longer time to type essays and stuff like that.*

*(Heather, 43, Canada)*

Similarly, Lilly's and Joyce's experiences illustrate the vital importance of supportive social networks as a means of working around the wider inaccessible geographies that often intertwine with the academic experience:

*I did my first attempt at a Bachelor of Education at the University of Toronto ... I had a difficult time there, I couldn't cope with the change in the environment just because I was going through a new course of study and the transportation system was terrible at the time ... I was also in an apartment [that] was so far away and accessibility was not that great, so there were a lot of structural and access issues related to that part of my experience, so I'm not surprised to say that I did not adapt well and did not perform academically well because most of my days were spent around trying to get transportation ... Sometimes I would get transportation one way and would have to find my own way back, and I had to do my practical work not only in downtown Toronto but also in Scarborough [some distance away] in some of the suburbs and would not be able to get transportation there. So most of my time was just spent trying to cope with the daily demands of living in a strange city ... I just ended up dropping out and coming home to Ottawa, feeling defeated. At that time I didn't understand that having a well established social network and also having the resources were important to my academic success, I took that for granted ... I came back to Ottawa, worked for a year and applied to the University of Ottawa, got accepted and moved into residence and did fine, no problems.*

*(Lilly, 34, Canada)*

*Actually what I'd realised at that point was that, if I didn't, I couldn't see the board, and again the boards were used a lot. I'll have to start shouting out, I'll have to start cultivating allies in my class, and I'll have to start putting strategies in place. So once I actually started to speak to people collectively, there was like five people that I was really close friends with, and they said 'right let's look at how we can do this', so when lecturers wrote diagrams on the board what they did, out of the five of them they would take a week each one, and they took carbon copy paper and they just drew the diagram and gave me the carbon copy and they described things to me.*

*(Joyce, 34, Scotland)*

As we have found talking about schools, the individual must fit into the existing and established criteria, and it seems that access is controlled and allowed so long as non-disabled students are not inconvenienced. The crisis response approach to policy development and protocol, which is rarely produced by or in consultation with individuals who need or use them, is a manifestation of the singular approach to the accommodation of disability. The presence of disability within the academy is still viewed as an anomaly and disruptive to established routines. Frequently it is left to the student to take the initiative to problem solve situations, and commonly this will mean trying to figure out micro-level organisational matters - often to do with what Heather terms the 'time-space relations' - in such a way as to accommodate the disabled student but without inconveniencing anybody else too much:

*I found that they had no initiative, like they had to be told things, you know I would always have to be thinking ahead, like what I needed rather than them saying 'oh you've got exams coming up or you've got labs coming up, what do we need to do?' They never asked me that, I always approached them ... so I always had to be more organised than other students had to be. And also I think once they know you, they think that's okay, you're a special case, I don't think they would really generalise that to other people. I don't think they would think 'oh we had a disabled student before', so the next time somebody comes along it would be okay, I don't think they really think like that.*

*(Vicki, 29, Scotland)*

*I sometimes feel angry at the university because I feel as if I'm doing twice as much work as I have to because I'm fighting and I don't want to be fighting, I just want to do a degree, and I don't want to come in and worry about whether or not the lift is working so I can actually get to the lectures, the lectures I'm allowed to go to.*

*(Trudy, 33, Scotland)*

Babette's experience also shows how tentative and peripheral accommodation for disabled students can often be very much secondary to able-bodied aesthetics to do with what environments should physically look like:

*I went and got hooked up with the disabled students office and asked them if they could paint the strips along the kerb yellow, so that people like me with vision impairment could see where the indents were and that the kerb was there, and they thought that was a really good idea, and they did it, and I went back, I was very grateful and thanked them for it, and they said 'well we have bad news for you, it's coming off today', and I was quite puzzled by that, and they told me that they had had complaints from faculty members that it wasn't aesthetically appealing so they removed it. So I was left again with no awareness of where kerbs were and what not.*

*(Babette, 47, Canada)*

Trudy provides many observations about the problems with various environments and practices in universities, but also illustrates how the person being pro-active in making positive suggestions about overcoming obstacles is seen as aggressive or a 'trouble-maker' and the like:

*Stupid things, like they sometimes design lecture theatres so that the only accessible point is right at the back of the theatre so because my sight isn't good I then can't see the board, so you've not only complained about the seating you're then complaining about the board, so you're labelled a trouble maker! And I know I am. I know I'm labelled a troublemaker! I'll come into a room and they'll say 'we've moved the chairs for you Trudy we've moved the chairs' ... It's also the stuff like I asked them if they could do my handouts in large print, and they just looked at me as if I came from another planet! It was that kind of sighing like 'oh God she's moaning again', ... I've seen other students ... becoming subservient like 'excuse me, is it ok?' or you know 'I don't mean to pester you': and I think, like, bugger off, you said you knew I was coming and it's access for all, and you say that the [it] university is accessible so prove it, yes, and if you're not going to, ... then I will say stuff about and I would! ... because even though they know the problem they still won't fix it, they'll say 'well we don't have the money to put a lift in there' or 'do you know how much it costs to put all this stuff in large print?' And I say well I don't care, you've a statement that says you're accessible and accessible doesn't just mean a ramp, I need more than a ramp you know. So there's this kind of stuff. (Trudy, 33, Scotland)*

## **Placement and bridges to employment**

Education is supposed to provide an important bridge to employment. After all if such bridges exist, they do signal possible routes into the wider world of paid work, and hence compromise; perhaps bridges from sheltered spaces of disability (even in mainstream education) to the fast-paced largely able-bodied working world. But, if such bridges are limited – leaving many with a dead-end after years of education – then this must be heavily criticised. Alternately, there may be bridges but only of a partial unsatisfactory kind: ones which only really lead into 'sheltered' work or into a limited range of occupations considered suitable for people with disabilities. These bridges will be explored at greater length in the employment Chapter Eight.

Placements and educational encounters may provide students with experiences in 'real' work spaces with both positive and negative results:

*There's also things like my placements, I've had a struggle getting placements because they didn't bother to explain to any of the placements that they would need access, in the way of ramps, but not even just ramps but even room sizes, like the placement I'm going to they're saying it's accessible but actually it's not accessible because the room I would be working in with people I wouldn't be able to manoeuvre in and out of the chair, the wheelchair, because the room itself isn't big enough for that so not only that but the kind of placement I wanted I couldn't get because they weren't accessible so I've not been given the same choice as the other students. I've basically been given a placement I can adapt to rather than a placement that I wanted, so it was like dreg bottom, it might be a good placement I don't know, but it wasn't what I wanted, it wasn't what I would have chosen to do, but because I could physically get into the building I was given ... this placement, so that really really*

*pissed me off!*  
(Trudy, 33, Scotland)

Olive's experience shows the detrimental impact that a negative placement experience can have:

*At the end of first year you went out on probation to a doctor's surgery and the surgery they sent me to just wasn't accessible. The loo was upstairs and the files were on these swinging shelves. I would have to step up balance myself and get the file out ... It was just so bad ... I just never went back ... Nobody ever said 'is it because you're unable to access the building?' ... I just left. I gave up.*  
(Olive, 52, Scotland)

It would appear that the 'all or nothing' composition of the benefits system may impede individual transition from the educational environment to the world of paid work:

*One of my colleagues who's nearing the end of her diploma ... was very anxious to become independent ... She's stymied ... if she does that, there isn't any net ... you could have your benefits stopped, but, if you were to become ill ... there would be such a procedure to go through to get back on them that I think she has probably given up on the idea now.*  
(Olive, 52, Scotland)

Kim's experience shows the difficulties associated with the transition from an educational setting to a work setting:

*Well I finished and I was working, I got a post doctoral fellowship for two years, about six months before I submitted in the University of Ulster ... and that was great but it was two years and at the end of two years I was on the dole for about nine months or ten months, it was a hard time.*  
(Kim, 49, Scotland)

Marilyn's experience shows the contrasts between the time-space demands of university and of professional life, understanding the differing time-space requirements of each:

*Glasgow University is such a kind of you know amazing place ... even the buildings take your breath away, but I just feel as if it is so inaccessible on so many levels, not just physically difficult to get about ... I think when you are working, as a professional person, the only way you can manage to get through work is by being organised and having deadlines and that includes having meetings, and you know you set aside a certain amount of time so that you can get that piece of work done later in the morning, and then another series of seminars or whatever. University life is kind of like, oh well, I've got three days to discuss this particular thing, when, no I actually have ten minutes, it's just a completely different culture, it's almost as if we're not in the real world. I'm not saying we're right and they're wrong, but just in terms of the two marrying up they just don't marry up particularly well. At the time I had just taken on a new job and it was very hectic ... I had just moved house and I was on my own with the children and stuff like that it was all too much.*  
(Marilyn, 39, Scotland)

## **Positive spaces**

Respect, acceptance and support, both environmental and ideological, has a significant positive impact on individual educational experience; and it is possible to find individuals

reflecting on the positivity and not just on the stress of their educational experiences at the post-secondary level.

*I just love the place, so best choice I ever made ... Everything at medical school within the university with colleagues, I mean medical students, has just been brilliant. My first and second year...especially my first term in first year, I was very homesick and that meant that I didn't make friends very quickly ... I was very secluded ... being by myself ... I didn't like being by myself, that was the whole point of it, and I think I got quite down about it. I felt very on my own, and then in third year when we started doing clinical medicine I started to get to know other medics, other students more intimately, and I think a few people realised 'mmm, well we don't really know Lynda but she is actually quite cool'. I got to know a lot of people and then doing the BSc and people doing the BSc, and the people that I am doing medicine with now are just brilliant. If ever I need any help at all ... the only help I need is physical help, ... the time I am walking with someone, I take their arm, and even if it is someone I don't know well, [they] always offer me their arm, they will also carry my bag for me, they always make sure that I get home safely. It's just great! The professors, the doctors fortunately I haven't come across any bad attitudes.*

*(Lynda, 23, Scotland)*

*The Prof's were really good, I was allowed to tape record my classes without any difficulty at all, there were a couple of funny comments made because the tape recorder would go off and it would go 'BANG' in the middle of a very quiet section of the class, whatever, and the Prof would turn around and say 'well we know who's in today!,' something like that, it was all done very good naturedly and I never felt badly about it and students were really open to extra support and I didn't have any problem like that.*

*(Babette, 47, Canada)*

*Like the other students I've had a great time with, they just treat me as me, there's no leeway for me whatsoever, which is brilliant it's just like other students, same as them, and I probably piss them off some days as much as they piss me off and they're quite happy to say you know, you're in my face, get out of it! Which is fine you know, I don't want them to tip toe round me.*

*(Trudy, 33, Scotland)*

*I had a really great adviser when I was doing my Masters programme, actually I had two really great Profs. One, she was really supportive of me and was very supportive of the way I approached disability issues and said 'you're marching to the beat of a different drum, or as compared to everybody else but that doesn't mean it's wrong, it's okay.' It's sort of given me a bit more space, but I mean even this year is the first time I've ever really, really felt comfortable talking about the whole time-space relation thing, it's 'cause I've had such a supportive academic environment where I'm working and stuff in my academics ... Now I'm doing a PhD at Glasgow University, as of October 1998 I'm on educational leave from my employers and it's been great. Initially up until December of 1998 I was doing disability research in the Disability Studies department at Glasgow Uni., but I wasn't getting a lot of support from that department, strangely enough, to the point where I was again questioning my academic ability to do ... well, really I wasn't questioning my ability, I just needed to get some academic support in that somebody would trust my knowledge base a bit more, but I found that my adviser in the Disability Studies Programme was very ill-informed about basic disability issues and I found that I was explaining to her a lot of really basic stuff which got in the way of what I wanted to do and I felt that I was doing my job and her job ... I went to the Student Services Adviser and explained the situation, and she said 'you know you can have another adviser if you want, the Human Geography Department is doing disability stuff and there's some really cool people that work there', so I thought, great, fine, get me in there, so I went to talk to the academic adviser of that department, ... who is also the Postgraduate Adviser. She was great, she said 'yes, we can take you on', it sounded great for me, it sounded really open ... I went through the proper channels: I went to talk to the various people in the Graduate School and the Graduate School Adviser and they were all really supportive of my situation, mind it was still difficult to do it. Needless to say, as of December 1998 I moved into Human Geography doing the same stuff that I'd*



*done before in Disability Studies, only I was able to add these various human geography elements to it which give me a much more solid thesis to work with, it's been great ... It's been the most rewarding experience of my life.*

*(Heather, 43, Canada)*

### **On approval: the stress of tentative acceptance in academia**

Trudy's experience illustrates the stress often experienced by disabled students having to deal with countless individualised 'small' access issues that are a vital necessity to the actual study process. It is interesting that the study process itself is supposed to be central to the post-secondary education experience, yet it is often secondary to the on-going quest for an accessible educational environment. One wonders what the outcome would be if students were able to use the bulk of their physical and mental energy solely on study:

*And I actually got really distressed near Christmas and I said to my director of studies, 'look I don't have time to keep writing complaint letters, I'm here to be a student and get a degree and writing complaint letters to you is actually taking up my time, I need to be studying not writing bloody complaint letters! No just fix it, I'm not asking for much just sort it out. ... I worried that I was going to fail because I didn't have the same study, the other students could get up and down the stairs but I couldn't, and then they said would put a computer downstairs in the library for me but they didn't, it never ever happened, and I kept saying 'when is this computer going to be put in the library because I need to print out essays and type up essays?', and they said soon soon, just be patient, but when you're doing an exam and the essay has to be in for the final day and your essay is part of your exam you know you don't have time, you need it now!*

*(Trudy, 33, Scotland)*

The presence of disabled students in elite academic space is not commonplace. In many ways disability is still looked upon with suspicion or at the very least a curiosity. Perhaps on a much deeper primitive level, it is indeed a threat to the 'spatial control' imposed by the dominant non-disabled social order. A peripheral acceptance is palpable. As a reflection of this phenomenon, many women identified the need to perform at an exceptional level as a means of validating their presence in the academic environment, gaining acceptance and approval, and thereby affirming their right to be present in these spaces.

*I don't think it's adequate for me to perform at the normal level, because ... I think it's all above and beyond, same as at Queens [University], you know perform, had the most paintings, the biggest painting and also in terms of quality, you know, well I would have to be better than the rest, I guess, so that's why I graduated as one of the first class not just adequate but above and beyond that.*

*(Lilly, 34, Canada)*

*I was fifth in the class, so it was like going from being last to fifth and I just thought 'yes this is what I have to do', and so then that sort of gave me a huge boost, I thought 'oh my god I'm fifth' I couldn't believe it, ... it worked really well and then by the end of my third year I finished with a Diploma in Horticulture with Distinction, and ... sorry there's so much to go through [cries] ... I just couldn't believe I'd got a distinction, because there was only four people, and I got the John H Warwick Memorial Prize for best final year project, I'd got the highest mark that had ever been given, and I*

*got a prize for the highest mark that had ever been awarded for an engineering paper.  
(Joyce, 34, Scotland)*

*I never really came across any kind of ablest attitude or anti-disabled attitude until I got to university which was kind of interesting. Although, I must admit in the back of my mind I was always afraid that if I didn't get it right I'd be sent back to segregated school, although I never told anyone.  
(Heather, 43, Canada)*

## **Conclusion**

The women that I interviewed felt the need constantly to 'work' on several levels at the same time simply to be present in the academic environment. Many women spoke of having to maintain an exceptional academic standard in order to be perceived as competent. This situation was of course coupled with the need to 'pass' (see Chapter Seven) or minimise one's disability according to non-disabled perceptions of physicality or aesthetics. There is a type of reflexivity here that is rarely discussed: the energy used to be present both within and outwith the academic environment. Established boundaries or comfort zones are constantly challenged by the 'outsiders' having a tentative presence on the 'inside' of academia. Such efforts use large amounts of physical and emotional energy for a population where energy is often at a premium. The question remains what could be accomplished if we as a society could move beyond such a grudging acceptance of disability in our mainstream educational spaces; what talent and contributions could be released if people, especially women with disabilities could 'move' through the educational system more easily, without all the hassles of securing access to both closed classrooms and closed minds that have been faced by most of the women who I interviewed (as documented in this chapter).

## Chapter Seven

### Community spaces and private places

#### Introduction

Community membership space, or the state of belonging or not to communities, may be determined, in part, by socially defined identifiers of acceptable physicality. Socially ascribed markers determine degrees or levels of inclusion, and the presence of disability seems to challenge the accepted markers of humanity or normalcy. Social assumptions, including reactions to perceived differences, appear to hark back to ancient belief systems ingrained deep within the collective social consciousness, ones arguably rooted in fear and limited knowledge. As Chouinard (1999) explains:

At one extreme are conscious, overt acts, such as racist remarks. At the other are mundane responses to someone who is perceived as different or 'other' – responses such as ignoring their presence or reacting to them in ways that help to mark them as negatively different (e.g. singling a visibly disabled person out for unwanted attention).

(Chouinard, 1999, 142)

Often, everyday social interactions experienced by people with disabilities in what are conventionally regarded as the public spaces of ordinary communities, the likes of shops, pubs, clubs and taxis, seem to be profoundly marked by residual fear and ignorance on the part of the non-disabled (Butler and Bowlby, 1997). This can lead to practices of exclusion.

On the other hand, encounters with strangers, certain caring professionals (social and health workers) and other service providers (taxi drivers, shop assistants, and food servers) often cross the public/private divide, apparently fuelled by 'primitive' curiosity and out-dated beliefs, such that non-disabled curiosity about people with disabilities - these 'aliens' in the scene – can lead to disabled people being treated in an oddly intimate fashion.

This may result in the 'private' issues for people concerned becoming strangely available for public consumption, a dubious form of inclusion. As a result, many people with disabilities experience a chronic sense of displacement. In many ways work reflects the community and the community is work. Attitudes and beliefs from the community are part of the workplace as work is a part of the larger community.

The social construction of disabling differences as markers of inferiority and 'otherness' has, at both macro and micro scales, helped to situate disabled women as 'out of place' in society and in spaces of everyday life.

(Chouinard, 1999, 150)

In this chapter, I wish to explore such matters to do with disability, community spaces and private places. I will gradually focus down from the wider community (a public space) to that of the more intimate household, kith and kin relations (a private space): in practice, though, what is happening with these two scales blurs irretrievably together.

### **Making space or taking space: a matter of perspective**

Whereas non-disabled people claim space in ‘public’ places as a matter of course, the presence of people with disabilities in these spaces is commonly perceived as exceptional rather than expected (Butler and Bowlby, 1997). The appearance of disability outside of socially ‘designated’ areas such as day centres or protected workplaces known as workshops is often seen as disruptive to the natural or established social order. Probyn’s (2001) thoughts on proximity, gender and sexuality are of use here and draw strong parallels to disability:

[C]oncepts are not geo-politically neutral. In other words gender and sexuality are not universal: *how* they are used in different contexts greatly affects *how* they may relate in proximity to other sites. (Probyn, 2001, 179)

People with disabilities are often viewed as being out of place in public spaces. Elements of fear, ignorance and social titillation are bound together to reinforce, but also on occasion to scramble, boundaries between those individuals with disabilities and the non-disabled. Boundaries defining what is ‘public’ and ‘private’ here seem to be instantly obscured. Society has yet to develop a ‘comfort level’ with so-called ‘messy’ or ‘leaky’ bodies and accordingly, there is an assumed right of public ‘correction’ (Longhurst, 2001).

Consequently, people with disabilities are not assumed to have the same degree of anonymity accorded to the general population in public spaces. Disabled men and women, the latter particularly, those with the socially defined ‘makers’ signifying disability such as a varied gait, speech difference or using hardware (callipers, wheelchairs, canes or crutches), are often on ‘public display’ to a degree that is largely unknown to the non-disabled population. Joyce’s observations illustrate the sometimes difficult reality of this perverse form of ‘celebrity’:

*You become public property where complete strangers ask very personal questions. Boundaries in terms of privacy ... just don't seem to exist.*  
(Joyce, 34, Scotland)

At the same time, this social distancing works to excuse invasive or intrusive behaviour that would not be permitted under *normal* or ordinary circumstances of social interaction. It is as

if the traditional *rules of engagement* are suspended or at the very least confused when this type of *difference* is detected. In many ways people with disabilities become, in effect, 'public property' subjected to intimate questioning. Trudy relates another 'public property' encounter illustrating that, while these situations are very difficult at times, there are also instances where they can be positive (two sides of the same coin):

*It hasn't all been negative. There's been some really helpful people and I don't mind if people actually come up to me and say 'do you need a hand to reach a shelf', that doesn't bother me, I'm quite happy. Or if the wee one stops me in a street, and they'll say to me ... 'why are you in a buggy?', and I'm quite happy to say you know 'my legs aren't very good at walking', but that doesn't bother me, people are just being up front. I'm quite happy with that. I've had some positive experiences with people being very helpful or like asking if I need a hand with that ... and just people speaking to me rather than being embarrassed to speak to me ... There's some really nice people about.*

*(Trudy, 33, Scotland)*

Trudy's and Cindy's comments nonetheless demonstrate how limited opportunities for encounters between people with disabilities and the non-disabled population may help to create and then to sustain a general awkwardness, one which may go as far as avoidance of social interaction:

*People mumble to me in the street, they'll look at their feet or look at the chair, they'll not make eye contact with me because they're scared in case they'll offend me.*

*(Trudy, 33 Scotland)*

*A couple of people told me afterwards that they thought I'd been drinking, and one girl in particular ... she [a friend] chose not to come across the street and she said to me a few weeks afterwards ... 'I was really worried about you ... because you appeared so different to what you normally do', and she said ... 'I knew there was something wrong, your speech was so different I didn't know what was wrong', but why didn't she ask me?*

*(Cindy, 52, Scotland)*

Lynda's and Trudy's experiences illustrate the level of public scrutiny many people with disabilities regularly experience:

*It's that kind of assumption that not only do your legs not work but your brain doesn't work either and that really irritates me and it annoys my son as well. He gets really embarrassed now that ... he's quite aware of being cool and when people stare at us and he'll actually verbally, very loudly will say 'why are you staring at my mum, have you never seen anyone in a wheelchair before?' ... I let him do that because they shouldn't be staring.*

*(Trudy, 33, Scotland)*

Olive's comments again emphasise the increased level of inspection that many disabled people appear to undergo regularly in public, coupled with the emotional strength required to manage the collective *public* stare:

*I go into the gym and I'm cumbersome moving from my chair to the machines and everything, you'll get certain people that will stare at you ... you'll still get old ladies saying 'what a shame', and ...*

*you feel that you've got to be extra strong to put up with that. Nobody else would put up with that, they'd sort of go up and say 'what are you looking at, do you want a photograph?'*  
(Olive, 53, Scotland)

Joyce's and Lynda's poignant commentaries show the heavy emotional toll exacted from those disabled women who encounter the at times hostile public glare:

*No matter how long you've been a disabled person, when someone makes a negative comment about you in relation to your impairment, it is deeply hurtful and humiliating.*  
(Joyce, 34, Scotland)

*I don't like saying things back to people because ... even eight years on ... since I have had any problems [disability], every single time somebody says something to me it always upsets me as much as the last time.*  
(Lynda, 23, Scotland)

Mitzi voices a common frustration voiced by many of the women who I interviewed at having constantly to explain their personal situation to strangers as a *rite of passage* in order to engage in daily life activities:

*But why should I have to justify myself, why should I have to tell people that I've got rheumatoid arthritis? ... and it really, really bugs me.*  
(Mitzi, 46, Scotland)

The above quotes illustrate the larger theme of people with disabilities being made to feel that they are just 'taking up space', occupying public space when they really ought not to be there (even when invasive questions/treatments relating to their 'private' experiences are forthcoming); rarely, do these women feel in a position to take much control over public space, to feel that they are making it, not just taking it.

#### *On approval: a matter of inconvenience*

Gradually people with disabilities are making inroads into the non-disabled mainstream community. Wheelchair ramps, accessible toilets, lifts, Braille signage and mini-coms (telephones accessible to deaf people) serve as the visible markers of disability's growing place within the wider *able-bodied* community. The importance of these necessary accommodations in facilitating the physical access of disabled people into wider *public* spaces and places cannot be underestimated. However, what remains largely unrecognised is that the terms of reference and means of access have, as a rule, not been determined by people with disabilities but rather by the non-disabled. The level of access provided often remains tentative and superficial, so long as established patterns are not disrupted to any great degree.

Token efforts at cultural inclusion in many ways seem only to draw attention to the cultural absence of disabled of disabled women everywhere else. In the local spaces of everyday life, cultural practices contribute to oppressive living environments for disabled women. These practices unsupportive professional and informal care-takers, invasive questioning by strangers, aversive reactions to the presence of the disabled in public spaces of various types and construction of local spaces which either exclude or segregate disabled users (e.g. government council chambers which lack disabled seating and sign language interpreters; local arenas and movie theatres which provide only segregated seating to wheelchair users).

(Chouinard, 1999, 151)

The approach to disability within the larger community seems to be as an add-on or an afterthought rather than as a *natural or automatic* part of the process. This experience in some respects, mirrors that of non-disabled women in *public* space as noted by McDowell (1983, 61) discussing: “women’s unequal access to urban goods and services and the constraints on their spatial behaviour.” As with able-bodied women, the presence of disabled people appears very much a matter of convenience not *inconveniencing* the non-disabled occupants of public space – and it is usually allowed, it is felt, only on approval. As a result, many people with disabilities feel as if they are in effect out of place, and are often left having to explain or even to justify their presence under the most mundane circumstances. There is also the deep fear that the non-disabled’s ‘approval’ may suddenly be removed: that people with disabilities will be effectively told to ‘go home.’

Trudy’s comments illustrate how frequently even the most basic amenities in public spaces cannot be taken for granted, signifying that these places are not really *for* people with disabilities:

*I’m sick of having to explain to everybody every time I go out or want to do something or go to a restaurant or go to a shop or even go into a public toilet, it’s like can I go in there?*

(Trudy, 33, Scotland)

Longhurst (1994) has documented similar experiences for pregnant women:

A lack of toilet facilities, or toilet cubicles that are too narrow for a full-term pregnant woman to enter and use comfortably, is more than a little inconvenient. It may make it difficult for pregnant women to participate fully in the public sphere.

(Longhurst, 1994, 219)

Lynda and Joanne talk about how people with disabilities are put in the situation of regularly having to explain and to justify their needs in order to move through life on a daily basis.

Often, a person’s disability is mistaken for a sign of social dysfunction such as drunkenness:

*If I go to a coffee shop, and say can I have a cup of coffee, then they will speak to me about different types of coffees, different sizes of cups, whatever, and I stand and look at them and I haven’t a clue, and loads of times they must look at me as if I’m either thick, drunk or whatever, but as soon as I explain there is a problem [Joanne has aphasia] and ‘could they speak more slowly’, they will do it.*

*well some of them will be fine and some of them don't have a clue why they've got to do that, you know, however ... I'm not complaining, I will have to continue to explain!*

*(Joanne, 48, Scotland)*

*Half-eleven in the morning I have been in situations where they [strangers] have said to me 'have you been on the booze already?' when I haven't! I don't drink now before I go to a pub or a club because I have to have my wits about me when they [security people] say 'you're not getting in, you're paralytic', and I have to say to them 'no I am not, I've got this, this and this' [Lynda has a neuro-muscular disability]. There have been a couple of times when they've asked my friends whom I'm with for confirmation of what I have said and they apologise to them not me.*

*(Lynda, 23, Scotland)*

Many people with disabilities are more than willing to 'make the effort', perhaps recognising, accepting and to a degree internalising the mainstream view that the 'problem' is theirs' and not society's. There may be the realisation that in order to make one's way in the world, some allowances must be made to account for a general lack of knowledge regarding disability:

*And people don't understand and you don't have to explain yourself. I mean I don't want to say to people 'well there's something not quite right here, but it doesn't allow me to function the way I would'.*

*(Cindy, 53, Scotland)*

Joyce's experiences show the degree to which disabled people have to accommodate to able-bodied parameters of time and space in the endeavour to 'fit in' after a fashion:

*You have to plan ahead all the time when going to a new place ... this involves organising professional mobility [Joyce has a vision impairment] training which is usually undertaken at the trainer's convenience rather than yours.*

*(Joyce, 34, Scotland)*

Olive's encounters shed light on a disturbing element that, at times, underlies social interaction for disabled people within the wider society. Certain bodies have yet to 'belong' (Longhurst, 1994). It is as if their presence is treated as a form of trespass, unwanted or disruptive to socially established time and space factors, thereby engendering a hostile reaction. Longhurst's (1994) study of pregnant women reported similar experiences:

[D]uring pregnancy in some places women find that their usual behaviours in public become increasingly socially unacceptable the more visibly pregnant they become. The familiar, the 'everyday' of some places though the medium/experience/physicality of their pregnant corporeality can become unfamiliar zones in which they at times they feel uncomfortable and unwelcome.

*(Longhurst, 1994, 219)*

People with disabilities are often treated as though they or their presence are seen as being disruptive to the 'normal' flow or circulation of capital because these individuals 'take up' more time and space than they should, maybe reducing profit margins:



*I think they have this power thing, they [taxi drivers] don't like taking disabled people in wheelchairs, they think we're a burden, and because a lot of us need the ramps down to get the wheelchair in, that makes it even worse because it takes longer you see, so the longer they spend with you the less money they are making whereas if they just pick somebody off the street and drop them again it would be a lot easier, so they tend to take their bad temper out on you and you get comments like, you'll go out ... on a rainy morning and they'll say, 'why do disabled people want to come out in the rain anyway?', and there's just no answer to that.*  
(Olive, 52, Scotland)

What is usually not recognised is that disabled people often bring sustained, regular capital to the economy when moving through public space in a non-traditional manner, injecting capital into the local economy because we have to be regular users of public transport, and in particular to take taxis when others might walk or take a bus. My own experience using the train and taxis commuting from Stirling to Glasgow is a case in point.

There are instances where familiarity with disability fosters acceptance, such as Trudy's neighbourhood where people do not appear to regard a person with a disability as entirely out of place or inconvenient:

*My neighbours and everybody round about the area I live they know me as me and that's great. I never get any help unless I need it, because some of them will come up if I look as if I'm struggling, they'll say 'do you need a hand' or I'm not frightened to say to them 'could I get a hand', if I need a hand, and people have been brilliant, like there's days when I'm stuck up on a kerb or something, I've had to say to someone 'excuse me can you give me a shove' ... They've been fine, so within the local area it's been great because people know me, and there's not this pitying.*  
(Trudy, 33, Scotland)

People with disabilities would seem to get caught up in a cycle of limited social expectation on the part of the able-bodied mainstream, perhaps fuelled by a combination of factors ranging from lack of exposure to disabled people in regular social situations to projected discomfort levels (the 'pitying') arising from the assumed helplessness regularly associated with varying levels of physicality. As a result, disabled people may spend significant amounts of time and energy negotiating their way through public spaces, as Heather explains:

*I find too that often in the general public the expectation levels around the capacity of what a disabled woman or a disabled person is able to do are so limited that I find myself putting people at ease or explaining the most basic things to enable me to ... get on with my life the way that non-disabled people would just take for granted. I spend a lot of time putting non-disabled people at ease.*  
(Heather, 43, Canada)

### *Colonisation and infantilisation: the cycle of limited expectation*

In Western society individual worthiness, indeed humanness, is often defined on the most primitive level by the body. The presence of people with disabilities challenges the

entrenched social ideals of what is the *acceptable* adult body. In many ways disabled people are viewed as not fully human by society at large, although this form of dysfunctional reductionism is rarely perceived or acknowledged within the collective social consciousness. In considering how non-disabled people react to the embodied presence of someone with a visible disability, Wendy's comments articulate these sentiments:

*Before I was disabled I never thought about it. It's very sad, people think that if you're in a wheelchair, you're not quite normal.  
(Wendy, 56, Scotland)*

Wendy's comments are echoed by Trudy as she relates a recent experience at the benefits office:

*They saw me in the flesh, in the wheelchair, it turned to being an irritant into somebody who was stupid, so it was like being spoken to like I was three, 'do you know what this benefit is for?' You know this kind of slow talking, and I remember thinking 'why is he speaking to me like that'! I wondered if he had a speech impediment, you know like he was speech impaired!  
(Trudy, 33, Scotland)*

There seems to be a tendency on the part of the general public to *globalise* disability in that disability is believed to be the singular defining factor in a disabled person's life, and that the individual's life activity is measured and often judged according to this one element:

*People's attitudes are the worst ... When they realise I live alone, and there's this big myth that you have this crusade of helpers and you live like in a clinical world, and there's also this thing that really gets to me when people are speaking to me, especially people you don't know, but because you're in a wheelchair they do assume you're disabled in every other part of your life, and your brain is dysfunctional. I mean the amount of people like when I tell them I'm at university they think I'm in a special class it's like no, I'm just in a normal [sic] class.  
(Trudy, 33, Scotland)*

There would appear to be little public understanding that people with disabilities are capable of, and are indeed, leading active and meaningful lives. There is an on-going use of personal time and energy labouring under and dealing with the limited expectations of others:

*You're coming home having seeing a difficult client [Olive is a Counsellor] and you'll get ... 'have you enjoyed your lunch club dear?' They have no idea.  
(Olive 52, Scotland)*

Trudy's encounters also show how disabled people regularly confront deeply entrenched social stereotypes concerning disability. Many times the level of engagement would seem to be quite primitive, occurring solely in terms of the individual's apparent dysfunction. These experiences also appear to illustrate the degree of social invisibility and dependence commonly associated with disability, as well as the lack of space accorded people with disabilities in society:

*It's always the question 'is someone with you?' ... It's like no, I'm doing my shopping, I don't normally take all my pals with me shopping, I'm just doing my week's shopping. I don't know what it is, when I'm using my stick that's not so bad but as soon as I'm in my chair people assume I can't speak, and I don't know why. I've still never figured it out whether they associate a wheelchair with muteness or what is it about wheels that makes people think you can't speak? People have actually leaned over me to get to a friend who's been with me and said 'what does she want?' in a really loud voice, either that or they speak to me in a really loud voice as if I can't hear.*  
(Trudy, 33, Scotland)

A limited understanding of disability hence gets all too readily coupled with the common misunderstanding that a perceived physical difference somehow informs a lack of maturity or emotional development. Joyce and Trudy, both women, relate instances of what might here be termed infantilisation, and recount being treated as though they were perpetual children by strangers:

*I often have people just about cuddle me when they're trying to guide me somewhere - despite my protests! These maybe seem a bit negative, but they are things that happen in my life on an almost daily basis.*  
(Joyce 34, Scotland)

*I get my head patted all the time but I'm really rude if people pat my head, I just can't stand that, don't pat my head ... 'I'm not a dog, don't pat me', just get off my head now or you've had it, it's that simple.'*  
(Trudy, 33, Scotland)

Again, exploring the encounters above we return to the issue of disability as 'public property' with whom able-bodied people feel they can be intimate, much like what happens to children. Lynda relates how overwhelming this level of attention can sometimes be:

*I quite like wandering about the town on my own. I like shopping on my own ... I like the freedom, I like being able to do what I want when I want. You are always offered help everywhere you go ... it can get quite smothering, because, you know that if you were a person who could walk with no problems, you wouldn't get that help.*  
(Lynda, 23, Scotland)

### *Keeping up appearances: the fine art of 'passing' and resisting*

It would seem that disability is often equated with a lack of development. There would appear to have been a *colonising* approach adopted toward those individuals with disabilities in Western society. In the possible belief that the appropriation of certain degrees of able-bodiedness can turn disabled people into something approaching the norm, *normalising* or *corrective* are measures are often *presented* as a 'civilising' influence ostensibly for the betterment of the individuals toward whom it is directed. This is another manifestation of people with disabilities being perceived as sub-human in much the same way as Aboriginal People in Canada have been regarded as sub-human 'savages' in need of the Western

‘civilising’ influence. Here ‘civilising’ equates with being able to fit in with the expected time-space routines of respectable Western society:

*Other than telling me every remedy in the book [Camryn has arthritis]...which you get tired of hearing, but sometimes it's good you just don't want to hear it.  
(Camryn, 39, Canada)*

Many of the women I interviewed related instances of being ‘schooled’ in the ways of disability or, particularly, in ways of disguising disabilities. As part of *normalisation*, people with disabilities are routinely told how to ‘act’ in the public spaces of mainstream society, or rather what their behaviour *should* be:

*Like this is what I should be doing, and people who have been to special schools are conditioned in a certain way, because I know before I was disabled, you know, people assumed they couldn't do certain things, 'oh no I shouldn't be doing that'.  
(Trudy, 33, Scotland)*

This quote from Trudy raises the whole question of ‘passing’, and many of the women who I interviewed spoke of the necessity of ‘keeping up appearances’ or of looking as *normal* as possible in order to make one’s way through the world on a daily basis with the least amount of difficulty.

*I still sort of believe, wrongly I think, that we've got to sort of put on a wee bit of a show every time we go out in the morning, put a smile on our face, 'oh nothing's trouble to me', you know, and [be], overly thankful for anybody that does anything for you, whereas nobody else would be like that, permanently sunny, without a care in the world.  
(Olive 52, Scotland)*

The irony is that this kind of action may well create a greater personal obstacle for the individuals effected. It may also reflect a larger internalised social pressure to conform to what is expected, and thereby to keep what is often perceived as a *personal* ‘problem’ private. Disability often involves what is conventionally defined as a ‘private’ concern (the individual and their body) displayed publicly, and so the heart of the matter is obviously to do with appearances and how these can be managed.

As explained, there is a constant scrambling of ‘private’ and ‘public’ here that is what causes unease, arising whenever there is a failure to conceal something ‘private’ in ‘public’, be it by accident or design. The result is to lead some to set up boundaries against the offending person/body while others start to treat that person/body as if they were in an intimate private circle. Cindy and Joyce’s comments are typical of the confusions arising for the interviewees and the severe personal consequences:

*I mean you don't make it known that you're sick or you're poorly, well at least I don't, well why can't you? There's nothing wrong with you because I don't have a plaster on my arm, I don't have a wound on my face, there's nothing visible, you look well and some days I look great and some days ...*  
(Cindy, 52, Scotland)

*People treat me differently when I use my cane. When I try not to use it I masquerade as a sighted person and when I walk into things people assume I'm drunk.*  
(Joyce, 34, Scotland)

So passing does sometimes break down on occasion, prompting confusion for all concerned. Perhaps the most telling aspect of the passing phenomenon is that the 'normalising' element often has little to do with accommodating or addressing the requirements of people with disabilities, but rather is all about acquiring an acceptable level of able-bodiedness so as to better fit within the 'normal' continuum or comfort zone. The colonising element appears to cater to the sensibilities of the able-bodied and what is deemed to be proper and acceptable rather than to meet best the requirements of the women involved. The focus indeed seems to be on appearance over substance, as Trudy's experience illustrates:

*I'm supposed to try and walk as straight as I can, but that's because that's the normal [sic] way to walk not because it will benefit me, so I did that for about year and really struggled and when I finally asked ... 'is there a purpose for me in walking like this?', They actually told me, 'no it's just that's the way I should walk' ... So now ... I do a sideways walk, [my son] calls it my 'crab walk', so I just walk like that and hang onto the walls, and I take quite a lot of seats ... but I've sort of adapted my way around.*  
(Trudy, 33, Scotland)

Heather and Stella relate poignant stories concerning their experiences of normalisation and their decision to find a better, more suitable option that ultimately enabled them to function more effectively, and to have greater self-esteem in the process. It is interesting to note that Heather felt that using crutches increased her physical attractiveness. Stella spoke of wearing her artificial limb as a child to look pretty in church, but even then questioned its cosmetic value. What is evident is the personal strength that these women exhibited at an early age by confronting accepted social conventions, by, like Trudy, refusing to pass as able-bodied:

*I remember when I was twelve I said ... 'Look I'm not going to walk the way other people do but that doesn't mean I'm not going to get around and that's OK', and that was it ... I gave up practising to walk without my crutches because I knew that walking with crutches was a lot more comfortable for me and it was OK with me and it gave me a lot more independence and when I was walking without crutches I always felt that I was walking that I looked like Quasimodo which was not too cool.*  
(Heather, 43, Canada)

*I used to have an artificial arm, I got that when I was a baby, up until I was about 14 and then I handed it back because it was useless. What I found is that it was only cosmetic and even the cosmetic value was ... they were just so decrepit but I used to wear it to go to church on a Sunday to look pretty but then when I went home ... to eat my dinner I took it off, and I would sometimes wear it to school but even sitting at my desk I would ... take it off and shove it in my school bag ... If you*

*were out playing I mean you couldn't play with this thing. They're [artificial limbs] so uncomfortable ... I hated it and then eventually ... I was about 13, and I didn't tell my dad what I was going to do, I just went in to see the doctor, because you had to get fitted with a new one every two years ... and he said 'you'll be getting fitted for a new one today', and I said 'no, I don't want one anymore', and my dad just sort of looked at me because I'd decided it was a waste of everybody's time. I was never forced to wear it, I mean it was never 'you'll wear it' I mean I'd wear it if I wanted to, but sometimes, like if I went to church on a Sunday, if I wasn't wearing it, my parents would never make me wear it, but my family doctor, my GP, that had absolutely nothing to do with it because he didn't know anything about artificial limbs. I don't know, he was an older man, whether it was for the sake of appearances I don't know... he would give me a row, and say 'you should have your arm', and I didn't like that, I didn't like him, but my dad stood up for me and he would say 'well it's her decision.'*  
(Stella, 37, Scotland)

The extent to which many women with disabilities are driven to 'keep up appearances' and to pass is most dramatically exemplified by Flo, a lone-parent, who for twenty years raised her three children as a sighted woman for fear that they would be taken away from her if the authorities discovered she was blind:

*I denied that I was blind because I was trying to live in a sighted world with my three children. I didn't ask for a lot of help from the authorities because I thought that they would think I couldn't look after my children and they would take them away and I didn't want this... I would tell them to tell mummy if there was anything in front of us that I couldn't see, so they would do all that and we would come to the pavements and I would ask people to take us across the road. I would know where the bus stop was and then I would go to the hospital and I found ways to get off the bus on the right side of the road so you didn't have to cross the road. You just had to find your own ways for doing all these things, it's just something you had to do, you didn't have an option.*  
(Flo, 63, Scotland)

### **Shifting boundaries: changing status**

Contrary to popular belief, most disability is not present from birth or the result of a genetic difference, but rather disability usually has its onset in adulthood. Consequently, many of the women who I interviewed experienced a profound shift at this time, not only on a personal level but on a social level as well. Not only were these women frequently dealing with a new physical reality very different from what had gone before, but also with a simultaneous social status shift often involving new kinds of encounters with strangers as well as with family and friends. As such, interactions and relations within the more private spaces of home, garden and immediate neighbourhood could start to take on new qualities and meanings. In part, this could entail clinging to private spaces in a manner never done before, given a fear of what might happen if venturing out into public space:

*I used to be very sociable ... No I'm not very sociable now ... I was never in, I was always out enjoying myself, meeting people, now when I do go out, I feel very uncomfortable ... because when you've been sitting for a wee while you need to ... get up ... your knees are stiff ... and people look at you.*  
(Mitzi, 46, Scotland)

*What struck me initially, how much we take for granted, how people change towards you ... I wanted to avoid people at all costs, I went out of my way to avoid people because I didn't want to be seen, I didn't want to be heard ... I wasn't me, my head was my, you know it was a zombie-like existence, as I say I did things because ... I wanted to be fit but it was obvious that it wasn't going to be a seven day wonder ... and I didn't know what I was going to have at the end of the day, and I didn't know what I was going to be ... I fell a lot and I couldn't articulate properly ... and my gait wasn't right ... I found that sometimes people kind of shied away from me, but it was mutual.*  
(Cindy, 53, Scotland)

Mitzi and Cindy here show how social distancing can sometimes be mutual, in effect, a two-way insertion of barriers and boundaries to act as a buffer and a form of personal protection from the mainstream environment.

Camryn's and Chris's experiences reflect on the changing nature of some types of disability which may have a profound impact on personal capacity or capability within both 'public' and 'private' spaces, as well as in family spaces:

*I pretty much ignored it until I had to deal with it and I dropped down to part-time [work] at one point, because I couldn't accept, but I wouldn't admit that it was the arthritis that I couldn't deal with, it was the part that was making me ... but there were a couple of times when I just had to come clean ... actually I'd say the first time I even admitted that I would even consider that I had a disability was when I started working here, and that was I don't know ... a huge step.*  
(Camryn, 39, Canada)

Chris also talks about how her disability changed her relationship with her husband, who now had to take responsibility for more of the tasks in the private realm of the household:

*It's taken away my independence that I used to have. I now have to have my husband do a lot more things than I used to ... My biggest thing was losing my independence outside work, inside work I was able to cope with it a bit better because I don't have to do lifting and moving, things like that and learning to use the computer in bits, but it's teaching myself that I no longer can do the other things, even in the workplace, learning that I couldn't sit in front of the computer for hours, it was very hard for me because I'm one of these perfectionist types, and it was just devastating for me to go 'what do you mean I can't do that anymore?'*  
(Chris, 42, Canada)

A full and moving account of the changes in private practices as well as in wider social life, brought about with the onset of disability, is given by Maureen:

*Before the disease [M.E], I was an extremely active person ... Spontaneous ... Everything has changed... everything has to be prioritised and organised, an outing with a friend, the schedule two or three days ahead of time has to be planned for in the sense that one has to make sure that the day before the outing one rests or gets a good night's rest ... an afternoon sleep, and nothing else gets done except for that outing so the concentration is on that outing and nothing else. When working with chronic fatigue one of the main things that one recognises is that there is no social life whatsoever. All energies are spent working ... when you come home ... you immediately go to bed, and you sleep ... for two hours ... and the rest of the evening is spent trying to recover from the day at the office, no social life, you eat, just spend a quiet evening at home preparing for the next day which is a rest day usually, and then preparing for the following day when you go to work, so there's no spontaneity and your social life ... is also changed in the sense that you just now orient it around*

*quiet social ... activities such as lunch, movies, coffees, strolls, things of that nature, there's no longer any skiing, skating, dancing, drinking of alcohol of any sort, anything more than let's say one glass. The medication gives you headaches, so the lifestyle has considerably changed, you're no longer the life of the party, and even returning to school, even on a part-time basis as a mature adult, is out of the question simply because it simply takes too much energy.*  
(Maureen, 49, Canada)

There is a simultaneous existence in public and private spaces, with intersecting changes in both public and private social routines that play off of and evidently influence one another. Sleeping a lot leaves little time to socialise in the evenings. Refraining from alcohol means adapting to a different less carefree, less participatory approach to socialising.

Several women spoke emotionally of the loss of friends who were unable to accept their disability. This is yet another way in which the social is reconfigured, showing that it is not *just* an accessibility issue:

*The one thing you learn when you become disabled is that you lose all your friends, the friends that you had. First of all you can't afford to keep up with them because you aren't bringing in money, and secondly they usually don't understand.*  
(Louise, 53, Canada)

*People who were friends of mine and stuff, that I now don't see anymore because they became quite scared I was ill or this thing they thought my head was damaged and it's this kind of thing.*  
(Trudy, 33, Scotland)

*Someone I planned to have lunch with, then I had to call her that day and say to her you know that I couldn't go for lunch, even though I'd rested for two days before without doing any housework, and so she said to me. 'It was about time I got myself out more'. Basically, when you do that to a person once or twice then they never ask you again out for lunch, and they give you such scoldings and make you feel so terrible for not going to lunch that you decide that you really don't need that type of relationship because it's abusive, so you chuck them. My lifeline has been the telephone, in fact I've had other disabled people with M.E. who I've talked to on the telephone for a couple of years before I've met them and I always talk to a couple of people a day on the telephone.*  
(Louise, 53, Canada)

Louise's use of contemporary customs such as telephone and e-mail signals new forms of sociability that are less demanding of physical presence in public space. Despite the gains of the telephone, e-mail and other assistive devices for people with disabilities, there are still dangers of celebrating this 'technological fix' too much. (See also Chapter Eight for a further discussion of this 'fix' in the workplace). It is arguably not going to provide people with as much emotional support as interacting on a face-to-face basis with friends, particularly if this can occur in everyday spaces of social life.



## *Encounters with caring professionals*

Reflecting the gradual reduction in scale and focus from the community to the household, health and community care professionals are usually the first point of contact when an individual has a newly acquired disability, and often play an important role in assisting the individual with the adjustment to a different embodied geography. In many ways this sector is hence a conduit between community public and household private space. A medical diagnosis is usually required to obtain access privileges to essential programmes that are supposed to facilitate and to maintain independence within the mainstream community. However, a lack of information or awareness of disabilities can create greater difficulties for the women seeking information concerning their changed circumstances. Barbie recounts the remote, clinical, manner in which she was told about her disability. There appears to have been little thought given to the psychological impact of dealing with the reality of physical disability and how disability can profoundly change every element of daily life activity:

*He [consultant] said right away, 'you've got rheumatoid arthritis, ', I was devastated, absolutely devastated ... 'Don't worry, there are drugs' ... that's what he said ... I was so distraught ... I sat in my wee flat ... thinking 'what does this mean', and ... you think of all of these awful things like you're going to be in a wheelchair next year.*

*(Barbie, 38, Scotland)*

Cindy relates a similar experience illustrating her physician's apparent failure to understand the complexities of her role or her life beyond the basic physical functions. There is a failure to understand the trauma that can result from extreme changes in timing and spacing realities:

*I went to see the doctor at the hospital, he said 'how are you today' and what do you say 'fine thank you' ... 'I see you're managing to get about now, have you resumed a normal sex life?', and I just about fell off the chair because it took me all my time to get there and he said 'right, I don't know if there's much point in seeing you again' ... and that was me.*

*(Cindy, 52, Scotland)*

Audrey talks about dealing with out-dated stereotypes about illness, disability and the use of 'hardware' (wheel chairs, crutches or canes) which still abound even in medical settings:

*You still get the same kind of patronising attitudes in some hospitals ... But he [her husband], was in hospital for a couple of days. [He] was in this dressing gown and I was in my coat, and we went along towards this other ward, which was male, and the staff nurse looked at me and said 'would you like to stay in your wheelchair?' ... I said 'excuse me, but the patient is behind me!'*

*(Audrey, 55, Scotland)*

Similarly Audrey relates how even in 'women centred' spaces, ableism is present and disabled women are not approved of as suitable mothers:

*[I went to the] Well Women Clinic and they were just so patronising [in the] ... assumptions that they made about ... not having children. I don't have children but the assumptions that they made, about 'well it was for the best'... I just about ate her.*  
(Audrey, 55, Scotland)

Joanne's and Wendy's experiences bode well for the future, showing what is possible when practitioners listen and take on board the lived experience of their patients and provide information with care, respect and sensitivity:

*My GP is fine, he's been very supportive, he does know a bit about what aphasia means but not totally. I should say that when I had to go into hospital, he took over fine. Nevertheless, though, consultants, doctors and nurses don't really know what aphasia is or mean or how they should react to people, one person, though, was a speech and language therapist, who's part of the hospital, is a superb woman, and she has helped me and my partner to get through this.*  
(Joanne, 48, Scotland)

*My GP has been pretty good just like everything and takes the weight of everything and takes the time to listen.*  
(Wendy, 52, Scotland)

### *Support systems*

The women with whom I spoke all had a strong support network that worked to shield or to cushion against the harsher or more inflexible elements of the wider society. There may well be other women with disabilities, more isolated and lonely, with whom I have not come in contact (a reflection of their specific circumstances). These networks appear to provide a form of sanctuary where one can be oneself freed from the daily pressures of passing:

*I think the relationships I have with a key close circle of friends go beyond the realms of straightforward friendships. We support each other ... It's brilliant to have such strong relationships with a number of people. I really value my friends and I know they value me.*  
(Joyce, 34, Scotland)

*I'm in a really good space, but it's been hard to get there because a lot of times you feel that you are out there in the wilderness, hacking through the wilderness on your own, but I have a lot of support of friends and family, both in disabled and non-disabled friends, I have a really supportive network of friends ... It makes such a difference in what you can do when you're in a supportive environment, if people ... just respect your needs.*  
(Heather, 43, Canada)

Perhaps the most painful and poignant dialogues, though, occurred when several of the women who I interviewed spoke of transition difficulties and a lack of acceptance from spouses or other close family members:

*The worst part was phoning my Mum and Dad because they knew I was going to the doctor and I had to phone and tell them ... and they were distraught.*  
(Barbie, 38, Scotland)

*I have a daughter that's six, so I didn't hear her first words until I had my implant [cochlear] hooked up, communication was next to nothing. If we were trying to talk and she had some basic signing skills, if she was asking me a question and she couldn't sign it, while her dad is fully hearing, so she would go 'never mind I'll ask Daddy', and so the relationship was very strained and separated. The same for my husband, my husband is a fully hearing person, and ... he keeps forgetting the signs and he is a very shy person, so mingling in the deaf community, for me, was a necessity, for him it was a very strained effort, but trying to communicate with me, you know signing very slowly, or writing it out on paper, you know so that strained our relationship. My mother ... has known me as being fully hearing all my life. When I lost my hearing my mother ... my mother, poke, poke, poke really hard. She stood behind me one day pulling like this and shaking her keys in her hand and, you know, you get really good at catching stuff out the corner of your eyes, and I turned around: 'What, are you doing', and she said 'Oh I'm just checking', I'm like, 'Mum, the deafness just comes and goes'. ... It's been my experience ... with the people that I'm friends with, they say 'oh well my family doesn't sign', and this is how they've grown up, me, excuse my language, I'm pissed off. Listen, if you have a problem, I would make the effort. I can't hear, make an effort and sign a little bit ... I might as well not be here, I feel like I'm a wooden post standing here you know,' so it's a strained relationship. My sister has a little girl that was born deaf and her signing, she signs fluently, for other deaf people but not for me. Adult conversation, for them, but for me she doesn't sign, I don't like it. (Josephine, 33, Canada)*

The above quote compellingly details the stresses resulting in a family environment from one member's onset of disability, including physical and attitudinal stresses, in how family members deal with one another. It cannot be overstated, though, just how substantial and far-reaching such changes can be to the micro-dynamics for everybody concerned, but particularly for the person with disabilities. More absolutely representative of this point is Flo's story as introduced a moment ago:

*I was married when I lost my sight and I had two wee boys ... Soon after I lost my sight I learnt that I was pregnant with my daughter and my husband, he couldn't cope with blindness, so he left us. I mean it was forty years ago ... but my daughter was two when my husband left, so my oldest son would be five and half, the younger one would be four, nearly four, and my daughter ... would be just two, and so that, well what I had to do was I just depended on my children as much as they had to depend on me ... So that's how we went along. I taught them [the children] to be my eyes. My son ... would read all the letters ... we didn't get any support from my husband (Flo, 63, Scotland)*

Loss of a non-disabled partner who was unable to cope with her blindness forced Flo into a position of power and competence as sole provider for her children. She was able to build the skills base of her children in the loving but difficult circumstances of an impoverished household, so typical of many disabled people's lives, especially disabled women. Many women are 'unable to go out to work' because of individual bodily states and wider social expectations:

*... Well we lived on National Assistance Board, as it was at the time, but it was nothing like what it is nowadays, it's quite means tested so things were very, very difficult and it was difficult trying to come to terms with my blindness and trying to live off a very limited amount of money, so that we had all the other things in, you know the poverty and all that as well, so it really was quite a difficult time and I didn't really ... I didn't ask the authorities, but nobody came forward. No, because the children then were quite young, so I didn't have a lot of people coming ... So a lot of the times I was*

*just with my children ... So it was really quite difficult ... You were trying to do all these things and I didn't know anything about blindness, I didn't know any other blind people so I didn't know how blind people coped ... [The] Society for the Blind and we had home teachers for the blind and they would come and visit us, every six months ... just to see how you were doing ... but that was as far as it went. It was difficult because I didn't know all the things that was available ... I was more or less trying to raise my children, but not as a blind person if you know what I mean so that I was more wanting to know ... how I was going to manage, how would I get tomorrow's dinner or tomorrow's tea because we didn't have enough money ... It was very, very difficult ... there wasn't really an awful lot of support. Normally as far as I was led to believe after this, I was a different case because, normally if anybody loses their sight, they don't normally lose their husband at the same time, and because I was so young people my age would be taught to go to work, but because I had three children I didn't have all this. I remember my first home teacher for the blind, she would say that they normally visited people that were elderly because the people that were blind were either working or they had a husband, I was one of the odd cases.*

*(Flo, 63, Scotland)*

### *Partners, wives and mothers*

The concept that women with disabilities lead full adult lives that encompass disability is still often seen as an anomaly or an oddity. As a result, at times there seems to be primitive curiosity that manifests itself, returning us to the theme of 'private' issues brought out into public space:

*I mean when we were getting married, I have a friend ... one of her neighbour's would say, 'aye he must have a big heart'.*

*(Audrey, 55, Scotland)*

*I had a friend who was disabled, her colleagues at work asked her one day how she managed sex, so she said 'well how do you?'*

*(Audrey, 55, Scotland)*

*People have asked me who the wee boy is with me, and when I tell them 'it's my son, they're really shocked, they say 'god you've got a son, did you have him before you got ill?' Like, I'm not ill but they assume you're ill and they're also very shocked.*

*(Trudy, 33, Scotland)*

The relationship of disabled women with their children is one where social expectations are often very clear, and such relationships also reveal the remarkable achievements of many individuals (or is the attribution here of 'remarkable' a patronising and ableist conceit?). Several of the women who I interviewed were mothers who nonetheless clearly did provide a positive, nurturing environment for their children in particularly demanding circumstances; and in this example it is telling that the real extent of Flo's disability was repeatedly denied because of her seemingly exceptional ability to cope:

*I think they looked on me as being a different case, if you know what I mean, and because I was so determined to raise my children and because I didn't want the authorities to think I couldn't look after them and that, I think that you do give out that you are more capable than what you really are*

*... He was working class and similar things had happened to him [Another home teacher]. He could understand some things so you could talk to him, but he would always say to me if he was talking about somebody 'oh but Flo they cannot cope' and I would say 'well, but you know what about me?' and he would say 'aye, but Flo you can cope you see'. So that I think sometimes when that goes out, even people that understand, know that you are maybe more capable than somebody else who would maybe have fell to pieces and said 'I cannot do that'. Yes at the time you have to deal with it the only way and I felt that it was easier to live as a sighted person, than live as a blind person, and that's what I done for years ... They didn't look at that situation, people just always thought ... 'oh Flo I would never be able to do that', but I think that anybody could if they love their children, they would if the same thing happened to them.  
(Flo, 63, Scotland)*

The ironic statement 'you can cope you see' made to somebody who clearly *cannot* see, nicely illustrates this point.

On a different but related tack, Trudy and Stacey spoke of the constant need always to challenge the educational authorities to take an active role in their children's education:

*'Trudy is coming, get the ramps out!' And like everyone knows they're [the ramps] out for me, it's just like 'Trudy is visiting the school, I wonder if she's going to complain about something!' It's like the parents' night, they put the ramp outside so I've got the ramp into the building and then she said like my son's classroom [is] having the parents' night up the stairs! I said 'I don't believe you, because the ramps only go part way up stairs and this is upstairs!' So I thought 'well how am I going to get up there?' ... because the teacher had to stop the interviews upstairs and told everybody ... I don't want to be doing this either, you ... just want to be a parent and go to a parent's evening like everybody else but, oh no, 'Trudy has arrived, we're going to have to reorganise the room and shift the teacher', so they know I've arrived in the building. I hate the way I'm viewed ... I know to them ... I'm a pain because no other parent complains, but no other parent has to do the stuff I have to do because they can go to parents' night, they can go to the kids' nativity night, but I can't. So they now have ramps which they keep in the office, and I have to phone if I need to go into the school, they put the ramps out for me which I suppose is better than nothing. But they still have a long way to go.  
(Trudy, 33, Scotland)*

The issue of Trudy in convincing the non-disabled world that she has the right to be there (in the school on parents' night) can be seen clearly here, and notably the need for changes to be made to the 'geography' of school (getting the ramps out and moving classrooms). Yet, all of this all stems from Trudy wanting to be a 'normal' mother caring about her child; which suggests there are certain limits to normalisation, in that a disabled mother is *not* supposed to be so normal that she has children and she wants to be involved in their education. Similarly, Stacey tells of how her request to accompany her daughter on a day trip with other parents was denied:

*They said it wasn't an officially organised nursery trip so it didn't have to be accessible. That's how they get around the law.  
(Stacey, 29, Scotland)*

Olive's experiences also show how a disabled person's individual environmental needs are often considered in isolation from their role and requirements in the wider world as a parent.

It would seem that this experience is a further manifestation of the traditional globalising approach to disability as the singular, defining factor in their lives:

*My children were still quite young, and they said [social services] ... the bathroom wasn't suitable because I wasn't going to be able to get in and out of the bath, that they would drag the bath out and put a shower in because they weren't concerned about the children, they were more concerned about me, and ... I said 'yes but they're still at an age when they need a bath not a shower', and I had this real fight with them, because I've got such a big bedroom that my argument was that it was very near the water, just through the wall that they could plumb in a special separate shower in my room which wouldn't affect the bathroom but they wouldn't do it, because they said it would add money onto the property and my argument is that if people in social services could look beyond that and say 'right if you sell the property we need such and such money back', such as the shower fitting, that to me is logical.*

*(Olive, 52, Scotland)*

## **Conclusion**

The positive mental attitude that some women with disabilities develop is impressive, allowing them, as it were, to rethink themselves (in their most intimate, bodily, family moments) as a basis for striking back out into the wider community/public spaces to claim these, to make space for themselves. As Chouinard (1999) explains:

To negotiate ableist spaces of life, in which disabling differences translate into marginality and exclusion rooted in economic, political and cultural oppression, disabled women need to actively re-place themselves: to create spaces in which marginality and marginalised collective identities can be embraced and valued. Such re-valuing of disabling differences in turn makes it possible to venture across boundaries of exclusion and to disrupt and challenge ableism in multiple spaces of everyday life.

*(Chouinard, 1999, 142)*

Trudy and Bev both related how this attitude shift bought personal growth spiritual elements to their lives:

*I see myself as sort of being able bodied and then being disabled as an advantage because it's what I would expect from the world, you know I would expect all this, I wouldn't expect anything less you know, I can see it from two sides, I was so used to it, I was just, it was just a natural course of my life, I would go to the shops, the pictures, I would go to parents' night, go to university, these things never entered my head, I just assumed it would be a natural progression. Now that it's not, not because it's not for me, it still is a natural progression for me, I'm still in the mode of 'that's what I'm going to do with my life' and 'that's how it should be', and it's like all these not just physical barriers but like mental barriers and attitudes.*

*(Trudy, 33, Scotland)*

Trudy's is a reflective response, able to put into context her experiences as just another set of 'natural' challenges to meet, and the implication is that she feels herself to be mentally stronger and more able to cope with 'physical barriers', thanks to overcoming 'mental barriers and attitudes', than she ever was before. Bev echoes similar sentiments:

*I started using a wheelchair ... because it was starting to be a real struggle getting in and out of the flat, and since then its actually meant that, although it's harder for me to do things in the house, well I couldn't be doing them anyway if I was trying to balance on two sticks. I actually feel somewhat liberated having a wheelchair, although I have to plan where I'm going, making sure it's accessible, making sure there will be someone there to help me if I need it, and I can put my wheelchair in and out of the car if I absolutely have to but sometimes I don't feel like it, and I get help, so it has to be planned. But certainly in some ways I sometimes feel that developing a disability has allowed me to be more the person I really can be, because it's forced me to be more assertive.*  
(Bev, 53, Scotland)

Thus with this shift in perspective disabled women are slowly making a space in the wider world. They no longer feel daunted by supposedly taking up space that has previously been restricted to the non-disabled.

## **Chapter Eight**

### **On approval: work and employment**

#### **Employment and disability: reflections of a bygone era**

Obtaining paid work is often seen as the socially prescribed expression of achieving full adulthood within Western industrialised society (Barnes, 1991). Gainful employment is usually taken to be the public demonstration of individual social usefulness. The work environment is often structured in masculine terms (McDowell, 1999). Current assumptions about the nature of employment are often at odds with social perceptions of the incapacity that is commonly associated with disability, yet in many ways these can be argued to be nothing but doctrinal relics of an earlier industrial age associating socially ascribed markers of physical fitness with the ability to work. As discussed in Chapter One, disability and employment are frequently viewed as cultural opposites, that is, disability and employment are often considered mutually exclusive. Parallels can be drawn with the presence of able-bodied women in the workplace: “the embodied woman appears as an inferior ‘other’ (McDowell and Court, 1994, 734). The globalising connection with the body as a ‘working’ machine is a fixture buried deep within the collective social consciousness. Unemployment is not an innate consequence of disability, therefore, but rather the product of long held beliefs grounded in ancient times linking imputed fitness with utility and ability. An adaptation of this approach is often used in established studies of employment as it relates to people with disabilities. As a rule, these studies are concerned with physical bodily mechanics. Agility, mobility, dexterity, speed and spatial relations are usually considered solely in the context of the individual and his or her disability type. Traditionally, individual physicality and work activity is looked at solely within the structural confines of the ‘public’ work environment. Factors which are usually considered include: availability of wheelchair accessible toilets, ramped building access, adapted work-stations and technological devices. While these elements do play a significant role in day to day working life, they should not be viewed in isolation from other equally important considerations.

#### **Paths to employment: a long and winding road toward the job interview**

Looking for a job was often a long drawn out process for many of the women who I interviewed. Cultural stereotypes labelling disabled people as ineffective workers appear to have had a negative impact on disabled workers. The public perception of disability is often equated with complete incapacity or at the very least minimal ability. Once again, this belief



seems to indicate a fear of difference resulting from lack of knowledge about or exposure to disability. These mind sets can pose formidable barriers to employment. Alice's job-search ordeal provides a graphic illustration of how primitive, entrenched attitudes concerning physicality and competence may have had a negative impact on the job seeking process thirty years ago:

*I walked in and there was a receptionist and she took a look at me from head to toe, and just got the most aghast look on her face, ... and said 'excuse me please' and went into an office ... She said she was sorry that I had wasted my time ... there really weren't any jobs available,... it was just lip service ... without asking me anything about my level of disability. So I went to see this guy's boss, he proceeded to tell me that 'unfortunately for somebody like you Miss so and so, there would be no employment, after all you're quite crippled ... Not even the Bank of Canada would be a place for you to work', and he grabbed a pocketful of change and slammed it on the desk ... He said, 'I'd like you to count this out for me as quickly as you can' ... I'm pretty dextrous with my right hand although it has only one and a half fingers on it, so I counted it out very quickly and accurately and handed it to him ... 'two coins at a time'. I did it ... a little slower... 'three times' ... I started to cry I just realised I was up against a brick wall here and it didn't matter what I did.*

*(Alice, 51, Canada)*

Conversely, many employers are reluctant to discuss disability issues during a job interview. Consequently, the subject is often avoided and incorrect assumptions can be made owing to a lack of information which may be detrimental to the disabled job applicant:

*There was one job I applied for when I was still in Belfast and I had been told I had a very good chance, and it was to do with the prison service, and I didn't get it and I think possibly it was because of my disability and it was the first time that I thought it had in any way influenced the outcome of an interview, it might have been for other reasons, I don't know.*

*(Kim, 48, Scotland)*

Patsy's recent experience demonstrates how fixed these beliefs remain twenty-five years later and the limited progress that has been made in the meantime concerning public education about disability and the ability to work:

*A lot of employers just saw the chair ... they never went past the chair ... I saw a 'help wanted' sign [in a shop window], I knew the manager by going to the store all the time ... I thought ... she would be a little bit more willing to give me a job because she knows me and knows my personality ... but I was shocked when she said 'the job was already taken'.*

*(Patsy, 25, Canada)*

Both Heather's and Rhonda's job interview experiences indicate that the single factor approach to disability remains intact. That is, the 'healthy body healthy mind' connection is strong. The basic level of the interview questions is telling in that would seem to demonstrate a lack of both expectation concerning ability and understanding of disability on the part of the employer.

*My job interview was really interesting in a bizarre kind of way, they had questions like 'can you use a paperclip?' and 'can you file alphabetically?' Of course I said 'yes'... I was just thrilled to have a job.*

*(Heather, 43, Canada)*

*So basically things like 'you will be able to take clipboards', 'you can write' and things like that, because you have to do paperwork, and it was like 'yes, yes I can do all that'.*

*(Rhonda, 31, Scotland)*

Audrey's experience shows that lack of structural access remains a serious barrier to employment for physically disabled women:

*They were obviously flabbergasted when they saw me, since I had the experience in paperwork, and all the offices were inaccessible except their director's office ... At least they were highly embarrassed about it ... but I knew I hadn't got the job, because there was no way they were going to move offices down to ground level.*

*(Audrey, 55, Scotland)*

Stella's positive job finding experience provides some cause for optimism, on the other hand, demonstrating that there are pockets of enlightenment among some employers who are willing to explore employment opportunities outside of the traditional physical parameters, yielding positive results:

*I was ... 17 ... I got the job and I've not really ever had a lot of difficulty, in the first bar job that I had that wasn't an interview ... as I say, just sort of stepped in and I worked there for about seven years ... I just phoned round a few other pubs and asked, you know, if they were looking for staff and I went for an interview and they didn't even comment on my arm [one of Stella's arms is not fully formed].*

*(Stella, 37, Scotland)*

There is still a tendency to channel disabled women away from the mainstream job seeking structure in much the same manner as they have been screened out of the mainstream education system. Once leaving school, many disabled people are put in contact with job search agencies developed specifically for people with disabilities. This parallel job search process to (outwith the mainstream non-disabled employment search network) was ostensibly developed to represent more effectively the skills of disabled job seekers to employers. Although perhaps good in theory, the reality of application presents a somewhat different picture. This 'parallel universe' has retained the worst elements that are common to 'sheltered' employment (protected work environments, away from the mainstream). The practice once again places disabled women in residual spaces with limited resources. It would seem that such agencies focus on finding jobs deemed 'appropriate' for disabled people, rather than marketing and matching individual skill with ability and vacant positions. There is a need: "to shift to the characteristics of work rather than the workers..."(McDowell, 1999, 134)

Being outside the main employment network has yielded mixed results, as Dolly's and Rhonda's experiences show:

*I don't think that they really teach a person with disability about how to find a job. Looking for a job is very different for a person with disability ... I don't think it should be but it appears to be, for instance you're supposed to be at agencies specifically for women, well I'm a disabled woman and I registered with Line 1000 [employment agency for disabled people] ... I got this counsellor [job seeking advisor] that seemed to be totally out of it ... I just never seemed to get anywhere with this person.*

*(Dolly, 34, Canada)*

Rhonda made several positive comments about the employment agency with which she dealt with. However, one is left with the impression that the only reason for such comments is that the agency was marginally better than what preceded it, not that the agency represented her abilities effectively:

*Into Work, [employment agency for disabled people], they were quite good that is about the only thing I could say was quite good for disabled people. If you want to go and apply for a job they will put you forward for it ... you're still getting paid by REMPLOY but you're not working for them.*

*(Rhonda, 31, Scotland)*

Extended periods of unemployment often coupled with limited information provided about the situations presented and weak negotiation skills appear to have left the women in a difficult position. Many of the women felt as though they were pressured into accepting the positions that were offered to them. The women believed that they did not have a choice in the matter:

*I got another counsellor and it took her almost two years to find me a job.*

*(Dolly, 34, Canada)*

*DRO [disabled employment service], ... they kinda are responsible for getting people with disabilities jobs, but really what it means is that they talk employers into interviewing you, and talk employers into at least giving you a start ... the DRO at the time said ... 'you could always work your way up', so I believed him ... and I said right 'OK' then ... he wanted me to take this job, he said 'look they're offering you the job, you want to take it' ... but, it wasn't really the job I wanted to do but I had to take it, I was forced into taking it.*

*(Elise, 34, Scotland)*

*She wouldn't exactly give me any other options ... it was secretary or basically that was it, it was a case of ... I'll do that, that's fine, that isn't a problem', but if I could go back it would be 'no, I'm not doing that, I'll do something else, I've not made up my mind yet', but sort of like that was the options she sort of gave me, 'why don't you be a secretary'?*

*(Rhonda, 31, Scotland)*

Many disabled women engage in job training programmes designed for disabled people after leaving the education system. As we have seen with previous 'special' disability-gearred projects, this type of training scheme reflects the ethos of the segregated school system (see Chapter Six). These training centres concentrate on vocational training for disabled people,

and the programmes usually have a low-skill manual focus which does not necessarily suit the needs of the client-base who they are supposed to be designed to address:

*I was a wee secretary on one of the scabby YTS schemes. Basically it was to do with my fingers, [Rhonda has arthritis], me and keyboards don't really get on, I'm OK with filing ... but me and typewriters ... .  
(Rhonda, 31, Scotland)*

Flo has been blind since the age of 21. However, as a lone-parent with sole childcare and household responsibilities for three small children, she did not have the opportunity to acquire vocational training until her late forties. Flo's positive experience with a traditional vocational training programme demonstrates how at times this type of programme can provide a gateway to a rewarding career, personal fulfilment and a sense of community:

*Series is the rehabilitation centre for the RNIB and people that are blind go there just to be rehabilitated because normally it is for people who have lost their sight, maybe through an accident or maybe for people who have lost their confidence and they need to find out exactly where they are and what they are wanting to do ... and there they taught us the basic skills of computing, engineering, Braille and woodwork and I thought it was great. ... And the better you were, you could go to the college ... I couldn't type so I was just learning the basics of how to type with a computer so that's all I learnt there and I learnt woodwork and I made my own ball clock and my bread bin and a wee footstool ... I must have been about 48 ... I got my RSA certificate for typing ... I'd never ever met blind people before ... it was really great .. I was at college ... I could do all the modules, nobody had ever suggested me doing any work and I knew I wanted to do something, but I just didn't know what I wanted to do or what I could do ... I thought 'how can I really get a job, I mean who's going to take me?' ... A co-ordinator on the Women onto Work course Work [work preparation programme] for women with disabilities ... said to me ... 'now Flo ... it helps you to get your confidence and be more assertive and maybe just see what skills you have' ... They ... never said ... 'You're too old or too disabled' ... the course was great ... because it was for women with disabilities.  
(Flo, 63, Scotland)*

The widely held belief that disabled workers are incapable of functioning effectively in the mainstream labour market may limit employment opportunities for disabled people. Segregated or sheltered disabled-exclusive employment is hence often the only job option provided to many disabled men and women. This type of system was originally developed to provide a 'safe' protected working environment for disabled people, but this type of environment is not necessarily 'disability friendly.' Many of the jobs are seen to be 'normalising': that is, training positions geared to preparing disabled workers for the 'rigours' of daily work. However, posts are usually manual, low-skill, low-pay 'busy-work' activity as opposed to career development in a mainstream workforce:

*I went to work at REMPLOY, which was a disabled factory, which I loathed and hated for six years ... I didn't like the people, I didn't like the atmosphere ... Nasty, ... very tense sometimes ... just wasn't me, sitting working in a factory ... it was making police jerseys, army jerseys, sewing them together ... they were trying to make you work so hard, it was like trying to get things through, everything done,*

*time schedules, things like that, it just wasn't a very nice environment to work for, I wouldn't go back ...*

*Interviewer: Was there any opportunity for advancement?*

*No, I would have been a machinist ... forever.  
(Rhonda, 31, Scotland)*

### **Mainstream workplaces: together apart**

Although there are now more positions available to job applicants with disabilities within the mainstream labour force, residual elements of the sheltered or protected work experience remain. Many of the employment opportunities provided for disabled people in the mainstream workplace often reflect this expectation of a limited skills set, thus mirroring the sheltered option which has gone before, as Candi explains:

*I ... got a job with the government through the disability programme ... cutting corners on stamps ... that was the only thing that was available.  
(Candi, 45, Canada)*

Job opportunities can be tied to social assistance eligibility: that is, only those disabled individuals who are in receipt of welfare benefits can apply for certain posts with a training or work experience component Dolly's evidence is instructive here:

*They had positions, social service employment programmes that you could go to and have work experience and get subsidised but only if you were eligible for VRS [income support agency], and I remember being counselled by this welfare worker at VRS and being totally humiliated when she asked me a couple of questions about my financial situation, and I thought nobody else would have to go through this, it was very offensive  
(Dolly, 34, Canada)*

Some women thought that employers may have been anxious to comply with disability equality legislation, thereby actively seeking out a visibly disabled person (an individual who is readily identifiable as such) for public 'display' purposes. Yet, many of the women placed in this type of situation rarely felt at the forefront of employment opportunity, and Elise and Heather both expressed feelings of isolation and frustration in this connection. Some women said that, even though they were in a mainstream workplace, they often felt removed and isolated from non-disabled workers due to programme requirements, attitudinal barriers or physical environmental constraints. Again, the negative environmental factors of the 'disabled' position tend to remain poor salary, together with lack of stimulation and expectation:

*They wanted to employ somebody disabled anyway.  
(Rhonda, 31, Scotland)*

*I felt like I was the token disabled person ... they were very good at putting you right, in the main spot, everybody could see, on display, ... that's how I felt, and they paid you the least money for the same job that everybody else was doing and ... I was earning a lot less wages than I was in my previous job, I was given a lot less responsibility ... I was just opening mail, which after a while gets a bit boring when you're so used to doing something more challenging, using your brain you know.  
(Elise, 35, Scotland)*

*I was sitting in the back, I didn't have an office and I was in a hallway and I didn't have any sort of private space that was mine ... I was the only visibly disabled person working there for the most part.  
(Heather, 43, Canada)*

*I have a cochlear implant [a hearing aid device] so I can hear some things and the more I get used to your voice the easier it is for me but she [supervisor] had a very quiet mouse like voice, didn't move her lips a lot, she didn't really make an effort to connect with me and so that was a very uncomfortable position for me, I felt very isolated.  
(Josephine, 33, Canada)*

Some of the women who tried to improve their working conditions spoke of experiencing great difficulty and personal sacrifice. Elise's and Candi's comments are similar to those found in the chapter on education. Individuals are labelled as pushy trouble makers if they try to resist or change the ableist arrangement of the world:

*Well I think I got branded a trouble maker! ... The first report I got was fine, it was great, as long as I was happy sitting there doing nothing, I found that a lot of the people that started at the same time as me were getting opportunities that I wasn't and that's when I started to talk up for myself ... They were getting on training courses to do better jobs to get more money ... So I thought, right I can work my way up, that's what I had in my head, I'm going to work my way up and after six months I got a good report and I thought that's fine, that means I'm doing well. I was quite happy to be told that, because really the job was so mundane. You got an interview when you got a report, at the interview I said, 'well when am I going to start doing the training courses that everyone else is doing', and they said 'oh well you're not that good, you wouldn't be able to do the work if you did get promoted', and ... they were talking about being able to reach high cupboards, and because I was so determined I deliberately asked for no help and did all the jobs that were a bit awkward for me ... They were classing physical ability with ... brain power... if you couldn't do a physical job there was no way they were going to help you get more money.*

*(Elise, 34, Scotland)*

*I was being harassed by a manager ... because I was a women, because of my disability, because I was a single parent, he would make comments like 'you need this job so just shut up and sit down'... when I questioned ... I would be threatened ... when they were going to put me in the mail room ... that was the last straw and I went to the doctor and I told him I wasn't going back there and he put me on sick leave for six months.*

*(Candi, 45, Canada)*

### *Passing in the workplace: covering up disability*

Fear of job loss or misperceptions of inability stemming from negative social attitudes and stereotypes lead many women to minimise or to conceal the reality of their disability in the workplace. Passing and resisting can be both physically and psychologically demanding:

Social and physical environments are designed and built to exclude particular minds/body differences...histories of ableism, medical categorisation and surveillance can enlighten us, and how people collectively and individually resist embodied and social limitations that mind/body differences can bring...

(Parr and Butler, 1999, 10)

Consequently, these individuals take great pains to 'fit' into the non-disabled workplace framework with as little disruption as possible. McDowell and Court's (1994) study of women in the banking industry noted that many of the women they spoke with:

[S]uggested that their workplace persona was unreal. They talked about "building up a shell", of "adopting a different sense of myself", of "not using my real personality".

(McDowell and Court, 1994 746)

This is often done with great personal effort, leading some women to feel the need to justify the right to be present in the working environment in the first place:

*I didn't want to arrive with one wonky wheel [Kim uses a wheelchair], because this is going to draw attention to the fact that ... I'm in a chair, and they knew that from my application but they also knew, because where you state you have a disability, I always say that it's not progressive and that I'm fit and healthy enough, because really, I mean it means nothing, but yeah, it's good, it's hard work.*

(Kim, 48, Scotland)

Camryn tells of the advantages of having an invisible disability (arthritis) as she is able to maintain some degree of privacy about her disability. She is not on 'display' to the same degree as those women with the more visible markers of disability: wheel chairs, white canes or crutches. Nonetheless, Camryn's experience again shows the level of energy required to maintain appearances:

*I'm lucky I guess in that way because I can pretty much hide it ... Some bosses I haven't told either ... and I wouldn't because I don't think they would be excepting ... after a while you forget who knows and who doesn't know! ... So somebody asks ... what happened, have I hurt my leg ... or... if my feet are sore because of the shoes I'm wearing, and I can't remember if that person knows the real reason or not, so you tend to get into a bit of a mess.*

(Camryn, 39, Canada)

Mitzi relates a similar experience:

*It wasn't something that anybody knew about [Mitzi has arthritis]. The only thing that bothered me was stairs ... Everybody knew I didn't like going up stairs, if there was a lift in the building I'd use that, if I had to go up stairs then I would, but other than that, no, I didn't go upstairs, that was really the only thing ... I was always able to work and able to do things myself ... so it never really disabled me enough to stop me working. My knees used to be sore all the time, but I mean no it never bothered me.*

(Mitzi, 46, Scotland)

Some women told of their disabilities being minimised, dismissed or discounted by their employers because the disability was not readily identifiable and therefore 'all in the head':

*I think everybody was very concerned, I got lots of help actually and I saw lots of different neurologists and I had everyone telling me it was probably a psychological problem, and so we couldn't imagine quite why that would be. I even went to the extent of going to see a psychiatrist who told me that I seemed to be a very level headed type of person  
(Molly, 63, Canada)*

*My director said 'there's nothing wrong with you Chris, [Chris has Repetitive Strain Injury], its all in your head', and I've had comments like that because people can't see anything wrong with me, and I think sometimes people with visible disabilities have a better chance at things than people with invisible ones [disabilities] because they know there's nothing wrong with her.  
(Chris, 42, Canada)*

Babette refers to what she calls 'tricks of the trade' to 'pass' as a sighted person in the more 'public' spaces of her job setting when she held the position of university lecturer. She did this in order to obtain social approval to be seen as competent and professional by students and colleagues:

*I taught three courses a year and I always got really good ratings but I used to go into the classroom before I would actually teach in it and get the lay of the land, so that I'd know where the steps were and if there were stairs that went up into the classroom, or how the ledge was for the board, and I used to write on the board and I used to memorise my overheads and point to them as though I could see it, then I'd stand back, you know the tricks of the trade, you'd stand back, and somebody would say what's the fourth word and I'd say, 'oh I haven't got my glasses on, what word are you talking about?', and do silly things, so no-one ever knew I was vision impaired.  
(Babette, 47, Canada)*

Heather talks of the subtle mechanisms such as personal appearance that can be used to address competency issues in an indirect manner:

*In order to be seen as professional, especially for a woman, you have to dress in a certain way, you have to look good all the time, you have to be on top of things because if you are not it is attributed to your not being able to cope with your disability or accept your disability, or that you are not performing.  
(Heather, 43, Canada)*

Both Barbie and Olive expressed real fear that their employers would discover their disability. Barbie felt that employer knowledge of the disability would compound an already difficult working environment:

*I didn't tell them, it was actually, that was when I worked in the Department and it was really very hard going because ... I had to put up with a lot of jokes because I was the only girl.  
(Barbie, 38, Scotland)*

Olive, on the other hand, did not want to change her work activity for as long as possible and adopted a label to help explain her disability in a manner that she felt would be more palatable to her supervisors:

*I still continued the job I was doing, but not telling anybody that I had MS ... I was frightened, I think because the group of people I used to go round [Olive was a community nurse] and see it was in the*



*evening ... I did a round where there were quite a few people with MS, really bad MS, and I felt that if I told ... the people I was working for, the health board, that they might stop me from going to these people, so I didn't tell them. I didn't want a lighter load, so I didn't tell them. I did get support from my GP, who used to write out 'post-viral debility', instead of saying she's got MS, so that was quite useful.*

*(Olive, 52, Scotland)*

Alfie speaks of different levels of disclosure arising because some forms of disability are thought to be more socially acceptable than others. She hence feels that her bodily scars resulting from burns in a house fire are actually more socially acceptable to others, as opposed to the less visible impairment associated with depression. She speaks of the possible detriment to her career should her bouts of depression be found out. Again, a great deal of her time, effort and energy is spent maintaining appearances, in addition to carrying out her work duties effectively. Dolly also relates the conditional nature of the level of acceptance of disability in her workplace and the reality of the 'public' and 'private' nature of disability. That is, the 'comfort level' or lack thereof for able-bodied workers (or non-disabled workers) around various aspects of disability:

*I don't think they know about the psychiatric piece ... a couple of people at work that know I'm on medication, that I see a shrink once a week, so it's possible that they knew and if they do then they're OK about it ... With the appearance thing, I'm fairly up front with people once I get to know them a little bit and can assume that they want to know what's different or wrong with me, and so I'm fairly forthcoming about that I guess the fear is that if people actually knew, if my boss or senior people in the department who may in the future be looking at hiring me or promoting me were aware of my psychiatric disability, that could ... would ... impede my chances of climbing the ladder, even though I really don't want to climb all that much higher than where I am now. I want to at least maintain the flexibility, and if they knew, if it was known that I have problems of chronic depression, then I'm fairly certain it would not be a good thing for my career in the medium to long term, I think they would potentially be very ... initially supportive, 'oh that's really too bad I hope you're getting the help you need', whatever, but how that would actually translate I'm fairly certain that it would have negative implications or a ripple effect [Sometimes] I ... leave, to have my appointment with my psychiatrist and I say I'm having dinner with a friend or just get out early that day and try to make my excuses ... Even though I'm working with some really great people, and actually they're social workers ... I don't feel as if it's safe or advantageous or neutral for me to actually share that with them, that I'd be looked upon as being less competent, less able to handle stress, neurotic, whatever.*

*(Alfie, 34, Canada)*

### *Coping with stereotypes at work*

A limited exposure to and knowledge of disability, coupled with a lack of public education about disability issues, has meant that long-held stereotypes concerning disability remain intact. Just as sexism remains embedded in the workplace environment so too does ableism (McDowell, 1999). Consequently, dealing with these notions is often a part of the daily work activity for disabled workers. Comments that are meant to be well-intentioned may

underscore an unease or an inherent lack of expectation regarding the ability of disabled employees on the part of some supervisors, probably indicating a need for disability awareness or equality training:

*I got a job ... a receptionist or clerks kind of thing ... the boss was quite naive, he was quite intent on employing what he called 'people that were unemployable.'*  
(Elise, 34, Scotland)

*She would keep telling me, 'Heather, I never think of you as a disabled person' ... It made me cringe, I felt it was offensive, it's like ... 'I never think of you as being a black person' ... or 'I never think of you as being a woman', it's just as offensive as any of those phrases but she thought she was being nice.*  
(Heather, 43, Canada)

It would appear that some work colleagues may be unwilling or uncomfortable speaking with disabled employees concerning skills and abilities. Rather than risk discomfort or possible embarrassment through direct communication with the employee, unfounded and often stereotypical assumptions can be made to the disadvantage of all concerned:

*The biggest problem here is that people are afraid to offend so they don't ask ... they don't communicate, it makes my job harder because I have to tell them stuff ... because they seem to have a variance in beliefs on what I can and can't do ... They take away projects without explaining to me why ... They assume that I can't do them ... they don't want to make people feel uncomfortable, so instead of asking me ... they just assume I can't do it ... I find this frustrating ... I've approached people repeatedly on the subject, one of the persons is gone right now and, so that has made my life easier, things are a bit better in terms of working environment because of that.*  
(Ariel, 27, Canada)

*Well my feeling is that the last two competitions, I was not made aware that there were competitions and I also wonder whether it's the fact that ... it is known that I do have a disability, I question whether it was a factor in deciding not to consider me for other positions even though they were not competitive processes, it's very difficult to prove but it just does cross my mind.*  
(Rose, 60, Canada)

*I have a feeling that my supervisor is not sure what my abilities are and so I guess, plus I'm not sure what they want me to do, so it's like walking in a place not knowing where you stand, so I guess that's why I find it difficult but I'm very optimistic, I'm sure that things will be better.*  
(Sahara, 40, Canada)

Babette's and Alice's extremely negative experience show how certain visual cues can trigger prejudicial stereotypical assumptions and responses on the part of managers, and thereby have a profoundly negative impact on one's work experience:

*One year I developed a scratch in my cornea and I couldn't wear my contact lenses any more, and without my contact lenses and my glasses I would have to use my white cane and I just would not do that, so I decided that I'd have to wear my glasses. Now they were the lenses that looked like fried eggs, you know, with the circle in the middle, and really grotesque, but I had to wear them and my ratings dropped that year. and the next year I went back to wearing my contacts and my ratings went up, and my reading of it was that I looked disabled, and I went from being perceived by the students*

*as a non-disabled teacher to a disabled one, and that shift was something they couldn't handle.*  
(Babette, 47, Canada)

*The manager ... called me into his office ... and said to me that he noticed I had put an application ... He said to me that he wanted me to voluntarily withdraw my application, and I asked 'why' ... He said 'well frankly somebody built like you, who can't wear proper shoes, would never be accepted in the board room, and if I let you apply for this level of competition it will probably encourage you to apply for higher jobs and that would be completely unthinkable'.*  
(Alice, 51, Canada)

The attitudes and perceptions recounted above lead many disabled women to modify their appearance or demeanour, if possible responding to stereotypical prejudices to gain 'approval' and thus being able to 'pass' according to socially accepted parameters of 'normality' in order to manage within the 'non-disabled workplace:

Women in the workforce have to find strategies of resistance that enable them to challenge their designation as 'other' and find acceptable ways of being women which do not automatically define them as powerless or 'lacking'.  
(McDowell, 1999, 139)

### *Super woman: the burden of proof*

Many of the women interviewed felt that they had to prove their worth as employees by performing at an exceptional level in order to justify their presence in the workplace to their supervisors and other workers. It appeared to them that their acceptance was conditional and tentative. They felt that they were always 'on approval', and because of that having to work to a much higher standard than the 'average' non-disabled worker to be perceived as competent. There appears to be an ever-present fear of being seen as not quite good enough:

*You feel that you have to prove yourself to be superhuman and do everything, you can't compensate for anything.*  
(Stacey, 29, Scotland)

*You always had to prove yourself, as I say I worked myself up to assistant supervisor that was after I'd been there a year, ... This was not the same job, but somebody once asked me if I could type the same, as fast as the rest, you know that kind of attitude, you were always proving yourself all the ... I mean you get tired just trying to prove yourself all the time.*  
(Audrey, 55, Scotland)

*I feel at times I'm having to always sort of make up for that and put in maybe a 150%, but I'm getting better in that regard I do my job as best I can and don't have the same sense that I'm always having to really prove that I can in fact do with my training what I'm trained to do.*  
(Mary Lou, 45, Canada)

*I feel that I have to do my job twice as well to be seen as half as good as like a non-disabled person, that's changing but still it's there.*  
(Heather, 43, Canada)

Part-time work may be a necessity for disabled workers in order to manage levels of associated fatigue or discomfort that may be associated with certain types of disability. Chris expressed sentiments common to many disabled women working on a part-time basis, and this is yet another indication of the tentative level of approval of disability in the workplace:

*I think that even though I work part time I still feel as if I should be doing the work of a full time employee and I still fit five days work worth of work into four days, I often take work home with me to compensate for the fact that I'm not in the other day, but then I do all that towards time off, I don't do it for free, I'm not that crazy! But I feel like I do have to work that bit harder because I'm only here part time.*

*(Chris, 42, Canada)*

This is similar to Camryn's comments about the need to 'perform':

*Some days I don't find ... I have the energy levels I used to, so I do feel I'm under-performing but that's not really anything that's said to me, that's just me, I do feel pressure, the bosses ... I can't even put it into words.*

*(Camryn, 39, Canada)*

Josephine tells of the personal energy level required on a daily basis to manage as a deaf person trying to fit within a largely inflexible hearing work environment. Her comments underscore the 'taken for granted' element of being able to hear as an ordinary natural part of doing a job:

*I do have to perform at an additional level ... When I come to work, because I can't hear I have to try that much harder to be able to understand what is going on, so I'm focused, I'm concentrating and it's not being taken for granted and I know what that is because I was like that before and I know what that is, you just take it for granted that you can hear what's going on around you, you can hear the chit chat going on so you literally hear the rumours but for me just to understand what's going on in a meeting I have to be 110%.*

*(Josephine, 33, Canada)*

Although Sahara's experience was generally positive, one is left to wonder whether *being treated like their own daughter* verges on that infantilisation discussed previously in the thesis. However, she found the working environment to be positive and nurturing after a series of negative working experiences:

*I wasn't very ... computer literate and working with ... software ... but I had supervisors they were treating me like, they were a lot older than I am, so they were treating me like their own daughter, in fact in that division everyone was old, like the youngest one was like 50 years old, but they were treating me with a lot of kindness. with lots of support so I had a great time there.*

*(Sahara, 40, Canada)*

Mary Lou and Alfie relate how a supportive management structure and workplace environment can go a long way in enabling employees with disabilities to work to the fullest satisfying degree. Having an 'accessible' physical and social environment allows restricted

energy levels to be used as *the women* feel it would be used most effectively rather than having to use energy coping in a hostile workplace:

*The years prior coming to my current job site was at a rehabilitation hospital and actually they were very accommodating there. I really had the opposite experience, things were in place for me immediately, certainly one example comes to mind, that I had trouble holding the phone to dictate reports into a central word processing centre, so within a few days of mentioning that to my supervisor I had a hands free dicta-phone system on my desk which I used with a foot pedal, and I could simply just sit and dictate my reports and it was terrific, also just in terms of shelving and things that were adapted in my own office they were done very quickly sometimes even before me pointing them out. I just had a really exceptional supervisor who just seemed to be willing to have everything in place to enable me to do my job.*

*(Mary Lou, 45, Canada)*

*I ... go through a lot of stuff, low self esteem, that kind of thing, and I think my boss notices this and tries to be ... very supportive.*

*(Alfie, 34, Canada)*

*No, none in the position I'm in now, it was at the lower levels, but it was also a respect issue, there's a lot of difference between when you have somebody you're working for that respects you regardless of whether or not you're a person with a disability or a person without a disability.*

*(Candi, 45, Canada)*

*I've never once been looked at as disabled and if I've ever needed time off because I've been ill they've said to me that's fine you do that and when you're better just come back to it and the people I've done contracts with I've explained in advance I may suffer from tiredness and contract time, I've had longer time normally than others because they've known I may need periods in-between to sleep or just rest so I've been quite lucky.*

*(Trudy, 33, Scotland)*

*Building a comfort level in the workplace: from hostile to humane workplace, support and accommodation*

The presence of disabled people in the workplace is not yet commonplace. Disabled women employed in the workplace are often viewed with scepticism as of a rare and exceptional practice. As a result, the work environment may present interesting challenges that may not necessarily be accepting or accommodating of the disabled employee. Again, many women spent their energies trying to create and to maintain their physical 'space' in the workplace. These women work hard at trying to accommodate their disabilities in addition to meeting the requirements of their position. Indeed, these requirements need to be addressed before they are able to really engage with the requirements specific to the job:

*I'm just feeling that I have to continually advocate to make sure the accommodations are in place ... It really has taken a toll because your energy is being channelled in that area instead of ... being able to ... do my work.*

*(Mary Lou, 45, Canada)*

*Originally I had to fight ... for my accommodations, I had to fight very very hard ... I had to get workman compensation [labour arbitration board] to prove to my employers that I would need a*

*special set-up and I need special equipment ... Now that I've got them, there's no problem.*  
(Chris, 42, Canada)

Performance and ability remain bound up in physicality (McDowell, 1999). Lack of creativity and inflexibility on the part of some employers and an inability to explore beyond the conventional has resulted in a restricted or closed working environment for many disabled women:

*I mean they said things to me like 'well you can't get training anyway because you won't be able to stand and you can't use your arm.'*  
(Barbie, 38, Scotland)

Josephine is deaf and requires a sign language interpreter to participate in order to fully participate in staff meetings:

*There was never an interpreter, there was always problems with the equipment and technology to like my T.T.Y [telephone communication device for the deaf], people just wouldn't talk to me, I guess they were uncomfortable.*  
(Josephine, 33, Canada)

Joyce has a vision impairment yet, she rarely received materials in a format she was able to access:

*I feel as though I've been set up to fail, you know as a visually impaired person being sent letters in standard print, people not understanding that I'm blind, you know ... I've lost letters, I lost a really important letter, it was an instruction from a funder and now I'm going to a meeting on Wednesday and I'm going to have to admit that I lost that letter and that I contacted the wrong person, but actually I'm going to make the point that they, knowing that I was blind, sent me a letter in standard print, which is just outrageous, it's like asking a deaf person to listen a bit closer.*  
(Joyce, 34, Scotland)

Any environmental and related accommodations that are made by employers are often done grudgingly and not in a spirit of co-operation, and disabled employees can be made to feel that their need for adaptation is disruptive to the natural functioning and order of the working environment:

*My line manager was really quite offensive ... she would try and make adjustments ... I was an inspector in a residential care home, so I went to visit them and see what the standards were like, some of the weren't very accessible so she would try and arrange things so that my colleague went to the ones that had the most stairs and ... I would go to the ones that didn't. But she made a big song and dance about ... it ... 'look I am doing you a big favour ... and this isn't normally the way I would work but ... we will have to accommodate you' ... If I ever challenged her ... she would [express] a very dogmatic stance of equality on what discrimination was ... so she made life quite difficult.*  
(Marilyn, 39, Scotland)

Chris needed a voice-activated computer key board system to accommodate severe repetitive strain injury. Her experience provides important insight into the personal stress often

experienced by employees with disabilities endeavouring to acquire necessary accommodations in the workplace:

*It's very stressful, especially as disabled employees are, well obviously if you're disabled enough that helps to start off with, but you're not as strong, you're weaker, not necessarily weaker but you don't have the energies often to fight with, and I think they use that knowing that you're more apt to back down and a lot of disabled people I know that feel uncomfortable asking for special things or something different, not necessarily special, but something they need ... I think that our employers need to be more aware of this and it's still happening a lot, that people aren't getting what they need because either they don't want to ask or they feel like they're being a burden and you know the first thing you always hear is 'we can't afford it' ... just nonsense.  
(Chris, 42, Canada)*

Many women were reluctant even to bring up the subject of employment accommodation for fear that it may draw into question their ability to fulfil their job requirements:

*I just don't even go there and I should right, so that would make it easier, and most of that might just be me too right, but I'm not willing to step out of that one and say I need this, I want this, it would make life easier I think being able to order ergonomic equipment ... like I would want something better for my arm to rest on, right now I have something but it's not that great, but asking for something better or different you feel kind of like you're asking something unreasonable and it's not really, but you just feel like, and then people look at this equipment you have and I don't have a proper keyboard that's ergonomic ... stuff.  
(Camryn, 39, Canada)*

High levels of stress and anxiety resulting from a lack of accommodation is thus a common issue discussed by many of the women who I interviewed. One is left to wonder, for individuals whose energy levels are compromised, how much of this precious commodity is expended trying to function in a hostile work environment:

*The frustration it causes, it was like I wanted to do what they asked but I couldn't ... physically do it and ... I ended up phoning a help line ... a group of visually impaired people.  
(Joyce, 34, Scotland)*

*I certainly have sensed from early on that it probably isn't a level playing field in terms of some of the accommodations I've needed, I often have to really persist, certainly in terms of getting a wheelchair accessible washroom, it took about eight years for that to be completed. In terms of my office set-up too, it's just a constant struggle to make sure that I have easy access to filing cabinets and assistance with portering for example so that I'm not required, sometimes I have to push a wheelchair whereas other staff might have to do that if need be. I find it really depends a great deal on the direct supervisor how easy it is to ask for certain modifications to be done and hopefully to see them done properly and that's ... [that there is] support to make sure these things are done to facilitate me doing my work ... Your energy is being channelled in that area instead of, you know, being able to get back and do my work two days a week, which is very challenging and can be stressful just working with the patients.  
(Mary Lou, 45, Canada)*

Moving from the physical environment of the workplace to the social environment of work, many of the women I interviewed spoke of coping mechanisms that they had developed in order to increase the 'comfort level' for their non-disabled colleagues regarding disability

issues in the workplace. The 'workings' of the workplace entail much more than just doing the job itself. The social-cultural intricacies of the workplace are often very complex, involving far more than the physical environmental adaptation. There are a host of micro-social relationships and encounters, some of which bear directly on the successful conduct of the job, bonuses promotions, and the like. Accessing these elements can be particularly difficult for employees with disabilities because of suspicion and fear on the part of non-disabled people reluctant to socialise with those who are 'different'. Again, it is usually left to the disabled employee to address the situation:

*I sent out an email to everybody on the floor and I said 'I'm deaf, I've been hearing, hard of hearing and deaf and back to hearing again sort of. Come and join me at lunchtime, we'll have a couple of sessions, I'll teach you how to swear in sign and you know we'll have fun. I'll answer anything you want, just ask me and I'll tell you anything you want' ... I think that there is, until people get to know me, and get to know that I'm fairly comfortable with you ... you have to crack a joke or do something to ease the tension. People are reluctant to approach me, reluctant to talk to me. I have a tendency to be, not excluded, but isolated in meetings, in particular with regard to getting interpreter services or services that are omitted because there's a lack of knowledge and 'well how do we do this?' or 'what do we do?' and I think people are nervous about asking me and saying 'what are we supposed to do to make sure you understand?' and because I don't want to impose on the workplace in a meeting and say 'I don't understand', you kind of get left out and then you have to follow up really quickly after. You miss out on a lot of banter that goes on in an office that you know, if you worked yourself with a computer and that's all you did you'd probably be OK ... but all the jokes ... going out to lunch, you know, people are getting together after work to go out or kind of bonding things that happen in the workplace that help with your workload and your promotions, and ... know those 'you have to strengthen those social interpersonal relationships', and I have to work a lot harder for those.*

*(Josephine, 33, Canada)*

*I've developed more of a sense of humour about it, and I try and kid around a bit, or if they're opening a conversation and I'm comfortable with the person or the people there, I'll use the opportunity to explain and they're usually quite surprised, well not surprised, because they all usually wonder what the scars are about ... they're OK with it.*

*(Alfie, 34, Canada)*

*I was asked to go to a conference ... it was very physically demanding, I'd never done that kind of travel before, I'd never manned [sic] a booth before at a trade show, I'd no previous experience ... I was expected to just go in and do it and it seemed to be a real shock to my clients that I needed any extra support but at the same time I was kind of afraid to not tell them right off that I was a little bit concerned so I waited until close to the ... about two weeks before the conference started, but I was very hesitant to articulate what I thought I would need because I hadn't done anything like this before. But at the same time I knew things like setting up a display needed standing all that time. I was on my own, yes, and what bothered me was that I knew there were other people going to the conference in the next couple of months, that were going with other people and I thought this was very odd that they're just sending me [i.e. alone] at all.*

*(Dolly, 34, Canada)*

The following excerpts are examples of willing employers and show how well disabled workers can be supported and accommodated within the work environment when information is shared, creativity is valued and empathy is shown. When a disability-positive



supportive workplace environment is created both physically and socially, the employee's emotional and physical energies can be directed to the job at hand. In many instances this holistic approach to the workplace has been instrumental in building self-esteem and a positive self-image for these women:

*Arthritis Care ... offered me the job ... it completely changed my life in a fantastic way, and I just felt so valued and useful and I felt like I was creative for the first time in my life, and I felt I was innovative for the first time in my life and I felt I had good ideas, it was just a fantastic job for me and I was working from home and I had incredible flexibility and if I had to travel, which I had to do quite a bit of travelling, they were happy to pay me travel expenses because they knew I couldn't drive far... so it was just a great job, it was really sort of putting back together again, it was kind of like a remodelled person!*  
(Barbie, 38, Scotland)

*Oh my god it's so much better, it really is, very flexible, really forthcoming group who'll say 'just tell us, we don't know', not that I didn't get that before, but it's the attitude that goes with it ... My supervisor and her supervisor both came to me and said 'we want to strengthen the team effort here, we feel it's just as important to speak in your language as it is for you to speak in ours, so during working hours we're going to spend one hour during every week during working hours and you're going to teach us to have a basic signed conversation'.  
(Josephine, 33, Canada)*

Employers can be ill-at-ease at the prospect of a newly disabled worker returning to the job. Fear and ignorance may account for a possible lack of enthusiasm for accommodation:

*I met my boss in the corridor ... I think probably the first person I bumped into when I went back, ... he made all the right noises ... but I must have stood and spoken to him for about twelve minutes and he never said 'come in and have a seat' which I found, and I was feeling the standing, you know, but it wasn't until afterwards that I thought, 'gosh you know, ... I wouldn't have kept you, you know, I only wanted to go through the pleasantries.'  
(Cindy, 53, Scotland)*

*I was thinking maybe I could go back to work... and they just said, 'you know, 'this isn't working' and if I went back to work I wouldn't be allowed to stay on as an Assistant Manager and they wouldn't let me keep that grade because I was trying to maybe reduce my hours and go back part time, but they said well I couldn't do the job and that, and that was it.  
(Barbie 38, Scotland)*

Joanne's employers showed what can happen when teamwork and creative thinking come together to facilitate accommodation of a newly-disabled employee:

*They've been fantastic ... really good, they tried to keep me on, much longer than they need to, I don't just mean legally, they kept me on even more than they had to within the local authority, they've been very very supportive, given me equipment at home, computers, comfortable chairs, you know, worked with me to decide, what little bits and pieces I could work with them, even though I was still off work  
(Joanne, 48, Scotland)*

### *Timing and spacing at work*

Time use is a pivotal factor for individuals with restricted levels of mobility, agility, dexterity and energy. Maintaining time, speed and personal energy levels is a constant, delicate balancing exercise for people with disabilities living in an able-bodied world. This level of time management is largely unknown to people who are non-disabled. As Chouinard (1999) explains:

For women with disabilities, negotiating spaces of everyday life, such as the home and work place, is often a difficult, contradictory and oppressive. This is because experiencing spaces through a disabled body not only involves significant physical and mental challenges, dealing with significant limits to ones ability to act, but also encountering and responding to complex, often social rules and cultural codes which mark the disabled body as negatively different and less valuable than the 'taken-for-granted (norm) of the able body.  
(Chouinard, 1999, 142)

These 'hidden geographies' are experienced by disabled women using and battling with space and environments just to present themselves as competent workers:

*What I try to do with my timetable is I have it organised so that most of my teaching is in the morning because if I get a kidney infection, which can floor me, and I've more energy in the morning, I've said to them 'look if I can do my teaching in the morning then I can go home and crawl into bed in the afternoon' and that's fine. And again there's been lots of time when I work at home.  
(Kim, 48, Scotland)*

*I have to organise things like the amount of liquid I drink in the morning or during the day because part of the ... side effect of ... cerebral palsy is that you don't get a lot of lead time when you have to go to the toilet, so when you have to go you have to go ... I have to do a lot of organisation around that so as not to drink too much liquid.  
(Heather, 43, Canada)*

*I have to empty my bladder every couple of hours, and I also have to make sure that I'm not sitting or standing for long periods of time, that kind of thing, maybe I tire easily.  
(Dolly, 34, Canada)*

Whereas, time-space demands are an integral part of the job for *any* employee, there are those which apply specifically to people with disabilities managing their own time and space to allow them to be seen as competent employees *before*, as it were, any of the specific requirements of the job are taken into consideration.

Barbie speaks of her utter exhaustion linked to the travel associated with her work:

*Travelling all over Scotland ... every week you were somewhere new and you were either maybe away from home or you could be travelling to Dundee on a daily basis, it just killed me.  
(Barbie, 38, Scotland)*

Olive also speaks of extreme fatigue experienced at the end of a workday and how it impacts heavily on her domestic life:

*Sometimes it's quite hard because I have to go in maybe at lunchtime and then I'm not getting home until after 8 p.m. which is very tiring, it is very long but I usually have somebody waiting in here so that when I come back they can sort of help me get to bed and maybe make me something to eat if I'm not past it by that time so that's quite a hard day.  
(Olive, 52, Scotland)*

Candi relates instances of individual adjustments to she has had to make to her timing and spacing both with her 'embodied geography' and her working environment to manage in the workplace on a daily basis:

*In the workplace ... I've had to make, the workplace doesn't necessarily make those adjustments' I just print out things larger and then I readjust it for normal people [sic] ... [Candi has a vision impairment] ... it takes me longer to read things than ... normal people ... I have to make the adjustment for the eyes ... if people move things on me or they come at me too quickly mostly a people interaction thing because I can adjust for stationery things ... People know not to move the garbage can in my office because I'm inevitably going to trip over it ... I've learned now to come around that corner ... slower, but when somebody is barrelling down in a cart or electric wheelchair ... I don't see them right away, I can't make those adjustments as quickly, ... I don't have the eye-hand co-ordination that most people have because of the depth perception issues, so when I'm drinking a cup of coffee I could slam the ... cup down and the next time I could miss it completely, depending on what kind of things are happening on that day, and when I'm stressed it gets worse.  
(Candi, 45, Canada)*

Similarly, Lilly tells of how the structure and organisation she has developed in her working environment enables her to utilise her timing and spacing abilities to the fullest and thereby work effectively:

*I need to be very structured when I work, on the days I work I tend to follow a very tight structural schedule because I have to, but I notice that if I'm organised I could get the day off to a pretty good start, via my work environment ... the work environment itself is pretty structured, and the type of work I do is not physically intensive ... Working with computers, working with people ... there's not a lot of things I cannot do.  
(Lilly, 34, Canada)*

Kim's and Maureen's positive experience shows how, with a bit of creative thinking and flexibility employers and employees are able to develop approaches to timing and spacing together for mutual advantage:

*One of the ways that we managed to accommodate my needs [Maureen has M.E.] to work in this environment was to have a seven day week and flexible hours with the ability to work from home, as needed and not scheduled ... I was given taxi chits to go to courses whereas most employees would have to travel by local transport system, so again in a confidential and privileged manner I was allowed to spare energy by the government into paying for my transportation costs. [avoid fatigue by taking taxis rather than using public transport].  
(Maureen, 49, Canada)*

*If I think a bug is coming on, I just say to my senior ... and it's 'fine, right, look don't come in here until you're better', I mean there's no problem with any of it, particularly when ... they know I'm probably going to end up getting into bed in the afternoon ... they know, they get their money's worth.  
(Kim, 49, Scotland)*

## *Domestic time and work space*

Traditionally, the 'public' environment of workplace has been viewed as separate or distinct from the 'private' environment of the home. This approach can be understood to a certain degree in the context of socially ascribed lines of demarcation. Convention holds that 'private' home or domestic activity does not impact on the 'public' domain of the workplace. But as Davies (2001) explains juggling the time/space demands of the of homespace and the workplace are not clearly defined for women:

Space and time are thereby not individual resources as such, rather they must be understood in a relational manner. Put in simple terms, *where* women find themselves and when they find themselves and *when* they find themselves where they are, are importantly determined by the needs of others. (Davies, 2001, 137)

The 'private' domestic or home environment has a profound impact on a disabled women's ability to access the workplace. However, following customary practice, personal care and domestic activities are generally treated as both 'personal' and 'private' Yet, particularly for people with disabilities these two spheres share connections.

In her recent study, Fawcett (2000) found that respondents with disabilities often spent significantly more time and energy on household and personal care responsibilities than they did on employment-related duties. Fawcett (1996) also drew strong links between help and support in the household and the disabled person's availability for and labour force participation. Organisation and timing in this spatial arena can often play a pivotal role in workplace success. Joyce, Vicki, Lilly and Heather all speak of how detailed planning and organisation are key elements in making the transition to the workday appear to be effortless. This skill is of even greater significance given unpredictability of daily life:

Activities cannot be neatly scheduled; the unexpected repeatedly rears its head and demands flexibility and a process relation to time. (Davies, 2001, 143)

These passages give a unique insight into how the public/private or home/work environments are strongly interconnected:

*I am working part time, three days a week, I do have to be really, really organised, so I always have to plan ahead, like plan ahead at the weekend and decide what we're going to eat Monday, Tuesday, Wednesday nights, you know I get in from work at 5 p.m. and my son has to be fed at 5 p.m. and there's no deviating from that whatsoever, and it's like feeding in the house so I have to have everything ready, so yes it's like you know really organised ... like, say, working on a Monday, my week starts say on a Monday, well on a Sunday night, I have to look out what I'm going to wear, what my son is going to wear, everything that will need to go to my mum's, so it's like all his changing stuff, you know that all has to be done the night before, and then you know, when I get up*

*on a Monday morning, you can't sort of think 'oh I feel like another five minutes,' you just have to get up, so I'm up about six 'o' clock at the latest.*  
(Joyce, 34, Scotland)

There is hence a whole complex 'science' of timings, spacings and organisational skills being used here to enable these women to manage in a non-disabled world, and to be seen as competent women and workers and gain the 'approval' of colleagues and of society in general. However, it is as if these private activities just happen, taking place in a vacuum remote, isolated and unconnected from other activities of daily life. No wider account is ever taken of the time and energy consumed in relation to completion of these mundane yet necessary tasks of daily living. Nonetheless, it is often these 'taken for granted' and 'private' activities that have the greatest individual and social impact, yet these activities are so deeply engrained within our collective consciousness, so obvious as to be 'unseen' unless something goes wrong. Parallels can be drawn between housework or refuse collection. These essential tasks are often done on 'auto-pilot'. That is, there may be little conscious awareness of the time, effort or importance involved in completing them even though it may well be significant. Therefore, limited public reporting of these activities should not be interpreted as a lack of personal or employment-related importance to the individual or society as a whole:

*It's a science, I've been working on this for the past four years, just because I have difficulty getting up early so in order to catch my 7.30 a.m. bus I need to be very organised and structured the night before, do all the prep the night before, otherwise I would not have enough time in the morning, given my situation.*  
(Lilly, 34, Canada)

*It's planned to the minute, well I get up as late as possible - I hate getting up, and I just shower or wash, get dressed, if I'm really organised I'll have planned what I'm going to wear the night before, I'll have it all out even down to jewellery I'm going to wear, I don't wear makeup to work unless it's something important because I can't be bothered, I used to, but I can't be bothered with the time it takes, I have to feed the cat, make a packed lunch, have breakfast and I have to be out the door by 9:00 a.m., so it's about 9:00 a.m. [when Vicki goes to work].*  
(Vicki, 29, Scotland)

*I usually have to get up at 6 a.m. to be ready and out the door at 7 a.m. to get my ride to work. It takes a lot of planning, I arrange what I'm going to wear the night before, I make my lunch, if I'm really organised the night before and sometimes I have some of the clothes on [in bed] that I'm going to wear the next day, the night before, just to save me a bit of time in the morning.*  
(Heather, 43, Canada)

Time, energy and fatigue are indeed all too often realities in the daily life of physically disabled people. People with physical disabilities frequently have to sustain a difficult balance between fixed amounts of time and limited or restricted personal energy levels (Fawcett, 1996). Depending on the nature and severity of the disability or condition, it may take longer for a person with a disability to complete personal care or domestic tasks. Many

people with disabilities do not have assistance with these activities. Babette's story shows how careful timing in the domestic sphere enables her to address both the needs of her clients and her need to conserve limited personal energy:

*I'm a really early riser. I'm up at 4:30 or 5 a.m. and I do all sorts of computer work, start seeing clients anywhere between 7:00 in the morning for people who want to be seen before they go to work to 10 a.m. on some mornings, it's very varied and sometimes I'm through at 3:30 p.m., ... other times I'm working right through until 7:00 p.m. Very variable, yes, some days I find it really difficult to get out of bed, I'm sitting on the side of the bed thinking 'you can do it, you can do it' and talking myself into getting out, and I'll make it into the kitchen and then I'll say maybe another twenty minutes in bed will help and I'll go back to bed and if I don't have clients twenty minutes can stretch into an hour and if I do have clients I can't make it through the twenty minutes because I start to get really sluggish, I need to get up and get going.  
(Babette, 47, Canada)*

Barbie and Dolly begin their mornings at a very early hour in order for their medication to take affect, thereby enabling them to function effectively on the job:

*I'm managing really by, I have to go to bed really early, I have to rest as much as I can, I have to get up really early to get myself dressed and ready in time, and to be able to drive in the morning is quite difficult, as it's really painful driving in the morning, so I have to get up really early and get medicated really early and I do that. I waken up about 6:30 a.m. and take all the medication and I eat at 6.30 a.m. and then I get up at 7.00 a.m.[some medication must be taken with food to prevent stomach damage], and so by that time normally the medication has kicked in and I can get showered and dressed on my own, and then my husband drives down most of the way, and I drop him off at work and then I just have a short drive into here, so that's how we manage in the morning.  
(Barbie, 38, Scotland)*

*I get up quite early in the morning, just after 5 a.m. ... I have medication I have to take, it probably takes me an hour or two to get ready in the morning, I don't like to rush.  
(Dolly, 34, Canada)*

Timing takes on yet another important role in the daily working lives of women with disabilities. Elements of personal care such as washing, bathing, house work activity and meal preparation are usually studied in terms of individual physicality or agility. The time and effort required to take on one's personal care is often overlooked or discounted. Time effort and energy spent by the individual on the tasks of daily living, although personally taxing and fatiguing, are generally unrecognised: and unreported but it is the real 'work' that begins the working day for many disabled women:

*I start working at 8.30 a.m. so I usually get up about 5.00/5.30 when I'm lazy, it takes me forever to get showered and changed in the morning, I've tried showering at nights but it didn't do the trick for me, basically I've got to get up at the crack of dawn and the biggest part is getting dressed. The showering part doesn't take all that long it's the getting dressed part, it's worst in the winter because there's more clothes to put on.  
(Ariel, 27, Canada)*

*I get up, get up usually, it depends, during term time I'm up about 6.30 a.m. and 6.45 a.m., shower, breakfast, unlock the door, because I hate sitting in traffic and my first class is at 9.15 a.m., I like that*

*quiet hour, if I'm in at 8 a.m., I can have a coffee, a blether with the person in the office, I can organise myself for the day a bit ... so yes it's up and out after a healthy breakfast, just my usual shower, sometimes some kind of, I have bladder problems, sometimes I have to put a bladder wash in, that takes 10 minutes, and then I'm out the door and then face all the traffic. I'm a morning person, that helps.*

*(Kim, 48, Scotland)*

Audrey's comment shows the social policy connection that links the work environment with the domestic domain. The connection between employment and domestic help needs to be rethought: just because someone goes out the door to work does not mean that they do not need domestic help, or that such help might not assist their overall work performance. One would think that access to domestic assistance would be a cost-effective mechanism enabling more women to enter paid work who are unable to do so at present. The point is given further credence when taken in conjunction with the personal time and effort factors discussed earlier:

*We tend not to get home help because you're working ... Well ... they seem to think that because you're working, if you're able to work you're able to do housework.*

*(Audrey 55, Scotland)*

*I would really benefit from a couple of hours of home support where someone could chop vegetables for me or whatever and I could make a chilli but I don't have that ... You have to be incapable of standing for a certain amount of time, and I am sometimes, but other times I'm perfectly capable of doing it, so it's the variability of my symptoms that prevents me from accessing anything, and it's also, and I say this with some caution, but it's true, I say it because I don't like to say it but it's true, it's also because my physicians don't want to see me as needing home support so that when I broach it with them it's ... 'oh you're young and you're ok.'*

*(Babette, 47, Canada)*

One's wider community space environment in relation to work is also an important factor in a disabled woman's ability to function in and to gain access to the workplace. Many disabled women are not able to drive or do not have their own means of transport and therefore utilise other mechanisms. Proximity takes on a greater significance when speed, fatigue and distance are complicating factors:

*I can't drive so I have to live within a bus area, or be able to walk, so you depend on other people to get you to places or a return bus schedule, you have to make time, you have to adjust for times to get to places ... now that I've moved into a new neighbourhood and I'm working downtown I now have to adjust for that unless I walk and then I have to adjust for that.*

*(Candi, 45, Canada)*

Wendy's and Babette's working-life experiences are markedly different. It would appear that Babette has more control over her working life (she is a psychologist), and thus over the whole 'geography' of her life. Her experience in this respect is very different from many of the disabled women who I interviewed. There are obvious class/status issues that come into

play here. Yet, despite a different educational experience, Wendy has been able to adapt her work in the home around the changing degree of her disability:

*Recently I've closed an office that was out of my building, because I was travelling by para transpo [disabled transport system] and it was taking me roughly an hour and a half to get to work in the morning, so I now have a practice where my office is one apartment away from my own home, so getting to the office is no longer an issue, it's just basically walking to an office.  
(Babette, 47, Canada)*

*I don't get myself into situations where I can't control it as much as I can anyway ... I haven't worked outside the home since I had the children, three boys who are now fully grown. I did bed and breakfast, just two rooms, when I found out I couldn't work, I wanted to do something, and bed and breakfast is fine when you have a young family. What I did when I was running the b&b is, I'd rest in between each activity, like after making beds I'd rest for an hour, after cleaning I'd rest for another hour, I really had to measure what I did, I never hurried, it's hard because I was always a fast person, now I do everything in sections.  
(Wendy, 56, Scotland)*

## **Conclusion**

It is clear the labour required to engage in work (paid or unpaid) begins long before women with disabilities cross the office threshold. The work in the illusory private/domestic and personal spaces is for the most part, unrecognised. There is no easy course, but the journey may be made marginally easier (but ultimately easier for who?), if one stays out of the way and takes one's place in the so called 'disability appropriate' residual time filling spaces (day centres and institutional settings) that have been established from a residue of fear, ignorance and a lack of expectation. The amount of 'work' required in order for many women with disabilities to 'go to work' in 'regular' workplace is staggering. Constantly, working against physical, social and emotional barriers exacts a heavy personal toll. In many ways these women like their non-disabled counterparts remain 'out of place' in the workplace (McDowell, 1999). Nonetheless, these women have embraced their unique embodied geographies and devised complex and creative methods to work within and around the able-bodied parameters to make their own way in the world. Imagine if the non-disabled majority would think beyond established boundaries and recognise the potential of women with disabilities on their terms, the possibilities are endless.



## Chapter Nine

### Conclusion

Many of the women who I interviewed had never spoken of their daily life experience before, and indeed I had never addressed these issues before in the context of my own personal space either. I have been given a great privilege and access by virtue of disability community membership. The validation of knowledge and safety of shared experience acts as a catalyst for the frank disclosure of information. The silence has been broken through dignity, self-respect and the quiet courage of disabled women making space in 'public' places where we as yet take pains to gain peripheral access every day. There is no going back, but this does not mean that the battle is won or that the struggle is getting easier

*I think that there are stereotypes that I wish we could battle, and if I was more courageous I would ... wear my depression as a badge and try to fight it, but I don't see it as being a terribly easy or winnable fight and I also feel that I'm tired of fighting, because of growing up in a body that's disfigured and looks a lot different than anybody else's that's always been on public display and I've had to answer for that or explain that for 27 years and I feel like ... that's been a challenge and it will be a challenge until I die ...*

*(Alfie, 34, Canada)*

*I think if I felt that I could really disclose a lot of my concerns ... I can joke about it with my husband, ... and be funny about it but a lot of disability stuff isn't very funny, a lot of it I just wouldn't talk about it.*

*(Dolly, 34, Canada)*

In this final chapter, I want to bring together some final thoughts reflecting the crux – and the original motivation - of my thesis research: namely, the enormous difficulties facing individuals with disabilities, especially women, who want to work and to escape the benefits trap. These remarks will then lead into some closing remarks where I return to the experiences of disabled women as voiced to me: as breaking through the silence to provide new knowledge that challenges the ableist status quo.

#### *Work, all or nothing*

*Means tested personal care places a humiliating cap on disabled persons' aspirations. As soon as we work or save we face punitive charges. If we don't work, our care is free. The underlying message of this seems to be that society would rather we didn't even try to pursue a normal [sic] dignified tax-paying career. It wants us to be passive, dependent, grateful and invisible.*

*(Colin Hughes, Why People Hate Disability, BBC Radio 4 June 11, 2001)*

Primitive notions of the nature and reality of disability and impairment appear to influence the programmes and services seemingly developed for people with disabilities. A globalised approach to disability and impairment means that these elements are usually considered in

isolation from a multiplicity of physical social and environmental factors that have a profound influence on the ability of people with disabilities to consider or to pursue waged employment, particularly outside of the home:

Income support programs for persons with disabilities which include the concept of “unemployability”, which further detracts from their effectiveness. This assumption about the unemployability of persons with disabilities - which, unfortunately, has been woven into our culture and our social policies - is based on two misconceptions. First, it assumes that disability alone can prevent a person from working; second, it assumes that disability is a static state. In fact, it is the combination of a disability and the environment in which it is experienced that creates an employment handicap.

(Fawcett, 1996, 180).

There is a general understanding within the public at large that Britain and Canada have developed a sophisticated income support system to aid citizens recognised as being disadvantaged, particularly disabled persons. Ironically, these assistance mechanisms often serve as the biggest obstacle to economic independence and employment for this population group. Income support programmes have arguably contributed in large measure to the continued institutionalisation of disability.

Contrary to popular belief, there is no co-ordinated disability policy *per se*. Most policies have been formulated in the post-War era. Programmes and services have not evolved in an orderly fashion. Legislators have adopted a crisis-response technique concerning policy formulation. Assistance policies related to disability are largely add-ons to existing social policy, the latter arguably being designed to maintain nothing more than a poverty-level in order that recipients not become overly comfortable outside of the labour force (Fawcett, 1996; Drake, 1999). Poverty is a constant for most disabled people, and particularly disabled women (Moss and Dyck, 1996). Thus, we are left with a sporadic approach to disability policy development. People are categorised according to perceived dysfunction - a further product of the medical model. The abundance of programmes may also be explained, in part, by the lack of a clearly defined population base. Other minority groups also experience this problem, although to a lesser degree. Privatisation and devolution has led to a fragmented and disjointed service delivery structure (Drake, 1999). Recent changes to social welfare legislation retain the existing model, focusing on an enhanced interview process to maintain benefit eligibility, and the structure is closely aligned to employment benefits (Thornton, 1998). State social agencies mandate deficit concerns and, guided by constantly changing criteria, determine who may or may not legitimately make claims from the benefit structure as a disabled person (Bach and Rioux, 1996; Cormode, 1997).

The 'add disability and stir' approach to social assistance systems fails, in large measure, to recognise the diversity and complexity of disability between and among disability groups and in everyday life. Programmes of this type rarely complement one another, each having different eligibility requirements and administrative mechanisms (Roehrer, 1990). They are seemingly designed to provide social absolution, compensating for lack of access rather than facilitating independent living options (Imrie, 1996; Drake, 1999). Seemingly benign aspects of policy may also have significant consequences for certain sectors of a given minority, due to race, class, gender or ability issues. The failure of policy makers to account for such factors as dependant care costs, transportation and flexible work hours has contributed directly to the inability of non-disabled women to participate in the paid labour market. These same arguments could be put forward for disabled women (Metcalf, 1993). Similarly, programme implementation has been particularly detrimental to disabled women because many programmes are inherently sexist in their design. Whereas disabled men receive assistance with domestic labour as a matter of course, disabled women are expected to manage with household duties as part of their everyday activity (Marks, 1996). However, lack of assistance with housework often prevents disabled women from accessing the paid labour market (Fawcett, 1996). Another aspect of the public/private life split that causes particular difficulty is personal attendants or carers. State-funded carers or attendants are only to be used in the 'home' environment. Yet, many disabled people would be able to function better in the workplace with the provision of similar kinds of personal assistance there (Fawcett, 1996). Lack of flexibility in the public/private sphere effectively keeps disabled people in their place on the periphery of mainstream society.

### **Benefits (for whom ?)**

The current benefits structure does not promote labour force activity for most disabled people, given that the costs associated with disability both in and outwith the medical domain are unrecognised. Entry level or part-time positions do not cover costs associated with disability. Although legislation does make provision to deduct disability-related costs from taxable income, it is of limited use to most disabled people, particularly disabled women, as those individuals with incomes are far below taxable levels. These provisions do not compensate unwaged labour activity either. In order to be effective, social support systems must assist with the real costs of disability rather than the compensation aspect that permeates social assistance policy (Drake, 1999). One should not be faced with an 'all or nothing' choice for labour market entry. Subsidies geared to match the actual cost associated

with disability such as personal and domestic assistants, transport or counselling would truly facilitate labour market access. Yet, at present, monies committed to the existing benefits structure far outweigh the amounts directed to employment policies. and, unless this imbalance is redressed, the status quo will remain unchanged (Berthoud *et al*, 1993).

Lack of flexibility within the benefits system would hence appear to be a real stumbling block to those disabled women both within and outwith paid employment. Several of the women who I interviewed have subsequently had to stop paid employment because of it. The ancient beliefs would seem to remain the core philosophy that the appropriate place for disabled women is outside the paid workforce, as Stacey, Babette and Olive illustrate:

*Either you're able to work or you're not, there's no flexibility. I'm signed off from working. I'm really stuck, the system isn't flexible enough. I have a disability, I'm a single mom and I want to work ... It used to be that you could work part-time and get income support but now ... As soon as you start working they take your income into account to pay for your care so you're working for nothing...*

*(Stacey, 29, Scotland)*

Babette's commentary underscores the all or nothing philosophy of the benefits system. Here, we have a potentially valuable worker being effectively forced into a dependent 'disabled' role owing to the inflexibility of this system:

*Six clients a week right now is not quite enough for me to live on because I've got to pay for both my professional and personal stuff, and with the extra costs of being disabled it's hefty, so if I could get say \$400 a month from the government, or a fund of some sort, then I would be able to continue working, seeing six clients a week and being a productive member of society, but the way the system is set up is you've got to be totally disabled or totally functioning and I've had to admit that my disabilities have now reached the point where I am totally disabled, I'm too wasted to do what I'm doing so I've applied for CPP [Canada Pension Plan].*

*(Babette, 47, Canada)*

Olive's misgivings about setting up her own counselling service again reflect the rigidity of current benefits system. There is little recognition of the real day to day cost of disability within the benefits system:

*[S]ometimes the clients I see, I see a lot of clients with learning disabilities and I would like the opportunity to counsel maybe somebody that didn't have a disability, quite honestly. But that would mean that, I'd like to learn how to do that but this counselling is definitely for people with disabilities, I would have to pay for my own supervisor and my own supervision, I would have to pay for an office to see clients etc ... it's just, again, prohibitive.*

*(Olive, 52, Scotland)*

Trudy's encounter with the benefits agency illustrates how individual agency personnel may internalise and reflect misconceptions concerning disability. Her experience also shows the

vast amounts of physical and mental energy needed to challenge and access the established system in order to obtain the basic essentials for daily living:

*They said 'well you'll have to come up to the office' and I said 'well I can only come up if you can pay my taxi fare because I don't have enough money to pay the taxi fare up there as it's £5 or £6', and they said 'get a bus' and I said 'no I'm in a wheelchair I can't get on the bus' and they said 'we only give funds for bus fares we can't give you money for a taxi', and I said 'well I can't get on the bus' and it was their mistake, and they're saying 'oh well I don't know what you're going to do then', and I said 'well I need the money I can't get on the bus, can you fix something for me,' and I spoke to about four people before they finally gave me half the money back and it was just like, you know, it was your fault I don't have the money but I'm having to pay for it! And then when I got there it wasn't accessible and I couldn't get up the steps anyway, it's two flights of stairs and I ended up having to stop a complete stranger and asking them to go up the steps and say to them that I was there and could they get someone? And they had to wheel me in through the back entrance, through a car park, ... the back entrance ... through their staff offices ... to get me in ... they treated me like an idiot ... I was on the phone and they couldn't see me, I was just an irritant but I was an irritant that could speak up for myself ... I was very up front and I just said 'you know I don't understand why you are speaking to me in this voice' and then, you know, so they said 'what voice?', and I said 'this really slow voice, I said I thought you were very busy so why are you taking all this time to speak to me in this slow, loud voice?', and I then went on about the access to the building and said did 'they know that it was illegal?' .... So then after that they got me a giro there and then, they told me I didn't have to wait for one they actually went away and got me one and told me that in future if I had any other problems, I was to phone this, they gave me a number, and they would speak to me there and then and sort it out over the phone to stop me coming in and then in the end they gave me the full taxi fare back.*

*(Trudy, 33, Scotland)*

On the other hand, Olive's experience with the benefits system is somewhat more positive, but the need for 'professional approval' is unchanging. The intrusive probing used to determine programme eligibility is a regular feature:

*I've been quite lucky because I've got a very good social worker whom I only let in on the understanding that she wasn't going to pry and probe every single thing. It's just that I get money from the social work department as well as the Independent Living Fund so I've got to fill in forms every three months to say how I've spent the money.*

*(Olive, 52, Scotland)*

*The Independent Living Form themselves ask you to fill in a great big long complicated form about once a year, saying where the money has been spent and also because I'm on benefits and income support somebody comes from the DSS every nine months and demands to see your bank statement.*

*(Olive, 52, Scotland)*

Olive explains how emotionally demanding this level of public scrutiny can be:

*It's very stressful especially if you'd rather be out there working not dependent on anybody. I think if I had one wish that would be it to say to social services 'everybody just forget it. I don't want benefits!'*

*(Olive, 52, Scotland)*

It would appear that the benefits system in its current format does not recognise the added costs of disability, and does not facilitate entering the labour force or accept and confront the

instability within it. Many women are doing a small amount of part-time work address a benefits shortfall:

*It felt like part of the black economy, as they call it, but then I really, I do do voluntary work, I can't afford to risk going off benefits now until I've got something guaranteed, which would maybe be a job, it's very hard.  
(Bev, 53, Scotland)*

Vicki found that in many ways she was more financially secure while on benefits as opposed to doing paid work, owing to other assistive elements attached to benefit eligibility:

*I found I'm worse off working than I was on the dole ... I had quite a high premium when I was unemployed, like I had, ... income support and you automatically get rent paid, council tax, everything was paid for, I mean I really had to think about whether it would be worth working full time, part time, or whether it would be worth working at all and I came to the compromise of part-time because ... initially that left me at the same level, not being worse off, and not being better off, whereas working full time meant I would be worse off, I would lose housing benefit and council tax benefit, but recently the government have changed a lot of the rules like with tax credits and [these are] supposedly meant to make disabled people better off, but in fact when the new assessment came out in April I'm worse off so I've yet to kind of look into that ... Every year you have assessments for housing benefit for council tax benefit, for things like money to pay for care, that gets re-assessed every year, so as soon as you think you've made a few more pounds they just take it back again.  
(Vicki, 29, Scotland)*

Other women felt that some of the numerous professionals assuming an assessment role lacked an understanding of the situational fluidity of disability. Moss and Dyck (1999) raise an important point in this respect which parallel's the experience of many of the women I interviewed:

*Ironically, these women are challenged on the same criteria used to define the group as a whole as ill or deviant, as for example, in being 'not sick', 'not sick enough' ...  
(Moss and Dyck, 1999,163)*

In addition, many women felt that they were at the mercy of the ever-changing definitions of disability found in social policy taxation legislation.:

*I do not fit the criteria for disability, so I've not been getting it since 1995 and recently I've submitted another one, depending on how you've filled it out, how your physician fills out the certificate, whether they have a diagnosis, and to indicate what is permanent, the severity of your so called disabled position, so I've been allowed this credit for this tax year, but you can see the inconsistency.  
(Lilly, 34, Canada)*

*I'm not eligible, I'm not blind enough, I'm not unemployed enough, basically I don't need a Seeing Eye dog, I don't need a white cane yet and ... the short answer is 'no'!  
(Candi, 45, Canada)*

*I'm not entitled to that because I'm not disabled enough, it's the definition.  
(Chris, 42, Canada)*

*When I was losing my hearing I went to Indian and Northern Affairs. Indian and Northern Affairs told me that even though I'd lost hearing, that hearing wasn't an essential characteristic ... and therefore you don't need hearing aids. ... Anybody that wears hearing aids, lip reads or speech reads, on the disability claim, for taxation purposes it says, 'Can you, even if you have these aids (or something like that), do you have to lip read?'; Everybody that has hearing loss, lip reads. But it's Revenue Canada's way of sort of filtering out those who just have ... a horrible thing to say, but you understand what I'm saying, 'well they have mild hearing loss', so you know, as if to say, 'oh well you only lost one leg in the accident, so you're OK' ... Yes, and that's a whole attitude waste on that, but the first year I applied and filled out the form, someone from Revenue Canada called and I was hooked up, no I wasn't I was on T.T.Y and they said 'well you don't qualify for this', and I said 'I don't qualify for that, you want to see what a big stink I can create about this, I can't hear.', 'Well, do you use hearing aids?', 'Yes, I don't hear well enough to hear on the phone, of course I have to lip read even with hearing aids' and I said, 'do you wear hearing aids, do you have any hearing loss?' 'No', 'well then you have no right to say to me 'Oh well you have hearing aids, you should be fine'*

...

*(Josephine 33, Canada)*

Some women were unwilling to pursue benefit or support programme options because of the social stigma associated with being labelled 'disabled,' even though access to these benefits and programmes may ease daily life activity.

*I've no idea [about benefits eligibility], see that would be on the admission scale again, I've never even pursued that at all, I just don't even go there and I should right, so that would make it easier, and most of that might just be me too right, but I'm not willing to step out of that one and say I need this, I want this, it would make life easier.*

*(Camryn, 39, Canada)*

## **Positive and proud**

Today, people with disabilities like women and racial minorities before them are fighting back. They are no longer content to be the passive recipients of paternalistic largesse ... they have become a politicized advocacy movement, asserting a right to full participation in society. Are we prepared to hear them now that the humility has left their voices?

*(Catherine Frazee, Ontario Human Rights Commissioner, Davidson Dunton Lecture, Ottawa, Ontario Canada September 26, 1990)*

What is remarkable and inspiring about the personal and collective and collective passages discussed in this paper is that, despite often seemingly overwhelming odds, many disabled women continue to struggle for their places and rights as citizens on the political maps of local, national and international communities.

*(Chouinard, 1999, 153-154)*

*I am astounded by the effect one simple question had on me ... I have never been asked about the impact of my impairment on my daily life ... I haven't really given my daily routines and tasks any conscious thought ... what I do in my daily life, the ways I do things and why... It has been a painful and liberating to begin to confront and analyse ingrained and internalised ideologies.*

*(Joyce, 34, Scotland)*

Legislative reform is held out as another method for positive change. However, recent efforts in this arena mirror the familiar individualised model and response. *The Disability*

*Discrimination Act (Charter of Rights and Freedoms in Canada)* is reactive, dependent on individual complaints and lacks a punitive element for the likes of employers who contravene the terms of the Act (Roulstone, 1998b). The disabled person must work their way through the legal system, and again the power differential is ignored (Roulstone, 1998b; Drake, 1998).

Despite recent legislative initiatives that define lack of access to disabled persons as illegal and thus unjust, inaccessibility is still a salient feature in the lives of disabled persons...Accessibility for disabled persons to public buildings and services...is legislatively provided unless, of course, it is unreasonable to do so. The legislative notion of "undue hardship" offers reasonable grounds for not providing accessibility. Unfortunately, the social and physical environments remain a barrier to disabled persons, since the "social construction" of barrier free environments is "unduly hard" to achieve. Although the contemporary (especially legislative) concept of disability includes the idea of injustice, it still tends toward misfortune as its primary interpretative category. (Michalko and Titchkosky, 2001, 209-210)

This narrow linear response mechanism does little to modify existing power structures (Berthoud *et al.*, 1993). Maintaining a voluntary approach to disabled employment by the state, requiring only at bottom voluntary actions on the part of employers and other institutions, demonstrates only a superficial understanding of the equity concept, not wishing to go beyond the well-established boundaries of the status quo. However, by introducing 'progressive' legislation of this type, the state gives the appearance of having dealt effectively with a difficult social problem while maintaining the existing social structure.

The individualism embedded in modern law stresses that above all; individuals are the makers of their own destiny. Standing alone they bear the responsibility for the omissions attributed to them. It takes no account of social or cultural factors. (Imrie, 1996, 66)

Unlike gender or race, the interpretation of disability as "misfortune" allows for the understanding that inaccessibility too is a misfortune and not necessarily an injustice...Disability is not framed within the idea of the "natural" in the same way that gender, race and able-bodiedness are. (Michalko and Titchkosky, 2001, 208)

At present, employers, if they search at all, are looking for the disabled person best suited to fit the existing workplace culture with minimal disruption; in effect, creating a hierarchy of disability preferences (Drake, 1999). A January 2002 decision of the US Supreme Court Decision lends credence to this view:

The central inquiry must be whether the claimant is unable to perform the variety of tasks central to most people's daily lives," not just those of a particular job".  
Justice O'Connor, *New York Times*, January 9, 2002

Recognising that disability needs to be understood in several areas simultaneously is an important breakthrough (recognising daily life activity in relation to the capacity to work). It illustrates some growth in the understanding of disability and impairment. Yet, this new insight may be a double-



edged sword acting as an opt-out for employers to avoid responsibilities to certain categories of disabled people whose impairments, while severe in certain contexts and with great implications for what they can do and achieve, are not necessarily classifiable as major impediments to the basics of everyday life.

(Philo, January, 14, 2002)

If disabled people are to achieve true integration into the labour force, rather than minimalist assimilation by it, a fundamental shift in perspective is therefore required. As yet, the basic tenets and structures of the workplace have not been seriously examined or modified in relation to the physical, social and psychological needs of disabled people (French, 1994; Imrie, 1996). The daily experience of disabled people in the work environment, particularly concerning disabled women, is largely unknown given their limited profile (Drake, 1999). Revolutionary changes are needed in order to achieve substantive results. In order to facilitate this process, the depth, texture and complexity of disability in a relational context must be fully understood, which is why the kind of inventive qualitative research undertaken by myself in this thesis, research that is time-consuming, trying to obtain in-depth, to be textured and to be open to complexity will arguably be of great importance if real progress is to be made. A grounded sensitivity to the timings and spacings of everyday life for people with disabilities is needed, without which much thinking and policy on disability, employment, and social participation seems to be limited in scope.

The knowledge and experience of persons with disabilities has to date been largely discounted by mainstream society. Knowledge has in effect been imposed upon them with diagnostic, bureaucratic and other labels. Legislation and related disability policy, informed by this knowledge, while appearing to serve an ameliorative function, has in reality maintained and reinforced existing barriers to full participation by people, especially women, with disabilities. Persons with disabilities have been denied the right to name their own reality, and their own knowledge rooted in daily experience has been refused by the dominance of non-disabled 'professionals' and bureaucrats. The traditional medicalised approach to disability places the onus on the individual to 'fit' into a social structure and system to which access for people with disabilities has been tightly controlled from the outset. The power of dominance rewards passive behaviour with pensions and welfare payments, arguably as a form of control mechanism.

If persons with disabilities are to move beyond 'token' participation in mainstream society and become full and equal citizens, a change in philosophy is hence required. What is needed is for persons with disabilities to reject imposed labels and expectations, and to affirm our

own experience as the basis of relevant knowledge. The inflexible 'boxes' created by non-disabled 'professionals' and bureaucrats must be challenged.

Poststructuralists often attempt to blur these hierarchies by claiming that power is not confined to particular nodes (like the economy) but is diffuse---it exists everywhere. However, we do know that everyone does not have "equal access" to this power, particularly when such access involves access to knowledges, technologies and most important, the means to production.  
(Erevelles, 2001, 98)

Understanding the embodied reality (timings and spacings) of disability in everyday life is crucial. We must above all reject the idea that disability is an individual 'personal problem' and recognise it as a social construct. Only then is it possible for persons with disabilities to assume our rightful place beside their non-disabled counterparts as active, vital members of society.

[D]isabled women can build strength and determination to continue to fight for spaces in everyday life in which differences such as disability are not viewed as something to be 'corrected' and avoided, but as part of the spectrum of human experiences that enrich all of our journeys through life and society.  
(Chouinard, 1999, 155)

Let me now conclude this thesis by giving the last words to the women who I interviewed in a series of quotes that convey the willpower, dignity and even empowerment of many individuals to whom I have talked.

[S]uch accounts draw our attention to the significance of personal transition and growth in the development of disabled women's capacities to struggle for social change, both individually and collectively.  
(Chouinard, 1999, 154)

Their words suggest to me huge possibilities for imagining, and hopefully one day achieving, a much more inclusive 'space' for women with disabilities in the social and economic world. Every woman to whom I spoke was positive and proud in her community and private everyday situation. People felt proud in and of themselves. The drive to survive in often hostile, residual spaces moves disabled women forward. There is no magic solution, but, one is left with the question about how much more could be accomplished if these women were able to make their way in the world more on their own terms. So much time and energy is spent trying to gain the 'right' of passage; to cope with the negative attitudes, the poorly arranged surroundings, the constant fear of being 'on approval' in the non-disabled world.

*Although being blind has its frustrations it also has really good points. I can't really see what people look like, which is great. In the past, when I had good partial sight I would make a load of assumptions and possibly judgements about people based on their appearance. I can't do that now.*

*which is great! I just take people as I find them.  
(Joyce, 34, Scotland)*

*I've always been proud to be a disabled person, I've never sat at home pining to be able-bodied but I mean you just get caught up in ... dealing with it and you don't think about it.  
(Heather, 43, Canada)*

*I think it's because people didn't understand, and I think that's the problem with the outside world, they don't understand what disability is; it doesn't mean that everything about you and your life and your head is disabled. I mean we've been given the wrong label, 'disabled', it makes you sound as if there's something terribly wrong and I don't think there's anything wrong with disability, I ... see myself as getting around differently, I can't use my legs, so I use wheels, it's that simple.  
(Trudy 33, Scotland)*

*I guess it's just become part of me, I just, what I do I try to picture myself in their place, I try to treat them the way that I would have wanted someone else to treat me if, ... someone else had a hearing disability and I didn't know, how would I have wanted the person to treat me? But that's the way that I do it.  
(Sahara, 40, Canada)*

*I thought I'm smart I can do it, I'm not invalid ... I am capable provided I watch what I do, I'm going to have to watch what I'm doing. I'm not saying I'll never work again, never is a long time, and you can't, life is not a never, life is an ever ... You cannot be scared forever because that's no life, so it's like everything else, you've got to go on.  
(Cindy, 53, Scotland)*

*I just take it as it comes, I'm very easy going, I don't feel sorry for myself. It's there [the disability] so I just have to deal with it.  
(Wendy, 56, Scotland)*

*You're constantly challenged; attitudes and stereotypes disable me, not my impairment. When I realised that it was so empowering.  
(Stacey, 29, Scotland)*

*I have no desire to be a non-disabled person. It has taken me quite a long time, but I like who I am and I feel proud to be a woman with a disability and I wouldn't want to change who I am.  
(Joyce, 34, Scotland)*

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